



PFDD Transcript

Lisa J. Pieretti

Good Morning! Welcome to our Landmark Public Meeting for Patient Focused Drug Development on Hyperhidrosis. I'm not a public speaker professionally so you'll have to forgive me for reading what I want to say today because I don't want to miss anything. I am Lisa J. Pieretti, the Executive Director and one of the co-founders of the International Hyperhidrosis Society. I have been at this post for nearly 15 years. During those 15 years, I've gotten to know so many brave, determined and beautiful people and I'm already getting teary-eyed.

One shining example is Caryn. She is a renowned flautist, who happens to have severe hyperhidrosis. But, she has an even stronger will to create, and she will tell you her story later. But, for now, I want you to know that the music you've been listening to all morning has been hers. So please join me in thanking her for her artful contribution.

I am blessed to know nearly all of you in this room, and many of you for over a decade. And, it's been through many of life's major moments. I have known Angela before she had children. And, many of you have known me before I was married. Today is another one of those major moments that we will share. And, I thank each and every one of you from the bottom and top of my heart for being here.

You have each been gifted with this stone to commemorate this day. You may wonder what the significance is. It's a weight when held by one person, but a build when we all join. It's through collection and collaboration that we transform from burden to build. I hope that every time you see this little stone, whether it be on your nightstand, your desk, your bookshelf or in your drawer of treasures, you think back on today. And you think forward to the way we can build a better future for the people in our hyperhidrosis community. I hope that you remember this day as one of inspiration and transformation. And, the start and the art of something great. Now let's get started.

Hopefully I'll get my act together in a minute. Let's talk about some ground rules. Take time now to put all cell phones on silent or vibrate. We encourage all personally affected hyperhidrosis experts and advocates to contribute to the dialogue. Maybe you've already figured out that everyone here with hyperhidrosis is an expert in hyperhidrosis. They're more than a patient, they're more than a sufferer. They're an expert today in hyperhidrosis, and that's who we are listening to today. Anyone who speaks from the audience should stand, state their name and one additional thing, such as when your hyperhidrosis started. Discussion today will focus on hyperhidrosis impacts, treatment and research. And, we're paying it forward for that little guy. Open public comment period is available until January 13, 2018, two months from today. Keep on adding your narratives. Anyone is allowed to speak in open comments, so all of us. We will comment on hyperhidrosis related topics, some that you've heard today. And, some that you feel we need to add to it, and all are welcome to contribute.

Remember this is a forum for constructive forward-thinking conversation and information sharing. Please refrain from negative comments directed at particular individuals or a realm of professionals as a whole, even in an anonymous manner. The views expressed today are personal opinions. The FDA regulators are here to listen and industry/innovators are here to learn.

This event will be live-streamed and video-recorded. Video will be available on SweatHelp.org. As members of the audience, you are part of this resource. You will notice polling data as visual aids throughout the day today. These polls were taken in advance of the meeting, and do not represent scientific data nor were the poll participants a representative sample. The polls are for informational purposes only as a discussion aid, and are not meant to represent the experience of the entire hyperhidrosis community. We've collected the data in advance of the meeting by emailing a survey to all patient representatives and individuals who themselves have hyperhidrosis. And I happened to send that out on Halloween night. I was busy, there's a lot going on. And, in 24 hours, we received 155 completed responses, and many of you here in this room completed the survey and some after we closed it because we had to make our slides and said 'I want my voice heard.' Your voice is heard.

So from a high level agenda, we will have an overview of the FDA's Patient Focused Drug Development initiative, hyperhidrosis clinical overview from published research and from the practicing physician's perspective. Then we will move to Topic 1 about hyperhidrosis impacts, and have a short break. And, it will be a very short break because we have so much to go over. And then hyperhidrosis treatments and research. We will talk about that. And very inspiring and fabulous remarks from Dr. Pariser. So we have about 125 in-person attendees and 350 in webcast right now. I'd like to introduce my hyperhidrosis physician panelists and welcome you to the stage. We will have Dr. Dee Anna Glaser with the Saint Louis University School of Medicine's Department of Dermatology, where she is interim Chair Director of the Division of Cosmetic and Laser Surgery and Director of Clinical Research. Dr. Glaser is also President and co-founder of the International Hyperhidrosis Society. We have Dr. David Pariser, Secretary and co-

founder of the International Hyperhidrosis Society and Senior Physician at Pariser Dermatology Specialists. I can't help but smile when I talk about these guys. Dr. Pariser is a Past President of the American Academy of Dermatology, and a Professor in the Department of Dermatology at Eastern Virginia Medical School. They're all my mentors. Dr. Adelaide Hebert is a pediatric dermatologist with a heart of gold at the University of Texas Houston, where she is Chief of Pediatric Dermatology in the McGovern Medical School and Children's Memorial Hermann Hospital. Dr. Hebert is also a co-founder and board member of the International Hyperhidrosis Society. Supporting us from the audience today, with their patients, we are honored to have Dr. Robert Sidbury, Dermatology Division Chief for Seattle Children's Hospital and University of Washington School of Medicine, where he is also Professor in the Department of Pediatrics. Dr. Zakiya Rice from Emory. Where are you Dr. Rice? Hi. She's from Emory University School of Medicine, where she is Director of the Dermatology Clinical Trials Unit and Assistant Professor with the Department of Dermatology and Pediatrics. Additionally, she is a Tele-dermatology Staff Physician. All dedicated to hyperhidrosis. You guys are champions. And now please join me in welcoming Dr. Kendall Marcus with the US Food and Drug Administration, where she is Director of the Division of Dermatology and Dental Products in the Office of Drug Evaluation.

Kendall Marcus, MD

Good Morning! I'm really looking forward to all of the discussion this morning. This is the 4th Patient Focused Drug Development that I've had the privilege of participating in. I have to tell you that I always learn something from these events. It's really been remarkable to me how these types of meetings have expanded my thinking and my understanding of disease impacts on patients and what's important to the patients. I just briefly want to thank and acknowledge my colleague, Meghana Chalasani, from the Office of Strategic Programs. Meghana's work is really invaluable to me because she and her colleagues do all of this tremendous amount of work in support of these types of meetings in order that I can just sort of show up and listen. And, I just want to acknowledge them up front. Including my presentation this morning. I told Meghana what I wanted to say and the things I wanted to focus on and the talk landed in my email inbox a couple of weeks ago. So, a special thank you for that as well. I am happy to see so many people here today. Patients, caregivers and advocates in the audience. In addition to those on the webcast. I'm really impressed with the web turnout and haven't heard from Meghana, but it certainly seems like it might be a record-breaker in terms of number of participants in this type of meeting that I've participated in. I just also want to acknowledge that there's representation from industry, academia and other drug development stakeholders as well. I wanted to focus in my talk on providing you all with a brief overview of FDA's role in the drug development process. I have found that some people understand our role quite well, but others have misperceptions about our role in drug development. And so I have found that providing people with a brief overview helps to understand our role, and is helpful in allowing you to provide feedback that will be most useful to us.

The first and most important piece of information that I think is important for people to understand is that drug development is initiated and carried out by drug companies, physicians and other entities. And those are all independent of the FDA. Our role is really to regulate the process, to ensure protection of the public health. Drug development process really begins with drug discovery, and that is part of the process in which we have no role. The next step before drugs are given to humans for the first time is what we call non-clinical work that is done in the lab. This is done in order that information can be gathered to support submission of an investigational new drug application, which is the IND abbreviation. And we live by our acronyms at the FDA. Once the non-clinical information is gathered, it helps ensure that people who get the drug for the first time are protected in terms of safety. So once that information is generated, an investigational new drug application, or an IND, is submitted to FDA in order to get approval from us to give drugs to humans for the first time. So once FDA receives that investigational new drug application, we review the information and determine whether that study is safe to proceed. These types of studies, once begun, are generally done in healthy volunteers and they're done at very low doses as compared to the dose that usually move forward as the proposed dose for marketing. In order to, again, ensure the safety of the participants in clinical trials. And, it's also done in low doses as we start to understand how the drugs are metabolized in the body, what kinds of drug interactions they have and whether food impacts how a drug is absorbed and that type of information.

After the completion of the Phase 1 study, the next stage is what we call Phase 2. During this phase, there is continued opportunity for interaction and feedback from the FDA. And, this includes the endpoints that are used to determine if the drug has activity for the disease that is being targeted.

These types of studies are generally conducted in volunteers with the disease of interest. And, they're usually dose ranging studies. Ones that are designed to determine the optimal dose that maximizes efficacy while ensuring safety of the subjects who receive the dose. One of the opportunities that drug developers have to interact with FDA is at the end of this phase. When they have some idea of the safety issues that have occurred with the product and the dose that is most likely to optimize efficacy while ensuring safety of the patients. So once these studies are done, an end of Phase 2 meeting is often held and the purpose of this meeting is to have interactions and come to what I would say initial agreements about design and what we call the pivotal Phase 3 trials. The trials that are designed to robustly demonstrate efficacy as evaluated by endpoints that are agreed upon between the drug sponsor and the FDA. As well as the design of the study to ensure that efficacy can be evaluated while maintaining safety protections of the subjects. These discussions include patient reported outcomes or outcomes that patients, that the drug companies, and FDA have determined are important to patients, and that have been validated in study of patients throughout this whole process. Phase 3 is typically the last phase of the drug development process. These trials are generally conducted using the to-be marketed formulation, and evaluate the proposed dose for marketing of the product. Although occasionally 2 or more doses are brought into Phase 3. Another opportunity for feedback from FDA occurs when the Phase 3 trials are completed, and the sponsors have the option to meet with the FDA to discuss the content and format of their future marketing applications. The FDA provides feedback on sponsors plan so that the application can be complete and reviewable at the time that it is submitted to ensure a smooth and timely review process. Once an applicant has gathered all of the data that they needed and decided on content and format of their NDA, they can submit the marketing application to the FDA for review and it's important to understand that applicants don't receive an invitation from the FDA to submit an application. Rather, an applicant chooses to submit the application whenever they feel that they are ready to do so.

The FDA review of the marketing application has many steps and a large review team, and generally lasts between 6 and 12 months depending upon the type of the application. Substantial evidence is determined by recommendations from the review team, which then contributes to the overall benefit risk decision by the FDA. This means that the decision about whether the benefits of the drug to the intended patient population outweigh the known or potential risks of the drug in that population. And benefit risk is really the way that I like to look at drug impacts on patients as opposed to safety and efficacy. Most drugs do have some risk for adverse events associated with them, and they have some benefit to the patients. Based on that benefit risk assessment made, of that marketing application, a final decision is made by the FDA to either approve the drug for marketing in the United States or to issue a complete response, which is non-approval that contains the deficiencies to be resolved by the applicant before the drug can be approved. For drug products that are approved, development of the product continues and in what we call the Post Approval or Post Marketing Period. In the Post Approval Stage, the FDA continues to monitor safety information about the drug from multiple sources, including adverse event reports in the FDA Sentinel System. In the Post Approval Stage, sponsors will conduct studies to fulfill post marketing requirements. If the FDA determines that there are additional pieces of information that are needed by the company, but ones that don't preclude approval of the product for marketing, they may continue to develop the drug for other indications. For example, sponsors are generally required under the Pediatric Research and Equity Act to study the use of their drug in children to generate information for labeling that will guide prescribers who treat children with the disease of interest. These pediatric studies are usually not done, they sometimes are, but they're usually not done

until after safety information is gathered in adults. This pediatric development usually occurs once the drug is marketed for adults. Often after approval of a drug for treatment of one disease, sponsors may choose to investigate their product to treat other disease, and this also usually occurs in this period.

Where do these Patient Focused Drug Development meetings play a role? As I mentioned, it is FDA's responsibility to ensure that the benefits of a drug outweigh its risk. So having this kind of dialogue is extremely valuable for us because hearing what you all care about can help us lead the way in figuring out how to best facilitate drug development for hyperhidrosis and understand how the patients view the benefit and risks of treatment for hyperhidrosis. We're looking forward to what we learned today, incorporating what we've learned today into the agency's thinking and understanding of how patients view the benefits and risks of hyperhidrosis. Once again, we're all here to hear the patient voice so thank you for your participation. We are truly grateful for all of you being here today. As I've said, I have learned invaluable information for every one of the meetings that I've participated in, and I'm certain that I will learn important information today as well. So, thank you for inviting me. I look forward to the meeting.

Dee Anna Glaser, MD

All right, good morning everybody. We're going to get started with the program and I thank all of you for being here, for sharing your time with us, for sharing your stories. It's really meant a lot. So, my charge is just to give you a little overview about what hyperhidrosis is and the prevalence of it. These are my disclosures:

Research Grants

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President, International Hyperhidrosis Society

I've worked with many of the companies that have developed therapies. All of you in this room, I think, you can recognize these pictures, you know what hyperhidrosis is, right? But there are some definitions to help physicians better understand what is going on with the individual patient. So we have to remember that sweat glands are all over the body. There's millions of them. Their numbers do vary by different sites of the body. You can see in the palms and soles, there's 700 glands. Remember that the sweating is there to help regulate our body temperatures. It's an important physiologic function when it happens correctly. And, the sympathetic nervous system is what controls that sweating to occur, so there's a signal that says "we're hot." The brain sends something down through the sympathetic nervous system and tells the eccrine glands to start to sweat. These glands are situated very, very deeply in the skin right where the skin and the fat meet. So the definition or how we think about primary hyperhidrosis is excessive sweating beyond what is physiologically required of us. So, if we're in a 100-degree temperature day in the middle of St. Louis where I am and it's humid, I'm supposed to be sweating. That's not hyperhidrosis. But, if I'm in a cool comfortable room like this and I'm profusely sweating and then I have these other characteristics, which are relatively symmetrical and bilateral. Usually the age of onset for primary focal hyperhidrosis is very young. Oftentimes, in childhood or adolescence. Typically before the age of 25. Most people who have primary hyperhidrosis don't sweat from that body site at nighttime when they're asleep. They may sweat if they have too many covers on. But, they don't sweat perhaps just from their underarms or from their head or whatever body site they may have. Many of them have a positive family history. Many of you expressed that concern yesterday when you were talking about what you were worried about. Are you going to pass this on to your children?

Most people sweat at least one episode per week. Usually it's multiple episodes in a day. Often as we're going to hear more from the other physicians about the impairment and from our patients here today, how it really affects your daily activities and that's a big one. So, we don't really understand exactly what's causing this. We know that there is a very strong genetic component. We know that the sweat glands are actually normal. They're normal in size, shape, the numbers of them. We know that the signal to the nerves and from the nerves to the sweat glands is normal. There is a normal amount of acetylcholine. There's a normal amount of acetylcholinesterase. There's something going on that's probably more in the brain and probably in the hypothalamus that's driving this. But the exact etiology,

we don't know. But, we're usually targeting the sweat glands or the nervous system as we're doing that. Originally back in the early 2000's, there's a study that was published of about 1,500 households, and we determined that this was common. So about 3% of the US population seemed to have excessive sweating. But the problem with that study was it didn't really correlate with what was going on around the world. And, the numbers were much higher in other parts of the world. Patty Walker, who is here today, did this study of 8,000 individuals, and found that really the prevalence was more around 5%. Not 2.8%. That was really in line with what was described in the rest of the world. I think what's so disappointing and what's so important on this slide is how few are the people who suffer from hyperhidrosis are actually brave enough to go and talk to medical professionals. And you can see only 50% of the individuals, and this was just a couple of years ago. Back in the early 2000's, we found that less than 1/3 of the people who suffered with hyperhidrosis had ever discussed it with any type of healthcare professional. But the number's still only at 50%. So, we're looking at 5% of the population, which is consistent worldwide. We know that in the US, that's over 15 million individuals who have hyperhidrosis. So for all of you who thought you were the only ones, no, you're one of 15 million in the US and many, many worldwide.

But why people don't go to their physician or healthcare professional? Because they feel like there aren't any treatment options, so we're here to help break down that barrier today. And they didn't really think that it was a medical problem. I didn't even know I should be thinking that there would be a treatment. So here we are again, the US prevalence back in the early on 2.8%. But, we now know that it's more like 5%, and when you look at the rest of the world, you can see 5%. 12% in Vancouver. 12% in Japan. 14% in China. More recently the International Hyperhidrosis Society helped to do a survey to find out in teens how prevalent it is. And so we looked at teens from ages 12-17. We capped our response at only 1,000. We had over 980 validated responses, and what we found is about 17% of teens thought that they had excessive uncontrollable sweating. It's a very high number and I think it took us what, four minutes? How many minutes to get a thousand? Four. Four minutes to get a thousand responses. These people are really determined to help make us understand what they're going through, and you're going to hear more about it.

So, the age of onset again about 1/3 of people were less than, or 25% the onset was less than, 10 years of age about 45% from about age 11 to 13 right around when puberty is. And, then about 28% older than age 14. What I think has been really telling over the last several years I've been involved with hyperhidrosis, is an understanding of how many different body sites. We always used to just think about underarms or hands, but what we're learning is that people are having uncontrollable unwanted excessive sweating from multiple body sites. It's not just the underarms and it's not just the hands, and you can see that many people have multiple sites of sweating. So, it's axillary, palms, faces, scalps, groins, the lower back, the back of the legs, the knees. All kinds of areas and many, many sites. So, I hope what I've impressed upon those who don't suffer from it, but those who do as well, just how common this is. It is an early onset of age. This is grabbing people when they're just getting through childhood and adolescence. At a time where their self-esteem is really being tested. When they're trying to better identify who they are and what they're going to do in their life. It spans an entire lifetime. So, it does not get better as you get older, I'm sorry to say. It affects people in their 80's and their 90's just as it does in their early teens. We still don't know exactly what the etiology for this condition is, but we do have a better understanding. We know that it affects multiple body sites and you're going to hear more about how it impacts all aspects of the individual's life. Can you imagine walking around like this? Right. Yeah, this is one of my patients. She's sitting in the exam chair and she stood up and I mean you know how miserable this is all day. This is how she walks around. She changes her pants multiple times because she just keeps producing sweat like this. And when it's really

important, she wears an adult diaper and she's only in her 30's. So with that, I thank you and I'm going to bring up Dr. Pariser, who will discuss a little bit more about research.

David Pariser, MD

Thanks Dee Anna, and again let me add my thanks to all of you who are here taking the time out to do this. I'm going to just show you some data that's been published about the impact of hyperhidrosis, but really every one of you has a story and every one of you is going to be different from every other one. And, although we can aggregate statistics for purposes of studying the problem and of population management, it's everybody's individual story that counts.

As we heard from Dr. Glaser I, too, have been an investigator consultant for virtually all the companies that make products having to do with hyperhidrosis. I do not have any proprietary interest in any of the products that I am going to discuss, and I will be talking about off-label uses of drugs and devices. So, here are some of the quality of life impairments that people with hyperhidrosis report, and I am sure that many of you can check off some or all of these and this applies to your own individual daily life: shaking hands, clothing changes. You know how many of you buy multiple shirts to change in the middle of the day so that your co-workers don't know that you're changing. Writing, school kids who get disciplined by their teachers for smearing their paperwork because their hands are sweating. I've had people short out computers, computer keyboards. Irritation and maceration happens to some areas of the body with hyperhidrosis. But not usually infection. I had a woman who dropped her baby, let alone dropping glass objects. Destroying your shoes and clothing, can't knit and do other things. Musical instruments. We heard about our flautist. I think this is Dr. Hebert's picture of someone's shoes who've gotten trashed by their sweat.

So, if you look at some of the published studies that I'll show you. And, again, the published studies aggregate these patient problems and complaints. But, again, it's the individual people and their stories that are by far for me more impactful. But if you look at a survey of patients who have excessive sweating, the number 1 is less confidence. I made the comment to somebody last night. Yeah, we can help people sweat less. Almost everybody can be helped some to sweat less, but what we really do is we give you self-confidence. That's what's more important, really. And, all of that leads to the other things on the slide, their unhappiness, depression, leisure activities, frustration with daily activities, not being able to do the things that you want to do. So, there are a number of published studies, and I'm going to go through these quickly. These are just asking patients some specific questions. Have you been emotionally damaged or injured? Significantly or moderately, 73%. Are you limited when you meet people for the first time? You can look at the numbers, they're all more than half of the patients respond to each one of these questions. Limited in developing personal relationships, limited when shaking hands, limited with being in public places (except maybe here today). Limited at work, prevented a particular career path. That's a common one. People who were just not able to do what they want to do. I had a woman who wanted to be a nurse, but there's no way she could ever wear those blue scrubs because the sweat shows up on the blue. Again, her life was changed by getting her sweating under control so that she could wear the blue scrubs. Effectiveness at work, and it goes on and on. Confidence. That's the big one. Feeling less confident, unhappiness, depression, change of leisure activities and it goes on and on. I just want to review very quickly for you some of the pallet of treatments that we have for hyperhidrosis. You all recognize many of these. And then later on in the morning, I'm going to talk a little bit about some of the deficiencies in the treatments that we have and what we might be able to do to help improve that.

So, everybody uses topical preparations, topical antiperspirants. Many of you, particularly if you have palmar or plantar, have probably tried iontophoresis. There's systemic medications off-label. There's no systemic medication that is indicated for treatment of hyperhidrosis, by its label. But we do frequently use systemic medications off-label for this. There's some minimally invasive treatments. Botulinum toxin injections, very effective for localized areas. Microwave thermolysis is a device that's used and FDA cleared for axillary hyperhidrosis only. There are some surgical treatments. Many of which are not done so much anymore. Particularly the local surgeries, and I'll talk a little bit about ETS surgery. So, I always ask this question when I talk about this. And, I ask this to groups of doctors. And I say, "So how many of you got up this morning, took a shower, and put on an antiperspirant?" Nobody in the room did that? Ok, "How many of you put your antiperspirant on last night before you went to bed?" Ok, so those of you know how to do this. And, I'll tell you why in a minute. Antiperspirants work best when they're applied to dry skin. And those of you who have axillary hyperhidrosis, probably find that you sweat less at night than you do during the day. So you want to put your antiperspirant on at night. That's true of anybody who ever wants to use any antiperspirant. Antiperspirants work through a chemical reaction that physically plugs sweat glands, and you don't wash that out in the morning. So people say, "Well, I'm going to get up in the morning and shower, I'm going to wash it off, it's not gonna work well." It is going to work, it'll continue to work. And, if you want to do something for good grooming, what you should do in the morning is put on a deodorant as opposed to an antiperspirant. The deodorant has no active ingredients, and it will make you feel clean. That's the best way to use antiperspirants.

There are some new topical agents on the horizon, and after many years of nothing new in the hyperhidrosis world, there are several things which may be available, may be available in the next couple of years. Glycopyrronium tosylate wipes will be the first thing probably, we hope. Sometime soon is a soft peronium bromide. These are topical preparations that involve topical use of anticholinergics. We use oral anticholinergics off-label. Topical has a better chance of producing a good local effect without the systemic problems of dryness, dry mouth and other problems with oral anticholinergics.

Iontophoresis, a very effective treatment if you can do it. There are several iontophoresis systems available, cleared in the US and in other parts of the world. Basically, what it amounts to is putting your hands and feet in trays of water, plain tap water out of the sink. And, an electric current is passed through the water, which tends to I'd say, it's not really true but I say, short-circuit the sweat glands. It doesn't really do that, but it is a valid method for many people who have palmar and plantar who can stick with this. Because you really have to do it for 20 minutes 3 times a week, and it's hard to do that for some people to blend that into their daily life. We don't really know how it works, but it probably plugs sweat glands the same way that the antiperspirant does by ion deposition.

Just a brief word about systemic meds for treatment of hyperhidrosis. There's nothing FDA approved for this. But we use it commonly, so our experience is based on very small published case reports, and personal experience. We generally will use systemic medications for widespread hyperhidrosis, multiple areas or in areas where other treatments have not worked as well. And, the main medications that are used are anticholinergics. The problem is it's hard to find a dose of anticholinergic drug that will produce enough sweat reduction without the side effects that you see listed there. Predominately dry mouth. So we start off low doses, we go up slowly, we try to find a dose where there's enough reduction of sweating where it's effective enough that doesn't leave you feeling like you're walking

around with a ball of cotton in your mouth all day, or at night your lips stick together. These are the people that we might want to or might not want to use oral anticholinergics on. You need to sweat and if you're a high school football player, you're not going to tell the coach that you need to sit down. You could end up having heat stroke if you're not sweating correctly, so it's not for everyone. Not for outdoor workers, not for athletes. The slide there says "think twice in children." Dr. Hebert will talk a little bit more about children, but we do feel comfortable about giving oral anticholinergics in some doses for children. There is a particular anticholinergic, glycopyrrolate, that is approved in children. Not for hyperhidrosis, but for drooling. And, so, we do have some safety data and feel a little comfortable about that.

Microwave thermolysis is a device treatment that's used to treat underarms, and only underarms. It does produce a permanent relief of sweating. It does destroy the sweat glands. It doesn't destroy 100%. And, I tell people realistically if you have this procedure done to expect after two treatments, 80% improvement that glands do not regenerate after microwave thermolysis. And, it hurts a bit, its done under local anesthesia, there's some swelling and numbness around the sites but that almost always goes away.

So, the injections of botulinum toxin is really the home run for treatment of any individual area of hyperhidrosis. Now although it is only FDA approved for the axilla, that doesn't mean it doesn't work in the other areas. It certainly does, and we use it quite commonly in other areas. There are a number of botulinum toxins that are out there on the market that are used mostly for cosmetic and for neurological indications. The only one that's been studied and approved for hyperhidrosis is the Botox brand. It works well, you can almost always get an area, a localized area, dry with Botox. You can do feet, its usually done to do hands. That's the most common area which we'll do, but you can also do the feet.

Time is running low, so I'm going to skip on to sympathectomy. Basically, my message about sympathectomy is for palmar hyperhidrosis, it works great. It doesn't work so well (50/50) for axillary, but the problem is not the effect, it's the side-effect. It's the compensatory hyperhidrosis that occurs in up to 80% of the patients, which means you start sweating even more somewhere else. I had a patient who had it done, a woman whose hands were so dry that she had to use hand cream all the time. But from her nipple line to her groin, she would sweat so much that she would wet a t-shirt in a few minutes. Another one who started sweating on her buttocks so that she had to wear a diaper, or she would leave a sweat puddle in the chair. So those are an overview of the treatments of hyperhidrosis, and I hope we have given you a little bit of organization of the facts on quality of life, which you all know about probably better than anyone else. And I thank you for your attention. Dr. Hebert is going to introduce us to some special considerations for children.

Dr. Adelaide Hebert

Thank you, David. I'm Dr. Adelaide Hebert, and I'm happy to be here today and I speak on behalf of all the patients in the room, the International Hyperhidrosis Society, and my two colleagues in pediatric dermatology, Dr. Rice and Dr. Sidbury, here with us today. I'm really glad I have the opportunity as the pediatric dermatologist to speak because I feel that this is a condition that so often starts early. Dr. Glaser has eluded to that, and I think that it really does affect children and it impacts as you go forward in life your self-confidence as Dr. Pariser has eluded to. And it is a tremendous burden for these young patients as they go through life to carry forward with this excess sweating. What are the special considerations that we must take into account if we manage children with hyperhidrosis? Well we've talked about the age of onset, it is early. 10 years. I have kids much younger than that, and I'll illustrate some of those for you. And I know as some of the patients speak this afternoon, they'll tell their stories of what impacted them during their early years of life.

The anatomic distribution of sweating can often be different in children. We most often see palmar sweating, but I'll illustrate some children who have sweating in multiple anatomic areas. And, of course, my colleagues have eluded to the fact that we can find sweating in multiple sites when we begin to ask and we begin to have those patients discuss this with us. We don't have any FDA approved treatments, especially in children. Botox, for axillary hyperhidrosis, is approved for 18 and above. But we don't really have products that have that coverage for children, which makes it very challenging. We have done a study on it, it's published. But again, no FDA approval. Education is a challenge when I talk to my medical students, and medical students from across the US rotate with us. Most medical students never get a lecture on hyperhidrosis, so when you've gone to those physicians who haven't really perhaps seemed supportive or sympathetic, they may not have been adequately educated on this topic. We, at my medical school, have very limited number of lectures in dermatology and that's its own challenge.

Dr. Pariser has eluded to the challenges in the athletic and art arena where kids are especially troubled when they can't keep up with their peers or feel challenges unique that they think is only happening to them. Social interactions, very, very meaningful in childhood. Self confidence can't be emphasized enough. We really do restore self-confidence as the patients come in to see us. And I agree with Dr. Pariser that may be one of the major roles we play is their physician in our hyperhidrosis clinics and then life decisions and direction. This is a little girl 5 years of age, who came a long way to see me in Houston. And her challenge is, her mother told me, was nobody would play Ring Around the Rosie with her in kindergarten. What a way to start your school life. And, when she had crossed the street and hold hands, no one in her class would hold her hand. Not only was her safety compromised, but think of her self-confidence starting at this age. So, very early beginning and very challenging for this young patient. This is a tell-tale sign they may not come in and say they have hyperhidrosis. But when I see young kids come in and they're already wiping their hands at their sides, that's when I start the conversation that maybe they're there for a totally different condition. A wart, acne, a splinter in their finger, something else. But this is a sign that I look for, and I begin the discussion with the parents. This little one came in because of thinning hair, but look at the sweating on the top of the head. Not every child who sweats on the top of the head means that they'll go on to have hyperhidrosis. But, indeed, this child did continue. This child was about 18 months of age. Hyperhidrosis wasn't even on the wave

length for the parents. But, to me, that was going to be the more long-lasting challenge compared to the thin hair at this stage. So, the conversation was begun.

These are some patients I think that are very traumatic that come into my hyperhidrosis clinic where I see children and adults. Age is not a barrier here, it's all comers and as my colleagues have described, how do you go through life when you have this barrier? And I know as patients here in the room you understand this and you often think you're the only one. But who do you talk to? Where do you begin? Many of the patients are very grateful to find that a hyperhidrosis clinic even exists. Here was a youngster that came in for some unrelated problem. But as he waited for me to evaluate him, and his hands were on the mayo stand, look what occurred. They often find me a rather funny physician that I actually want to take a picture of this. But I think it's very impactful here, the picture telling a thousand words and indeed they can't just make this up. This is what they deal with every single day. Here's another patient sweating heavily from the feet. A great challenge in wearing shoes or even finding footwear that will sustain their ability to walk comfortably. This was a young lady who came in from the Houston area, this was the only kind of shoes she could wear to attend school. Notice that they're ventilated, she's like a little sweat box there they have little holes in this plastic footwear. Again, the only shoe that would allow her to attend her school. We know that we have some very limited treatment options. They're even more limited in children than in adults. I do use oral anticholinergics, again, off-label for children because it does allow them to go to school. And in a survey that we published in a poster at the pediatric dermatology meeting a number of years ago, we found out that oral glycopyrrolate was the single most on time prescription that I write in any of my clinics. Not medicine for acne, not medicine for psoriasis, but their regular medicine for hyperhidrosis. So when we challenged the patients as to why this was true, they didn't want to sweat, they didn't want to run out of their medicine. So to get a medicine that allows teenagers to be compliant, that's remarkable.

We do know that the age of onset can be early, this has been eluded to and you can see that early childhood in each of these three studies over 60% of the patients reported early childhood initiation. And in puberty, about 30% up to almost 40%. Then, many at 18 years of age and older, but again a very problematic challenge for childhood. 13 years of age, we can see that many of the children start with palmar hyperhidrosis, a very common presentation. 19 years of age, many begin with axillary. 22 years, many patients may have axillary and palmar, and perhaps one other location so we're aware of this. Dr. Glaser eluded to a study that we had worked on in 2016. We really wanted to know, not just from the patients represented by the International Hyperhidrosis Society, but patients globally across the US to understand indeed what was the impact of hyperhidrosis. The International Hyperhidrosis Society was actually founded in 2003. My colleagues, who are some of the founding members here with me, realized the impact this has had both in education and opportunity grants research and really a home for those sufferers with hyperhidrosis. It has been so meaningful. We have not been paid to participate in this group as physicians. We do it because we think there is a unique need and we needed a platform to be available and to be helpful to all of us in the room. I think this has been one of the most successful organizations in which I have participated in, and I am very grateful to Lisa and all of her efforts and the support we have received from our colleagues and industry to make this organization the success that it has been.

Why do we investigate the prevalence of hyperhidrosis in children and teens? We really wanted to have a better understanding when hyperhidrosis began. We knew that there was not enough data up until this time point and what data was specific to those patients 12-17. About 17.1% of the patients in the

teenage years reported hyperhidrosis. Dr. Glaser has eluded to this. And 75% of that teenage population with hyperhidrosis told us that they had a major or moderate daily impairment. So, again, starting at the most formative years of life. These teenagers really have to deal with something above and beyond teenage angst and all that goes with it. Most of these teens sweated from 2 or more areas, so it's not just a single problem. Anatomically for them, it's multiple areas. The average areas that they recorded was 5, so they really are having great impact in multiple sites each day. So, in conclusion, what I want to share with you is that there are a large number of teens who suffer greatly, have a major impact on their life at a time in life where so many things are already challenging. And, the prevalence is indeed much higher than we understood. Part of the initiation of this particular grant and investigation and the average age of onset in our particular study was 11 to 12 years of age in the United States. So, the importance of treatment, this is going to be our great focus today because we know we don't have enough treatment. If we had treatments that were wonderful probably you wouldn't be here attending today as patients. You'd be home living your lives. But we must stay focused on how to better the stage for those patients who suffer with hyperhidrosis because we know that this functional impairment, the social impairment, has lifelong impact for each of you.

Our therapeutic options, of course I have definite need to enhance these for the pediatric population that I serve. Currently, we have glycopyrrolate or Robinul. We have oxybutynin, which is often used in pediatric patients for bladder issues. And we have iontophoresis. And, we use all of these in our patients. We recognize that perception by parents, by teens, school and school attendees and teachers varies greatly in children. And, there has not been nearly the research that we need in pediatric populations to adequately serve the patients who come to us for advice, guidance and therapy. We want to have engagement of the entire team, pediatricians, dermatologists, colleagues across the spectrum and good communication, much of which is afforded now through the International Hyperhidrosis Society. We know that many of the patients we treat with glycopyrrolate get tremendous improvement. 90% experienced improvement with two milligram per kilogram per day. I appreciate and reflect back on Dr. Pariser's comments about our football players, or those who spend a lot of time outdoors engaged in sporting activities. Our sprinters, for example, in the hot Houston weather may not be the ideal patient to take this as they have to cool themselves with sweating in order to participate fully in the sporting activities that they enjoy. Side effects we have these, dry mouth and dry eyes. We try to compensate appropriately and allow these children to reduce their sweat even though these side effects can be problematic. We know that 92% of those patients who took glycopyrrolate did improve. And 75% would recommend it to their friends. I know this is certainly true in the patient population. And, I've had so many patients in my hyperhidrosis clinic tell me that glycopyrrolate has been truly life-changing for them. Now the long-term use of oxybutynin for palmar and plantar hyperhidrosis has been investigated by colleagues in pediatric dermatology. 97 patients were looked at, 59 of the patients were ages 4 to 14 years with therapy for more than 6 months, they had a 94% improvement in quality of life and they're at about a 91% reduction in their sweating. So, very efficacious off-label use of oxybutynin in the pediatric population. Anticholinergic side-effects, of course, were experienced and we know that patients need varying doses depending on their age. Currently, we are not recommending the extended release form because we have less control of that dosing currently. Now, I do use iontophoresis in the pediatric patients who come to me who have palmar and plantar hyperhidrosis. And, especially for the drug-resistant parent who doesn't want to have their child on a systemic medication. We can use this. We sometimes drop the glycopyrrolate into the iontophoresis tray. Again, an off-label use, but we can produce great benefit.

Like Dr. Pariser, I'm not a big fan of surgery intervention for patients with hyperhidrosis. It's a very expensive treatment. It may do lasting harm and it seems that children may undergo more compensatory hyperhidrosis even than the adult population. Up to 70% of those children who do undergo thoracic sympathectomy, 70% have compensatory hyperhidrosis. And, many state that they wish they had not had the surgery at all. In Sweden where this particular surgical procedure was first given great promise and the authority to be done, it's now banned and I cite that often. This was a mom who came in with her child. She has different size pupils because she had thoracic sympathectomy and, again, she stated she wished she never had it done because of compensatory hyperhidrosis. We have a number of other reviews that deal with pediatric hyperhidrosis published by colleagues in pediatric dermatology, and I want to give them full credit as well. So, in summary, the pediatric population certainly warrants careful attention because this condition begins during childhood, and the burden of disease that these children carry forward with them is so impactful in many aspects of their life. We'd like to have on-label treatments as many insurance companies denied to children medications available to our adult patients simply because it's not FDA-approved. I deal with that on a daily basis in my clinic, and I believe my pediatric dermatology colleagues in the room would support that finding. Hyperhidrosis does begin in childhood, thus it has a lifelong impact and certainly warrants our full attention and all the help that we can bring to this patient population. Thank you.

Lisa J. Pieretti

Wonderful. I'm sure all of the experts in the room are probably so psyched to hear physicians and such esteemed physicians understanding the struggles that they go through. Must feel really validating, right? I see some yes's. So, I'd like to, please join me in a warm welcome to Angela Ballard, who will facilitate our discussion with the expert hyperhidrosis panelists as well as the open forum dialogue with all of you in the audience. Most of you already know Angela, and I'm sure you will agree she is aptly named. Angela has been with me in the International Hyperhidrosis Society since we began in 2003. Nearly every blog, tweet, post, manuscript, page, agenda, slide, reference, poster, postcard and tutorial has been authored by her. She is a nurse, a champion, a humanitarian, a conversationalist and an athlete. We are in good hands.

Angela Ballard

Thank you so much. I am so honored and privileged to be here, and to help facilitate this discussion. So I would like to invite our panelists for our first topic to please come up. So that would be: Maria, Lucio, Christina, Caryn and Sachin. So, as you guys make your way up, I'll just give a little overview of what we're going to do now. And this is really where you guys are hyperhidrosis experts and take the stage figuratively and literally. We're going to begin our discussion with comments from our panel, and the purpose is to set the context for a broader discussion with all of you, our audience, who personally experience hyperhidrosis. The panelists reflect a range of experiences with hyperhidrosis and some of you will find that yours are very similar or different and we want to hear about the similarities and differences. After we hear from each of our esteemed panelists, we will broaden the dialogue to include individuals and family members from the audience. Because we want to build on these experiences and create a bigger picture of what's going on, we're going to ask questions and invite you all to speak and a microphone will be brought to you so don't worry about that. Please stand and state your name and maybe one other thing about you. Maybe when your hyperhidrosis started or something else you'd like to share. And, let me just make sure I covered everything. So, when we get to the discussion, please try to limit your comment to a minute or two as we have a lot to cover today, and also we'll try to stick to the topic at-hand. And, hopefully, we'll get to cover all of the topics and certainly at the end if you have something that you feel like we totally missed, let's bring that up. I want to recognize that these are very complex and serious issues for many people with hyperhidrosis. And, there is support available and I would like to mention the National Suicide Prevention Hotline and suicidepreventionlifeline.org and we have that phone number available for anyone needing support. So, another round of applause for our panelists please. And, we're going to start with Maria and go on down the line. So, Maria...

Maria (Panelist)

My name is Maria. I'm 37 years old. Six years ago, I launched my blog, [My Life as a Puddle](#). But my story begins in 2nd grade, the earliest I remember having an excessive sweating problem. Wiping my palms on my catholic school uniform, using my sleeves to hide the sweat dripping from my fingertips, watching the edges curl up on the big chief tablet on which I was practicing my cursive handwriting was

a scene for the books. Never wearing sandals because my feet would slip and slide all over them. Looking around to see if other kids had sweaty feet and avoided the same types of shoes I did. Remember jelly shoes? I could only wear mine with socks. And that made me feel like a dork. I didn't want to stand out. As humans, we are wired for the touch. What happens to us psychologically when we feel unworthy of it? Hyperhidrosis is rooted in shame because we can't control our sweating. We come up with unique ways to hide it. Sweating makes us feel out of control and many of us turn inward to wrestle with our sweat demons.

I was 36 years old before I had my first pedicure. My best friend dragged me to the salon and made me do it to get out of my comfort zone. When the person massaging my feet leaned over to grab the bottle of nail polish, she gently rested her hand on the top of my foot. I almost cried over such a simple gesture because for all of those years, I thought a pedicure was something I could never do. I was ashamed to be touched and worried that they'd discover my secret. In an effort to clamp down on the never-ending sweat commentary that runs rampant in my head, I developed a few life hacks for the biggest day of my life, my wedding. I was excited for my bridal debut, yet also anxious that I'd ruin my satin dress. I wore boring white ballet flats with no-show socks because I was afraid I'd break an ankle if I wore slippery high-heeled shoes. This is why people with hyperhidrosis feel like they can't buy nice clothing and shoes. We may ruin them with sweat stains, so why even bother? And what about my wedding bouquet? About a month before my big day, I spotted a surgical towel in the exam room of my doctor's office. It just happened to be the exact color of my wedding flowers. As I soaked through the paper on the exam table during my appointment, I bashfully asked my doctor if I could have the towel. Thank God for my crafty mother-in-law. She hand-sewed it around the handle of my bouquet. When I handed it off to my man of honor to recite my vows, it was still drenched in sweat. A few years later, many of my friends were having babies. Driving to the hospital, my palms gripping the fabric-covered steering wheel, I tried to think of ways I could hide my sweating. While still being able to hold those little bundles of joy. I was absolutely petrified that I would get them soaking wet or, worse, lose my grip and drop them. My friends didn't care about my sweat. They just gave me a kitchen towel to hold when I needed it.

I have an auto-immune disease called ulcerative colitis. Last year over Easter weekend, I was actually hospitalized because of it. When my doctor told me I had exhausted all other treatment options and would have to self-inject a biologic medication. My first thought was 'how can I stab a needle into myself with sweaty hands?' If my hands were to slip, I could lose a precious dose of this life-saving medication. So not only is hyperhidrosis socially, mentally and emotionally debilitating, it's a downright safety issue for me.

Earlier this year, I tried on two separate occasions to qualify for and enroll in a clinical trial for an underarm treatment. Wearing a paper-thin gown that was definitely not sweat-friendly, I was placed in a cold exam room for 30 minutes to acclimate. Then my underarm sweat was collected on cotton pads and then weighed. The first numbers came back within range but, sadly, all of the times afterwards did not. Then the protocol was changed, and I had a chance to re-qualify. Never have I attempted to will my body into sweating before, but in that exam room on that day, I was trying my hardest. Hyperhidrosis is not constant, it is episodic. I guarantee that I would qualify for this study today if you were to come up here and measure my sweaty underarms right now.

We all want to be seen to know that we matter. It takes a great deal of courage to face life with hyperhidrosis. Please don't be disgusted when you shake our hand, instead admire us for having the courage to do so in what you may know as a dry world. When an organization like the International Hyperhidrosis Society comes along and empowers us, suddenly doors like this meeting that we never thought we could knock on in the first place. The International Hyperhidrosis Society opens doors so that we can get a grip on our future. I ask you today to please walk through these open doors to bring us better clinical trials, better treatment options, and better lives. When it comes to drug development for hyperhidrosis, think of it this way: The International Hyperhidrosis Society built the car and we, as the patients, are buckled in and ready for the journey. But it is you, pharmaceutical companies and industry innovators, who hold the keys to take us where we need to go.

Angela Ballard: Thank you so much, Maria. Lucio...

Lucio (Panelist)

My name is Lucio. I'm 27. I'm from New York. Um excuse me, I have to read from the narrative. I'm not too good at this public speaking thing either. I've been suffering with hyperhidrosis, more specifically, palmar hyperhidrosis for what seems like an eternity. I would have said living with hyperhidrosis. However, it has been nothing but an incarceration on my life. It is said that high school years are supposed to be the best years of your educational career. Unfortunately, I would have to disagree. It was the start of high school that I realized I had a problem on my hands, literally. I was so skeptical on why my hands were always so sweaty for no reason, so I spent hours and days researching the symptoms, causes, prognosis and treatments of this condition. All of the information was very vague, and no medical professional seemed to have true knowledge and experience on this condition. I felt doomed. From the moment I woke up, to the moment I went to sleep, I was constantly trying to dry my hands. I would compare my symptoms to washing your hands under running water and not drying your palms. This brought me extreme embarrassment. Being a teenager, shaking hands with your friends was a given. But seeing the people you shook hands with wipe their hands after shaking yours was even more embarrassing. To top it off, some people would even ask, "Why are your hands so sweaty?" I had no answer to give them. No explanation on why my hands were profusely sweating and theirs was not. This made me not even want to go to school. I began avoiding people altogether if I knew I had to shake their hand. In addition to shaking hands or giving high fives, it was difficult for me to use touch screen electronics or take tests. With my palms being so sweaty, these simple tasks were not so simple for me. Besides the everyday embarrassment, hyperhidrosis has prevented me from establishing relationships with women that I've had interest in. Furthermore, it has sabotaged relationships that I have been in. My significant others often thought they were the reason I didn't want to hold their hands or touch them. However, they could not understand it was my own self-conscious and fear of rejection. By my senior year in high school, it was time to decide what career path I wanted to take in life. In fact, I based many job choices on jobs that I didn't have to shake people's hands. The constant thought of having to shake my future employer's hand after interviews scared me to the point of skipping out on a potential job. I eventually followed my heart and began a career in the medical field. More specifically, emergency medical services. I started employment as an emergency medical technician for the Fire Department in New York City. A few years later, after a strenuous educational program, I was promoted to paramedic. Over the years, I've acquired tactics to completely avoid shaking hands with my co-

workers and supervisors. However, even though I was successful in my avoidance tactics, I was unable to avoid wearing my protective gloves for patient care. Wearing protective gloves is the most important way to ensure my safety as well as my patient's. So based on the urgency of the patient's condition, putting on gloves has to be extremely fast. The easiest way to explain what I endure is to quickly try to place your wet hands inside large latex gloves. It can be nearly impossible if you have not improvised ways to put them on like I have. Another nuisance I face with gloves is how they act as a reservoir for my excessive sweating. After a short duration, the sweat seeps out from the glove cuff and down my arms. This feeling is extremely uncomfortable. I couldn't even explain how I feel when I see my patient follow the beads of sweat travelling down my arms. In conclusion, I feel hyperhidrosis is overlooked, under-treated and poorly managed. Not only by physicians, but by pharmaceutical companies. Speaking for myself and millions of sufferers that haven't had the courage or opportunity to speak out, we all need real treatment. This includes effective, safe and accessible care. Thank you.

Angela Ballard: I can see many people in the audience are being really affected, so I again just want to thank you, panelists, for all of your sharing because it's clearly so important for everyone. And, just to mention Lucio has created his own iontophoresis machine, which is pretty awesome. But, perhaps, also a testament to the lengths that people are having to go. Christina, you're up next. Thank you so much.

Christina (Panelist)

I'm very sick and I may have the flu, but I needed to be here. My name is Christina, and I'm from Tennessee and I have hyperhidrosis on my hands and feet and other areas. But those are the main parts that kind of hinder my day-to-day life. And I want to kind of create an image a lot of people kind of tell us to deal with it and that it's not a real problem. But I think the people that don't have to deal with it, maybe if they could just imagine for a second. Just imagine if it's a rainy day and you step into a puddle maybe you just get wet and then you go back home and take a shower and you dry off and it never goes away. You're constantly wet all of the time, and it never goes away. For me, in the fifth grade, I remember putting on lotion and this is, I remember exactly where I was and what I was doing. I put on lotion and, shortly after my hands started sweating. So I thought it was the lotion. I thought what type of lotion is this that makes my hands sweat? I wanted to sue the company or something. But, days later, months later, years later, I realized it wasn't the lotion. It was something that's going on. I told my parents about it, and they told me to deal with it. They told me it wasn't a problem, so I didn't even get to go to a medical professional and obviously some of them don't even understand what we have to deal with. There isn't much treatment. The treatment that is out there is too expensive to be a temporary fix. And everybody doesn't have the money to every six months go and get a treatment. So I just kind of just dealt with it. And, I was a very smart child and my teachers would try to high five me and I would have to awkwardly try to find ways to, you know, I became a master manipulator and I had to find ways to avoid handshakes. I feel like I'm a social person, but I was never able to become who I am because I had to learn to stay away from people because people would always shoot me down. "Why are your hands so sweaty?" Even when I was at church, it happened to me. And, it was a very traumatic experience and so, I know I'm not reading off of this. I'm kind of ad-libbing. But the things that we have to deal with, we have to change clothes multiple times. Just imagine going through life that way. Not being able to have a good quality life, and I just really want to reclaim my life, to get it back and to also allow other people who after me, the younger kids, I think there's a baby here that has it, for there to be treatment for them so they don't have to go through life that we're going through. Having to pretend that everything is ok, when it's not. We're going through this battle. We're battling

every day just to do normal things just to talk to people, just to do normal things and it's a really terrible experience. But I really hope that you work diligently and hard to help us because this is a problem that we're facing in the world and we would really like for you all to fight with us and to help us overcome and reclaim our lives.

Angela Ballard: Thank you so much, Christina. And, now Zeb...

Zebulon (Panelist)

Thank you. Wow, I guess we'll continue to feel this way as we keep going today because the stories are so powerful. My name is Zeb. I'm a college professor. I teach history, I teach African American history at a university. As you can probably imagine, so many accomplished people that are part of this and I've been getting such a broad sense from talking to people about the different ways that we all deal with this. My case, sometimes we're in intimate environments working one-on-one with students, I think of cocktail parties or sometimes you may find yourself in a pretty nice environment. A library, a work in archives. As you can probably imagine, sweating can be a problem, you're working with documents, you're sort of in close with people and you know, it comes up. People remark on it. People mention it. I think there's that old sort of sense that when you're talking and you're sweating a lot, sometimes people doubt what you're saying. "Are you lying?" "Are you misrepresenting yourself?" And, when you work in an area where knowledge and the acquiring of knowledge and the sharing of knowledge is part of what you do, that can be a real sort of problem professionally. So I have axillary hyperhidrosis, and t-shirts over the years just thrown in the trash. Nice suit jackets and that kind of thing, someone else mentioned. And, so, it's tough. I didn't write down a narrative exactly. You could call this sort of thoughts on hyperhidrosis. Random thoughts. I think it seems to me that with this kind of condition, it's not life-threatening. Although in some cases, as we've been hearing, it kind of can be. Depending on what the situation is. I think sometimes when you have a condition that is not as extreme as other health conditions, it's hard to dramatize it. It's hard to explain it to people and it's hard to get people to realize and to take it seriously. I had to do a TED talk. That was fun. I was already terrified, my first TED talk. Which was cool. It's nice to be asked to do a TED talk. But if you know you're going to be perspiring on camera and that kind of thing, it's pretty terrifying. I should do a TED talk on hyperhidrosis. That's a good idea. I didn't think of that. I just sweated through the whole thing. That's kind of been some of my experiences. I was also thinking, sort of writing up some thoughts...I always notice on tv or commercials, movies, you don't see people sweating anymore. You'll never see someone in a movie with sweaty underarms and that kind of thing. It seems to me like back in the day, just old enough to remember, I used to watch a lot of reruns. You'd see that in television, you'd see that in movies. You don't see that anymore, and that has an effect. It's sort of like creates like a standard. It's like that fake world we see on television. That becomes the ideal. No one sweats, no one is ever uncomfortable looking, everyone's always clean, and neat looking and that kind of thing. We don't live in that world. It's very superficial, but it does seem to me to have an effect. I also think that there's a culture of bullying that we're in the midst of, and it affects children. It's sort of part of that, too. As a professor, I'm in front of millennials every day. Just because that's at that age. Millennials can be a little bit harsh sometimes on things. They have a little bit of a way at looking at things and so it becomes an issue. It's a little embarrassing. People are worried like, "Are you having a heart attack?" "No, I'm ok, I just sweat a lot." It's tough, it can be tough, but again like I said it's not tough like some other things out there that everyone agrees are just really, really tragic. This is more in that gray area, and that seems to me makes it harder to do what we're all trying to do right now, which is to understand it and talk about

it. I find myself being much more emotional today than I anticipated. Hearing these stories, even the clinical research that was presented in the beginning. It's fact based, you're not supposed to be feeling emotional from facts, but I did. And, what a powerful presentation, so to wrap up that's been sort of my experience. I love the conversations that have been had, people asked me things like, "When did this start for you?" I never thought about that for some reason, like when it started for me. I'm realizing it started about when I was in college and it sounds like that's consistent with the research. Anyway, that's my story, thank you very much.

Angela Ballard: Thank you, Zeb. I think your students are really lucky to have you. And, now Caryn, whose music we've been listening to this morning.

Caryn (Panelist)

Thank you. My name is Caryn. I'm from New York City, and I'm 30 years old. I have palmar and plantar hyperhidrosis. I first learned about my condition during elementary school. I didn't understand why no one wanted to hold my hand in dance class. I asked my mom what was wrong with me, and she said that when I was a toddler, just learning how to walk, I used to leave sweaty foot prints on the ground behind me. And ever since then, I've been excessive sweating. The doctors never mentioned my condition, and there were no treatments. Back then we didn't even know my condition had a name. And little did I know how hyperhidrosis would strongly impact my entire life. Hyperhidrosis makes ordinary tasks a struggle. Handshakes are my nightmare. At a job interview, I am sometimes more nervous about that handshake than anything else, and I watch and cringe as people try to discreetly wipe my sweat off their hands. While people might think my handshake is gross, they'll never fully understand how uncomfortable I feel in my own skin. When I write with paper and pen, the page will curl up and the ink will smear. I don't like holding newspaper because the ink comes right off on my hands and my phone doesn't recognize my fingerprint password when my hands are too sweaty. I have to type in the numbers all of the time. I've even had trouble turning the doorknob with hyperhidrosis. I feel bad if my hand accidentally brushes up against someone on a crowded subway. And I was mortified when I was starting out my first job in retail. When I was cashing someone out at Barnes & Noble someone was buying CD's from me, and they realized all of their items were all wet and they wanted to replace them. So, I'm a classical flutist and my sweaty hands are always an issue. Sweat will drip from my hands all the way down to my elbows while I play. And, often times, I'm concentrating more on not dropping my flute than actually the musicality of the piece. I've rusted my flute several times to the point where a repair person needed to take the flute completely apart to clean and fix it. And, this would happen every few months. And, it's about a \$200 cost each time. The repair person had never seen anything like it. I remember growing up I would be so sweaty and I couldn't get through just a practice session. So to cool my body temperature down, I would fill my bathtub with ice cold water and stand in the tub with my music stand in the bathroom and get through my music that way. Sometimes I wonder if it's possible to reach my potential because of this condition. My fingers don't move as fast as I think they could with hyperhidrosis. And you know flute players need to be very fast. Throughout these challenges, I've continued doing what I've loved, but I never felt like there was anywhere that I could turn to for help. I felt very alone. At rehearsals, I would fan my hands with my sheet music, or ask for a window to be opened. And I always had my towel with me to soak up as much sweat as I can. But hyperhidrosis is persistent and has a mind of its own. It's really hard for me to tell people about my condition and I try to hide it the best that I can. And I think it's actually very harmful in a social way because I'm not comfortable networking as much as I should be as a musician. Hyperhidrosis has made

me become a more introverted person than maybe I would have been without it. And I'm not fully able to enjoy activities and be myself. I'm always anxious about how hyperhidrosis is going to embarrass me next. Today and because of hyperhidrosis has inspired me, I am going back to school to become a special education teacher to help others overcome their obstacles. I currently have the opportunity to teach music to kids who are blind at a community music school on the weekends. And because of their visual impairment, I need to use my hands a lot to guide them. More than once, the kids made a statement out loud for the rest of the class to hear. "Why are your hands so wet?" Or, "Stop touching me." I'm always nervous that the kids are going to say something like this when I'm working with them and make a scene. Sometimes I question if I should have avoided this career because of my hyperhidrosis. And I don't want hyperhidrosis to hold me back, but it definitely would have been easier not to put myself in these situations. The truth is, I do feel uncomfortable in my own skin in a lot of ways. When my hands get extremely sweaty, I don't know where to put my hands. I don't like the feel of the touch of my own hands. This condition affects us all physically, socially and emotionally. And the best chance that we have for a cure and for acceptance is increased awareness and understanding, so thank you.

Angela Ballard: Thank you so much, Caryn. And last, but not least, Sachin.

Sachin (Panelist)

Hi everyone, my name's Sachin and I'm 25 years old. I'm originally from Sri Lanka, but I flew out from the Bay area for this event. I just want to say thank you so much for being here. I truly appreciate your presence. So, I must have been about 7 or 8 when I had my first encounter with hyperhidrosis. I vividly remember being at home and watching tv with my mother, with the AC turned on to keep us cool from the tropical heat of Malaysia. I moved my feet and placed them on my mother's lap and she noticed they were drenched in sweat. Exclaiming something to the effect, "Why are your feet dripping, it's cool indoors." I was so phased by this incident, it made me cognizant of how other unusual ways of my body sweating started to affect my daily life. For example, I'm a left-hander and when I used to complete written assignments in elementary school, I remember having to continually wipe my palm on my school shorts to keep them dry or else I risk my assignments turning into an illegible mess of sweat and lead smudge. However, because this was an embarrassing topic to speak about, I mostly kept my mouth shut and got on with life. Especially knowing how unforgiving kids could be. I remember when I was 12 or 13, the condition had reached a boiling point for me. I recently gone to a school dance wearing a gray shirt and developed large underarm sweat stains. The stains were considerably larger than the size of my outstretched hands. This caused me to panic and I recall crumbling and stuffing my underarms with a handful of paper towels. My wardrobe was thereon stocked almost exclusively with black clothing. And, if I wore a light-colored shirt, I made sure I brought an extra shirt in a drawstring bag just in case my hyperhidrosis set in. My biggest frustration with hyperhidrosis was that it was mostly random and episodic. It was extremely hard for me to predict when I was going to break out sweating. Make no mistake, there were certain triggers that would cause hyperhidrosis such as events that would cause lots of social anxiety or even extreme heat. However, I was also sweating uncontrollably when I was having causal conversations with people or relaxing in an air-conditioned environment. After the sheer embarrassment suffered at the school dance, I disclosed my experiences to my primary care physician. It was a daunting task for my 13 year old self to share this embarrassing issue with my doctor. The

doctor responded with something along the lines of, “You’re living in a tropical climate and are entering puberty, you don’t have to worry about it.” “It’s not important.” His response humiliated me and made me feel like my condition was a trivial matter. I convinced myself that it truly was a hormonal issue that was exacerbated by the tropical setting I was in. I also blamed my excessive sweating on mental or psychological weakness even though I was a happy confident person by nature. I’d gotten through my teens becoming a master in disguising the issue. My first guitar class at 14 with the fretboard all wet and the teacher asked me what the problem was. “Oh, don’t worry, I just washed my hands.” After a handful of lessons, the embarrassment was too much to handle. And I ended up self-teaching myself. Greeting people at social events, “Oh sorry, I just used hand sanitizer.” These responses would often result in an awkward encounter making me a nervous wreck. Creating an excuse was easier than explaining that I had excessively sweaty hands, some sort of medical condition. Especially since I didn’t even know what this medical condition was. Fast forward to my college years, I was in America and it was winter. This was a big moment for me. Was I still going to sweat in the cold weather after puberty had stopped like my doctor so confidently stated? The resounding answer, yes. Not an ounce changed. Sometimes when they got really cold, my hands and feet would sweat even more. How this phenomenon is described physiologically, I don’t know. This prompted me to extensively research excessive sweating. Where I learned about the many forms of hyperhidrosis, and the treatment methods ranging from topical antiperspirants like Driclor and Drysol, two major surgical procedures like endoscopic thoracic sympathectomy. I was a young student not willing to undergo surgery, so I tried my hand at the antiperspirant. It was minimally effective, and also caused pain to my hand. A weird, stinging burning sensation. The minimal benefit wasn’t worth the pain, so I stopped using the treatment. I had then tried various forms of meditation. Perhaps thinking my condition was related to stress or some sort of psychological or mental weakness to minimal effect. Fast forward some years and I came across a clinical trial claiming to treat the effects of palmar hyperhidrosis using heat wave technology. I was so sick and tired of dealing with hyperhidrosis, so I signed up. Was the treatment effective? Kind of. Was the procedure painful and invasive? Absolutely. The doctor injected 20 mils of nerve blocking agent in the base of my hand before proceeding with the treatment. My hand took three weeks to recover, developing painful blisters along the way. At one point, the pain of one of the blisters became so severe and unbearable that I had to resort to draining myself using aseptic technique. And because the treatment was only partially effective, I made the decision to continue with follow up treatments hoping the intense pain and discomfort would be ultimately worth it. In conclusion, I hope my story paints a picture of the childhood hardships one with hyperhidrosis goes through. And the troubles an individual will endure to receive treatment. We’ve been battling with this condition for our entire lives, and I hope this forum will generate the need awareness in the medical industry to develop safe and minimally invasive treatments by top researchers and physicians in the audience so that scared kids like my 8-year old self can one day receive effective treatment without feeling misunderstood or undermined by other children, parents and doctors themselves. Thank you.

Angela Ballard: Thank you again for all of these really incredible testimonies from our panelists. And as we head into the open discussion, I’m just curious who here feels like they heard part of their story? Yes. So for those of us on the web, it seems like the majority in the room. Thanks again to the panelists. So, just a reminder we have these visual aids. We took the survey ahead of this meeting. About 150 people responded. It’s not scientific data, but we’re going to use it to help guide our discussion. Quick

note about the demographics for this survey. Most of the people who participated were from the US. We did have some respondents from Canada, Australia, Greece and the UK. 70% female, 30% male. The age breakdown was about 20% each in people in their 20s, 30s and 40s. About 30%, age 50 or older. And 10% younger than that. Younger than 20s. Race and ethnicity: 65% White, 13% African American, 10% Latino, 6% Asian/Pacific Islander and 6% multi-racial. If anyone wants more information about the survey, we can provide that later. As has come up, we know hyperhidrosis starts pretty young often. So most people in our survey were 10 or younger. So who here in our audience felt that this started in their childhood? Again, majority of people. So you guys really are the experts on this condition. Most of you have been living with it for a very long time. So we're here to talk about first the burden of this condition on your lives, limitations in daily life. Kind of it's overall impact on your daily life and how it's affected your choices. Who would like to kick off our discussion? Would anyone? So, just a reminder our staff will bring you a microphone. Stand, tell us your name, first name's fine.

Open Discussion

Audience Member: Hi, I have craniofacial hyperhidrosis. My question for you guys is I feel like I have from dealing with it, I have gone through like this mental craziness and I know that we all do. I'm just wondering if you have gone into any mental prescriptions or medicine from it other than just the medicine that supposedly helps it? That's my question.

Angela Ballard: Anyone want to respond to that? Any of our panelists? Anyone want to share? This is a throwable microphone for those with a good arm.

Audience Member: Well, I'm not sure what exactly you want me to answer. Whether I've tried medication in that field. Well, social anxiety and anxiety meds, depression meds, bipolar disorder. I mean that's something that my doctor diagnosed me with. She said I have that. I don't know. A lot of it kind of has to do with hyperhidrosis as well. It's sort of intervenes. So, yeah. And I do want to say some of the things I need meds to help me with it a little.

Angela Ballard: Thank you for sharing. Yes, there are some complex issues. So, show of hands who here found that in the past week, hyperhidrosis affected your actions, your planning, your wardrobe. Right? Yeah. Ok, so from our survey, we saw that social impairment was one of the top most bothersome impacts of hyperhidrosis. Would anyone care to kind of elaborate on that? Like some of the social or relationships. How you go to work. Things like that.

Audience Member: Hi, I'm an advocate for inmates in St. Lucie County and I have this problem that when I go into the jails and I sit down because I have hyperhidrosis, I sweat between my legs, that I was very much like the picture that the doctor showed. And so that's embarrassing. You know when I have to get up and leave and um people look at me. Like, "Did you wet your pants?" You know, but also I have to go into the courtroom and I'm in front of the judges and the lawyers and I'm sweating like crazy. Sweats coming out of my forehead, my hair's all wet, and it's very embarrassing. I begin to be shunned. People don't like shaking my hand. It's like I'm the crazy one. Here comes the crazy lady or the wet lady. I'm the drip. So, it's it has impaired my ability to be able to communicate and to have people take me serious. And especially when I'm dealing with the inmate families. So, that's my experience.

Angela Ballard: Those are really important points. Thanks for bringing those up. I think back here in the corner, we have another comment. Thank you.

Audience Member: I've got palmar and plantar hyperhidrosis. It started as a baby. My parents put footy pajamas on me when I was just a couple of days out of the hospital and I soaked through them. So they took me back to the doctor. And thankfully that doctor kind of instinctually knew hyperhidrosis. He didn't know what to do about it, but he knew what the issue was. And this has affected me in school, in my education. People look at me differently. I oftentimes just try to be the last one out of the class, so I sit in my chair a little longer so somebody's not looking at my chair like, "Why is her chair all wet and why is her table all wet?" I, uh, actually in high school, I withdrew myself from school and I was the top of my class. I put myself into an independent study so that I could put myself through school and go at my own pace. I actually ended up graduating when I was about 2 months before my 16th birthday and I graduated with my high school diploma, but I didn't have to deal with the embarrassment of sitting through school with my sweaty hands and my sweaty feet and my sweaty legs. Then college came around and I was a 16 year old in college. And, I didn't really know what to say to my professors when I couldn't keep up with the note-taking because I didn't have a disability that would allow me to have a note-taker and whether I used my computer or I tried to handwrite. Either way was difficult for me to keep up. I would constantly have to stop. By the time I would pick up my pencil again or my keyboard again, the professor is way far ahead of me. And you know professors have different ways of doing things. Maybe they upload their notes online and I can look at them afterwards and just sit and listen to the class. But, it wasn't something that they would recognize as a real issue in my classroom. And, something that affected me and I eventually didn't end up keeping up. I went to 3 years of college. My plan was to get my PhD, but I ended up finding another path. I became a private investigator as an independent contractor so that I could do my own work and make my own work. That way, I wouldn't have to deal with the pressures and the social anxieties of other people and what they may think of me. Because that first handshake just like Caryn said, I'm much more nervous about the handshake than the interview itself because I'm very confident in myself and what I can do and my knowledge and who I am. But that first handshake is terrifying and it really uh, it just sets the stage for everything.

Angela Ballard: Thank you.

Lisa Pieretti: Ms. B.R., I was just wondering if you could share. Tell me, because I know you so well. I think everybody's feeling a little shy, maybe even a little chilly today. But, when did your hyperhidrosis start?

Audience Member (B.R.): My hyperhidrosis started when I was way, way little. But when I first started going to kindergarten. I would have to put a white handkerchief under my hands and I was going to Catholic schools, and the nuns would come by and hit my knuckles because I had this white thing underneath my hands. Then I would put a piece of paper as I grew older, I put a piece of paper under it. Then I would get accused of cheating. So the teachers really didn't have very high remarks towards me. And they would tell my mother that I would never make anything of myself. So, when I graduated from high school, I wanted to go to college and my mother said, "No, you're too dumb." And I never had any friends. During school, I was always the outcast. I was just, you know, nobody wanted to hold my hands. And that thing about Ring Around the Rosie, I did that so many times. I just finally, I just would hide. And I kept to myself. But I know what the depression is like. It has affected my whole life. It's something that I had had to deal with.

Angela Ballard: Thank you. Thank you so much for sharing that.

Lisa Pieretti: And, Ms. B.R., that you're a new friend to us at the International Hyperhidrosis Society, and we got to know you because of a clinical trial that you tried to enroll in. And were you able to be in that clinical trial?

Audience Member (B.R.): No, I was not able. Lisa returned my telephone call. I was at my wit's end and I was just crying and my husband said you've got to do something. So I started calling around to the doctors in Port St. Lucie, and nobody dealt with it. And so they told me to call the International Hyperhidrosis Society. Anyway, Lisa returned my call and I was just crying my heart out to her. So she gave me this number to call about a research study. So I called them, and I was too old to be in the programs.

Angela Ballard: Thank you. We'll be talking more about clinical research and people's experiences with that in the second portion, too. So, thank you for bringing up that really important point. We'll go here first and then over there. It's great to see everyone's warmed up.

Audience Member: Good Morning everyone. First of all, I want to thank everyone for actually sharing their stories and the reason why I say that is because dealing with this condition it felt like at one point I was pretty much the only person that was actually dealing with a condition like this and I didn't know anyone else that was actually dealing with it. I had friends who I would always shake hands with and they would look at me and say, "Man why are your hands always sweaty?" And I never had a comeback for it. But, I'm not gonna keep you guys too long. But I would share a little bit of my story. When I was about 17 years old, I found out that I actually had hyperhidrosis, which I didn't know exactly what it was at the time. But, I played football in high school and I was a quarterback and I could never be able to grip the ball when I turned 17 or 18 and I was trying to figure out exactly why my hands would always sweat. And I'm from Georgia. If anyone knows in Georgia, it's very hot and it's humid on Friday nights. And, so, so I couldn't grip the football. I would always use the stickum that you actually put on your cleats when you're trying to tape your ankles up, and I would use that to actually be able to throw the football. And so I started doing a little bit of research and end up figuring out that this is actually a disease and something that I was gonna be able to have to deal with through my life. So once I did research, I reached out to Lisa one day just you know throwing something out there because I was going through the internet each and every day trying to figure out exactly what was wrong. And she ended up inviting me and my family to Atlanta so we could do one of the researches. And for the 6 months, I did the Botox and it was great. It really helped. But after that, I really couldn't afford to actually continue to do it. So, since then, that was about 3-4 years ago maybe, I've been dealing with it ever since then. Like I said earlier, I really appreciate everyone sharing their stories. I could probably go on all day talking about situations that I actually have. Of course with me working in an environment where I have to shake hands each and every day, it's very embarrassing to have to go up and shake someone's hand and feel like you're confident. Then as soon as they wipe their hand somewhere then you say, "oh man," you know there goes and then you know you have to run into the restroom and go wash your hands and stuff so you can try to gain that confidence back. But I really do appreciate Lisa for inviting me and my family out here so we can try to tackle this issue and deal with it.

Angela Ballard: We appreciate you being here. Um, Caitlyn, is there something going on in the web you want to let us know about?

Caitlin McDonald: Several friends from all over the world who are listening and on the webchat and we have Australia and India and they're on a 30-second delay, so they're hearing things a little bit delayed

as far as this goes. We've had some good questions and I thought I would ask for them. One of them was, "Are there ways that we can cover the cost of insurance and decreasing the cost of these drugs that many of them cannot afford and it's covered, but the copay or out of pocket expense is so high. Is there any way that we can advocate for that?" That's one and then because some of our friends are worldwide, they also are asking about chapters in different locations because even if they were able to get here, the cost of the plane ticket wouldn't be covered. And, then a huge issue that they're all sharing from childhood on, a lot of them are saying they suffer mentally and they really want some help and it's really affecting them.

Angela Ballard: Obviously we're bringing up some really powerful issues and emotions and I do want to reiterate that we do have information about that Suicide Prevention Hotline if someone needs more professional support. In terms of cost of treatment, that is a frustration that is pervasive and we will probably touch on that more in our second session when we're talking about treatments more specifically. Lisa, I think, will touch on chapters perhaps? Yes, we are an international organization, so we do expand our reach globally and we do sometimes travel to other countries. Let's get back to impacts. There were 2 women at this table right here that were anxious to share. Thank you so much for your patience.

Audience Member: Hi, I wanted to tell you about my story. I have hyperhidrosis of my hands and feet and it's been a major impact on all aspects of my life. I can't remember a time when I didn't have it. I have the same Ring Around the Rosie story that other people said so I remember back to kindergarten. In school, I was never able to write without a towel under my hands and at 6th grade graduation, one of my so-called friends wrote in my autograph book quote "Dear mushy fingers..." then drew a picture of a sweaty hand with water dripping from it. Hyperhidrosis affects me on a daily basis. Shaking hands is an embarrassment. Because my hands and feet sweat so much, I plan my vacations to avoid hot humid climates. I don't go anywhere without paper towels to absorb the sweat. I'm unable to wear boots, they're too hot. And, unable to wear sandals, my feet slip right off them. So choices for my everyday wardrobe are dependent on what I can wear on my feet. My career choice was very much impacted by hyperhidrosis. I'm a retired diagnostic radiologist. But I started my career as an internal medicine physician. I changed my specialty because of my difficulty examining patients. My hands were always very wet and cold and it made for a very uncomfortable situation for both my patient and myself. I also want to note that hyperhidrosis was never mentioned when I was in medical school. I never heard of it. My recreational activities have also been dictated by hyperhidrosis. I love to dance, but it's difficult to find dance partners who will ask me to dance more than once. It's embarrassing and also difficult to dance because my hands are so slippery. I was never able to play tennis because the racket slipped out of my hands. I couldn't participate in gymnastics because my hands would not grip the equipment even with chalk on them. And my feet slid right off the balance beam. When I knit and crochet, I have to wear gloves and yoga is not possible because I slip off the mat. I know that studies have suggested a hereditary component to hyperhidrosis. Both my parents and my brother suffer from it, but are not bothered by it now. Maybe I'll grow out of it. I can only hope. Thank you.

Angela Ballard: Thank you.

Audience Member: I'm from Dallas. I've had hyperhidrosis my entire life. And I feel like I have a lot of the same things that everybody has been saying. But one thing that I want to mention that I haven't heard today. But I have talked to some of you about it last night and this morning. I feel like when my

hands start sweating, even though we're in a cold room like this, and it helps it kinda slows down a little bit. But because my hands are still damp, my fingers get very, very cold. Like ice cold and sometimes it even gets to the point where it's painful and I feel like that's important to mention because it's not just I feel uncomfortable, but I'm actually experiencing pain in my fingertips from the coldness so I just kinda wanted to throw that out there and see if anyone else has that or at least let the drug makers know that this is another important thing to think about.

Angela Ballard: Yeah, who else, raise your hand. Who else gets extremely cold? Yeah. Cold and uncomfortable.

Audience Member: Ok, I'm going again. I'm going again. So, about daily activities and life, I'm a dancer. Hi, I'm a dancer, I do it for a living. And, what has been the craziest thing is that the Lord has chosen me. This is my calling. I feel like dance is how I express myself, but um, the stage and the lights and the people looking we all get nervous. All of my friends get nervous. They've been professionals forever. They get nervous all the time, but I get nervous and I sweat crazily. Like over my face, everywhere. And even though I keep seeming to get opportunities, I don't feel happy with them because I am still trying to be dry. I am the life of the party, I'm always laughing, I'm always talking but I'm also known as the person that you can't really depend on. He doesn't really like to communicate. But those are because I don't want to put myself in positions where I have to cover up my sweat. I feel like I'm a master of cover up. Like I need to make sure when I walk in the room, I need to know where the bathroom is, where the exits are. I always have my handy trick all the time, even now. I recently got on the poster of my company. My picture, yep. My picture will be everywhere in New York City, and you would think that I would be like, "Yes, it's me, it's me." I am terrified to see myself or to walk through the train and have someone notice that it's me and ask me "Is that you?" I don't know what's going to happen after that. I'm terrified of being seen because I don't like the way that I look when I'm sweating. I don't see myself doing anything else. I have to dance. I wake up thinking about dance. Dance, dance, dance. Like even yoga, I like to take hot yoga where everyone's sweating. So, it's fine. So, I've made necessary precautions like we all have done, like we all do to help deal with this. And, I don't want to anymore. I feel like I would be a better dancer. I would be a better person if I didn't have to deal with it or learning. I feel like all of us want a cure, yes, yes, that would be like the greatest thing right now. But I feel like a way of dealing with it for me. I keep hearing palmar, I haven't really heard about craniofacial at all.

Audience Member: I would like to speak for those of us who do have craniofacial hyperhidrosis.

Audience Member: Yes, please take it.

Angela Ballard: You're right, we need to talk about craniofacial. And we'd love to hear you share on that.

Audience Member: I'm a sweater. I have craniofacial hyperhidrosis or whatever you want to call it. The reason for my being here, and it's, Lisa thank you so much for making this possible. I live in New York City as well. I don't live in a car society. I walk and I take public transportation, so I can't hide behind an air-conditioned car. I was born this way. I do not thermoregulate like average people. I walk on the streets of New York City. Buses and subways, and never see anyone like myself. Coming here and having met Mary, having met these girls. People who actually understand what it is that I've lived with since I'm a child. I've been asking for help, begging for help for over 50 years. And, have been

disregarded by the medical world. Nobody cares. Nobody cares. I have been fluffed off since I'm a child. "Oh, she's hot." I'm hot? I've lived my life with folded up squares of paper towels and hand fans. I've got them like flowers in vases throughout my apartment. I mean fans, air conditioners, there is not moving air. Right now, it's really chill in here. I mean to the point where, yes, when you don't thermoregulate, you can go from thinking my head is going to blow off my shoulders to having to run around my apartment 20 minutes later with a sweatshirt with a hood up around my head and gloves on like a nut. But this is how it's living your life from a place of extraordinary humiliation and embarrassment. Not to mention the discomfort. The thing about craniofacial hyperhidrosis that is not addressed, I'm the one who wrote I am a human volcano. Because I am a human volcano. Whatever this is, it's not necessarily about the sweat. I hate the sweat. I hate the fact that I can feel what it feels like to follow this eruption. I mean it just it stems from within. And it crawls up your entire body and blasts through your scalp and your face, dripping rivers, rivulets dripping down your face, down your neck, through your hair, down your chest. Bright red. I cannot make eye contact with people on the street anymore because here's my story. Post menopause it has gotten so much worse that I can oftentimes not leave the house. I lost a job because the universe tells me I'm old. And I can't even go to a job interview because I cannot get from Point A to Point B without looking like an alien. I show up everywhere with a hand fan like a nut. With a hand fan and paper towels, you cannot cool down you get where you're going. I have to plan to go places 20 minutes to a half an hour before I have to be there, find someplace air-conditioned, sit down, fight tears and hope that I can thermoregulate to a point where I can actually have a conversation because when you get that hot, you cannot think. You cannot, I can't form sentences. I never leave my apartment, I never get from my apartment door to the elevator without blowing a gasket. I cannot, I never walk into my apartment building. I never ever, ever get home without being on the verge of tears. So hot that I can barely think, and so embarrassed that I'm going to have to face somebody and have to explain. Because I have to explain all day, every day. Someone's going to say something to me. Tired of it. I'm tired of it. When you talk about anxiety and depression, this has ruled my life. It has ruled my life. It has, my career was kind of intimate even though I worked in factories whatever it is everybody has always known that I'm the woman, I'm the girl with the fan. Can you even imagine being the only person in Asia, in airports, I'm the only one with a fan. I'm in China, I'm the only one, I'm looking around this airport, I'm the only with the fans going.

Angela Ballard: I'm so glad you brought up craniofacial, and it reminds us that we do need to talk about plantar. We have about 5 minutes left. So, thank you so much for sharing. You brought up such valuable points. Thank you. So, I'm wondering if Ms. K.A. would be willing to talk about her experience with sweating of the feet, plantar hyperhidrosis. Is that ok?

Audience Member (K.A.): Absolutely. I'm from Omaha, Nebraska. I have had hyperhidrosis, plantar, palmar, axillary. I just sweat. I'm just a sweaty one. Since I was, since I was very young. I remember at 12, I think that's because when you start realizing that you're socially awkward. Versus when you're younger, and everyone's weird. So, my feet sweat so much and I love cute shoes. Really love cute shoes. But I can never find them and I can never keep them because my feet sweat so much. It's not worth the investment. So, I'm like orthopedic shoes, yay! Absorbent socks, you know you just have to overcompensate in so many different ways just to get through your days. When it comes to the depression aspect, yep, I'm medicated. Because it's hard to, you have to pretend that everything is normal through all of your days, and it becomes overwhelming and exhausting because you can't be you because who you are it's not acceptable. With my plantar sweating, I can't wear sandals like many of

you. Once I found a pair of flip flops that had like the wicker, woven pattern and I loved those things and I wore them out. But those are the only ones I could wear where my feet wouldn't slide. I've twisted, sprained, darn near broke my ankles from trying to wear just regular shoes. Trying to be barefoot in my house. Where it's a danger, where I can't, I don't feel safe being barefoot. Or I don't feel safe wearing shoes. It's like what are my other options when you have such limited resources?

Angela Ballard: Thank you. You know, I think it's really important to bring up the safety issue because that's something that we've heard before that there are aspects of excessive sweating that bring up safety issues. So we only have a couple of minutes left. I'm so sorry. Just want to talk about this slide very briefly. What worries you most about your hyperhidrosis? And you guys can see some of the responses. A common worry is that this is something that one will pass onto their children. So I was wondering if...Ms. D.C. had sent us a great family tree. Is Ms. D.C. here? We only have like 2 minutes. Can you just talk about how it's impacted your family?

Audience Member (D.C.): Absolutely. My parents do not have it. My sister has both plantar, palmar and under her arms (axillary). The interesting...my brother never got it. However, I have 2 daughters. One has it, my granddaughter has it. She will not wear shoes. She will not wear socks. Her feet will be ice cold, and she will not put on shoes and socks because she cannot handle the sweating. She's 18 months, by the way. I have a brother who has 4 children. His oldest daughter has it. She profusely sweats under her arms to the point where she was a nurse and quit and is trying to figure out what to do with her life. He has a young son who's had it since he was born. So, we have it through our family. My sister has 3 children. Only 1 daughter has it. None of her grandchildren have it. So, we don't understand what's causing it, or what's happening. The interesting thing is my daughter married a man who has no history of it in his family, but his daughter has it. So they, between the two of them, because my daughter and he's passing it down, their children are having it, so my grandchildren now. I have it so now I think its interesting to have it and from my perspective, I didn't know what this was. We just all have it. Because I had it, I could tell my daughter. I could help her get through, what was this, right? "Mom, what did you give me?" And, she can pass it on and help her children because its not fun and I really appreciate everybody today because it's something you don't think you're all by yourself. I had no idea that anybody else had it, I had no idea. So, it's been really important to me to find out that we're not alone.

Angela Ballard: Thank you so much, Ms. D.C.

RETURN FROM BREAK

Lisa Pieretti: All right, every minute is a precious minute for us here today. All right. We're all settling down. Phones are off, right? Vibrate or turn them off. Put them in airplane mode. Okay, I know all of you have so much more to say. So, when we do the open discussion later we're going to try to clip through it so that every voice is heard. But at this moment, I want to welcome you back to Topic 2. Each of our 5 new panelists will present a personal statement regarding their hyperhidrosis treatment journey. We will hear from each of the 5 panelists and then we will have the open forum for audience members to share as well. Please welcome Angela and our second panel of hyperhidrosis experts.

Angela Ballard: Great, so our topic for this second session is current approaches to treatments and we will also talk about the downsides to current treatments and hopes for the future. We're going to start

with our esteemed panelists. And with: Samantha, Eric, Michelle, Megan, Wendy and Sophia. And, we'll get started. Samantha, thank you for being here.

Samantha (Panelist): I do not remember when I was diagnosed or when I first heard the word hyperhidrosis. But, like most of you in this room, I have suffered from chronic excessive sweating for my entire life. However, after years of misunderstanding and trial-and-error, with numerous treatments, I am finally on a path to better understand, treat and cope with my primary hyperhidrosis. Since there's no known cause, hyperhidrosis is often not widely known to or understood by healthcare providers. As a child and young adult, doctors prescribed treatments with little or no success. I've tried topical aluminum chloride products like Drysol, iontophoresis, Robinul (an anticholinergic). I even tried herbal remedies, but ultimately none of these treatments was effective. Experimentation was frustrating for my family and me. I had to determine what specialist to see, how long to wait to see results, what each treatment would cost, how much time it would take, and in general know who would have the best answers. About 15 years ago, the dermatologist suggested treating palmar hyperhidrosis with Botox injections. At the time I was ineligible for insurance, so the amount used was minimal and therefore had only a moderate effect. However, this opened a new path and for the next several years, I would experiment on and off with injectables in my hands and later my feet and underarms. I saw many physicians who administered this treatment, but the results were less than satisfactory. More than once the dose was too low. Other times the injections were so deep and caused severe muscle weakness and pain, even more debilitating than the excessive sweat. I also had successes and failures with insurance authorizations, reimbursements and appeals. Sometimes they were covered, sometimes not. And found many doctors unwilling or unable to advocate with insurance companies on my behalf. In between treatments, excessive sweat always returns. Water drips off my feet and hands, invisible sweat beads, shoes slip off my feet, body temperature issues develop when a dull sweat penetrates for several hours causing my fingers and toes to swell leading to an overall discomfort and chill throughout the body. I was discouraged until I connected with the International Hyperhidrosis Society and had the opportunity to participate as a patient volunteer for physician's training workshop for treatment of hyperhidrosis. I participated in 2 events, one in Boston and another in Atlanta. Dr. Rice. Everyone thought it was ridiculous to travel from New York, but to me it was worth the time, effort, money and overall experience to work with an organization dedicated to this condition. At these sessions, knowledgeable physicians administered the treatment using techniques I had never before seen and took a hands-on approach with patients, truly understanding their individual needs and concerns. They knew how many units of Botox to use, how and where to make the injections, techniques to minimize pain and prevent or reduce post-treatment muscle weakness. Because of my success, after years of hits and misses, I decided that going forward I would go to Dr. Pariser's team in Virginia for my Botox treatment. I live in New York. So now multiple times a year, I make the trip to have injections in my hands, feet and underarms. The treatments have been extremely effective and the sweat, which negatively affected my life for so many years has stopped or diminished. Well, it is a far distance to travel, I'm willing to make the effort to go where I need to go, do what I need to and suffer through any pain or side effects. Notably muscle weakness and its effects just to have relief. This has all become my new normal. However, since Botox is not a cure and its effects wore off after a few months, I started experimenting once again with an anticholinergic during the interim periods. This time it has been successful. I am dry. However, this too is not without its side-effects. Constant and severe dry mouth, difficulty urinating and more. I'm well aware that all of these treatments are temporary remedies, they are not cures. My journey is ongoing and likely everlasting. And, I know that if I stop treatment at any

time, the sweat will come back. There's also the uncertainty of any long-term effects of medication that I may conceivably take for the rest of my life. I am fortunate to be able to travel for treatment, and to have insurance coverage that alleviates a significant financial burden. However, that is subject to change at any time. In the past, coverage was denied only to be re-approved the following year with no explanation. My prescribed dosage of Botox is currently covered, however, at a higher specialty drug co-payment refilled 3 times per year. Plus, multiple co-pays for doctor's visits. My hope is one for healthcare professionals to research and understand all aspects of the condition to learn, study and be trained on the best practices for diagnosis and treatment. And two to have insurance companies cover treatments like Botox and to make sure that they cover enough dosage and with enough frequency like they would for any other disease. The same opportunity should be afforded to all sufferers.

Angela Ballard: Thank you so much, Samantha. That's really well said. And, now, Eric.

Eric (Panelist): My name is Eric. I'm a fourth-year medical student. Hyperhidrosis has created a daily impact on my life. Causing me to create new routines, do extra planning, and always be thinking one step ahead as to how I can control my environment to avoid being drenched. My journey with hyperhidrosis began back in middle school when I noticed that I was the only person at the middle school dances who couldn't stay out on the dance floor. Song after song without needing to step away, cool down, or wipe my face and head in the bathroom. The first time I tried to stay out just like everyone else, I got comments that I look like I just got out of the swimming pool or just took a shower. Because my hair and face were soaking wet. I tried to not let it get to me. But it definitely impacted my social interactions at the time. My new routine for those events was to alternate dancing for a song then retreat to the bathroom for a song to keep things in check. Some people probably thought I had some sort of issue with going to the bathroom so often. But, it was better than the reactions I would get by visually being soaked in sweat. My instinct was to avoid or flee situations where the sweating became an issue, so I missed out on some important moments with friends. But, overall, I felt like I still developed strong, lasting friendships and that the impact of hyperhidrosis was manageable. My first treatment for hyperhidrosis was using over-the-counter SweatBlock wipes that my dad purchased for me from an online Canadian pharmacy. He had noticed and we briefly discussed that I sweat easily and excessively, but we didn't have a label for what it was. I just figured that I was slightly different in that capacity, and there's something simple like a wipe that could fix my issue. Life went on and things really didn't change, even in high school. While playing on the Varsity soccer team, I was the only one who was sweating while stretching and during warmups. I figured since people sweat while they play soccer, it was no big deal that I was sweating a little bit earlier and a little bit more than everybody else. I was in tip-top shape then, running at least 7 miles a day. So, sweating was not due to a lack of conditioning. The social impact throughout high school was similar to middle school and I kept using the wipes, which still weren't available in the United States. And, they've helped maybe a little bit. As I was about to graduate high school, my dad had heard of this doctor in St. Louis who would inject Botox in order to stop sweating. As a high-schooler, my only knowledge of Botox was that it was the thing that people use to stop aging and prevent wrinkles from developing. Interestingly as a fourth-year medical student, soon-to-be a physician, many of my classmates now share the same understanding of what Botox is used for as I did back in high school. I can also echo the fact that hyperhidrosis was never mentioned once in our medical school curriculum. So my dad asked me if I would be interested in seeing this doctor in St. Louis, and considering a Botox treatment to help with sweating. To that point, I had never approached any physician about this "problem" that didn't even have a name or diagnosis. Unaware

that it was actually a medical condition, I went out on a limb and agreed. One Friday morning, we drove six hours to St. Louis from Cincinnati where I met Dr. Glaser for the first time. I told her my story and she had so much understanding and compassion for what I was going through. She agreed this sounded like a condition called hyperhidrosis, and offered to treat me with Botox given that I didn't find much relief with the topical wipes. My variant of hyperhidrosis is craniofacial, meaning it's my face and head that sweat excessively. I do not have issues with underarm, hand or feet sweating excessively, which is extremely debilitating to others. The focus of my issue is that your face is the first thing that people see when they meet you, and it's the thing that they remember you by. I sat on the exam table and Dr. Glaser turned up the temperature in the room. And almost instantaneously I began to sweat. So she observed where I was sweating from, and focused her treatment on those areas. I was repeatedly stuck by a need as the Botox was injected. The feeling of being stuck nearly 100 times sounds crazy to do willingly, but if it would provide relief, I was willing to do just about anything. A few thousand dollars later, we got back in the car and drove back to Cincinnati. I didn't feel any difference at first and was unsure how I would know if the Botox was even working. Within just a few days, I began to notice I wasn't sweating in situations where I used to be sweating. And situations where it was completely normal to be sweating, for example, playing sports, the sweating was similar to everyone else. After years of feeling like my body had a broken thermostat, I finally felt normal. I was incredibly relieved to find a treatment that would work for me. It is great that companies have developed prescription-strength antiperspirants, but these are designed for use in the underarm only. Not on your face or in your scalp. And if you have hair, like me, it is really difficult to apply an antiperspirant to your scalp. I was so encouraged that this treatment worked so well, but the effects started to wane at about 4 ½ months. I found myself right back where I was before I got my first treatment. Why can't I just go get another treatment? Oh yeah, the closest doctor is a 6-hour drive so it's not very accessible and it costs a few thousand dollars because it's paid out-of-pocket since insurance didn't cover it at the time. So, it's not affordable. That was convincing enough, and I was fortunate to have had those few months of feeling normal and having relief so I face the reality that I would have to live with this condition that I at least now have a name for. For the next few years, I used a combination of at least two topical wipes or gels at least once a week. I felt that the additive effect of using a SweatBlock wipe before going to bed and using 3B Face Saver Gel would give me some layer of relief, but nowhere near as effective as the Botox. Right before graduating college as I was about to be interviewing for jobs, which I was terrified about doing, my dad agreed to pay for one more treatment by Dr. Glaser if I was up for it. The drive from Nashville to St. Louis was shorter than from Cincinnati, but it was still going to be a trek. That particular treatment was incredibly worthwhile because it allowed me to go off and confidently interview in cities or around the country for jobs without the fear of being judged by the sweating effect on my personal appearance. After getting a job in Atlanta and subsequently being accepted into medical school, I found out that seeing a dermatologist in the State of Georgia is the same as seeing a primary care physician in Georgia. No referral is required. As soon as I found out about this, I looked up dermatologists in Atlanta on the International Hyperhidrosis Society website and came across Dr. Rice. My initial consultation with Dr. Rice was extremely comfortable and I shared my journey with hyperhidrosis again and Dr. Rice was incredibly understanding. Especially knowing that I was in the throes of medical school at the time. Since Botox worked in the past for me, she was willing to offer me that treatment which is now covered by insurance with only a \$30 copay for the drug itself. Until I could get in for that first treatment, she offered me an oral medication that would help prevent all secretory glands in the body from being overactive. The downside from this is that it dries you out globally. So

just because you don't sweat as much, you also walk around with a dry mouth like I am right now. Side effects like this may be an annoyance, but my approach is still just to accept them if I am provided relief. Ideally, some day there will be a treatment that's as effective as Botox, but without the repeated needle sticks. Something that doesn't require daily application like remembering to take a pill or using wipes. And doesn't have the systemic side effects like the pill. Something that all patients with hyperhidrosis can use in their variable applications. Not just treatments focused on the underarms. The ideal solution I envision at this moment is a Botox wipe that only needs to be applied every few weeks or months. And, finally, a treatment that is covered by insurance, is widely accessible to all patients, and doesn't cost an arm and a leg would all make a difference, too. At least for now there's a strong community of individuals that get what we are experiencing and are making the best of the situation. Individually, we can have hope, but together we can create change. Thank you.

Angela Ballard: Thank you, Eric. You're going to make a very fine physician. And, Michelle...

Michelle (Panelist): Thank you. So as I begin, I see that there is an empty table right in front of me, and I would invite anybody who doesn't have hyperhidrosis, if you'd like the full experience, to come down and sit in the 'splash zone.' So, I have hyperhidrosis on my hands and if I gesture, I can fling sweat to that table. So if you're interested, feel free. So, my name is Michelle. I am a litigation attorney out of Pennsylvania. Typically that's not the first thing I start off saying when I'm in a room full of doctors. Because immediately the thought from the doctor's perspective is, "Well, do you practice malpractice? Do I have to worry about you suing me?" And it creates kind of an awkward doctor-patient relationship, but you get the same impact when you walk into a doctor's appointment for the first time and you say "I have hyperhidrosis," and the doctor doesn't know that term, hasn't had a patient that has hyperhidrosis in the past, and you say to them, "Well, I want you to treat me with Botox and stab me in the hand a hundred times." The doctor panics, and really we need to increase education, increase training so that that situation isn't arising for people with hyperhidrosis. But, the patient, the mindset that they're bringing into that room is very different than the doctor who is there to treat the patient. Lisa said it the people in this room with hyperhidrosis are the experts, and when the patient is the expert rather than the doctor, that's a difficult situation. People with hyperhidrosis are desperate for treatment. We are desperate to find relief. I was talking to a group last night who I met for the first time, who also have hyperhidrosis, and I posed a question to them and I'm going to pose this question to the individuals in the room right now that have hyperhidrosis. The question is, if I had a treatment available right now that would stop your hyperhidrosis, stop your symptoms permanently, but the catch was you had to cut off your pinky finger, would you do it? Raise your hand if you would. Take a look around the room. It's crazy if one person would have said "yes" to that question. But here we are, there's dozens of people that would be willing to give up a finger to find a treatment, an effective treatment for this condition. That's what we need, we need something that will help everybody get through this condition, live their lives, but without the need for having to cut off a finger to do that. I want to talk terminology, and I'm not talking about medical terminology. I'm talking about everyday terms that people with hyperhidrosis understand. For example, how do you describe somebody with hyperhidrosis? Does that person live with hyperhidrosis or does that person suffer with hyperhidrosis? Suffer, exactly. So I have fair skin, I have freckles. I live with freckles because that doesn't affect my day-to-day life. It doesn't affect when I get in the car and have to drive from point A to point B. It doesn't affect when I have to shake someone's hand. It doesn't affect my day-to-day living. People with hyperhidrosis are suffering. In everything they do. You heard from so many people, and I think everyone in this room could relate to

those stories. We truly are suffering with hyperhidrosis. And it's because there's not enough treatments available, there is no insurance coverage available. We really need to make a change and get the help that is desperately needed. Another term is "manage" and that's somewhere in between living with a condition and suffering with a condition, is managing a condition. My dad has diabetes, and he manages his diabetes. He takes oral medications and really for day-to-day, he is not impacted by his condition. He's able to manage it. There's another term that's similar to manage, and that's "make do". I think most of the hyperhidrosis treatments available really allow us just to make do with the condition rather than actually manage the condition. Botox is temporary. I have had Botox a couple of times. It's painful, it's expensive, it's not covered by insurance and really that is a treatment that's allowing people to make do with the condition rather than manage it because it's cost-prohibitive. People have to travel far distances to have access to it. The iontophoresis treatment, that's another kind of make do treatment that is available. And, it's great that these treatments are available. That there's something out there so that we're not suffering. At least we are making do. But, those of you that have the ability to work on these products, to support the research, please push the products from make do to manage. Because that's really what we're asking for is to be able to manage in our day-to-day lives. The iontophoresis treatment you really have to have the time in your day to sit down and do 20-minutes per session, and it's really longer than that because you have 2 hands and you can't do 2 hands at the same time because you have to have a free hand to work the equipment. So, it turns into a 40-minute procedure or longer than that. And, it's multiple times per week. People really don't have that time in their schedule so that's another option that is just helping people make do rather than manage the condition. Another interesting response I've gotten from doctors is, "Well, I understand you have this condition, but it's really not that bad. You don't have cancer, you're not dying." Well, no one in this room is saying that they're dying from hyperhidrosis. But, how is that an appropriate response when I say that this is the medical condition I have? If I walked into a doctor's office and said, "I have acne" or "I have allergies," the response would not be, "Well, it's great you don't have cancer." Why is that an appropriate response when somebody is saying, "I have hyperhidrosis"? We are seeking out something to help us manage this condition, and get away from suffering with this condition. In terms of impact, I have had various treatments, but I am still impacted by my hyperhidrosis. Yesterday, for example, we had a meet and greet where we were able to interact with some of the other individuals that are here with hyperhidrosis. We were here for a couple of hours and after that, I went up to my hotel room and I had a wet stain under my shirt. Under my arm. I have hyperhidrosis under my arms, on my hands and on my feet. So, I was scheduled to meet up with my cousin later that evening. My cousin is in Virginia, and I thought great opportunity. I have a little bit of time, and I can meet up with my cousin. So, I went up to the room and I grabbed the hairdryer, and I took my sweater off and I used the hairdryer to dry the wet spot under my arm. I didn't have a change of clothes. Coming in from out of town, I didn't have anything else I could use so I was forced to use the hairdryer to get through my day, and manage in that situation. I met up with my cousin and he said, "Oh, what are you doing in town?" And, I said "Oh, I'm here for a conference." And, he says, "Oh, well what kind of conference?" And I said, "Oh, it's a work thing." In that situation, I lied to my cousin rather than telling him the truth. Rather than saying, this is what I'm here for and having to explain to my cousin that I suffer from this condition and explain to him what it was, I lied to my own family member. So here I am talking to a group of strangers more comfortable explaining to you guys what I'm going through. And I couldn't tell my own family member that this was why I was down here for the weekend. My journey started when I was a child, before I knew the term hyperhidrosis. Before most doctors knew the term hyperhidrosis. Doctor after doctor, I

went to. I was telling them what the term was. I was telling them about the condition. I became a member of the International Hyperhidrosis Society very early on, and have been blown away by the research and the efforts they've gone to to promote people with this condition and the changes that need to be made. The most common treatment option that didn't work for me, that I was given from doctors was, "Well, you're young why don't you wait and see if you'll grow out of it?" Well, I'm an adult now, and I'm still waiting to grow out of it. That treatment did not work. Another treatment that I kind of came up with my own, was encouraged by doctors to use, was white cotton gloves. Every day when I came home from school and had to do homework, I would put on my white cotton gloves so that I could use a pencil and not sweat through the piece of paper and get my homework done. The problem is with white cotton gloves, you can't go to school as a child and wear gloves all day long. It's just not socially acceptable. I can't go to work and wear white cotton gloves all day long. It's not socially acceptable. So this treatment, for me, just helps me make do. It didn't really help me manage my symptoms. I tried all sorts of topical creams and ointments, and various different instructions that the doctors gave. Put it on at night, you're not going to sweat as much at night, wrap your hands in saran wrap after you put the cream on and go to sleep like that. I tried all of that unsuccessfully. I did have Botox twice under my arms, once in my hands. Again, it's a great option if you can afford it, if you can maintain it. For me, it's one of those things that is for special occasions. When I was planning a wedding, it was factored into my wedding budget to get Botox injections on my hands so that I could really get through that day and enjoy that day. But it's not something that I can afford to do on a regular basis. I then moved onto miraDry. I have had two treatments of miraDry, and like the doctor said earlier, I have seen about 80% reduction. Another treatment that I have attempted and that's not drinking a whole lot of water. And, that's not a good thing because you're dehydrating yourself. A couple of years ago I got a kidney stone, and now looking back, I wonder did I do that to myself? So to wrap it up I would say, please, please help us find solutions to manage this condition. Thank you.

Angela Ballard: Thank you, Michelle. I've been immersed in hyperhidrosis for a long time, but I learned a lot of new things. So, thank you so much. And, now Megan.

Megan (Panelist): Angela, you've been immersed. Hi everyone, my name is Megan. I am a registered nurse, I've been practicing about 10 years. I suffer from hyperhidrosis of the palms, and the soles of my feet. Also, axillary to an extent. Although that's more manageable for me. We're up here to talk about treatment. I think for all of us that suffer, treatments and impact are kind of inextricable. There's no way to talk about one without talking about the other. One thing that struck me as we've been here this weekend and I've spoken with other people here is that I think for those of us who had onset of this condition when were infants, from birth, as children, and also those of us who have started to suffer later in life, is that this disease impairs people's ability to develop as human beings. I think of the process of early childhood development and how part of that process when you're a child, you learn to interact with the world through your hands. Facial recognition is such a huge part of childhood development. And when those things are impaired, as a child, and even as an adult, it profoundly affects how you interact with the world. How you perceive yourself, how you perceive the world around you. And, some of the physicians talked about how accessible and effective treatment for hyperhidrosis really inspires self-confidence and develops self-confidence in people. And, I think even kind of from a philosophical standpoint, even prior to that self-confidence, we all as human beings need to have feelings of control and control over our own bodies. So, again, access to that, to effective treatment helps us all develop as human beings and become more actualized as human beings. So, along those

lines, like I said I have palmar and plantar hyperhidrosis. And what that means on a day-to-day basis, a minute-to-minute basis, is that I am unable to reliably grasp or hold any object. It's pretty existential. I am unable to reliably grasp or hold any object in my hands for any period of time. And, this is minutes. So, imagine having to touch and then withdraw from everything that you touch or hold for fear of destroying it. Whether that be paper, whether your cell phone, a laptop computer, dropping it as we've heard. Concerns about dropping babies. Holding pets. Fear of offending or disgusting anyone you interact with. And, as we've all talked about, think about the effect on people's mental health that brings. Think about the sadness and isolation that comes from that. And, again, when we're talking about treatment. It sounds like we need to be discussing mental health treatment, treatment for depression, treatment for anxiety because it's interconnected. These photos here, the one on your right is actually my hand and it is post-treatment with Botox injections. Botox injections in my hands are, I've tried a variety of treatments like we've discussed, things like systemic anticholinergic medication, topical medication. Botox is the thing that has been the most effective for me. It's just primarily a matter of getting access to that treatment and having it be covered by insurance.

Lisa Pieretti: Megan, I'm so sorry, but we're running really short on time. We have 45-minutes left in our entire day. Do you want to say why you like this picture?

Megan (Panelist): I love this picture. This is a photo that I took at one of the continuing education seminars or conferences provided by the International Hyperhidrosis Society. This in particular was held in Scottsdale, Arizona, and I was graciously invited by Lisa to attend and to participate and to receive treatment. On the house provided by the International Hyperhidrosis Society. And, this picture is symbolic to me because it represents access to treatment, it represents the way treatment should be for us all. And, it was just beautiful. Kind of also I guess shows my sense of humor. Just here was this huge silver container full of all these pre-filled Botox syringes that were just accessible to these doctors that were here in this location to learn how to provide treatment to patients. It's a very happy picture for me. If I may say one more thing, I know we're going over. When we were asked to talk about what sort of research and development we would hope to see for treatment for hyperhidrosis, I had a very difficult time imagining that. For me and I think for a lot of us, it's just as much about access as it is the kinds of treatment. Again from a psychosocial perspective, you need access to something before you can think creatively or develop or innovate, but I would specifically ask please for research into treatments more research into treatments for areas other areas of the body than axillary. Axillary is super important, it's no less important than any other focal area. But, in my experience, research and development has focused primarily on axillary treatments and then also just that research be done to create just for treatments for palmar and plantar and other body areas to be designated. Botox to be designated as on-label vs off-label because I think that will improve insurance coverage of these treatments, which is necessary.

Lisa Pieretti: Thank you, Megan.

Angela Ballard: Thank you, Megan. Wendy, looking forward to hearing from you.

Wendy (Panelist): You know, it's humbling being on a stage and in a room with everyone. I've really enjoyed listening to everyone's stories. My initial discovery really is like many that you've heard today. I remember being in kindergarten, sitting on the carpet during circle time, one of my classmates noticing my hand was sweating and proceeded to laugh at me and share his discovery with everybody else. Running to the back of the room where the bathroom was, locking myself in the bathroom for hours

because I knew that moment I was different. And I couldn't control it. My journey began in the late 70's/early 80's. At that point, hyperhidrosis was not something anybody ever talked about. My sister's even here in the audience, she said we never talked about it as a family. I have zero pictures of myself like the people on my panel. It wasn't that I was ashamed, I just didn't want to be depicted as that person because I'm more than that. I'm more than just the person that sweats. And for the first 20 years of my life, I can't tell you how many doctors' offices I walked into. I was a very verbal child. I know you probably find that hard to believe, but I was a very verbal child. And, I would say, "Hey, I'm sweating." And I was blown off. I was dismissed, and you've heard that a lot today. But, in my doctor's defense, I don't think it was personal. It was just that it wasn't something that they truly had the education and knowledge to the extent that we do today. It honestly was not until I went to a podiatrist in my area and I was getting consultation for bunion surgery of all things. And he held my foot in his hand and I remember distinctly watching my sweat drip down his gloved hand. And I immediately, like you've heard from many, many people, started to make apologies for why I was sweating. "My gosh, it's so hot outside today." Because I lived in Virginia Beach, you know it's a beach community. So, I started making excuses. He was the very, very first doctor that said, "Stop, you can't control this." And, he gave me a name for my condition. That very first day, he started me on Drysol. It was a topical drying agent, and I broke out in hives within a day. But, now actually having a name for my condition when the first 20 years of my life I never did. I started on the internet to see what my other options were out there. And, that's when I discovered that the FDA had recently cleared Botox injections to treat my condition. So, I called my insurance company because I needed to get prior authorization to even go to a dermatologist, and that was a process in itself. And, what I say to people is the stars were aligned the day I called my insurance company because the only dermatologist in my area accepting my insurance was Pariser Dermatology. When I called the office, the only doctor available to see me within a short window was Dr. David. But when I went online and saw that he was the President of the Board of International Hyperhidrosis Society... I was a school teacher and I stood in my classroom and I did a happy dance. Because I said at that moment that I was going to the best of the best. There was no one better. And, in my opinion, there really is no one better. Sorry, no offense to all of the others at the table. And, when I walked into his office that day, he started me on iontophoresis which you've seen pictures of. Putting your hands submerged in salt water. My condition was actually so severe, I would cut my hand and it would fill with water. Imagine that, like a bowl I would dump it and it would refill. And, my shoes would fill with water. So we started on iontophoresis and I was actually able, through my insurance, to get the device at home. But, here's the thing, you can't travel with the iontophoresis machine. It's not a practical treatment, and I don't care how people sugar coat it. Putting hands in water hooked up to electricity is just not the smartest of treatments out there. And, my condition was so severe. It did stop it some, but I would still have breakout sessions. And I had to do it as you've been hearing multiple times every week. We went through the channels of actually getting Botox cleared to treat my condition because back in the early 90's, insurance companies really only saw it used for cosmetic reasons. And, I remember one day I was in his office and I was getting my iontophoresis treatment. He walked in and he said, "Hey" because I knew everyone in the office well because I was going there three times a week and I would bring snacks and it would be like a little party. And he said, "Hey, guess what? Good Morning America called me this morning." He said, "How would you like to go on national tv and share your story with the world?" So, I was 21-22, I went on GMA and actually shared me getting my very first Botox injections with the world. To give hope to people like us in this room. I would get about a hundred shots in every single hand because literally for those of you that are in the

profession and don't know what they do, and back in the day they used to give me a nerve block. But now they don't, they simply put ice and then they inject. They start at the base and they literally line your hand going to the tops of your fingers and in between. A hundred shots each hand and then thirty under each arm. That lasted for about 6 months, and it worked really, really well. But, I changed jobs and when I got my new job in education. I'm now in school administration, my insurance no longer covered it. It was \$1,000 out of pocket for each. \$4,000 total. And, I don't care what job you have, that's just not an expense people can muster every 6 months. So, I remember being in Dr. David's office recently and we were catching up. And, he said, "Hey, guess what? There's a new medication out there called Robinul." It's an oral medication that you can kind of regulate. You can take from 1 pill to 3-4 pills, and it essentially is a drying agent. It dries you out. And, when he says it dries you out, it dries you out, you have cotton mouth. My eyes are dry. But, here's the thing, it also dries my muscles. I get no less than 15 crippling charley horse leg cramps at night to the point where I can't lay in bed and just work it out. I have to physically walk the room. So, to say that I can't remember the last time I had a good night's sleep is truly kind of an understatement. I take Gatorade, magnesium, potassium supplements and none of that helps. And yet last night, we were at our social and I was talking to Dr. David and I said, "Hey, guess what?" Because he said, "Hey, I haven't seen you in a while." I think that was how our conversation started. And I said, "You're right because guess what, for the first time in 44 years, I can tell you I'm sweat-free." And I said, "However, I have these crazy side-effects" and he just looked at me and I said, "I know" I said, "I never came back to your office to tell you" and I said, "Because here's why, I'm sweat free." And I say this to you all today that are out there. As sufferers, we shouldn't have to say to you I'll suffer the side-effect because I no longer have this. There truly, truly has to be a better answer out there. And I want to just conclude by saying this: last night in our meet and greet, we did these amazing posters that I hope you had a chance to see when you came in because it gives you an inside look as to what we think and what we feel. And I want those words on those posters to resonate with you guys. Because what I want you all to remember is everybody in this room and everybody watching online, we're not just a number. We're not just 3.5 million, we are people, we have voice and that voice is loud. But it's not loud just for us, it's equally as loud more importantly for the children and the future generations that are getting ready to begin their discovery and treatment journey. And, I'm hoping, my hope is that and that's why I put that quote up there about hope. My hope is that conversations like today really pave the road a little bit smoother than the one that I had to personally travel and ones that you've heard from my colleagues traveled. So that other people never ever have to question their self-worth and I can't tell you how many times growing up I questioned if I was worth it. So I say to you and more importantly, I beg you, you all are the voice, you all are the voice, but most importantly, you're the hope for all of us. So, thank you.

Angela Ballard: Thank you, Wendy, for sharing your voice. It's really important to hear. Sophia?

Sophia (Panelist): Thank you, Angela. My name is Sophia. I'm from Virginia. I was an educator, I was in education for a lot of years and I recently...well, not too recently, I became a business owner and you know, it's just I'm really so excited to be here and it's been amazing hearing all of your stories. I know that every time I hear someone speak, I'm like, "Yep, uh huh, that's me. I can relate to that." And I think really having the courage to share our stories is empowering. And I think that we need to continue to share our stories and use our voices because, quite frankly, there's just not enough awareness. It's shocking to me that doctor's offices and in medical schools, they don't know what hyperhidrosis is. And, I've heard so many people say they try to hide it. That's something I did my whole life. Tried to

hide it. Hide it from my loved ones, hide it from the rest of the world. And, it does impact you psychologically when you're trying to hide. And, just the reaction so many people have shared what reactions they get when they would shake someone's hand and then that person would wipe their sweat off. It's a horrible feeling inside to know that you gross someone out. They're just thinking "Eew." So I think by talking about it, raising awareness and using our voices and being courageous to share is really what's going to bring about change. We all have stories, but I'm just going to share one that really sits, really still hurts my heart. And that was when my son was born in 1999. It was the winter time, and he was born 6 lbs and I brought him home and I have palmar hyperhidrosis. So palmar, plantar and a little bit of axillary as well and back then I was, I didn't know I had hyperhidrosis. I just thought I was weird, it's very strange, there was no one else in the world like me. And so here I am at home, a new home, with my little teeny 6 lb baby. It's winter time and every time I held him, I would soak him. So, it wasn't just that my hyperhidrosis was affecting me, it was now affecting my child because I was not gonna leave the house when it's 20 degrees outside with a 6 lb baby who was now wet. From my hands. And that just made me feel even more alone. And, it just made me feel really horrible. Even his blankets, I would soak through everything just holding him. I was really happy when summer came around, and I could go out and leave the house. Anyway, so it was about, I was in my 30's when I finally went to a new doctor. I was going to a doctor and it was for probably a cold or sinuses or something. And you know the doctor went to go shake my hand, and this is normally when I would say my white lie like I heard some other people say, "Oh I'm sorry my hands are wet, I just washed my hands." That was my go-to saying. Well, for whatever reason that day, I just couldn't. I blurted out the truth and I said, "I'm sorry my hands are wet, and I just don't know why." And, the doctor looked at me and he said, "Oh, you have hyperhidrosis." And, in that moment, my whole life changed. I could not believe this was a medical condition. I could not believe there were treatment options, there's a name for it. And, most importantly, I just was so happy that I wasn't alone. There were other people like me, and that was a really wow moment for me. So, I began seeking treatment options and exploring all of those things. I started in the usual way, I tried Drysol, the topical that we talked about. It didn't do much for me. It really didn't, it was a small change, but nothing significant at all. I tried oral medication, which like Wendy, it's been successful for you. I got dry mouth and still sweaty hands, so that did not really do it for me. And, so I've done Botox injections, which I do believe works very well. I've heard people say it doesn't, and in those instances when they say it doesn't work, I believe it's because they need to go back to the doctor for a follow up, do the starch iodine test because if one little part of your hand has not been treated, then the sweat from that region is gonna migrate and it's gonna seem like it didn't work. But, Botox does work. My issue with Botox is expensive. Good luck getting it covered under insurance, and you have to do it so frequently. But it does work. Currently I manage with iontophoresis, and again I've heard people say that it doesn't work. But, it does, you just have to do it 3 times a week for 3 weeks. You have to stick with it weekly, and you have to get the device up to the minimum therapeutic level, which I believe is a 12. My issue with that is the time that it takes, the discomfort that it is, and good luck traveling with that thing in your suitcase. Can you imagine what TSA would think seeing that device in your suitcase? So, anyway, I really would like to see going forward in the future, treatment that's accessible, affordable, just like everyone else, that's safe and that's a little more permanent to help us manage our conditions. So, thank you for your time.

Angela Ballard: Thank you everybody. So, for our open discussion, Lisa.

Lisa Pieretti: We're running so long on time, we probably have about 5 minutes for open discussion. So, we might want to focus on the future since I think our histories were very similar.

Angela Ballard: So, let's cut to the chase. What do you want and need for the future? So, let's see a row of hands. Is there anyone who has not had a chance to speak at all yet maybe? I want to give a new someone a chance who didn't speak yet, I'm so sorry.

Audience Member: I'm sorry, but I haven't heard anyone speak about ETS.

Angela Ballard: You're right, we have not had a chance to talk about that. Are you going to touch on that with us today?

Audience Member: Yes, I had it. I was that desperate, and I'm one of the 3.5% that ended up with severe compensatory hyperhidrosis. I have five other chronic, incurable diseases. And, I can tell you, I have suffered my whole life from one thing or another and these are serious conditions. That my hyperhidrosis is the most debilitating disease out of all of them that I have. I have been offered disability by just about every kind of doctor you can imagine. But, I have refused. I have refused, I have fought back. I have fought every day of my life. And, time? I'm only allowed four hours a day to actually live. The rest of it is completely immersed in managing my life around the diseases that I have. Hyperhidrosis is not bothersome, it is debilitating.

Angela Ballard: if you could sum up very quickly in a few words, what you could foresee as a positive future in treatment for you?

Audience Member: What I see as a positive future, and the one that will have the greatest impact in/ with the FDA and excuse me, Lisa, I'm going to steal this. You gave this to me. She said that if ETS were a pill, that the FDA would never, never approve it.

Angela Ballard: Those are powerful words.

Audience Member: Lisa said that, and I just want to say to answer your question, educate, educate, educate. Get the word out because I didn't have that information and now, there's no hope for me. But, I hope there will be for people in the future.

Angela Ballard: Well, we're all here to educate and support each other, so I'm glad that you were able to share. Thank you. Let's hear some more about what we need, what are meaningful endpoints.

Audience Member: I think that a lot of the treatments that are out there, I've tried everything except surgery and nothing works for me. And, I think that a lot of the treatments are focusing just on turning off the sweat. But, I wonder if there's anything coming that would be more of an internal treatment. Something that's in our brain or whatever makes it happen. If there's any treatments that are focusing on that aspect of it.

Angela Ballard: That's a great point, and I hope we can inspire some creativity here. Who else would like to talk about hope for the future?

Audience Member: Hi, I would want to see more treatment, more research, more awareness, and more education.

Angela Ballard: More is good.

Audience Member: Hi. I actually, I've gone through hyperhidrosis my whole life, and didn't start really getting into knowing about the condition until I participated in this organization. So, I'm very thankful that there is a platform now, and I have actually tried Botox through this organization, so that was very successful for me for a few months. And, for treatment, I think I've done some research and noticing that it's part of your nervous system, so I don't know if there is something that can be focused on that. I've tried something called Nerve Tonic to see if that could help the over-active sweat glands that's kind of transferred from your nervous system, so I don't know that might work. But, it's a topical kind of solution, and then I've tried using the antiperspirants on my hands at night. So, I think education and having physicians be more aware of this when you do go to your doctor's offices, who know this exists and obviously there's a name for it now. So, just focusing on educating and raising awareness through that.

Angela Ballard: Thank you so much. Lisa, do we have time for one more? Ok, one more about treatments for the future?

Audience Member: Sorry, not really treatments. My major concern today is my little boy here, eight months, and I just don't want him to have to suffer through this like everyone else here today.

Audience Member: We don't want him to either.

Angela Ballard: Thanks. It's good to have a symbol of the future with us. Thank you so much. Oh, we have one more.

Audience member: Hi, I'm a model and a second-year law student. For the future, I would definitely love to see treatments that help the patients, not only mentally, but also physically because I've actually ruined garments because I was dripping wet from different areas of my body. And most of these are sample designs and everything where you can't make that again. And, it is supposed to cost a thousand or so dollars for you know, the client. So I really, really hope that something can be done to help in this particular area because we really are suffering. Thank you.

Angela Ballard: Thank you to everyone who shared today. We couldn't be here without you. And, now we're going to welcome Dr. Pariser back to the stage. He's going to share some closing remarks.

Dr. Pariser: So this has been a great, great morning. Angela, I want to thank you for the great facilitation and moderation. You did a great job with that. We couldn't let this day go without thanking Lisa. Not only did Lisa arrange this great event, but I gotta tell you, she has been the heart and soul of the International Hyperhidrosis Society since forever, and we need to give her a standing ovation.

-Applause-

Dr. Pariser: Ok, wow. We heard a lot today from our experts. And you guys and gals certainly are experts in this. And we realize that it's sometimes very difficult for you to articulate it. And not really the you in this room because you've all come out, ok. You have all come out. It's all of our friends who have not. It's those half of those people who have hyperhidrosis that have never talked to anyone about it because of all the reasons we've said. They're embarrassed, they didn't know there was anything they could do about about it, they didn't know it was a medical condition. And, it's difficult for that to happen. So, what should be the target for treatment of this condition? What should we as physicians, what should the innovators as developers, what should the regulators look for as the target

of treatments with people? And, I would ask you this question, your own individual targets. What would your day be like today if you didn't have excessive sweating? That's your target and everybody is going to have a little different one. But when we develop treatments and drugs and devices, we have to boil this down into something measurable. And, what has happened as has been rightfully pointed out is that all of the approvals for drugs and for devices that we have have been for axillary hyperhidrosis. And, why is that? Well, the reason really is historical and it's because of the way that drugs are developed and approved in this country. There is a regulatory pathway for hyperhidrosis, for treatment of axillary hyperhidrosis because they're in previous studies that have been done, have measured certain things and have led to improvements. So, that's the easiest way for anybody to get a drug approved for hyperhidrosis, or anything, is to follow a path that's already been used. But what we heard today for almost everybody is that palmar hyperhidrosis is really, not for everybody in this room but for most, as important or more important than axillary. Not to mention, plantar, craniofacial, inframammary, infragluteal. But, and all these other places. So, these are the research gaps. These are the gaps that we need to address. We need to address the hands and these other areas. So, what have been the hurdles for this? Well, we talked today some of you who are unable to get into a clinical trial because of gravimetrics. Gravimetrics, the measurement of the sweating that you're doing on any individual day, any given day. And, you all know that you don't sweat exactly the same amount 24/7. You don't. Some do, but for most, it's variable. And, if you have to hit a certain gravimetric minimum, meaning that you have to sweat a certain amount at that very moment, when you're in the doctor's office, sitting in a room for 30 minutes to accommodate to the temperature, you may not be sweating that day. And you may be denied entrance into a clinical trial because of that. So, what should be required to demonstrate clinical relevance of a treatment, not just statistical significance against the placebo? So, to summarize, I think that hyperhidrosis obviously you guys know is a common problem. It ruins your life. The barriers for treatment include a lack of awareness by medical professionals. One of the things the International Hyperhidrosis Society does is that we educate professionals. How many of you were on this panel and others in the room were treated by somebody who was educated at a hyperhidrosis event or you yourselves were part of that? Lack of awareness. Trivialization of the problem. It's not important, it's not important to the doctor, it's not important to you, it's not important to industry, it's not important to the medical care system, it's not important to insurance payers. That's the big deal. And, a lot of providers aren't familiar with treatments. So, again, we've said this before. The current available treatments are limited to axillary hyperhidrosis only. Why? Because that's the easy regulatory pathway. Botulinum toxin, microwave thermolysis, expensive. Why is Botox so expensive? Well, I used to say it's expensive because it came from the world of a cosmetic. The cosmetic world, and this sort of was a side effect of the cosmetic world. And, I've often said if this stuff weren't Botox, if it was banana juice, it wouldn't be that expensive. And, nobody would care. It would be much more easily approvable. We don't have good data on the off-label use of many of the good treatments that we've had. Particularly, the systemics, the systemic drugs that we use in children and in adults. We need some good data for that, we need some good efficacy and safety data. And, we heard about how some of you are willing to endure these side-effects, dry mouth, muscle spasms (Wendy). I didn't even know about that, and she's my own patient. They're willing to endure that to get the effect, the therapeutic effect. And, so we gotta do something about the cost and as new things become developed, are they going to be costly, designer drugs for people who can pay cash? Like miraDry, microwave thermolysis? Or, are they going to be drugs that are going to be more easily available to others? So, the whole point of today is to develop some collaboration and to share ideas and to share

goals, treatment targets. Let's develop targets that are meaningful to you. You don't care whether you sweat 50mg of sweat in your axillae in 5 minutes. But, you care is whether you can wear a shirt. But, you care is how it affects your quality of life. Let's settle on some meaningful and reproducible endpoints, not necessarily this gravimetrics. Yes, it's an objective thing. Objective and subjective for that moment. For that 5 minutes. But, it's not really objective, and it doesn't really measure what your condition is doing over a period of time, longer than the 5 minutes. And, this is really a quality of life issue. Now, quality of life things tend to be trivialized. Particularly by insurance payers. There's no quality of life, who cares. But, this is what this condition really is. Somebody said nobody dies of hyperhidrosis. Well, that's true, you don't die of it. But, you may die if you commit suicide because you have compensatory sweating from ETS or you may have a tremendous psychological or other problems at the moment. So, let's develop a quality of life measure that is uniform, that applies not only to axillary, but to other areas of the body. And, let's develop this as the standard. The regulatory standard, the clinical standard so that we can evaluate one treatment versus another. And, this is on a practical basis, everyone wants a cure. But, until we get that, let's figure out how we can do better. And let's do it by developing a quality of life measure that we can use for all forms of this condition. So, again, I want to thank you all for coming. I want to again thank Lisa for being the heart and soul of this Society. It only seems like a 150 years, but a long time. And, look forward to greater and bigger events in the future, all keep in touch with the Society, look at the website, read the newsletters, as I'm sure you all do. So, again, thank you all for coming. Any closing remarks, Lisa?

Lisa Pieretti: Thanks everyone, this has just been amazing. I just want to remind you that you can send us comments in the open comment period. Just email Christine@SweatHelp.org. Everyone here knows Christine. The public comment is open for two months starting right now. And, all of the comments and the webcast, they are all going to be part of our official report that we make widely available to the FDA, to our innovators that are in this room. We want you to share your experience, expand on something you heard, or something you think maybe we missed. But when you send in your public comment, there's no limit. There's no limit to the length. So, we had to rush through today. But, you can write a novel and put it as part of the comments. Everyone is welcome to be part of it. That includes advocates, industry, everyone. Your mom, and they'll be incorporated into our summary report, which will be available to all and widely distributed in third quarter next year. Thank you! And, this meeting is adjourned!

Public Comments

Hello, I am a sufferer of hyperhidrosis. Ive had my entire life. The earliest memory for me was 5 years old filling my little purse with tissues as a way to hide and wipe my sweat. As I got older, I became dependent on sweaters. I could not leave or be without a sweater; using the sleeves to cover my hands. In middle school I would even go to school in mittens and teachers were always suspect of why I constantly had mittens on. I live in southern california for rarely do we confront any weather that requires warm clothing let alone mittens. My comment would be to educate not only primary doctors but teachers. Hyperhidrosis has affected my ability to succeed in the classroom. Specifically, it has immensely impacted my test taking abilities. On another note, every time my insurance changes I have to fight and appeal coverage for propantheline. Currently I have been paying \$40 for one month and a 90 pill supply (per trial and error 3 pill a day works best). Although it is "covered" it is indicated as a tier 3 medication. They recommend I take other alternatives but I cannot and I have been waiting 2 months for a response from appeals department. What the medical field and insurance companies don't realize is this is a necessity. I need to take it everyday to have a chance at controlling the sweat. Topical treatments are insufficient and this is the ONLY hope I have at maintaining the sweat. Action needs to be taken now!

-Commenter

Hi. I live in kenya. Am happy to know that finally there is a solution to my hyperhidrosis state. I know there are others out there like me. We are the 5% of the worlds population who have this problem. I call it a problem because I know how deeply one gets affected with it. There are some out there I know can't afford the treatment but am assuring them not to give up hope. I thank this organization for opening up to us the patients and also working on the treatments. I personally can't afford it to travel all the way to the united states will bee too costly for me. But still that doesn't bring me down because I still have to fight it by not giving up. I have been embarrassed, humiliated but am not shaken. I still have hope. Finally I still thank the international hyperhidrosis society for been there for us when no one was there.

-Commenter

On behalf of all of our FDA colleagues, we want to thank all of those *suffering* with hyperhidrosis and family members who so eloquently and courageously shared their experiences at the meeting this morning! We understand how much commitment and effort it took for them to prepare, travel, and participate in the meeting, and we truly appreciate it. The strength and determination these families have continuously demonstrated is inspiring, and we are incredibly grateful for the opportunity they provided us in sharing their stories.

-Meghana Chalasani

I have suffered from Hyperhidrosis for as long as I can remember, so probably about age 5. It wasn't until I started going to college and took a medical terminology class to realize that this is a real condition. I never did research about my sweaty hands, feet and underarms because I was too embarrassed and I thought that maybe I just got more nervous than other people. Come to find out there is a Hyperhidrosis Society and there are so many people who suffer on a daily basis with the same condition! I suddenly felt relieved that I wasn't alone. I thought this may be a quick and easy fix with a medication so I called my Dermatologist. Well it's not as simple as I thought. I started with a topical called Drysol. The instructions call for your palms to be dry when applying the topical which is never possible for me. After trying the Drysol for about two months it

didn't help with my Hyperhidrosis (this is meant for people who don't have it so severely). So I then started a medication called Robinul. A 2mg tablet totaling in eight pills a day. So just to control this condition I had to take at least eight pills a day which is the maximum dose you can exceed with this drug. This seemed to be helping at first, but then the excessive sweating would come right back only about an hour after taking the medication. It's been about 2 years since I've been prescribed Robinul and now I am to the point where I notice side effects from the medication more so than in the beginning so it's time for another doctor visit. I have severe headaches, and very bad dry mouth to the point where there is no saliva in my mouth and I can't eat. Even when I drink water my mouth just goes right back to as dry as it was, on top of stomach cramps. I did have these symptoms in the beginning but, I tried to ignore them because the only thing that seemed to control the sweating was the Robinul. Now I am to the point where the Robinul is no longer controlling my sweating and the side effects are taking over my life, so I have completely stopped the medication until I can speak with my doctor for further assistance. As of right now I've been what I call #FreeSweating because there is nothing I can do at the moment to control this. The dermatologist I currently see recommended I get in touch with another doctor who specialized in Hyperhidrosis. I have called just about every office in Berks County (Pennsylvania) to try and find someone who could help me. There are a few doctors that do a treatment called Iontophoresis which can be expensive and isn't covered under my insurance because it's considered for cosmetic reasoning. I think that a condition that impacts my life so negatively should be covered under insurance and shouldn't be made thousands of dollars for treatments. Another method was an ETS surgery but my doctor said it's not recommended because the sweating will compensate somewhere else and that I am just a very unlucky individual. So I disregarded the surgery because of the cons. This condition controls my life. It may seem harmless to some people but think about how inconvenient it is. How easy is it to open a door knob or even send a text message when your hands are drenched in sweat? It's very difficult, because gripping onto something doesn't exist when your hands are that sweaty. Not only do my hands and feet sweat but they also swell when these episodes are happening. The moment I wake up the hyperhidrosis is activated, my bed sheets can be drenched in sweat from just my feet, I cannot open the door without putting a towel or something around the knob. I cannot use touch screen devices unless I have a stylus. I cannot open a pickle jar, or a gallon of tea, anything that involves gripping. I constantly have to ask for help with basic daily routines. I actually have pictures of my hands and wrists that show the sweat dripping down my hands. My condition is severe and sometimes I don't understand how that much sweat can leak out of my hands. I also have to work around the condition so some jobs are not exactly primary choices for me. Anything that involves writing can be a downfall for me. The ink bleeds through the paper or I smudge my writing, The paper crinkles from the wet drops landing on it and in any business setting this is going to look unprofessional. I just want to find something that will cure this condition or help it stay calm enough to the point where I can do what I want and live my life. The biggest downfall for me growing up and even to this day is the inability to wear sandals or flipflops, even being barefoot in general, I will slip and fall, the flip flops become slip flops and I have actually broken my arm falling down the stairs because I lost my balance trying to walk in flip flops. Also the swelling in my hands in feet make it incapable for me to do certain things like heavy lifting since my grip is not there, or standing for long periods of time sometimes effects the swelling in my feet. One thing that I have noticed that has tremendously helped with my condition is small uses of marijuana. When my condition flares up, my hands actually start to swell and my nerves feel tingly, and then sweat begins to run down my hands, but with the use of marijuana for medicinal purposes has actually impacted my condition in a positive way. The sweating actually calms down and the episodes seem to stop. I am not saying marijuana has cured it by any means but it has controlled it to the point where I could use this medicinally and it would help a lot of the barriers I face on a daily basis like not being able to use my hands for certain daily routines. I feel calm and notice the sweating subsides on top of the pain/swelling I receive from the Hyperhidrosis in my hands and feet. I believe that there should be a study conducted

involving the effects of medical marijuana on Hyperhidrosis patients. I believe that the findings of this kind of study would be unexpected and positive. I didn't think that using marijuana in a medicinal way could actually benefit Hyperhidrosis but in my case it has. I want my voice to be heard and I would love to help anyone suffering from this condition. If medicinal marijuana is something that could help hundreds of thousands of people than it should be allowed and accessible for these patients. If there is some other type of topical medication that would help over another I would want someone to share their story and share their experiences to help other patients. There are so many side many negative side effects of pills and I agree with following the most natural way as possible. That's also why I eventually want to stop taking Robinul all together and find an alternative that isn't so harmful for the body but so far this is my approach and this is what has worked for me and my journey of trying to find a way to #STOPTHESWEATING. P.S. I really appreciate anyone who has taken their time to read my journey of Hyperhidrosis, and read about the medication I take that helps and a new approach that I believe could help many people suffering. Thank you so much for your time.

-Commenter

Today's web event was very enlightening. The sense of community became evident early on. No one understands sweating as well as someone who sweats. Although I had to sign off early, not long after the break, I came away with a sense of sadness. In a room full of people, and hundreds more participating online, there was an overwhelming current of patients being, at best, let down and at worst, ignored by the medical community and insurance companies. I understand the tears that were publicly shed today. I weep for myself and for others affected. Personally, I feel that Botox would be hugely beneficial for my cranial/facial hyperhidrosis. Obviously, insurance will not cover this treatment. For a drug to be approved to treat one area of the body and not another is beyond my comprehension. What can we, the patient/sufferer, do? I refuse to believe this is a rhetorical question. There must be an answer. Were representatives of Allergen in attendance today? I'm seriously asking this question. What can we do? Thank you and the IHHS for your work

-Commenter

First and foremost I have to say that you guys are truly my heroes! This weekend had such a huge impact on my life and I feel so empowered because of it. As I sat at the airport next to some gentleman for about an hour last night, the small talk began, then the conversation went on and he had asked where I was going I told him Pittsburgh and he asked why I was in Washington DC and when I told him I was at a conference for the international hyperhidrosis society I got that usual confused face look from him. My next question was "you have no idea what that is do you?" his reply "no I was just getting ready to ask you". as I went on to explain the disorder and told him about my ETS surgery and talked about the society and what we were doing this weekend he was still listening intently and I said "are you sorry that you asked yet..?" He said actually "no I'm not -I'm very interested I'm actually a general surgeon and I've never heard of this in my life." I just want you guys to know I would've never had the courage to admit that I even had this disorder before you guys- I would've lied and made something up that I was there for work just like the one girl in the panel said but it was so freeing to talk about it. The conversation continued and I shared our Facebook page as well as the sweat help.org and he was so interested I've been struggling with depression and actually hit rock bottom and crashed and burned a few months ago and I truly feel like this was all in Gods perfect timing. Thank you for giving me hope.

-Commenter

I wanted to reach out and express my gratitude for all of your hardwork committed to creating and hosting such an amazing, engaging, and inspirational event. You all fostered such a caring and welcoming environment which put me at ease and made me feel comfortable sharing my experiences with everyone else. And to the extended family and team, I am forever grateful for all of your hardwork and conviction in tackling hyperhidrosis and raising the profile/awareness of this condition, you are all rockstars. I am sad I wasn't able to personally say goodbye to all of you, but I hope our paths cross soon, I have never met so many HH champions in one setting and was so grateful to meet others just like me and hear their stories.

-Commenter

Unfortunately I was unable to attend the webinar but have lived with hyperhidrosis since I was a young girl and am grateful for the opportunity to share my experience.

My first recollection was being taken to the family physician for my overly-sweaty hands. My mother and I had no idea what the problem was - turns out neither did my physician. I was dumbfounded when I went to the pharmacy for his prescription and was handed a gallon tub of lotion with "FOR DRY SKIN" on the label – something I laugh about now. Throughout high school, things like holding hands and piano practice were confidence-busting – especially as a teenage girl.

As an adult there are new problems – shaking hands with new colleagues or clients, holding a golf club, using a touch-pad – thank goodness they still make mice. The new surge of touch screens on everything has been a nightmare; I get crazy stares at my old-fashion phone with a keyboard and dread the day when those will be phased out. An issue that has surfaced recently may be surprising. Being a veterinarian and surgeon, the ban of powdered gloves by the FDA was quite a blow. Of course this is a unique problem – unsure how many physicians, dentists, surgeons, glove-wearers have hyperhidrosis – but this is an issue that affects daily work life tremendously. Luckily I was able to find a dermatologist that knew what I was dealing with. As for treatments, like many suffers, I've tried several. For the past few years I've gotten painful and expensive injections of botox in my hands – not covered by insurance & putting me out of work for a few days – with the lack-luster results not lasting more than a few months. Thank you for the opportunity to share my story. I am always hopeful more research will be done on this condition, and that employers and insurance companies alike will recognize the affect it has on daily life and work production.

-Commenter

I don't think I can say this any better than Meghana has already, but I would also like to congratulate you and your team on a very successful, well-conducted and informative meeting! I learned much about hyperhidrosis yesterday, including important information about epidemiology, disease manifestations, patient impacts, lack of awareness within the medical community, lack of access to quality care for some patients, the limitations of available treatments, barriers in access to treatment, and the need for additional pathways for drug development that could result in wider availability of treatments for patients. My head is spinning! I would also like to extend a special note of thanks to all of the patients, families and care providers who traveled to DC to participate in this meeting. I am both inspired and humbled by their strength, determination and resilience in the face of the many challenges of living with hyperhidrosis.

Kendall Marcus, MD

Thanksgiving Day is tomorrow, and I am still in the process of absorbing how thankful I am to have been apart of an revolutionary event such as the PFDD Conference in D.C. It is still so surreal to me. I have

been dreaming about the possibility that Hyperhidrosis would even be a topic of discussion for what seems like my whole life (literally). I am truly thankful to have found the International Hyperhidrosis Society. I want to first thank each and every person who made this dream become a reality for so many of us, and to Lisa, for driving this ship that so many of us were lucky enough to come aboard. I also want to give a BIG thank you to Christine for staying in such great communication with me throughout this whole process and helping to get my family and I out there for this event. Last week's conference was truly an empowering experience. I am so thankful that I was given the opportunity to help create awareness and hopefully make a difference in the lives of so many deserving others. I feel so blessed to have found a community of people like me who experience similar daily struggles.

I am even luckier to have the many of you, who are compassionate towards advocating and understanding the struggles Hyperhidrosis sufferers experience. Your efforts to make a difference in so many lives all around the globe are impressive and worthwhile.

Creating a positive change in as many lives as I can is a passion of mine as well. I hope to become more involved in the International Hyperhidrosis Society. I believe I have what it takes to impact others' lives around me in a positive manner, and I can only hope to do so each and every day of my life.

Lisa, I know that I can speak for many when I say that you are truly an inspiration. Thank you so much and I look forward to being a part of more opportunities like this and to get more involved with the International Hyperhidrosis Society.

-Commenter

This last week has been difficult with the immense heat I feel due to the time in my monthly cycle. The internal volcano eased off last night so here I am. Unfortunately I missed the beginning of the webcast, but did watch the last panel discussion, which I found heart - breaking and warming at the same time just to know there are so many others with this debilitating condition. I await the upload to watch it in full. I did make a comment on the docket, which was I think there needs to be more research into the embryonic stage and hypothalamus development. I think this is where the malfunction begins.

With regard to ETS or ELS there definitely needs to be more strict regulations in place as to who performs these extremely intricate surgeries. No surgeon should be allowed to perform these operations without extensive practical experience. I would even say after having them, and been operated on by incompetent surgeons, that they should be banned altogether. An overall holistic view on this condition needs to be developed. I have somewhat given up on the medical profession for treatment on this as anything I have tried did not solve it, in fact the surgeries make it a million times worse, as in with CS and extremely imbalanced CS. The medication robinul which was developed for something entirely different will only slow the process- which at one time I was happy with but after fatty deposits appeared in my eyes I now would say no to taking this medication at all. My advice to women especially is- do not go the surgery route. Look into natural remedies, herbs such as sage, marijuana and medicinal Chinese herbs. Try having acupuncture around the hypothalamus area - I have yet to try it as I only thought about this possibility after hearing the webcast and others who have had this since birth. I guess we have to try everything and anything. I think it is a fantastic thing what you and your colleagues have done, it was only a few years ago I was still ashamed of this condition and hid it as best I could from everyone. If you have contact with any other Irish sufferers like myself please give them my contact details so we can be in supportive contact, I think it is important to reach out and help each other get through the dark days. Thanks again for being there and please let me know when the webcast is posted online.

-Commenter

Thank you so much for the great opportunity you all gave me to be a part of a great conference. The experience truly helped me to better accept and cope with my condition. I have shared with more

people about my problem and feel so much more confident about myself. I met so many just like myself that help me to feel support and less inferior. A wonderful thing happened to me even though when it was happening I didn't think it was so wonderful because I was still hiding. While being at the conference, A new friend posted some pics on Facebook of the conference and tagged me. When I saw that she had done this, I immediately thought, "why is she doing this now EVERYBODY will know my problem." It wasn't too long another friend of mine from back home messaged me and said, "I didn't know you have hyperhidrosis. I have hyperhidrosis. I hate it. Please get all information and share it with me". I was shocked. I didn't know she had the same problem. Now we will be able to help and provide support for one another. So I have a different outlook about this. If I can help someone who has the same problem, then I will stop hiding. I know that there are a lot of other people that go through so much more in life and this condition is not life threatening but it can be life altering and it has been life altering for me. Being around other people at the conference who shared their stories, was an incredible experience for me. I could relate to so many things that each one has to deal with. I felt so much love and support. I felt like I didn't have to hide my condition at all. The people that had an ID badge that were considered "experts" I felt so comfortable with them because I knew they were sufferers as myself. It was funny because I felt myself migrating to the "experts" instead of the "advocates". Not to say anything bad about the "advocates" because I thank God for my "advocate" my husband. He truly supports me and doesn't make me feel bad about myself in any way!! Meeting other advocates was good, but I felt myself going to the "experts" because I knew they knew.

My appreciation to all who helped with the conference to be a great success. THANK YOU!! To Lisa you are truly the best for this organization!! Thank you for advocating for us! You are an amazing woman with a big heart. Big big Kudos to you Lisa for getting such an elaborate conference together. Thank you for the stone paper weight, the towel and all the wonderful accommodations for a perfect stay in Washington D.C. You are truly amazing Lisa!!

May God bless you and your staff abundantly!!

-Commenter

When my daughter was around 12 years old she shared with me she had trouble with her hands sweating. To my great regret I told her everyone sweats, it's okay. I had never heard of hyperhidrosis. I thought she was just being overly self-conscious of a normal bodily function. She had to show me during one of her episodes what her sweaty hands were like. I was FLOORED. I had never seen hands that sweaty. Her hands looked like she had just put them under a running faucet and hadn't dried them off yet. She explained something as simple as writing is at times impossible. She can't grip the pen/pencil and the sweat smears the writing on the paper. Holding objects at times is incredibly difficult. Driving was a challenge, we had to get one of those velour wheel covers so her hands could consistently grip the wheel. So many every day tasks that someone without this condition takes for granted can pose challenging logistical problems for someone with hyperhidrosis. We tried the drisol which did absolutely nothing for her. We tried Robinul but despite her condition she's always been willing to engage in various activities like basketball and a national championship marching band program in high school so not sweating at all was not a solution. She has been unwilling to try iontophoresis because she's very skeptical it will help her and botox seems an unnecessarily painful one. The ETS procedure is scary though developments with the clamps seems more viable. She's 19 now and for the last 4 - 5 years she's been restricting her liquid intake to try to control (minimize) the sweating in her hands. She also has plantar hyperhidrosis but isn't as affected by that as the palmer hyperhidrosis. This is not a good course for her, she's experiencing recurring muscle cramps, dizziness, etc... but she sees that as acceptable if it will keep her sweating to a more bearable scope where she can work and do her college homework. I am once again researching to see what advances have been made in the last 5 years to see

if there is some help for her that doesn't involve risky ETS procedures. There are a few encouraging things however with the advancements in so many things in this country, I expected more.

The work that IHHS and other organizations perform is very much needed. This condition impacts a person on so many levels, physically, emotionally, and emotionally.

-Commenter

My hyperhidrosis condition began during puberty. I'm only 19 years old and I live in Texas. I have to wear a jacket to work because I'm embarrassed. I don't want this condition to hinder my future. I have my whole life ahead of me which is why I really need affordable options. I don't have money to spend thousands of dollars for treatment that may not last longer than a few months. I also don't want to take medication with a long list of side effects that will cause other health issues. I shouldn't have to...

-Commenter

My hyperhidrosis condition began in middle school. I was teased and learned to hide it as best as I could by wearing dark clothing or sweaters. Fortunately, last summer my daughter and I qualified for a research study using a topical gel. We had to complete a questionnaire each time we visited the treatment center. One of the questions was, "Does your hyperhidrosis condition keep you from doing regular activities or keep you from leaving the house?" We snickered when we read this wondering why it was even on the paper. Fast forward to attending the outstanding PFDD Conference in November where we meet other experts experiencing issues just like us. It was an incredible experience to hear and meet people struggling daily with this condition. Even someone as myself, who has this problem, didn't realize the extent and how debilitating hyperhidrosis can be in daily life.

Obviously, awareness is the key. After attending the meeting, I mentioned the condition to several people and almost every single person knew someone that had it but didn't know it was actually a medical condition. Thank you for helping the millions of people currently suffering in silence and please develop safe and effective treatments for us.

-Commenter

"Reflecting on this weekend and the amazing people (who are like family now) I met who suffer from this condition #Hyperhidrosis I am so thankful I met two women who inspired me to share my struggles and get involved a few years ago. Being part of an event with FDA, researchers, doctors, and patients to raise awareness and share treatment options for this condition was incredible. I hope we continue to shed more light and inspire more people to share their stories. #Hh #Knowsweat #youarenotalone #mommyihopeyoureproudofme"

-Commenter

I represent Filipino HH group. There are few websites dedicated for HH sufferers and FB chat groups as well. In Philippines alone, we almost have 200 members in my own FB group. Not to mention that its only one of the Filipino HH group in FB; not counted yet the other HH groups and individuals in FB world.. Sad to say, the mere status or count of increasing Filipinos with HH cannot be provided by DOH. I heard a lot of their fears and despair and needless to explain further, the most devastating effect of this disorder is the feeling of being an outcast in society. Most of them are literally afraid of social gatherings, like what you did at PFDD event. Others for the worst, lose faith on themselves.. afraid to study and to work.. and almost decided to stay indoor for the rest of their lives..

I myself has HH.. but my compassion for my fellows brought me to address blindly this issue to your organization. We earnestly desire the collaboration of DOH and the assistance of medical and pharmaceutical professionals to provide us affordable remedies especially for our HH fellows in the provinces and also introduce us to the latest technologies in treating HH. This I believe will greatly

decrease the 'fear factor' of these sufferers; and will allow themselves more to the importance and benefits of our society.

-Commenter

i am a 42 year old male from South Africa. I had ETS 20 years ago. The surgeon cut both nerves due to excessive palm and underarm sweating. Apparently a very small OP and indeed it was , but bloody hell, the consequences!! compensatory sweating !!!!! I am a farrier by trade, and i go through 4 to 5 sets of clothes per day, sometimes more. Hate summer time(always loved it before the ETS), cant wear any light colored clothes. i average around 5-10 horses a day. At horse no 2 my clothes are already drenched (pants included) it is extremely embarrassing and uncomfortable. The more i sweat, the more self conscious i become, a vicious snow ball effect that i have no control over. i try to motivate myself everyday in the summer time, and carry a huge tog bag full of clothes and underwear with me in my truck.i also feel that the CS has increase exponential from day 1 after the surgery. I want to make myself more valuable for my clients,as well as to increase my income, but this means i need to spend more time learning more skills around the forge, and this in a blazing Africa sun..... i don't need to say more. Just hoping that there will be an affordable surgery/medication option in the near future that will give me back my life, cure CS and help me sweat like a normal person without any harmful side effects

-Commenter

I live in New Durham, NH. I have had hyperhidrosis all of my life. Primary all over but my problem area is the groin and buttocks. I have used numerous products, pads, powders, prescribed antiperspirant, glyco with no avail. Thru suffering daily humiliation, depression and nearly a breakdown, people would think I was dirty or wet myself or just plain crazy. I went to a dermatologist in Dover NH he said on his website he was experienced with the illness. After numerous attempts of medications it failed. He referred me to Boston. I found the International Hyperhidrosis Society online. In November of 2014 I was part of the convention in Orlando, Fla. Convinced my husband to fly with me down to Florida to receive free botox injections. It changed my life.. But was only temporary. I was grateful but back to square one. When I returned home I went to Boston, Mass Dermatology first they referred me to a woman in Missouri and then they referred me to there cosmetic office who did not do botox in the groin. I did find a doctor in NY that wanted \$3000 for one treatment in which I could not afford. Then I remembered during the convention in Florida I met Dr. Pariser from Norfolk, Va. I contacted his office. The office manager checked my insurance and reassured me that I had a \$30 Co-pay and they would give me botox injections in the groin so I made my first appointment. Many doctors do botox injections but for hands, feet and underarms not the groin. Again shaming.... Again convincing my husband to fly down with me for treatment. Their staff were incredible. Absolutely top notch. I had a PA named Mallory. I cried thru the whole appointment. I had been shamed for years trying to be a productive part of society. Words arent enough to express the horrific humiliation..... They started with the iodine test. Looked as though we were baking a cake haha. I was severe, they had set aside 1 or 2 vials but I needed more. Mallory left the room and called Dr. Pariser (who was in Japan) to have a hand in his secret stash of botox (just kidding). He instructed her to give me as much as I needed. 4 or 5 vials. I was so overwhelmed. I can't even put into any words the emotional toll this has put on me. Thru the past few years I would go from NH to Virginia for botox. I finally left my job thru humiliation. Lost my insurance and am back to square one. I so wanted to be a part of the miradry research, a more permanent solution. But again only for underarms. And again people at my new job are starting to notice and comment. I have social anxiety and depression. This has absolutely devastating effects. Just ask yourself could you hire someone to work for you with wet pants!!!!!! I don't know how to keep my chin up anymore.

-Commenter

I have experienced varying levels of hyperhidrosis since my early 20's. I am a 41 year old male and believe the first time these episodes started were after I went through a bout of mononucleosis. Since that time, something in my nervous system was activated and I have dealt with the condition ever since. My symptoms go through ebbs and flows. At my worse, I can be in a meeting room and just break out into a full headsweat, literally dripping from my forehead and making the other parties think something is very very wrong with me and making them in turn uncomfortable. During more quiet times, I will have fewer of those headsweats and just sweat a lot more in heat and exercise than any other person around me. These issues have been debilitating in many respects. It has created social anxiety, the amount of social and work functions I can attend as I never know when I will break into an unnatural sweat etc etc. At times I have to control how much I run around with my kids because I will be drenched and need to fully change clothes. Quite frankly the depressing part is instead of focusing on enjoying life around me, I spend 80% of the time thinking about if and when I will have a break out and if I do, how I will manage it without completely embarrassing myself and family which takes a big chunk out of living a fulfilled life. I have been searching for solutions and so far have heard very little research as it relates to cranial/facial sweating. Seems like palmar and foot and even axillary can be managed locally or through surgery but these more complex conditions have very little in the way of solutions. It is unclear to me if I have primary or secondary hyperhidrosis, however, I am hopeful there is a systemic solution that generally reduces sweating such that even if I am in a worse period of time, it blocks the overreaction of the nervous system so that I don't have to worry about a full breakout in social situations. I would happy to help more with my story but would like my name to be anon. Thank you.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:
Doctor need to have morw knowledge or solution.treatment need to be cover by insurance.I spend 3000 on 2 botox treatment which didnt help at all.waste of time and money..

-Commenter

This is what I want the future of hyperhidrosis treatment to be:
Something that works without terrible side effects like urinary problems.
Hyperhidrosis has made my life very difficult and I've never had a doctor who understands. They all think it's a mental issue.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:
Doctors see this as a weight issue. Its not. They need to understand hyperhidrosis.
Doctors question legitimacy of research no longer.
I hope some day I can take a pill before a social occasion or work presentation and NOT go through 3-5 hankees and still find myself sweating.
There will be specific and practical crown and facial sweating treatments.
I hope I will be able to present to colleagues without the sympathetic questions of "are you alright" due to sweating while sitting and relaxing.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

- Available for reduced costs and/or covered by insurance
 - Longer lasting and less irritating to skin
 - Quicker acting
 - Available locally and at every major healthcare facility right in the primary care dept.
- Thank you from a palmar, plantar, and axillary hyperhidrosis sufferer.

-Commenter

My concern is that there is no effective way to treat Hyperhidrosis of the head.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

- More attention to accepting and providing treatment for the Groin area.
- More trained physicians in this area.

-Commenter

My hyperhidrosis started when I was 17 and impacted hugely on my confidence and stress levels throughout my 20's and 30's until the introduction of Botox into the UK. I am now nearly 50 and my daughter is 18 and also suffers, I am determined she won't go through the shame and anxiety that I did for over 20 years.

-Commenter

I have had hyperhidrosis in my hands and feet since I was about 5 years old (my mother recognized it first.) I don't even know where to begin. Growing up with this condition was EXTREMELY HORRIBLE. I limited myself AS A CHILD and still NOW as an adult, because of this. It has completely ruined my life and caused me so many problems. I know for a fact I would live a different life if I did not have this problem. I have been diagnosed with anxiety (mainly social anxiety) and depression. My treatments include just about everything except surgery and botox because it is too expensive for me. I have tried Drysol, Iontophoresis, Robinul (oral medications) natural remedies, etc. You name it. Also I am EXTREMELY DISAPPOINTED in healthcare knowledge regarding this condition. I have seen a handful of DRs who I feel I informed more about it than they did me. I live in South Tx But back to the main reason for this comment/email. A few questions I have are , Will there be an oral medication available to help our sweating without an uncomfortable dry mouth, nose, or eyes? Will there be something we will be able to take/do while being pregnant? Will the cost of treatment be affordable? And how much longer will we have to wait? I'm 25 years old, will be 26 in June. I am scared to pass this down to my future children especially knowing there is no treatment for it at the moment. I don't know what is harder, teenage years or my adult years. Dating was a nightmare. Wearing sandals and cute shoes are a no-go. Holding hands and living a normal life is impossible. I appreciate all of your efforts. Thank you for listening to our voices. I can not wait for a change.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

Sweat free from head to toe. I have hyperhidrosis and my worst area is the groin. Treatments are available mainly for the underarms, hyperhidrosis is not only that, it's the scalp, palms, back, groin, legs

and feet. The perfect future for the treatment of hyperhidrosis is one where I can wear a pair of khaki pants without having to worry if I'm sweating too much.

-Commenter

This is what I want the future of hyperhidrosis treatment to be: i want it to be atleast affordable by the majority of us. Easily accessible because the hyperhidrosis community are spread all over across the world. I would love the medication not to have any side effects such as reddening of the skin etc. Some of this side effects results to pain cause I have experienced it personally as a patient. Some of the medications I have taken havent caused any change but has only resulted to wastage of my resources. Am kindly requesting for a more efficient medication.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

I have hyperhidrosis of the scalp and face. My father had it. My son has it. My 11 yr old grandson has it. And I think my 1.5 yr old nephew has it. I am 66, my son is 46. My father is not living, he died at 63. I always sweated more than most girls when I played sports like softball or even when I went to the beach. I grew up in FL and as an adult, I moved to MN partially because of the cold weather. It didn't make it go away, but it made it bad for less time since it was affected by humidity and heat.

When I had my full hysterectomy, and several yrs leading up to it as my testosterone became more prominent and my estrogen less, the hyperhidrosis became worse and worse. (this was in my 40s) Then I got Rheum. Arthritis and have had to take medicines that add to the sweating and there are times when people think I have just come out of the shower because my hair is dripping with water right off the ends of the hair and the sweat is running down my hairline and forehead and dripping off my nose.

I can not wear makeup at all for the past 10 yrs due to the effects of the sweating. I can't style my hair because of it and I can't ever wear warm clothing even when it's cold outside. I am back living with my family in FL and of course the summers here are like hell for me. I rarely go out due to the embarrassment of sweating so much when someone right next to me isn't even breaking a sweat.

Luckily I'm retired so the times I worried about job interviews or job reviews where I was nervous are no longer a problem. But any type of stressful situation could trigger a small or major episode of sweating. At a large gathering in a restaurant of family and friends, after I had eaten a small amount, I started to sweat. I tried to keep dabbing my face with the cotton napkins, but my hair began to drip water onto my blouse and run down my face. My neck was sopping wet in the v-neck blouse to the point I had to wipe it dry also along with my whole face finally. Finally a woman who was sitting across from me and did not know me, asked if I was feeling alright right. I wanted to crawl under the table. That was one of the worst episodes I've experienced at my age. The men in my family that are affected by it don't have the same issues with makeup or hair styles, but my son will take 2 shirts with him if he will be out for an evening. And just yesterday, my grandson's face was very flushed after playing outside for less than 15 min. and I commented on how hot he looked and flushed. He said the kids make fun of him when he plays sports because he sweats so much and his hair is soaking wet as well as a flushed face. My 1.5 yr old nephew's beautiful hair can be dripping water on a hot day when other children or babies are not showing any signs of being so hot. It is definitely his scalp sweating and making his hair wet. Please find something to treat this that isn't botox. First, for all of us, it's too expensive. It's not covered by medicare or insurance. And second, it's not for youngsters. I have purchased items that I am supposed to spray around the edges of my hair several times a day to stop the sweating, but it makes my hair look greasy and is just as bad as if my hair was wet. And it does little if anything to help overall.

I don't want this trait to continue in our family. It does seem to be linked to high testosterone as I was diagnosed in my 20s as having an enlarged adrenal gland and have been taking medicine to suppress what the testosterone does to a woman's body and personality. In the case of my father, in his later

years, he would sit with a hand towel around his neck to wipe his face when he ate. When he was younger, he only wore white undershirts and white pocket shirts so they could be bleached and didn't show the sweat as much.

I don't know if anything will be found in my lifetime, but certainly my son's, his son's or my nephew's life shouldn't be effected like mine has been. There must be something that can be done for all ages of people with this problem. You can't hide it when your head and face sweat!!

-Commenter

I have been suffering Hyperhidrosis for 50 years, I have tried everything I can think of what's out there in market, but so far nothing works. Please help me and my family and everyone who has this disease, TO FIND CURE.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

I want people and health professionals to understand just how devastating this condition is. It's not just sweating a bit more than average. It's full blown overheating that makes me want to tear my hair out, claw my skin off and live under a rainfall of cool water. I don't want to be stuck on oxybutynin for the rest of my life to control it. Oxybutynin is the ONLY thing that helps me but the amount I have to take just dries up my body as a whole. I want more research and I am a willing subject.

Please help me and all sufferers with this awful condition!

-Commenter

As much as all Hh patients would love to just solve the issue all together, there are many of us who are trying to embrace it. I've had the sympathetic surgery, my hands are completely sweat free but the compensatory sweating is real. I see a lot of advice about how to dress to make the sweating less noticeable, different antiperspirants to try and such but I have found very few pieces of advice on how to actually deal with the ODOR the sweating can leave in clothing. We all know, once clothing has body odor, it's there for good. It's an issue I'm sure every Hh patient has dealt with. I would like to see more developments in the area of just preventing the body odor or even being able to remove it from clothing while we all wait for a cure.

-Commenter

My comments concerning are the following: I have had a sympathectomy in 2007. That surgery cured sweating in my hands immediately as the surgeon told me it would. I am currently doing Botox injections on my feet maybe once a year to reduce sweating in my feet. I do not feel like there is adequate knowledge of hyperhidrosis among health care providers. I was fortunate that my sympathectomy was covered by my insurance and that the botox injections were covered by insurance due to sweating.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

Something that is long term and works. I suffer at work every day. Injections and medication do not provide me with relief. I see a dermatologist and still suffer. Any help would be appreciated.

If you have any information or help to provide to me and my dermatologist that won't cost me too much I would really appreciate it. I have suffered from under arm hyperhidrosis for over 20 years since I was a teen and I need help.

-Commenter

My daughter and I both have hyperhidrosis. My daughter, now 15, was diagnosed at the age of 6. Mainly hands and feet. Now that she's a little older some under her breast and her underarms. We have tried everything. All the different anti perspirants, OTC and prescription. Iontophoresis, topical Robinul. At around 12 years old we started oral Robinul. She takes 1 mg twice a day. She can take it 3 times a day if absolutely needed for a special occasion. She doesn't really have a lot of side effects from the medicine. She will get a headache if she takes it 3 times a day. It helps but doesn't stop it completely. I have secondary hyperhidrosis. I'm not sure why. I have a thyroid disorder but my doctor said that is not the cause. I only treat it in the summer and if I will be outside and active for most of the day, like at an amusement park, etc. I use topical Robinul, in a spray that I buy from Canada as my insurance will not cover that (I live in USA). I also take, if absolutely necessary, oral Robinul too. 2-3 mg twice a day. I do get side effects from the oral medication, dry mouth and dry eyes. The topical Robinul helps. I mainly sweat excessively under my breasts and in groin area. It was so bad that I would look like I peed my pants and I would have to change my clothes part way through the day. The spray Robinul helps, I don't sweat as bad in those areas but I still sweat there. My doctor just does not understand. She says "everyone sweats" "Your body has to sweat" Yes, but not to the point where it looks like I peed my pants! My daughter sees a pediatric dermatologist that understands the disease better. I would like to see more treatments that are appropriate for teens, maybe 12 and up. That is middle school age and it is so devastating having a sweating problem along with all the other changes that happen in middle school. I would like to see treatments that are topical-botox that is topical, Robinul and other anticholinergics that are topical, and covered by insurance. My insurance won't cover it now because to get it in topical form it is a compounded prescription and they don't cover that. Anything that has less side effects. And affordable. I think Miradry is being studied to be used in other areas than underarms. That would be great.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

I live in a tropical country(srilanka) so the day time is very hot like 33 degrees.when i get out or in my house i get sweating very badly in my palm and feet like a water source so I can go nowhere and when i get nervous the result is the same.but i used to apply vaseline for my foot and palm daily when i go to sleeping,in my foot there is some kind of relieve from it but not 100%,so please do something for this.i think this would be a helpful for the community.

-Commenter

I recently watched the video of the event. It was great. I learned a lot and wanted to give my comment as well. I echo a lot of what was said, especially about focusing on areas of the body that are not just the armpits. For example, I believe palmer would be a good area since it seems from the statistics that so many suffer from that. Also, I heard a lot of people mention that insurance doesn't cover the treatments. So my ask would be that there is legislation that indicates hyperhidrosis as a disease and requires insurance companies to pay for treatments.

-Commenter

This is what I want the future of hyperhidrosis treatment to be: A life free to hold hands, write music, be affectionate get my nails done and not having to wear black shirts all the time. I've suffered palmer ,under arm ,and feet hyperhidrosis its taken my life in every way I fear day to day life because of being uncomfortable in my own skin. I don't have the funds or proper insurance for the expensive treatments but I'm definitely praying for a cure.

-Commenter

I have been dealing with HH for nearly 15 years and have not gotten any amount of relief from numerous healthcare providers and doctors. I always just hear the same thing - there's nothing I know of for you to try. it's just the way you are I guess, although there's nothing wrong with you. This is unacceptable and extremely frustrating. My particular type of HH is complete, whole body sweating, so normal treatments of antiperspirants or even botox would not work for me. So what I'd wish for is for more investigation and any sort of treatment for whole body HH.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

I want more doctors to prescribe anticholinergics for iontophoresis. I have palmar hyperhidrosis and iontophoresis with anticholinergic (glycopyrrolate) and the occasional roll-on antiperspirant works well. I have trouble finding someone who will prescribe anticholinergic to add to the iontophoresis water, so I had to order from a dermatology clinic in australia. Why can't I get this in the US? Specifically in San Francisco? Many clinics prefer botox, but my job requires a lot of dexterity and I can't risk a loss in dexterity with botox. Surgery is risky, and I hear had some permanent side effects like excessive sweating in other areas. Also, I wonder if we can have an anticholinergic roll-on antiperspirant?

-Commenter

I live in New Zealand and have zero support or understanding from my doctors past or present. I work in a frontline govt role and find it hard to cope with anxiety coupled with Hyperhidrosis. I use "scopoderm" off script at a cost which has a small effect but unknown long term risk? This is 2017 surely there is some effective over the counter help?

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

Please find help for compensatory sweating that occurs after surgery to stop palmar hyperhidrosis.

-Commenter

My 16 year old daughter suffers from Hyperhidrosis of hands and feet. We have visited many physicians and I have found some that are very familiar with the condition and treatments and others that are not. This condition has impacted my daughters life on a negative way from the emotional and physical point of view, but at the same time it has given us strength and unity to educate her and make her comfortable talking to others that don't know. She is still of age and won't say it openly, she has developed safety mechanisms to deal with sweaty hands, but as she gets older as a parent I have other concerns, such as career wise and even motherhood for her in the future. She wants to be a Dentist, a profession that works with their hands all the time and I can not imagine how she will do it even though I know she will do it. I read about other companies been sensitive towards employees with this condition but is not wide enough. How would she deal with this condition when she becomes pregnant. She is currently taking medication and is not working for her but she will not stop taking because is even worse. Through out her life she had to deal with teachers thinking she is cheating just because she is trying to dry her hands with a paper to feeling rejected.

I hope I can have enough information to be able to help her.

-Commenter

And thanks for asking! I suspect treatment for hyperhidrosis will need to be multi-faceted, as the syndrome in and of itself is multi-faceted. While some experience it in just one location, I experience it from every sweat producing pore in my body! The first remembrance of it I have is from the 2nd grade when my teacher got after me for having messy papers, writing that had been smeared by a wet hand.

And I'm now 75, an RN retired with many less episodes now that I'm not working. A much less stressful life! And I suspect we all have our stories. I didn't even have a name for it until, as an adult, I read about it in an Ann Landers column! How incredible it would be to have something, anything that would help. I appreciate what your organization is doing.

-Commenter

Too late for me but I pray there will be an end for this problem I am 65 years old now and my sweating has ruined my life.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

I wish more healthcare providers understood exactly what hyperhidrosis is. I live in MS and it seems most have never heard of it, much less know how to treat it. I have Palmer and planter, and have tried drysol, robinul, iontophoresis and Botox. None successfully. More research is needed on how to make this manageable without invasive, potentially damaging surgery.

-Commenter

Hello, when will there be a solution for compensatory sweat on abdomen, chest and back? It's amazing that there is nothing, nowadays, I await your answer, maybe stem cells can be the solution?

-Commenter

I have suffered with Hyperhidrosis for almost 60 years. It has never gotten better, but i'm no longer embarrassed about it. Having both the palmar and plantar type of this condition has been, in the early days, extremely uncomfortable...never wanting to dance with anyone at parties or events, and, in fact, i didn't want to have children for the fear of not being able to hold hands when walking with a toddler, for instance. Regarding the plantar type, it was and still is difficult to wear many types of shoes, although i have tried the Summer Soles ...they don't always work for me. Today, it's reassuring to know there are many other people with the same conditions...and there are many products available for the other types of Hyperhidrosis. I would, therefore, be interested in seeing more products for Palmar and Plantar Hyperhidrosis soon. The best thing i can tell you about having this condition is: i have the softest palms and soles!

-Commenter

Here's what I want the future of hyperhidrosis treatment to be: having doctors REALIZE the embarrassment that goes along with Hyperhydrosis ! My child has suffered for years (she's 11 now) and her concerns are dismissed as not significant - it is a real problem when doctors are not informed. I would also like more treatment available and more research! Let's make Hyperhydrosis manageable for all ages!

-Commenter

I am on a lot of medications so the thought of taking another drug makes me cringe. It would be nice if there was gene therapy to get our bodies to react normally to stress and temperature. I have been living with this affliction for over 40 years. I am resigned to another 40 unless there is a break through.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

- No pain or irritation to the skin unlike today's treatments.
- I don't mind having to do the treatment every few times a week.
- Not messing with hormones.
- MORE awareness for Hyperhidrosis so that we're not disabled or being looked at as weird in work place.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:
 Effective so all hyperhidrosis' patient can feel finally relief.
 Don't forget that it has to be affordable for everyone everywhere.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:
 The treatment needs to be non-invasive (i.e., not surgical). There needs to be a powerful topical solution so that people can live their daily lives by just adding in a simple daily activity.
 Oral medication would be fabulous to solve the problem but seems unlikely as a solution.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:
 Children with hyperhidrosis identified as a part of childhood medical screenings. Treatment for severe primary hyperhidrosis available as early as medically feasible. Severe primary hyperhidrosis needs to be recognized and treated in children as it colors and disrupts all childhood developmental stages in a manner detrimental to success and achievement and social interaction.

-Commenter

- This is what I want the future of hyperhidrosis treatment to be:
1. More doctor knowledge. I constantly get brushed off by doctors who don't seem to care that it can be debilitating to me.
 2. More drug treatments. While Drysol works for under the arms, that stuff is pretty toxic and you can't use it everywhere. One of my worst sweating areas is my groin, and I would love if I had an option to treat that area.
 3. More awareness from healthcare professionals.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:
 Healthcare providers who actually know how to diagnose & treat hyperhidrosis & medications that actually work!

-Commenter

Hyperhidrosis has negatively affected every aspect of my life.
 It starts as a child with kids running away and screaming, "eww she has slimey hands!" So you stop holding your friends hands until the teacher makes you for some game or on a field trip.
 Then you start doing more printing in school but no matter how hard you try to keep your work neat your sweaty hands soak your paper and the pencil rips your "wet spot".
 Being a teenager is hard enough without trying to hide your abnormalities, constantly trying to dry your hands on your shirt, never letting anyone get too close. Relationships at this stage don't exist because you're too let a boy try to hold your hand. Off to University at least now I don't usually have to write on paper. Except during midterms and finals, by this point I have worked out to wear a long sleeve shirt so

I can pull it over my hand to protect my paper. Oh ya and still to self conscious to let a guy get too close. It doesn't help that whenever you have to shake someone's hand they immediately wipe theirs off on their pants. Now I am a teacher. I'm 30 I've been in one short relationship. I get anxiety attacks at parent teacher interviews knowing that I will have to shake everyones hands. It still effects my life everyday and I am unable to imagine a time when it won't. Now I won't walk you through the story of my sweaty feet or armpits but I will list the things I have tried to treat my hyperhidrosis. Clinical strength deodorant - expensive, leaves a rash and burning sensation Botox - very expensive, painful process, Dr. wouldn't do it on my hands or feet Iontophoresis machine - very expensive, very time consuming, painful process, burnt my skin Carpe cream - expensive, very temporary I have considered nerve clamping surgery but there are too many horror stories of people Sweating just as much just in new places, or loosing feeling and movement in their hands. I hope my story can help doctors develop new treatments or at least get health plans to cover this debilitating condition that impacts every area of people's lives.

-Commenter

I am a 58 year-old male and I have suffered from Generalized Hyperhidrosis since the age of 14, approximately. At that vulnerable age, local physicians could only tell me to "sweat it out." This was a crushing predicament and has caused considerable damage to my life.

Years later I was prescribed Pro-Banthine (proprantheline) and later Robinul (glycopyrrolate), both of which successfully controlled my sweating while at rest, but had little or no effect when I engaged in even light activity (walking several blocks or vacuuming a room, for example) or when I was under even mild stress.

I would like to make the following suggestions:

1. Find a treatment that works like an elevated dosage of Robinul, but without the side-effects that such dosages impose upon the eyes and stomach.
2. Educate general practitioners to the problem of Generalized Hyperhidrosis. Few seem to be acquainted with the problem, attempting instead to describe or treat it like localized hyperhidrosis. Some are altogether dismissive of the problem. It would be especially helpful if school doctors & nurses were informed of this problem so that they can offer support to affected youth before their emotional health is damaged.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

Awareness

Better education to physicians and insurers

Better treatment offerings

Social consulting due to social implications.

Correlation with mental side: anxiety, depression, panic attacks, etc

-Commenter

I did not attend the symposium in person, but I did watch the conference via the internet that day and was so pleased to see so many joined together for the cause. As I sit here sweating from the armpits, palms, and feet, I can only hope that there will be further developments in the treatment for Hh, because it truly is an awful disorder to endure. Most successful for me in the treatments has been the botox injections. Unfortunately, the cost is prohibitive to be able to continue to do this. It's literally thousands of dollars for the medication. If drug companies could lower the cost of botox for those suffering from a medical condition, it would be extremely helpful. Save the price gouging for those that

are using botox for asthetic purposes. In a nutshell, what I'd like to see for treatment possibilities, is something that isn't cost-prohibitive, effective, and long lasting.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

Hi , I would like to know what are the clinical advances for palmar hyperhidrosis what padesco since I was 13 years old today I am 29 years old, and I already spread all existing treatments creams based on aluminum, botox, ionotrophoresis, glycopyrrolate all with temporary effectiveness, including operate ETS that only decreased my palmar sweat in 80%, fortunately I did not have any side effects after the operation, although I do not rule out operating again, I want to know please how advanced we are, we can now count on miradry for hands?

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

- 1) Cure the "soaks your clothes" version.
- 2) Don't exclude seniors from your studies.

-Commenter

I have been suffering Hyperhidrosis as long as I can remember. Just like everyone explained in the video, this condition takes a huge toll on peoples lives as it is a "disability." At my 38 years of age I have been embarrassed constantly by people because of my sweat. My problem is sweating all over my body. It starts with my scalp and face which makes me very self-conscious and as a result a get very anxious, resulting in sweat all over my body.

There are days when I feel hopeless, depressed, and out of options as the more I look into it, there is no definite treatment out there for me. I have tried Ribinol which does not work well for me. Right now I was put on lamotrigine because most doctors think this is a psychological condition. I don't want to be treated like a mental health patient when I am suffering from something else.

Please find a medical treatment that somehow targets the wiring internal system(thermostat) of our bodies that makes us feel overheated for no apparent reason.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

Ways to coach patients through their mental struggles that come as a byproduct of hyperhidrosis.

Also, many of the treatments seem to alleviate symptoms rather than remedy the cause. Practical ways to deal with the sweating, even when reduced would be great to know.

-Commenter

I am sending an email in regards to the PFDD comment. I'd love to see a more permanent treatment for hand sweating, perhaps something like miradry, although I am unsure if miradry is safe since it uses microwave technology.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

As a remedy I have been using ice pack and small frozen water bottles which are frozen in freezer, these are wrapped in tissue & put in my pant pocket or jacket, keeps it going for several hours.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

Can be provided by family physicians, not just specialists.

Is affordable

Is easy to use

Has little side effects

Provides immediate relief

I don't want to hide anymore :(

Hand and feet sweating have ruined my life :(

-Commenter

Just to quickly say: I wish I could be at the meeting, but I am from a small town in South Africa.

But I thank you for the effort to make our Hh sufferers' lives better.

So far I can't do anything without sweat blinding me and making it difficult to look 'decent'.

Here's what I want the future of hyperhidrosis treatment to be:

It should be safe to drink regularly

I would like to be able to drink it and then do exercise without drowning in my own sweat

It should work for everywhere on your body, not just armpits or palms. I sweat on my head

-Commenter

Dear SweatHelp,

Thank you for sharing the conference on your website. There is a lot of great information presented that is all in one place. I hope you will keep this on your website for anyone that is trying to find out more about Hyperhidrosis. I found it especially interesting that one of the guests in the audience that had palmar and plantar hyperhidrosis had been a physician. That was one area that I just eliminated right from the start due to my own hyperhidrosis.

I can't remember a time when I didn't have this disease. My father suffers from it but it doesn't bother him at all. He just wears more open shoes sometimes. His hands are really never a problem. Just his feet. His grandfather suffered from more significant issues. My brother doesn't seem to be affected and he is a dentist. My oldest son seems to be presenting with the condition in a minor way. I have told him what this is and encouraged him to not let it bother him, remove his socks etc and that this is normal. I think what makes things worse is thinking that this is the worst thing ever. It can turn into a vicious cycle. I was surprised by the newer information. I knew it was likely genetic but I did not know that the sweat glands and peripheral nervous system was normal. I am surprised that the person talking indicated the brain and the hypothalamus. Has the spinal cord been ruled out already? I think that figuring this out should be the number 1 priority. How can drugs be developed if the underlying genetics, anatomy and physiology are not understood? It seems like just shooting in the dark.

I would also like to tell the physician in the audience that was retired from Radiology, that I practice yoga all the time. I also do hot yoga and sweat buckets like every other person in the room which is amazing to not be the only one sweating. Everyone uses towels. They make special towels specifically that lay right on top of the yoga mat. If you are not sweating to start you can simply spray it with a little water so you don't slip. I also bring two additional hand towels and use those to grab my ankle when the need arises. I am glad that they are developing some topical applications. I will have to ask my dermatologist about these for my son to try potentially. I do botox treatment on my hands every 4-6 months which has helped significantly. It also affects the strength in my hands though so there is a definite trade off. I will be doing Yoga Teacher training in the spring so I am not sure I want to have limited strength in my hands. There are constant decisions that have to be made on a daily basis. When we decided to have children I really struggled because I felt like I was being selfish for potentially passing on this disease to my children or their children. I still feel like I was selfish but at least I know what this is and the struggle so I can hopefully help my kids gain a level of control.

Thank you for bringing this to light. I hope you will be able to develop some treatments that are successful with minimum pain and minimal side effects.

-Commenter

Compliments and thank to you and the entire team for the great concern about hyperhidrosis treatments. Here's what I want the future of hyperhidrosis treatment to be: Hyperhidrosis Treatment Decentralization (HTD). When the treatment is decentralized, it will give freedom and happiness to Hh patient all around the world. We who suffer from hyperhidrosis are dying inside, we want to fellowship, to be part of a development team, to be a health worker. We want to get among our friends (ect), how can we carry out these activities with sweaty hands? With tears rolling down my cheek I am appealing to this human feeling organization to come to our aid especially in undeveloped countries. Our education and talents are hidden. And lots of employer feels, we that suffer from hyperhidrosis are nervous, cause they don't believe there's anything called hyperhidrosis. Thanks for your understanding

Best regard

-Commenter

Hello, I sweat on face mostly. I need cure. Thanks.

-Commenter

Hello

This is what I want the future of hyperhidrosis treatment to be:

1. Flag up the condition in high schools.
2. Place it on the radar of the health administrations by lobbying Congress and worldwide equivalents such as the UK and Scottish Parliaments.
3. Here in the UK it's almost never discussed so people like me need to do more to flag up the work of the Hyperhidrosis Society and pinpoint it as a leading centre of excellence.
4. A cooling gel specifically for the face that dries clear without blocking pores - this may well exist but from what little I know, specialised deodorants for the under-arms are sometimes used by patients for the face but the ingredients might not always be suitable.
5. Unisex hand-held/automatic fans and which are sturdy and medically-sanctioned. Not everyone would want to use them but at the moment commercial fans range from wall decorations (very large) to thin paper fans (very small and ineffective). Automatic fans aren't much better and the batteries are weak.
6. Perhaps a badge so that if patients choose to do so they can wear it in situations they know will trigger their condition ie hot meeting rooms etc (Not everyone wishes to draw attention to their condition but it could be an option for anyone who does).
7. I'm not familiar with the current surgical procedures - although I do know there's a procedure which stops the sweat glands from being over-active.
8. Greater participation in clinical trials - this may be something that happens in the States but in the UK there's little to no news on research or how patients might participate in trials.
9. If it's useful, YouTuber Jackie Aina (a niche beauty and lifestyle blogger) is currently the only person with a profile who has admitted she has under-arm hyperhidrosis. It might be an idea to reach out to her - she's bright and very conversational - but what the condition could really do with is a high profile celebrity happy to share their experiences of the condition.

I don't know if the above can be bracketed under 'treatments' but they're ideas which might help stimulate other, better ideas.

-Commenter

This is what I want the future of hyperhidrosis treatment to be: Affordable, painless and easy to do/use.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

I want you to supply cheap treatment materials to everyone if possible or just open a free treatment centre. I don't have much idea about Hh as i live in India.To be specific i have palmar Hh.

I hope you understand my problem. I cannot even type this email properly due to this.i am sorry for my absence in your program for I am a student in a school. I hope you will help me through this and keep my future alive.

-Commenter

Here's what I want the future of hyperhidrosis treatment to be: taken seriously! find out what causes it and treat it without surgery. i have had head sweats for 10 years,and it is getting worse!

-Commenter

I wanted to reach out anonymously to share my thoughts on the below

What types of new treatments do we need? I desperately need Plantar and Palmar Hyperhidrosis treatments. I feel like there is a high focus on under arm sweat treatments, but the hands and feet have limited, difficult or ineffective treatment options.

What recommendations should we make for clinical trial endpoints or measurements? What could be a measurable data point to determine if a treatment is working? Treatment needs to help severe Plantar and Palmar Hyperhidrosis, not mild or moderate cases. Treatment should be long term or permanent.

What are the downsides to current treatment options? They either don't work (antiperspirant, iontophoresis) or are incredibly painful and not permanent (Botox). The idea of Mira Dry for feet or hands would be incredible.

Thanks for your help!

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

I long for there to be a medication to take that would stop excessive sweating but not have any side effects. It would be so wonderful to be able to take a tablet on a regular basis which would just stop the sweating so that you would no longer have to 'plan ahead' all the time. So that you didn't have to keep doing 'pro-active' things to deal with the problem. By 'pro-active' I mean all the things we have to do to cope: using powerful anti-perspirants at night time - usually with a cream to counteract the stinging and burning; sewing dress shields into clothes; only being able to buy certain types of clothes and shoes, knowing about social engagements ahead of time so that the previously mentioned things can be done. Could hyperhidrosis research be concentrated on why and how hyperhidrosis occurs? Is there something wrong with a person's sympathetic nervous system? Is it something to do with their genes? I feel that the future of hyperhidrosis treatment is to do with identifying the actual cause of the sweating. What is it that makes our bodies act this way? At the moment all the treatments are to do with stopping the sweating either locally, or by taking a tablet that dries out the whole body. I think research should try and find the actual cause of the sweating - then I'm sure a treatment could be found. Thank you for your wonderful organisation. I have learnt so much through it and for the first time in my life realise that I am not alone. I've always felt inferior, ashamed and dirty because of my hyperhidrosis (it has ruined and governed my life) so it was amazing to see all those wonderful people who spoke at your conference.

I wish there was a branch of your organisation in England. We need one!

-Commenter

The following is a response for information from the IHHS for patient-focused drug development. As a sufferer of multiple hyperhidrosis (Hh) areas for 35+ years, these are some of the experiences and treatments that I have encountered and my thoughts and hopes for future research and treatments.

Symptoms and Impacts

HH has been a major influence in my life. It has affected my career path, social interactions, personality and day to day routine. Thoughts and routines, that individuals not afflicted with this condition would consider debilitating or at least very strange, have become normal parts of my daily routine. I choose clothing based on how much I think I might sweat that day. I chose a career in Natural Resources because I figured it would be outdoors more and the breeze might keep my hands dry, not to mention the fact that I would be working with critters instead of people so I wouldn't have to shake as many hands. Due to Hh, my interactions with other people have definitely been affected. Although I did not know what it was at the time, it reared its head in my early teens, probably the absolute worst time in life that it could happen. Sweaty clothes, smeared writing, avoiding touching others, recurring athlete's foot, no dating, embarrassment, etc. all accompanied my new found affliction. It has changed how I engage with everyone I come in contact with. If I have to meet new people or old friends either personally or professionally, my very first thought is, "Are my hands sweaty?" My second thought is "I hope they don't want to shake hands!" and my third thought is, "How can I excuse myself to get out of here so that I don't have to have contact with them." While others might think this as neurotic, it's just the defense mechanism that my brain has come up with after dealing with the situation for 35 years trying to avoid embarrassment. The same goes for work meetings, social gatherings or any other situations where I may have to touch someone or even something that others may touch. When working or interacting with others, if I have to hold an object such as a tool or recreational equipment, I often concentrate more on how to wipe it off before handing it to someone else than I do on using it. Avoiding social situations by slinking off has become my easiest solution. If I know I have to attend a meeting or social gathering, I think about having to shake hands days or weeks before it occurs, that doesn't seem right. Instead of enjoying getting together with others, I dread it. Hh has "kept" me from pursuing career advancements, personal relationships and most social interactions. I have avoided relationships, marriage and starting a family because I knew it would impact others. It has caused uncounted awkward experiences and literally has shaped my life. After researching this condition the last 15 years, I realize I'm not the only one who has had these same experiences and that there are others that have it far worse than me.

Healthcare Treatment

The internet has been my greatest educational tool considering Hh. It let me know that this was actually a condition that affected others and I was not just an anomaly. Since figuring out what Hh was, I have taken steps to try and lessen the impact that it has on my life. Like others, I started by asking my doctor to get a prescription for Drysol. That helped very little. More research turned up Drionic iontophoresis so I bought one since they didn't require a prescription. The machines worked better than the Drysol but the batteries were a hassle to use. At that point I figured out how I could attach a 9 v battery to make them last longer and not have to constantly order from the company. I only used the treatment on my hands since the process was very time consuming (1-2 hours per week) and provided only some relief. Additionally, it could be fairly painful. Next, I asked a dermatologist about Botox injections and they indicated that they had used it for underarms but not hands so I got to be a test case for him after my insurance approved the procedure. Although it was literally a pain to do with so many injections, it worked quite well for me and it was amazing how different I felt being around people for the next few

months. It felt almost odd not to have to avoid meeting other people. It was also nice not to have to do treatment multiple times a week to get the desired effect. However, after a few months the sweat returned and by that time my insurance changed and was no longer covering the procedure. I couldn't afford \$4000 a year to keep up with it so moved on to the next option. More internet research turned up RA Fischer and their iontophoresis machine. Unfortunately, it required a prescription so I went back to the dermatologist who had only heard of this option but never had written a prescription for one. I had obtained the needed information from RA's web site and gave it to the doctor who was willing to write a prescription. After obtaining RA's digital model in 2014, I began using it with fairly good results, at least compared to no treatment. While it is the best option I have experienced to date based on cost and convenience, it is still very time consuming (1-2 hours per week) and logistically difficult to use, not to mention the \$1000 up-front cost. It can also be painful if you have any cuts on your hands and don't cover them correctly. I use it in conjunction with other topical antiperspirants and that seems to improve results. I still only use it for my hands due to the time commitment. If the machine had 4 outlets instead of two I would include my feet. My hand sweating is contained to a level that is tolerable to me on most days. Currently, I have light sweating of the hands during the day. As a result of years of dealing with the condition though, my sweat glands (I guess really my autonomic system) and negative feedback loop still really kicks into high gear in high stress or social situations and the control isn't good enough as I still experience sweat and cold hands and feet but it's better than untreated.

Goals and Expectations for the Future

The more I think about this condition and the financial goldmine opportunity for pharmaceutical companies that lies out there, it amazes me that more aren't pursuing it. If you have a condition that affects millions of people that desperately want to get rid of it, are willing to spend substantial time (maybe an entire lifetime) and money to alleviate it, can change lives by remedying it, why have not more companies pursued it? Look at the billions that's been made on blue pills and they're only used infrequently. This is something that affect folks every day. Anyway, I'll try and quantify what would be a meaningful expectation for me as it relates to Hh. If I were able to see a 90% reduction in perspiration in my hands, feet and armpits on 90% of the days with a 90% reduction in the amount of time it currently takes to treat my condition and would come at a reasonable cost, I would consider that management of my Hh. I realize that a "cure" is probably something that I won't see in my lifetime. However, here are some ideas of what I feel would be acceptable goals for potential treatments if they were very effective. Time commitment- 5-10 minutes a day maximum, one 1/2 hour per week or one treatment every 6 months or so at one hour or less. Delivery method –a topical lotion or application would be preferred or a localized treatment area using a machine. I would like to avoid a systemic drug if possible. Pain Level – mild please, I've done both botox and iontophoresis and while I can deal with both, something a bit less painful would be nice. Cost - \$1000 -\$2000 annually max, this is a life altering treatment if it works and I'm willing to pay for that but it would be nice if a treatment were affordable to an individual or at least not so bad that health insurance companies fight tooth and nail not to have to pay. Accessibility – it would be preferred if a prescription were not needed and I think that more people would use it if they didn't have to go through the embarrassment of asking.

Thank you for the opportunity to comment.

-Commenter

Thank you so very much for this forum and for giving those who suffer with this horrible disease, a platform. I watched the live meeting webcast over a period of a day! I was really impressed by the panel and speakers alike.....THANK YOU!

-Commenter

I've suffered from Hyperhidrosis as early as it really became socially awkward. Mainly plantar and palmer. I actually didn't even know what it was at the time, just thought it was my nerves. Until I realized, this was NOT the norm. I remember writing to my Dr after my visit and being too embarrassed to ask what was wrong with me. I can't really recall what happened next, but I believe she referred me to a dermatologist where I was given a prescription for Drysol. Thinking this would be the cure all, it was not, unfortunately.

Treatments I have tried over the years are:

- Drysol
- Robinol – slight relief but dried everything out, felt like my eyeballs were going to pop out and my tongue felt like a cactus; so dry
- Oxybutynin I can't recall the drying affect but don't believe this worked either
- Iontophoresis –like one of your panelist said, the thought of mixing electricity with water, but I did it anyway out of desperation

I did not try Botox as my insurance at the time did not cover it and the thought of having to get an enormous amount of shots in my hand was not on my favorite list, but I was willing to try anything...ANYTHING TO STOP THE SWEATING!

After many years of trying the above methods, I couldn't take it any longer. Did some research and came across a surgery option called Endoscopic thoracic sympathectomy (ETS). Knowing full on what the side effects would be of compensatory sweating, I did it anyway. I was really desperate.. my thoughts were, at least my hands wouldn't sweat and literally drip down my arm...the heat or any warm environment were my enemy. My hands and feet would swell if I was out in that tempature for any length of time. Shoes, OMG, I would have to get anything with cloth soles. Nothing with material that would allow my sandals to go flying a 100 miles per hour.

Testing out my new "me" had a day at Universal Studios, and this was the day I knew right away I was in the category of the compensatory sweating. Waiting in line in the 90 degree weather, feeling the drips of sweat stream down the front and back of my body... I was drenched. I could not wait to get on the water ride because as of that moment, I was becoming soaking wet without even being on the ride. And now, I live with a drawer full of tank tops to wear under my regular tops to soak of the great amount of sweat as the result of the compensatory sweating. I still avoid any social events where I know I will become heated, Summer time is the worst! When people tell me they love the heat, I cringe ☹ I can go on and on how this disease has severely affected my life. I am very interested in joining the fight for a cure, learning about new treatments, and keep in the know of any research studies! Today, my hyperhidrosis lives on..... HE is NOT my friend and I pray to get rid of him forever one day! All I want is a "divorce"!!

Want a new beginning,

-Commenter

Hi International Hyperhidrosis Society!

I have had to deal with hyperhidrosis ever since I could remember. At five years old I learned not to hold anyone's hand, try to keep your palms off your paperwork and wipe off your sweat from anything you touched before giving it to someone else. This was all considered easy once my parents started making me participate in so many activities. I did martial arts, but I left sweaty footprints on the mat. I played the piano, but pools of sweat would collect on the keys and my fingers would slip. I took art classes, but the paper would crumple from the wetness of my hands and the colors would mix. Soccer was the only activity I enjoyed. There was no hand contact in soccer. And with soccer, I continued my life. I was very fortunate that no kid bullied me for my sweaty hands. Of course the occasional, "Ew!" or "Gross! Your hands are wet!" would hurt, but I tried not to let it get to me. They just didn't understand. And how could they? I would give them reasons that weren't true like, "I just washed my hands," or "I just put on

lotion." I never once told anyone that I had hyperhidrosis. I didn't even know the proper name for it. My mother also has hyperhidrosis and she has shown me how to deal with it. Luckily, from her, I get all the support I need but it still took me a long time to feel comfortable with my own hands and feet. Just a couple years ago, I found out the proper name for our condition, hyperhidrosis. And today, I found this website. I grew up knowing I wasn't alone with this condition since my mother has it, but it's nice reading the other stories on here. Now that I'm 17, I believe my condition has gotten worse. Before it was just my hands and feet but now my armpits sweat as well. Although this is the case, I am completely comfortable with my condition. I have started to inform my peers of what I have and now, whenever someone says, "Ew!" I respond with, "It's just sweat."

And that's what this is. Sweat. I don't want society to let anyone with this condition believe they are disgusting. You will get through this, and with this website, we can do it together.

Thank you International Hyperhidrosis Society for creating this website. I have only heard of my mother's account on this condition, so it was so nice reading everyone else's. I feel even more confident now!

-Commenter

I am particularly interested in excessive sweating of the scalp and face. I am feeling very hopeless. Our electric bill is higher than everyone else's in our neighborhood. The air conditioner runs 24/7. People complain about how cold our house is.

-Commenter

Love seeing this get attention. I first noticed around 3rd grade, (40 now). It's such a miserable condition. I'm sure I've met people that suffer with it too, but you'd never know because no one talks about it

-Commenter

Thank you so MUCH to ALL of you!!!! I have felt so ALONE with all of this for 11 years. NOONE--even hubby, don't seem to understand!!!!!!

-Commenter

So so happy about this event. I feel "finally, I'm among my people". When I first discovered the International Hyperhidrosis society, about two years ago, I cried. Just today I'm having a very difficult day (to the point that I am actually feeling emotional). I've showered three times in the last 18 hours. I'm going to need to shower again in about 2 hours, before I go to a dinner and, depending on the dinner, I may need to shower a fifth time before going to sleep. And in between showers I'm not even fresh - within minutes I'm both sticky and smelly unfortunately. Right now I've locked myself in a meeting room in my office, to be away from everyone else until the end of the day. Oh man, love some of these photos where people are purposefully hiding their underarms and greeting each other with bumps, with a big smile. Makes me feel connected to them. While I'm very excited about this meeting, does anyone else wonder if any new drugs would be addressing symptoms, and not cause? That would still be great, but I am anxious about taking drugs which have side effects and may not even be addressing the root cause of whatever is causing my Hh.

-Commenter

i live in a small town in south texas and NONE of the DRs i have seen, knew how to help me. everything i tried i researched on my own. i have one also. iontophoresis worked for me for the first month and ever since then, ive had a difficult time with it working again. hands and feet. its a little irritating, and time consuming. worth it for the most part. i know for a fact that if i didnt have hyperhidrosis, my life would

be VERY different. relationships. careers. school. friendship. etc. i missed out on a lot of things i will not get back. i was also turned down for clinical research because they wanted HH patients with no anxiety or depression.

-Commenter

Its so great to finally be able to speak to people and listen to everyone stories. No one can understand what we go through unless they too are this condition.
Yes to the career path for me....I also wanted to be a nurse, but would be so embarrassed to have a job where I have to have physical contact with my hands

-Commenter

These gloves for typing will come off one day and I will be able to finally go outside and enjoy life holding hands with you all! Depression?? Of course we are going to have depression - we have felt alone and felt like we need to hide a dirty secret. We hide in our homes. We cancel plans. We lose potential relationships. We become aggressive. We cry. We are angry!!!!
ETS surgery??????? C'mon? This surgery should not be allowed! The sweating needs to compensate somewhere. I wish they would just ban this surgery.

-Commenter

Does the FDA currently view hyperhidrosis as a cosmetic disorder? How would the future of HH care change if the FDA recognized it as a functional problem instead?
Another nurse here, can actually pose a hazard when you cant get on gloves in a quick manner. Either risk patient not getting care or you being exposed to pathogens if you cant get them on

-Commenter

I had a physician make fun of me!!!
I am curious if any of the women in here feel less feminine.

-Commenter

The wet paper damaged my high school tests. I remember a teacher asking me "Why is your paper wet?"

I thought I was the only one who had suicidal thoughts as a result of HH.
Yes, mental health: depression, social anxiety, anxiety, etc. This needs more awareness.

-Commenter

Sometimes if there is a new person on the office sometimes I have to leave the area to avoid the handshake, or run to the bathroom to wash my hands with warm water to get them dry long enough to get through the handshake.

-Commenter

Isolation working at home is better than stress at work and exacerbation of HH. embarrassment, etc

-Commenter

Head and face for me too - have had to stop taking aromatase inhibitor for breast cancer.

-Commenter

I'm in sales and face an head sweating effects my ability to make a living.
Always wonder if my grandchildren will remember me as getting them wet when I hug them.

-Commenter

That is another fear, that I will pass this along to my 3 kids.

-Commenter

Im late to this conversation and trying to read some of this to catch up but I suffer from compensatory sweating due to a Sympathectomy procedure about 20 years ago and its impacted my life in a very negative way. I've been on a 20 year search for a solution.

Its an issue that needs a bigger stage. People that sweat normally have no idea the huge psychological impact this has, on so many people suffering in silence. Its a an issue not taken seriously, or unknown to many.

-Commenter

I even considered shaving my head because I was always dripping! My grandchildren said grandmas melting!

-Commenter

Whenever i hold babies, including my own, i have to turn my hands around and hold the baby not with my palms but the tops of my hands.

-Commenter

I've ruined family wedding pictures because of my facial sweating!!!

-Commenter

Hands and feet for me. I can't tell you how thankful I am for this webinar....been fighting back tears here at work but don't care because it's so important!!

-Commenter

I think there needs to be more neurological research, particularly at the embryonic stage and hypothalamus development.

-Commenter

This gave me a lot of hope, and allows me to face the day ahead.

-Commenter

This is what I want the future of hyperhidrosis treatment to be:

First, a definite answer to why people have this disorder. Where did it come from and how is anxiety connected with it. More research will create more solutions and treatments.

-Commenter

TREATMENTS and RESEARCH (Patient perspectives on current approaches to treating Hh, including journey to diagnosis and desired options for therapy.)

1. Treatments currently used or tried in the past.

standard anti perspirants, Driclor, odaban, hydrosol gel, home made iontophoresis, RA Fischer MD-1a Galvanic iontophoresis, Robinul, and Avert, and a million other things that were pure snake oil

2. Effectiveness of treatments and bothersome effects.

the clinical antiperspirants like Driclor worked from about age 16 to 22 for under arms and hands. I still don't really sweat from my arms anymore. Its like it permanently killed the sweat glands there. The

effectiveness of the Driclor on my hands just stopped one day. Even when becoming more rigorous with my treatments it just failed 100%. Iontophoresis only kinda worked and took 30 min to an hour everyday just to treat my hands. Not to mention it would be extremely painful. Even after doing it everyday for weeks it still only marginally reduced my sweating. Robinul and Avert are the only treatments that still work. I've been on them for about 10 years. Of course I get dry mouth, and dry eyes, but I wouldn't trade it for anything. I'm more concerned with more severe side effects, tachycardia, digestive atrophy, dementia, heat stroke, and possibly elevated ocular pressure.

3. Details of current regimens including of complexity and time consumption.

For the first 8 years or so 4 mg of Avert first thing in the morning on an empty stomach worked great or even more than great almost all day. Lately I've needed to increase my dosage to 6 mg a day to have the same effect. I've noticed that even the other side effects have been affected similarly.

4. Downsides to current treatments and unmet treatment needs.

No insurance coverage, or at least the drug is still fairly expensive. Costs me almost \$200 for 67 days worth of treatment.

Potential loss of effectiveness over time, nothing scares me more than the potential that I could lose the ability to take this medication.

I sometimes get food jammed in my esophagus, and it is beyond excruciating, it has to be the closest feeling to having a heart attack I can imagine. Never had this issue in my life till Glyco. I believe it is in relation to the anticholinergic effects on smooth muscle contraction.

5. Experiences with participation in clinical research.

None, generally there aren't any near me, and I don't have time to take off work. Also they generally focus on procedures I've already tried or find to be potentially dangerous to my health.

6. Goals and expectations for treatment recognizing we all want a "cure."

I don't think a cure is possible. There will always be treatment, unless the field enters genetic modification.

Honestly though, I would certainly like to see a greater focus on Palmar hyperhidrosis treatment. Nearly every new treatment is focused on axillary sweating. Which I had for a number of years, sweat marks from elbow to waist everyday. But honestly it is seriously the most manageable form of hyperhidrosis. Palmar is far more debilitating. You can't touch anything without soaking it, drawing, taking tests, signing a receipt. It makes driving far more dangerous, not only do your hands slip off the wheel but because they are so wet you'd rather have them in front of the a/c vents than touch the wheel. Intimacy is terrifying, no one wants soaking wet cold hands on their body. I worked in a restaurant cooking food and I honestly felt bad for people I made food for, wearing gloves is basically a job hazard at times, but sweating on people's food is literally disgusting.

Putting more money into axillary HH is wasteful and vain. We are only treating the symptoms of the condition not the condition itself. It seems likely the reason there are so many axillary treatments is purely for cosmetic reasons.

I think more research needs to be done correcting the systemic problem. I believe it to be an issue of too much acetylcholine produced in the body or an overactive sympathetic nervous system. Is there any conclusive data on this?

7. Key considerations when choosing a treatment and most meaningful endpoints. (What % of sweat reduction would be meaningful to you?)

I'd like to have what I have now, when on Avert. I basically sweat when I am too hot, usually from exercise or sitting in direct sunlight in 70 F days or hotter. I have no problem sweating when it makes sense. The issue with HH is you sweat completely illogically. I'd have to ask myself when walking home from class in the winter, "why am I so cold I am shivering, and yet the sweat keeps pouring out?" Its ludicrous! I'd prefer to have anxious sweating stop completely too, but I realize that's probably not gonna happen.

8. Financial experiences including out-of-pocket expenses, insurance coverage/ reimbursement, co-pays, and travel for treatment.

Insurance is bullshit, they don't care about anyone. Every treatment I've tried has been out of pocket, period. As if I had a choice.

SYMPTOMS and IMPACTS (Disease symptoms and daily impacts that matter most.)

1. Overall impact of Hh on life.

Its the biggest hurdle in my life, even when doing treatment to manage the condition. Avert creates so many more problems than it solves, it just so happens to solve the most important problem in my life.

2. Activities/choices affected by hyperhidrosis.

Everything, literally, and I literally mean that. For years of my life when I either had no treatment or my go to treatment for the time, lost its effect, my life would go to a very dark place. I've had massive depression, crippling anxiety, and drug and alcohol problems. Ive even self harmed and considered/ attempted suicide. Its not that I'm so upset that I sweat, its just that it has such a negative impact on every facet of my life. It makes everything more difficult, especially the things people need most in their life, other people. Honestly I really believe there is a physiological connection between sweating and anxiety. Now that I don't sweat as often, I'm almost never anxious about anything , at least not to any debilitating degree. And if I do get anxious its for good reasons, money, jobs, relationships, logical stuff. Before treatment I used to get anxious about going to a movie, because if it was exciting or intense I would be sitting in a puddle by the end of it.

3. Limitations in daily life (focus, concentration, work, school, hobbies) and in relationships.

Mostly concentration and focus. If my glyco hasn't kicked in yet, or for what ever reason just isn't working that day and I start sweating while talking to some one in person its like my ears just shut off. It takes everything in me to listen to what they are saying, I get completely incapacitated by mentally dealing with the sweating.

Sometimes in the mornings my girl friend and I get intimate, which is usually before I've taken my pills or before they've kicked in. Well I can tell you the minute I start sweating I can't stay aroused. It instantly kills everything. I have no idea why other than some sort of mental block I've subconsciously created over the years.

4. Embarrassment or social stigma/discrimination due to Hh.

Honestly, I think everyone that has this condition could tell you it sucks. But for me its only a small part of the problem. Its one thing if you shake a persons hand and they're like, "why are your hands so sweaty, gross!?" but its another issue when you're entire life style is built around this disease that causes you to move and act and say weird shit just avoid dealing with any of it. For me it became way more of just feeling comfortable. It got really old just being wet everywhere all the time. Also you're always freezing cold or really hot no matter what, I never knew the feeling of comfort. Most commonly something like my hands and feet would be ice cold and the rest of me would be absolutely on fire, dripping from every inch of skin on my body no matter the temperature.

5. Pediatric perspective including impacts on daily life/school, social ramifications, emotions, and development.

Fortunately, I never knew there was something wrong with me till I hit puberty. I mean my brother and my cousin would never use the video game controller after me, and would make fun of me, but I thought it was just that. It never occurred to me that my life would be dictated by this disease till the day I die. I've pretty much summed up most of the ramifications in the other parts of this survey.

6. Healthcare journey: interactions with providers, access to care, & diagnosis.

Most of them knew little to nothing about the condition. I had one doctor that had a sister in law with the same problem, so he asked me what I thought she should do to help her with it, hahahaha. Most every doctor I've had to teach about the condition, the various treatments, and all the problems associated with both. Anyone else I've had thought I was nuts or overreacting. Every step I've taken in

the journey in dealing with condition I've had to figure out myself, by doing countless hours of research. I've read medical journals, checked out library books, read thousands of anecdotes from other sufferers, and even tried experimental treatments on myself. The only thing I haven't done is go back to school and get my medical degree.

What sucks is even my parents think I am obsessed, they don't see how important treating this condition is. I can unequivocally say that when on a functioning treatment my life is pleasure to live. Even during some of the other hard parts of life not concerning this disease there is still this bright little light in my mind that reminds me that tomorrow will be a better day and that things will get better. Without treatment I never had that.

-Commenter

I want to thank you all again for putting in the time and resources to help people such as myself. I feel that we are on the road towards discovering more effective treatments for this condition. I apologize ahead of time for the lengthy "comment" but I do think you will find I have included some helpful insights.

I have palmoplantar hyperhidrosis and I have tried just about every treatment out there including topical antiperspirants, relaxation techniques, botox injections, and oral anticholinergic medications. The only treatment I have found to be effective is iontophoresis. Fortunately for me I do see great results with iontophoresis however the treatment still leaves much to be desired. It is very complicated, tricky, and sometimes even painful. And most importantly of all it is incredibly time consuming and inconvenient. I find myself stressing out when trying to incorporate the treatment regimen into an otherwise normal and healthy lifestyle. I am also about to graduate college and would like to spend a lot of time traveling in the future, however I feel chained to this treatment regimen as it is impossible to follow while on the go.

Obviously I think the dream "solution" for everyone would be a one-time procedure that resolves the issue permanently. And although miradry has mentioned expanding their procedure to cover other areas of the body besides the armpits, I feel that it may be a long ways off. Hyperhidrosis is a complicated condition and a permanent solution will be tricky to develop.

I think instead a more feasible and realistic expectation for hyperhidrosis (palmoplantar at least) is to make iontophoresis treatments more convenient and effective. Little has changed about iontophoresis units from when they first were created. I think this has more to do with a lack of research than it does not being possible. If a device could be developed that I could use while sitting at home on the couch, or in the passenger seat of a car, or in a hotel room while out traveling, I would call that a cure for me. Something that takes only about 30min to an hour a week and that doesn't feel as unnatural as sitting with hands and feet in buckets of water for hours on end.

-Commenter

I wanted to send a big THANK YOU to all of you that assisted in this conference. As a hyperhidrosis sufferer, I cannot tell you how grateful I am that there is action being taken and attention being given to this disease state. Although I try my hardest not to let HH impact me, it does have a persistent presence in my daily life. It effects everything from the shoes I wear, to driving a car, to my job (I am a sales representative), to the physical activities I decide to participate in (imagine doing Yoga with profusely sweating hands and feet!), to my personal relationships and so much more. So it truly means a lot to see this type of initiative being taken on behalf of all of us in the Hyperhidrosis community.

If any of my past experiences can be helpful to discussions or research, I'm happy to share. I'm a female in my 30s and have been struggling with palmar/plantar HH since about age 12 or so. It has only been in the past 3 or 4 years that I have been willing to share my issues with my family and clinicians. Up to now I have tried Iontophoresis with no luck as it is time consuming and ineffective for me. I tried Robinul and experienced the dry-mouth side effects. The only effective therapy for me has been Botox injections in my hands, which of course is painful, has out-of-pocket costs associated with it and only lasts 4 months at a time, but is certainly worth it. I have not yet tried it in my feet but plan to do so in the next couple of months.

If I could offer any insight into what treatments are promising to me that I have heard may be coming down the pipeline it would be the topical botox or miradry for hands. My hope is to find a treatment that offers long lasting results. As I mentioned, Botox injections worked very well for me but I experienced bruising for a week following and it was quite painful. If there was a topical solution for this I absolutely think it would benefit patients. Of course, the goal for all HH sufferers is a permanent solution, which it seems Miradry offers for the armpits. I know there has been clinical trials conducted on an applicator for hands, so if this was a safe possibility many, many patients would benefit. Based on discussion boards that HH sufferers participate in, I know that many patients feel desperate for any progress to be made. So if any petitions or communication would push therapy development along I would love to participate.

Again, thank you so much for all your dedicated work on this!

-Commenter

Here's what I want the future of hyperhidrosis treatment to be:

Thank you for making this event happen and highlighting the challenges of HH. Most people don't understand it. I never heard of before it affected me. My sweating started after a course of medication I took when I was about 30. It was called accutane, hopefully that drug is no longer in existence. This drug caused me to sweat from the face, something that had never happened to me before. I did a lot of research and discovered that it's a rare but documented side effect of the drug. I tried many treatments and went to many doctors, from neurologists to dermatologists to endocrinologists and nothing helped. I made the unfortunate mistake of having ETS, then a 2nd ETS to fix the first one. ETS brought about compensatory sweating that I've been trying to find a solution for, for the last 20 years. The sweating I had before is nothing compared to my present sweating. It has affected my life in a very negative way. HH is a problem for every sufferer but there is little doubt that people that sweat whole body have it the worst. These days there are many treatments for people that have isolated sweating, people that have general sweating have very few options. This is my situation. I have tried many treatments from pills like Robinol and the family of those drugs. They don't work and have very little lasting effect, not to mention they lose their effect over time and are also associated to Dementia. I have been to several specialists, for a Sympathetic injection treatment, contacted a doctor in Italy for a treatment of Topimax that has been helpful for some patients and currently speaking to a doctor about a highly risky ETS reversal surgery. I can confidently say that I have tried almost anything during my 20-year research. So, what I'm looking for is a treatment for generalized sweating. We are the ones that suffer the most as there are

no laser treatments, no suction treatments, no Botox treatments. I've spent a large portion of my life suffering with this and my hope and wish is a solution.

-Commenter

I want to thank you for the support of hyperhidrosis . I have suffered from hh from a young age and it has had a huge impact of my life . I would love to see a 100% result for a sweat free future . My daughter who is 3 looks like she will have hh and i really hope she gets better treatments so she can live her life to the fullest too . Its a horrible feeling to have your underarms soaked, your fingers dripping , your legs wet and your feet drenched . It is very hard to simple tasks and needs to be addressed so all hh suffers can do normal everyday tasks . Where to next i ask with treatments . I would like to get involved somehow to contribute to a hyperhidrosis free future.

-Commenter

Am glad to share my story with you and to know that I am not alone in this fight about hyperhidrosis. It's being great learning how you touch people's heart with you treatment and information that is relevant. Here in Kenya people don't know much about your organisation and more about hyperhidrosis. People always look at me in a weird way if I don't shake hands with them. It's hard to explain to them why. I believe with your organisation and your help people can be educated more about excess sweating. Where can I find these treatments and products for my hands in Kenya? I don't want to be ashamed anymore my self esteem is low I need to get my confidence back. Please help

-Commenter

I am a 32 year old woman from the beautiful "Wine Country," known as Napa, California.

I have multiple forms of Hyperhidrosis...but by far, the most debilitating form is palmar affecting my hands. Everything you do in this world you must do with your hands. Other areas I am less affected by are my feet, arms and groin area. Although in the most severe of severe conditions my entire body can sweat heavily.

I wish I could say that I am a person first...that I'm more than just hyperhidrosis, but in truth nearly everything I do in this world is completely ruled by my disease. Now, of course I literally am *more* than just being defined by my disease, but my disease does indeed define me in many ways. More than I would like to allow...more than I can tolerate. This terrible affliction has brought more pain and suffering into my life than most any other form of trauma that I have endured during my entire lifetime.

Let me start off by saying a little bit about myself and who I am. I am a very creative person inside...but hyperhidrosis has stolen away my ability to connect with the world around me, and as a result, I live a very isolated and lonely life. I don't have friends and I don't go out. I have a degree in Illustration, but my condition makes it nearly impossible for me to use my hands as an artist, so I am not currently using my degree that I spent much time, money and hard work to achieve. I have basically carved my niche into the workforce of the sewing/seamstress world throughout the years. I grew up sewing and have adapted ways to make do with my condition in order to scrape by. Though, the fact remains that every single minute of every day is a struggle...a living hell. Let me tell you a little bit about my own personal living hell:

My earliest memories of hyperhidrosis are as a child, roughly between the ages of 7-12 years old. The first memory I have with Hyperhidrosis was when I was 7 years old. I was being picked up at my Grandparent's house by my Mom after she got off from work. She was borrowing my Aunt's Volkswagen Bug and it had a faulty locking mechanism on the passenger side door. Sometimes it would latch, sometimes it wouldn't. So my Mom reminded me to slam it hard, and I thought I had. My Grandparent's lived up on a hill with a winding road off the mountain and they would always stand on the balcony and wave at us until we were completely out of site. We pulled away and down the driveway we went as I

waved. As we turned the corner on down the road a little bit, we took the corner a little too hard and the g-force of the turn caused me to be thrust against the passenger side door. The car did not have working seat belts, so because of the faulty lock, my bodyweight pushed the door open and I started to fly out of the car. My Mom caught me by my left hand as we rounded the corner and she tried to hold onto me as tight as she could, but my little hands were so sweaty, that I just slipped right out of her fingers and flew out of the car. I rolled along the gravel and was scraped up badly by road rash. My Grandpa who had been standing on the balcony waving had witnessed the whole thing and started running down the stairs and down the winding road to us as my Mom stopped the car, got out and picked me up screaming "Dad!.....Daaad! As she held me in her arms and ran to him.

I was taken to the hospital and treated for road rash and still have scars to this day. This is a prime example of how potentially dangerous hyperhidrosis can be...and the medical community at large refuses to agree that it is anything more than a petty annoyance that doesn't affect anyone's daily life in any meaningful way.

My second earliest memories of hyperhidrosis were around the age of 9, when I started out playing video games. I can remember **always** having a problem with sweaty hands while holding the controller. I was an extremely good player, (and still am to this day!), but I can remember as a kid getting so angry when my hands would slip off the controller right before I killed a boss or did x, y, or z. It got to the point where I started playing with cotton gloves on, just so I could hold the controller without it flying out of my hands. My third earliest memory was at age 12 at a Doctor's office getting stitches out of my ankle. I got into a bike accident with my friend while we were riding from her Grandma's to my house. We both at the same time went to pull onto the sidewalk unaware of the other. My sweaty hands slipped, so we collided and I ended up tangled up in my bike with hers on top of me. I wasn't crying until she pulled her bike off of me and I looked at my ankle...it was laid open like a fish fillet and blood was everywhere. I ended up needing stitches and on the day that I got them taken out...boy oh boy was I and everyone, including myself, in for a surprise.

I was sitting up on the Doctor's table, legs dangling, with that sanitary paper under me, as is routine. I was told to bend my right leg, lifting my injured foot up onto the table while I turned my upper body away and wrapped my arms around my Mom. The Doctor was only trying to make it the least bit traumatic for me as possible, having me not look, and of course being in the arms of Mom. No better place, right? Well, I was still scared as all hell and all I remember is crying and screaming in fear at the thought of what was happening to my foot as I looked the other way. The fear of what the Doctor could be doing to me was enough to create a scene that will stick out in my mind for the rest of my life...and I bet in the Doctor's too.

Luckily, I survived the alien autopsy and was convinced to take my arms down from around my Mom's neck, (whom I'm sure I had been strangling the very life out of). I was praised for how well I did and I looked down at my foot which was stitch-free. When I went to lift my leg back off the table and dangle it down alongside the other, revealed underneath, was a perfect impression left on the sanitary paper in the exact shape and size of my bent leg and foot...completely drenched in sweat. The entire process probably took 3 minutes and in that time I soaked the table. No, that was definitely NOT pee...it was sweat. And I'll never forget it.

After childhood, when social appearances don't matter quite as much, I entered my teens and that's when the condition really started to affect my social life. Up until then, hyperhidrosis had not affected my social life in any impactful way. When I entered my teens was when the pressure to be perfect and like everyone else really started to settle on my shoulders. And boys, don't even get me started on boys. Every single boyfriend I have ever had-I have had to give a disclaimer about my sweaty hands and how I cannot hold their hands. Luckily none ever let that stop them from caring about me or still trying to hold my hand...but even if it was okay with them-it wasn't okay with me.

I cannot express the utter disdain and disgust I experience at the feeling of "the touch of my own hands," if that makes sense. I literally *cannot stand* the feeling of my sweaty hands touching things. What's more-holding someone else's hand acts like a greenhouse, trapping all heat and airflow to my palm, by sealing it to another heat source (the other person's hand). Those are 2 of my biggest triggers: heat and no direct cool airflow to the affected area. As a result, I live my life "by the tips of my fingers." If I'm driving, I'm finger-tipping the wheel. You will literally never see me at a full-palmar grip on the wheel, unless my hands are not sweating or I absolutely cannot avoid it. Yes, I know...dangerous...but my palms will slip completely off of the wheel if I fully grip when my hands are sweating anyway. If anything, this is just another example why Hyperhidrosis undoubtedly is a very serious and potentially dangerous condition. Yet the medical community at large still refuses to deign to think so.

Anything I pick up, be it a cup or a remote control, I pick it up with the tips of my fingers. Making as little contact as possible in order sustain my grip. Again, I know...sounds kind of counter-intuitive...but if I grab with full palmar coverage-it will escape my grip completely because of the large area of contact I am making between said object and the sweat of my palm. The least amount of contact from palms: the better chance of holding it I actually have. It has become an art form...a science. I had to completely retrain myself surrounding how to hold objects in this manner and now it just comes as second nature. I also 95% of the time will never be seen with my fingers together either. My fingers are a majority of the time always spread out wide so that no one finger ever dare touches its neighbor, because in doing so, body heat is transferred and any cooling airflow is blocked.

I need the air flowing between all fingers and all possible surface areas of my hand in order to receive maximum effect of both the cooling air and the drying effect that air has. Again, I am affected in other areas with hyperhidrosis, but the absolute worst is and always has been my hands...hands down! This all relates to my utter contempt and sheer disgust of the feeling of the touch of my own hands. So more about that now: After a particularly strong session of sweating, (because it ebbs and flows with intensity), I produce what I call "bathtub hands." You know how your fingers get after you stay in the bathtub too long? -All mushy and wrinkly? Well mine don't get wrinkly-but they do indeed get soft and mushy just like that. It feels like I could cut my skin open at times by the slightest touch to something rough or hard, because of the mushy and soft state the constant sweat puts my skin in. You want me to grip tight and pull on that chain? -Not unless you want the first few layers of dermis to go right along with it! That's how it feels. If I am on the couch watching TV I am sitting with palms up and fingers spread with a fan directly blowing on them. Temperature is a huge key player in the issue as well along with my inability to thermo-regulate. I feel like when I'm at my worst sweating moments, if someone were to hold their hand an inch from mine that they would be able to feel the heat radiating from it. It's like all the heat in my body arises from the depths of my core and straight to my hands for desperate escape.

That brings me to my 2 biggest triggers: anxiety and temperature. Of course these triggers are not mutually exclusive, because any sufferer can tell you that no matter what you do right, hyperhidrosis can always randomly rear its ugly head for no good reason at all. Hell I've even been in line at a grocery store, noticed my hands weren't sweating, and that realization alone was enough to trigger them to start sweating instantly. In situations where stress or anxiety arises, hyperhidrosis is never far behind. It's almost like a switch gets turned on. In a situation like the anticipation of an interview, even the average non-sufferer of hyperhidrosis may get sweaty hands, but mine become hyperactive to the point where I will literally drip sweat. It's a vicious cycle too, because the anxiety of the situation makes you sweat, but the anxiety of sweating makes you *continue* to sweat even after the anxiety of the situation fades. Heat is probably my #1 enemy though. If I get warm-I will sweat uncontrollably. It becomes my soul focus to find any way to cool down in order to stop the sweat when I get warm. So I go for example: from being in a blanket, to getting warm and sweating, to taking off the blanket and turning the fan on in order to cool and stop the sweat. Then I get cold, so I put the blanket back on. Then I start to get

warm and start to sweat again. So the blanket comes back off again, and the fan goes back on. Then I get cold, so fan off-blanket on. And this cycle continues all day every day. Always going from one extreme to the other. There is never a comfortable in-between.

Which brings me to the "come on," or the emergence of sweat spells. You can always tell when it's going to happen...you can feel it tingling under your skin and then you say "no, please God...not again," but before the thought is even completed you look down and beads of dew have already started to appear. Not always, but a lot of the time, I feel kind of like a rush come over my entire body too. Like a heat wave that crashes from head to toe, then my hands get hot, then the tingle starts, followed by the flow of sweat. I guess this is similar to a "hot flash?"

Now continuing on: If I'm not sweating and I suddenly worry that I will...I will sweat. If I'm not sweating and I have an interview to go to, knowing I will have to shake a hand...my hands will sweat at the thought alone. Interviews...oh boy oh boy aren't those fun. I seriously don't even know how I get hired when I bag a job, because literally all I am thinking about is how to hide my hands the entire time as well as continuously self-monitoring how I appear until I can blast the hell out of there like a bat out of hell and never look back. Every single job I have ever had has been dictated by my disease. My very first job was at 15 years old and I worked at a fabric shop. It was a wonderful job for me, because nobody was able to notice my sweat for the most part since I would constantly be handling fabrics. Now I know what you may be thinking, and no-I did not just let my hands sweat all over the fabric. I have more integrity and respect for customers than to willingly do that. But I would constantly be wiping my hands as needed on my clothes for upkeep to get the sweat off and then there wouldn't be enough on them to notice while handling any fabric. Plus, the way I by nature of the job had to constantly flap my arms all over the place, when measuring and folding fabric, meant that I got to generate my own breeze, therefore cooling my hands and sending them into the "cooling and drying phase."

The "cooling and drying phase" is when you are able to take your hands from hot-to-cold via a breeze hitting the sweat, which then starts to cool the sweat and start to drop the temperature of and dry the hand. Think of it like when you come out of a hot shower in winter time and the cold air of the room hits you as you step out all wet...it can be enough to chill you to the bone. That's what I call the "cooling effect," or the "cooling and drying phase," of cool airflow on sweat. Though again, this is not a 100% concrete rule, because there are those times when I will still suffer cold sweats and those can be downright painful. Sometimes in order to stop the sweat, I need to chill my hands to the point where they are so cold that they actually hurt. And if they sweat in a state like that, they get even chillier if any air hits them. Which hurts...almost burns even. Kind of like I imagine frostbite may feel. I feel like I'm constantly going from one extreme to the other. Like I'm constantly jumping from a hot tub to a frozen lake and back again.

Anyway, I worked at that fabric store for 5 years before I went to college to pursue a degree in Illustration. The decision to do so was fueled by my passion for art, but honestly it wasn't a very good idea, because I did not give my hyperhidrosis enough practical weight in the decision. I followed my heart to my detriment instead. At home, I could control my environment and produce art, but in the real world it's a different story. Hyperhidrosis simply will not allow me to be a full time artist, because I cannot control the sweating reliably and for long enough periods of time. I took many classes online and eventually graduated college, but I continued seamstress related work afterwards, so I could hide my hands. In Fall 2016, the local fabric shop went out of business and in May of 2017 I landed a job at the Bottle Rock Festival here in the Napa Valley. I was lead seamstress for the Décor department and sewed everything from VIP entrance hangings, to trailer curtains, to the truss covers that lined the stage that Martha Stewart cooked on. That was my first gig where I decided to request a fan which became my holy grail. It wasn't easy either-it's not always socially acceptable to show up like a diva demanding your own little fan where you sit in the shade, while all the guys do backbreaking work out in the sun.

But it was May, hot as hell in the 90+ degree heat, and we were working outdoors, so I used that to my advantage and asked for my fan. The work was such that I had limited interaction with a small number of people every day, so I was able to keep my sweaty hands a secret in that type of scenario. It was wonderful, it gave me so much pride and it made me see a future for myself doing bigger and greater things than ever before, but the little voice in the back of my head always reminds me "nope-can't do that with your hands the way they are." So my greater potential has been stopped short, buried deep, and wishes it could break free and shine bright.

After 2 weeks the festival was over and I needed to find something else. I started looking for more legitimate seamstress work, which is extremely hard to find in Napa, but in July of 2017 I found a uniform place that served Law Enforcement, Firefighters, and EMT for the North Bay in Petaluma. As soon as I saw that needle in a haystack my jaw dropped, my heart sang and my hands started sweating like crazy...(which means you *know* I was excited). I wanted it and I wanted it bad...I decided that I was going to give it a try. After all I am a professional hand manipulator after years of experience creating sweat-hiding ways in most situations. So I took a chance and I dove in. I got a call back and an interview. As soon as I walked into the place I was almost shocked at how many fans they had setup in different areas and I felt like the heavens had opened up and God said "I love you Chelsey." Because nowhere...I-mean-NOWHERE...have I walked into the dream setup for my secret burden when walking onto a potential job site up until that point.

These people were fan-crazy and it was **perfect** for me!! They even kept the thermostat at 70 degrees. I got to sit right in front of a fan while I filled out my application, which kept my hands manageably dry-ish, so I at least didn't leave it a sopping mess and I was hired! I had a little room in the back where the industrial sewing machine was and they set me up with my own little desk fan. Now my boss, by default, would always turn on all fans in the morning before I arrived, to the circulation mode where it would constantly change direction. Though as soon as I got there and sat in my chair, I would click the button to make it stop rotating and would point it straight to the sewing needle where my hands would be and it was a dream. I would go from the sewing machine, to the ironing board next to me and wherever I went-so did the draft of wind. If I moved to the left where the board was-I turned the fan to the board where my hands were. If I moved to the right where the sewing machine was-I moved the fan to where my hands were. And I was alone back there most of the time, so nobody noticed this continual process. Eventually, one day as she was walking in, I was caught by my Boss while I was turning the fan onto the area where my hands were one day. I looked up at her as she walked in, while I was caught like a deer in headlights as I redirect the fan, but she never said anything about it to me even if she did think it was a little odd. She did move her eyes from mine to the fan and back at me as she walked in, but I didn't volunteer to explain and she didn't ask. But bless her heart and I will never forget her, because I feel like she eventually noticed something was up with me and those fans or heat in general. Because on a slow week when we didn't have any sewing, I was told to help with some inventory on the computer and low and behold she had put a whole new little fan there for me where I'd be sitting at the computer all day. There had never been a fan there before.

My eyes well up with tears as I write this, because even though it was unspoken, I felt she caught on that I needed the fan and she helped me. Whether she ever noticed my hands were sweaty-I truly don't know...but if she did she never mentioned it or discriminated against me for it. I love that lady and I miss her very much and I pray that my next job I can find an environment as comfortable and with people as understanding and caring as she was. That job was very hard on me in some other ways, but I loved it because of the controlled environment and all the fans. I would measure police, firefighters, and EMT and make alterations to their uniforms, sew on patches, etc. At times it was very intimidating to have a bunch of cops walking around, especially when getting up close and personal measuring them, but I did my best to hide my hands. There were some rules I made: when measuring someone-never turn palms up...or someone might see the shine. When pinning for alterations-never accidentally touch a cop's bare

skin and always touch their uniform by tips of fingers only. When hearing a cop approach my room to be measured-always get your hands busy so you would not be obligated to drop what you're doing and shake a hand as they entered etc. I was always able to distract them from offering a handshake that way along with my bubbly personality that I instantly engaged them with in order to distract them and have control over the direction the encounter took.

There however, was one incident with a firefighter that still leaves me feeling bad when I think back on it. It was on the day that I was at the computer. Now these cops and firefighters were so nice, as nice as they could be, so they wanted to always meet you and shake your hand if possible. Up until that day I had always been able to trick my way out of a hand shake, but not this day. I was at the computer and saw a bunch of firefighters come in all together. I instantly became nervous, because I knew that I would probably have to shake at least one of their hands since there were so many. I couldn't dodge them all. And the thought of having to shake all of their hands sent me into a panic. My hands started sweating like crazy. I turned my hand-fan up full blast, but it wasn't stopping the flow. I was too nervous. Sure enough one of the firefighters came up to me at the computer with an outstretched hand and said "Hi, I'm Tony!" I knew I could not shake his hand and I did not want to tell him I couldn't shake it because I had hyperhidrosis...because then my boss and the owner might find out and I would be exposed. So the only thing I could do was look up at him and say "nice to meet you, but I'm sorry I would be giving you a sweaty handshake right now. So no handshake please." And he said "oh...ya nervous that we are all in here?" and I said "um...no?" and wasn't sure if that was the right answer or not, but that's what came out. He looked genuinely concerned and confused...like what the heck is this girl hiding? Because usually the only reason a "normal," person's hand would sweat is if they are nervous or being dishonest. So I was freaking out wondering if maybe he thought I was doing something I shouldn't be on the computer or something...then I felt like a criminal. A moment later he was trying on shoes across from me and I looked over at him, he wasn't looking at me...he was looking at his shoes, but he still had this kind of sad/puzzled look on his face. Like he still hadn't fully figured out what had just happened with me and was still stunned by it.

I felt so bad...and I know firefighters live to help people. I almost wanted to say "excuse me...can we start over? I actually have hyperhidrosis...it's a medical condition that makes my hands sweat." But I couldn't. I was paralyzed by fear.

I regretfully left that job after some time, because of the distance I had to travel to get there and because after that incident I became more and more paranoid that another like it would happen again and I no longer felt as safe at my job day to day as I once did. The nature of that job was such that you couldn't avoid being social and physically close to people. We got to know our customers by name, because we served local law enforcement and saw the same people repeatedly. I knew the longer I stayed, the more about my disability would be revealed. I worked there from July through October of 2017.

Within days of quitting I happened to find a seamstress position in my home town of Napa, so I jumped on it, because that literally never happens here. Especially after the only fabric store in town that I used to work at closed in fall of 2016. I regret leaving the job sewing uniforms in Petaluma, because the environment I went into next was the polar opposite of accepting and accommodating. I had the exact opposite experience regarding fans at this new job in Napa where I live. It was another seamstress position, but unlike my previous job of sewing Police, Firefighter and EMT gear in a little air conditioned room all by myself...I was in an industrial setting sewing right alongside 6 other women in 1 large room that was next door to the industrial washing room...and it was HOT. The fact that none of them spoke English, save for 1 who slightly spoke English, made it extremely hard for me to be seen as a human being and express myself as one. In other places you can talk to people and get acquainted, find similar interests, get to know each other, build trust etc...but not here. I would just get stared at and hear whispers and giggling behind my back all day, being the only white English-speaker in the room. I was

alienated from the start even without my hyperhidrosis-now throw that into the mix and I got the resulting effect. Long story short, the industrial overlock machines I was sewing on were ones that I had never sewn on before. So I had to be shown in very close proximity, (and without words), what to do. That means with body language and a lot of hand gesturing from their and my part. And when the woman threaded the machine and then de-threaded it, handing the thread to me-it was then my turn to show that I could do it. Well the fact that my hand would be in direct scrutiny without any ability to explain why my hand was running like Niagara Falls sent me into a panic.

But I had no choice, so I threaded the machine and indeed left sweat all over it and you should have seen the look on her face when she looked at me, then at the sweat, then back at me...I felt like she was thinking "what the hell is wrong with this filthy white person?" because to them-I was just some sweaty alien far from their understanding, let alone someone with any humanity or personality at that point. The language barrier was hard enough and of course whispering and giggling and stares ensued after my teaching lesson when she went back to sew with the other Spanish-speaking women behind me. After my first day I went home determined to show them that I was a human being-and a goddamn kind human being. So I spent hours that night Googling and practicing how to say and ask certain things in Spanish. The next day when I showed up for my second day of work, I walked in with a smile saying "hola," to everyone and the room fell silent. Everyone dropped what they were doing and looked up at me in shock, like "oh my God-it can speak! It's actually a human!...What do we do?"

I added "como estas?"..."(how are you?)" as I walked to my sewing machine. Two or three of the ladies answered back with eye contact and smiles, so I knew I had broken down the first wall...but still had a lot to prove. As time went on I endured my condition and forced myself to continue to produce work and deal with the language barrier. I continued to learn Spanish as best I could and slowly gained more respect in the work room. A few of the women even started to speak a little bit of English to me, which I didn't even know they knew any up until that point. But I was still a complete outsider to them and had no way to show who I was beyond the work I produced and whatever they could tell about me by just looking at me...which wasn't much with my hands the way they were. One lady told me one day: "she say you work is perfect" after she had asked the lady receiving my work directly behind me if it was okay. So I knew that they respected my *work* at least, but still the fear of my condition and the stoic look on my face in horror of my own body at times, I am sure came off as awkward and didn't help my attempts to humanize myself. I couldn't tell them how I was suffering or what I needed.

One day I noticed an old dusty fan in the back corner of the room that looked like no one had used it in years. I eyed it all day...wondering how I may be able to figure out how to acquire permission to use it. I certainly couldn't just walk up and grab it without asking someone, what if it was for some special purpose and we weren't allowed to use it? Well one day I saw one of the ladies use it for about 15 minutes. I wasn't sure why she did, but the fact that I had seen it be used by someone gave me the confidence to use it myself. She had just got up and gotten it that day without asking, so the next day I casually got up from my machine and all eyes were on me from the moment I stopped working and got up as I walked over to the fan. I knew what I was doing would not be understood until they saw me plug in the fan and sit down, so I kind of had to tell myself "screw it," and disassociate from the situation. Kind of like the robber whom after robbing a bank may casually walk down the street to try and look inconspicuous as a cop slowly drives behind him checking them out for any signs of misdeeds. I felt like that robber who had no choice but to swallow their fear and say "screw it," as I continued to casually walk straight ahead.

I walked over to the fan, picked it up, brought it back to my machine, sat down, plugged it in, pointed it at myself and turned it on. I was nervous because it was October and it really wasn't hot enough to justify using it in any other normal setting. Everyone else was wearing sweaters and here I was in a short sleeved t-shirt with a fan on me, but nobody made reference to it-they just let me have it that day. Then the next day I did it again and by the third day I was really starting to think this job might work out. I

couldn't wait to get to work and sit in front of my fan. Well on the third day of my "starting-to-be," routine one of the ladies who could speak a bit of English got up and came over to me and said: "Chelsey...you have problem, because you use every day." And I tried to laugh it off like it was a joke, but in reality she had completely crushed me and any semblance of confidence I had started to gain. I went from feeling normal to feeling three inches tall and I was so ashamed and embarrassed that I never used that fan again. Two days later-I quit. You know...right after she had said I have a problem because I use the fan every day, whether she meant it as a joke or not, there was some truth there. And I remember thinking "dear God...I can't even communicate with these people, yet they see right through me." I was horrified. I felt like there was no way I was going to be able to humanize myself and no way I was going to be able to get the accommodations I needed to be able to work properly. So I ran away...I quit. I'm thankful for that experience, because it was an ethically eye-opening one of "shoe on the other foot," and I felt what it was like to be the odd one out for a change within a language barrier situation. But it still left a bad taste in my mouth. That was the first time I had ever felt humiliated by my condition and completely powerless to explain it in a work setting. It made me even more aware that in the future, a job that caters to my condition is absolutely MANDATORY. I am currently unemployed as of late October 2017 and am looking for wherever I can fit in...but it's almost impossible. My fabric store is closed and not another for 30 miles. Everything a person does in this world-they have to do with their hands. Can you name even one job that wouldn't require a person to use their hands, save for some rare trade I may need thousands of dollars and years of college to even begin to qualify for? I literally can't think of even one job that exists period that doesn't require a person to use their hands. Even a person doing voice work has to hold papers or use a computer. I would have gone back to my old job in Petaluma in a heartbeat, but they had already filled the position.

Anyway, please allow me to now share some experiences of horror that I have experienced *publicly*, outside the work zone, due to my Hyperhidrosis. One time I was having my oil changed and when I went to pick my car up, I tried to pay with my debit card, because us Hyperhidrosis folk do not use cash if we can help it. We can't mess around trying to handle sweaty money and change. It's a nightmare of a task even just to pay for something with this condition...yup...truth. So I handed over my card and it was declined. I knew I had the money in there, because I had just put it in! So I needed to make a call to the bank. I didn't have my phone, so I was forced to use theirs or walk 5 miles home to my house-nope. So I knew I had to use their phone and in the back of my mind I'm already planning my escape as I ask to use it. Where am I going to hold my hands? How can I position myself so that my fingertip-phone-holding-hand can be blocked from view? etc...then I go for the kill. I ask "may I use your phone to call the bank?" and I was obliged and kindly asked to come around the counter. In my mind I scream "Dear God-NO!! Why are you doing this to me? Can't you just pass me the phone through the window??" but no...I had to face my fears.

I had about 3 seconds to do something about my hands as I walked around the counter to the phone. I had my wallet in one hand-and the tip of my shirt furiously crumpled up in the other as to collect as much sweat as possible before I had to grab that phone. I made it to the desk, picked up the phone and dialed...making sure to swipe each key before I lifted my finger off, in order to wipe away any sweat that would be left (a trick I learned as a kid in piano class). I held the phone in one hand by the fingertips, but started to feel my hand sweating so much, that I knew it was about to drip down my arm...so I decided to drop my hand to my side and hold the phone between my head and shoulder like someone would do that has no free hands to hold it with. But I *did* have a free had to hold the phone with-so my anxiety was rising as I self-monitored myself almost out of this world and into another dimension completely. The hold times couldn't be any longer when calling a bank's 800 number either! I just wanted this 5 minute hold that seemed like 5 years to end already.

But before I knew it, I happened to look at the lady and make eye contact with her. As we made eye contact, I saw her looking into my eyes with the most serious and shocked look on her face I've ever

seen in a retail setting, then down at the desk and back into my eyes. I then took my gaze from hers to the desk where she had just glanced in horror, to notice that my previous phone-hand, (that I had abandoned in favor of my shoulder trick to hide my sweat) was drip...drip...dripping all over her desk. I was mortified and I instantaneously slammed my wallet down on top of the sweat puddle and tried to pretend like I had seen nothing. I instantly started to panic and became hotter...and hotter. I was trapped! I could not run! I had been metaphorically caught by the cop and was being arrested and cuffed. I'm guilty, just take me now! As I got hotter and my heart raced faster and faster: my face started to sweat, my feet started to sweat, my arm pits started to sweat, my butt started to sweat, my legs started to sweat...I had become a full-on fountain of bodily sweat. And if I was wearing sunglasses, I guarantee you they would have been fogging up from the radiation of my panic-stricken body heat. I then got even more paranoid and scared because as I self-monitored, I realized she must be thinking I'm some sort of a bank robber with a stolen card or something in order to be sweating like this. This is a great example of how Hyperhidrosis affects your mental health. It literally drives me into paranoid delusions such as mentioned above about what people might be thinking of me. It makes me feel like I am being dishonest when I am not. It at times makes me feel like I have actually committed those crimes, like I am a real criminal, when they are all just made up in my head. This paranoia and fear of how I am perceived has had intense effects on my self-esteem and has at times had me question my own sanity.

That was one of the most humiliating moments of my life regarding hyperhidrosis in public. But wait: there's more! One time in my teens, before I had a car, I would walk home from school every day. One particular day in dead summer, I was walking home in all black and was sweating like crazy. I was holding money folded up in my hand to buy some water and in the process of waiting in the long line had drenched the 2 dollars, (one of the ways I learned it was easier to pay with debit card). When I forked over the money, the teller took it and did a double take as he looked close at the money and asked "why is it wet?" I instantly pulled from my rescue-bank of lies and replied "oh-uh...me and my friends just had a water fight because it's so hot outside," and nervously chuckled...but I was the only one laughing. He clearly wasn't convinced. After all-I wasn't wet from what he could see. So I had failed to be a human being in the most simple of situations yet again.

Another incident was when I was a teenager, (before I had learned a lot of my hiding tricks or not to touch anything). I was with friends and we were going out to eat together. I forget where, but there was a black matte counter, (the enemy of all liquids because it shows up so obviously), and I remember resting my hand on it full-palmed as I placed my order. When I was done ordering, I lifted my hand back off of the counter to step away and left a giant handprint of sweat where my hand once was. As everyone looked down at the sweat and then back up at me I literally wished at that moment that I could just disappear and be completely erased from history. I pretended like I didn't see it, (again the forced-disassociation from reality in order to survive the moment) and my friends didn't ask me about it, but I know they must have thought "what the hell was that?" It was after more and more times like that that I began to withdraw from as many public social activities as I could, in favor of staying in my own climate-controlled environment where I could have the most control over my devices of relief.

When I became old enough to stay at home by myself, I chose to no longer go with my family on vacations to Hawaii and missed out on many, many memories that I sometimes regret to this day...because most of my family is dead now and I missed out on so much that I can never get back. But being in an environment like Hawaii, which is the average person's tropical heaven, was actually a full-on living hell for me. I hated every second of it-because it was so hot and so humid that it made me sweat like never before. Sometimes I wonder if I should just move to Antarctica so I can get some relief? Also during family holidays like Thanksgiving and Christmas, we would all gather around holding hands to pray before we ate. Even as young as 14 years old I had to steal my Grandma away into a dark corner, long before dinner came, and ask her if she could be the one to stand on one side of me...and of course

my Mom would be standing on the other side. They both quickly learned the rules: DO NOT....under ANY circumstance, hold my hand. Instead, grab me by the *wrist* and let my hands hang free to uphold the illusion that I was still holding hands just like everybody else during prayer. It probably didn't help the fact that I was an emerging Goth at that time either, because I think a lot of them probably thought I was rebelling against the fact that we were praying. Nope, I wasn't...I was just trying to hide my sweat...and from my own family no less. This is a great example of how shameful this affliction is. So much so, that you don't even want to tell your own family. It's because we've seen and *felt* the looks of disgust from strangers and we can't bear to *feel* that look of disgust from someone we love. I've even had that look of disgust from Doctors...oh dear God in heaven don't even get me started on the Doctors!!! Demons from hell, they are...at least the ones I've encountered when it comes to hyperhidrosis. NONE of them think it is a serious condition, NONE of them are willing to advocate on your behalf and a very select few of them even *know* what Hyperhidrosis is, let alone treatments for it. One time I even filed an official grievance with the head of the hospital I was seen at, because of the way I was belittled and dismissed by a so called "Doctor." To this day I still seethe with furious rage and anger whenever I revisit that moment in my memory. It wasn't until I was 28 years old that I found out what Hyperhidrosis even was and that it was an actual thing. I had found the International Hyperhidrosis Society online and registered to sign up on the website. Up until then, I had been living my life in shame and secrecy, growing up to know I was a revolting, sweaty, freak. When I found out Hyperhidrosis was an actual condition I felt like maybe there was hope for me to get treatment. I spent weeks and weeks doing research, preparing myself the best I could to understand what this Doctor was going to tell *me* about *my* condition, but it ended up being the other way around. I researched treatments and thought Iontophoresis might be a great option for me after Botox and Surgery scared me off. I did extensive research about what different brands were out there, what experiences people have had with them and what experiences people had with getting them covered by insurance, since I could not afford one. The only brand it seemed was covered was the Fischer brand model, (which was the cheapest one out there), and had terrible reviews. But I put it on my list along with two other options: a mid-grade and a high-grade model with great reviews as well as pros and cons of each of the three models. I couldn't wait to see what my Doctor thought would be best for me. I printed out my golden ticket of information and I was so optimistic, so grateful to be booked for an appointment and so happy when my Doctor walked in the door. And by the way-when I made the appointment and was asked what it was for-I answered "hyperhidrosis," and was asked what that was. Most people simply don't even know it exists...even many of those of us who have it.

Anyway, it didn't even matter to me that I waited an hour and 20 mins past my scheduled appointment to be seen. I couldn't have been happier when she came into the room. She introduced herself and stuck her hand out for a shake. I said "nice to meet you, but please...no handshake...I have hyperhidrosis." And added: "...That's actually why I'm here today." I said with an optimistic grin. She dropped her hand with a confused look and said "oh...okay?" as she sat down at the computer across from me and immediately started typing. She asked me to tell her about what I was experiencing and I said "I have suffered from palmar hyperhidrosis all my life and only recently even discovered that this was an actual condition. Can you please tell me what is causing this and what I may be able to do to stop it?" She started typing on her computer as I waited for a response and then she said "so...you have sweaty hands?" and I replied "um...yeah." And she asked me what treatments I've tried and I reiterated that I hadn't tried anything yet, because I'd only just found out a few weeks prior what Hyperhidrosis even was. But that I had researched treatments and thought the Iontophoresis might be good for me. I held up the paper and told her the three machines I researched were here with pros and cons and wanted to know what she thought. I asked her what Iontophoresis was and she simply straight up said she didn't know, offering nothing more, and continued to type. Strike one.

I told her "well we could look at the information I have here and talk about it," and she literally took the paper out of my hand, did not look at it and placed it on the desk beside her as she continued to type away. I sat in polite silence waiting for her to respond and resume engagement with me. A few awkward moments later she lifts her gaze from the screen and glances over at me and says she's never seen a machine like that, she's never requested a machine like that and that my insurance wasn't going to cover it. Strike two. I asked her "how do you know? Can you please at least try?" she gave me an annoyed look, did not respond and went back to typing. I asked "can you write me a prescription for it at least and try?" and she replied firmly "sure, but it's not going to do you any good." Strike three. At that point I was angry and realized that this so called "Doctor," was not even slightly interested in helping me. All this within the short 3 or 4 minutes we'd spent together in the room after my long wait. I was very disappointed. She seemed more interested in rushing through her appointment with me so that she could catch up on her other late appointments.

She made me feel like I was not important...(and on our next meeting not only would she make me *feel* like that-she would actually *say* that to me). So at this point I was only interested in getting the prescription for the Iontophoresis machine from her, (which you had to have in order to buy one insurance or not), and then she finished up typing, stood up and gestured me to the door saying "okay we're all done!" I said "That's it?...What about my prescription??" and she replied in an aggravated tone "I'll get to it when I can." I was furious. I said "what do you *mean* you'll get to it when you can? And how will I even get it?" and she snapped at me: "you'll get a call." I then grabbed my iontophoresis information paper that she had put by her computer, got up and left. I was completely crushed. All of my hopes and dreams were completely destroyed in less than 5 minutes. Even so, I waited...and waited...and waited. After that, a week had soon passed, and guess what? –NO CALL. What a surprise. I still think to this day she could have written my prescription right then and there at our initial appointment. So I called the hospital to follow up about my prescription, asking if I could talk to my Doctor. I was given the roundabout "we will pass your message to a nurse who will blah blah blah blah.." I decided I was going to be my OWN advocate and make an appointment with the Doctor, just so I could talk to her directly, guaranteed. She was booked till the next week, but yup I sure waited. And during that second week since my initial appointment, guess what...STILL NO CALL.

So the day of my second appointment with her, there I am again in the waiting room...an hour past my scheduled appointment, being rushed into the office where I waited another 20 minutes till she begrudgingly enters the room and looks at me like "what do *you* want?" and I say "so it's been 2 weeks and I still haven't received any call about my prescription." She replied she hadn't got to it yet...uh YEAH...CLEARLY. She said she'll get to it when she can. Well there went that good old rage rising up in me again..."same sh*t different day," as they say. Another "I'll get to it" just to get me to shut up and go away with no real intention of ever following through. I said "no-you know what...I've already waited 2 weeks for you to write this prescription. I want to know WHEN I can expect your call, what you're going to do and when you're going to do it" she replied "look...*your* condition...is not serious. I have other patients to see today that are *more* important than *you*." And oh mama...I swear...if I wouldn't have gone to jail for it that day, I would have straight up physically attacked this sadistic Woman who was parading around under the guise of a "caring Doctor."

But I knew that I needed her help. In that moment I wanted to strangle her, but I forced myself to push back those feelings and speak coherently without tone or attitude...I said "please...I'm suffering.....help me..." and she just grinned with delight like she had the full power to torture me at her will and was loving every moment. She said "there's nothing I can do for you." And at that moment, I had simply had it. That was it. I said "you know what? You're right...you CAN'T help me...that's right! And that's the ONLY right thing you've said!" I told her "I'm through with you and I'm going to see a REAL Doctor who actually *cares* about helping patients and *knows* what they're doing!" and I walked out of that office and straight to the front desk where I asked to file an official grievance with the hospital. And I filled it out in

full right there on the spot. I was told the grievance would be reviewed and a few days after I got a call to come and talk with the head of the hospital. I shared my experience with her and she asked me what I wanted her to do and honestly what I was thinking was "dummy-what do YOU want to do about this?" like did she not even think the way the Doctor treated me was wrong in the slightest? I told her "I don't know what I want you to do-but I want you to do SOMETHING." I said "something needs to be done about this, she cannot get away with this, because I guarantee you she will do this to someone else." And she said she would be talking to her and I never heard another thing about it again. But she still works at the hospital, so she wasn't fired or anything over it. I however sometimes wonder though if I had cause to sue for malpractice. I'll never know. That day the head of the hospital did write me my prescription right on the spot, and that is why I suspect the other Doctor could have done the same exact thing. But the trauma that I experienced over the whole situation left it with so much negative energy that every time I looked at that prescription it just enraged me and brought me to tears, so it sat collecting dust...expired and I never even attempted to use it.

She's lucky I'm as poor as a pauper without any knowledge of my rights as a patient regarding what happened, or else I might have indeed sought legal action. But also, the entire problem of my hyperhidrosis in itself was enough to shy me away from having the courage to even bring the case to light even if I legally had a right to.

That was the end of my attempts at treatment for my disease for the next 4 years. I had been so traumatized and disillusioned with medical treatment after that, that I never even went to the Doctor for a checkup or the flu. I didn't step foot in that hospital or any hospital again for 4 years. It wasn't until I saw a commercial on TV one day back in December 2017, (the first of which I had ever seen) for Hyperhidrosis that I had the ability to pursue help for myself again. Up until that point I had accepted that there was just no hope for me. The commercial I saw was for a hand and foot cream called "Carpe Lotion," and I instantly burst into tears. I started thanking God and holding my hands up to the sky as I cried tears of joy to see people like me for the first time in my life getting recognition on national TV! I ordered the cream and decided that maybe in the last few years things have changed and maybe I could try again with another Doctor. So I gathered up the courage and made an appointment with a new Doctor in November of 2017.

She was on time, but I would have happily waited, although she still rushed me and had little knowledge of Hyperhidrosis or its treatments. I told her in short about the horrible experience I had years ago with the other Doctor and that this was the first time I'd been back to a Doctor to try and seek help. I broke out into tears trying to convey the grip this condition has on my life and that I feel like no one wants to help me. I told her that I was almost pathetically desperate and was begging for help. I described some of the things I go through daily and I told her "Doctors don't think this is a serious condition and I don't know what I have to do in order to be taken seriously." I told her "You have no idea the way this condition is ruling and ruining my life...you don't know what it's like to have someone wipe their hand in disgust after you shake it, you don't know what it's like to be at work and hand somebody a sopping wet receipt.." and this disgusted look came over her face like that receipt thing was just too disgusting and shocking of a visual for her to handle quietly. Clearly if she was acquainted with hyperhidrosis she wouldn't have been shocked by the image of the wet receipt at all. But she hurt my feelings by giving me that look and she made me feel ashamed. I knew at that moment that this was not the Doctor for me moving forward either, but I tried to get from her whatever I could before I left. And she agreed with me that insurance companies don't think it's a serious condition and prescribed me Drysol.

I got the Drysol, but unfortunately it didn't work. I was supposed to apply to dry hands at night, (hahaha...ironic...someone with hyperhidrosis has to have dry hands in order to apply medication) and insert my dry hands into sterile latex gloves at bed time. Well my hands would not stop sweating, but I tried my damned hardest to get them as dry as I could, applied the Drysol and stuck my hands in the latex gloves. Well anyone with hyperhidrosis can tell you-the absolute LAST thing you want to do to stop

sweating is shove your hands in latex without any airflow. So as I laid in bed, my hands just itched as the gloves filled up with sweat. I was not able to sleep the entire night, because it was so unbearably uncomfortable. I tried in the second night and the third night and gave up completely after I experienced the same results and the same sleepless nights to no avail.

It didn't work. And I have not been back to a Doctor since November. I am currently trying the Carpe Lotion I saw back in December, but it's not working either. Although they say the more you use it-the better it works so I am going to continue use until it is gone. It is a cream you apply after washing hands day, afternoon and night. You just put it on and go-no staining of clothing/no need for gloves on hands. It gives your hands "grip," but so far has not stopped the sweating, but I've only been using it for about a month and have a three month supply. So we will see, but so far I don't have much faith in this either. I just decided to keep going and keep looking until someone wants to take me seriously, take an interest in me, and advocate for my health. And I think I have finally found that with the International Hyperhidrosis Society. I am so desperate for treatment at this point that I have actually found myself getting mad at commercials I see on TV addressing other people's issues that I consider "less debilitating than my own."

I can't count how many times I have screamed at the television "oh shut up!" when I see that Cosentyx commercial for eczema where they're all like "see me." I just get so upset crying: "where is MY commercial?! Where is MY 'feel me' " catch phrase? I find myself saying in my mind "screw you and your little scab-try living with THIS!!" when I see that commercial, because it just triggers something in me. I am jealous and envious and I want my moment...my cure. I think the thing that hurts the worst, more than the disgusted looks, more than the things I can't do because of Hyperhidrosis, is the way I was dismissed and belittled by my Doctor and how the next Doctor I saw pretty much told me the same thing, only in a *much* nicer way...that there's no help for me and that nobody cares. That I'm just one small dramatic jerk in this big huge world who needs to get over my little "non-issue."

That's how I have been made to feel, all of my hopes and dreams for a better life, crushed. And I cannot express the joy I felt when I received an email from the International Hyperhidrosis Society on 12/19/17, (that I had registered online with 5 years prior), accompanied by a link to a three and a half hour town hall with Doctors and sufferers of this horrific disease. I clicked that link so fast and oh man, the tears just flowed...oh boy did they ever flow like the river of my hands. It was a beautiful moment and I must not have blinked once that entire three and a half hours. And I could have watched another three and a half. I watched it in full and then I watched it again-because it just-made-me-feel-good. Every testimony I could identify with. From the first sufferer sitting in the chair on stage, Maria, who spoke and then grabbed the tissue at the end of her speech...(not for her tears, but for her beautiful hands), to Lisa Pieretti, Dr. Kendal Marcus, Dee Anna Glasier, and Dr. Pariser said that WE are the experts here. I felt SO proud...so validated and so powerful in that moment of confirmation. All Doctors who spoke so sincerely, eagerly and showed genuine passion and interest in this life destroying disease absolutely blew my mind. The International Hyperhidrosis Society has given me new hope with this step forward to the future in fighting hyperhidrosis. When you said you wanted to know what I wanted...what I wanted to see in treatment and to hear from *me*, I cried like a blubbery baby so hard that my eyes were swollen the next morning and my vision was blurry.

The work IHHS is doing for people like me is nothing that the world has ever seen before. Your team are the first line of warriors on the battlefield of medicine, for the first time ready to fight for us with passion, vigor and persistence! For the first time Doctors like those behind IHHS are taking us sufferers seriously and actually genuinely care! You show that you long to advocate for the health of people like me and that is what we have been waiting for all our lives. I thank God for the International Hyperhidrosis Society, all its members and all you are striving to do for those of us who are suffering. You are truly the answer to our prayers. The snowball has finally started rolling. I wish there was a place for me within IHHS. You know, as a matter of fact, that second Doctor I saw about Hyperhidrosis...I told

her on my way out that I hoped one day Doctors would start taking Hyperhidrosis seriously...I told her: "who knows...maybe I will be a part of that revolution?" and she smiled and said "maybe." It was kind of a patronizing "maybe," like she didn't really believe it could happen herself. But look-here I am but a few short months later and I am a part of that revolution and I am so proud and grateful! I feel so strong, so optimistic and actually have hope for a future once more! I wish there was something I could do other than just share my experiences. I will do whatever I can to help forward this cause, and if anyone from IHHS needs anything from me at all, you don't even have to ask. You just *tell* me what it is and if I can do it-you got it.

Now on the topic of what I would like to see as far as research and treatments go:

In my perfect dream world there would of course be a permanent cure. And a cure you didn't have to risk death for, like the risks surgery carry. That's way too invasive for me and the compensatory sweating thing that goes along with it-not willing to risk that. I don't want to trade my sweaty hands for a constantly sweaty butt or a sweaty face etc. Ideally there will be a non-invasive treatment option and a permanent one.

And most importantly-please do more research on the **core** issue of the problem deep within the nervous system of the brain! Many treatments address the symptoms of Hyperhidrosis, not enough treating the core issues deep in the nerve centers of the brains where it seems this problem originates from. I can tell you first hand-something as simple as the mere realization that you are not currently sweating is enough to trigger sweating. Like my example of standing in line at a store realizing I wasn't sweaty-only to at that moment instantly start sweating, because I started thinking about it. Some of these triggers are clearly linked to emotions/anxiety and are not physically triggered...the power of the brain sets it into full flow in times like these. Also please research in great depth the problem many who suffer from Hyperhidrosis have with thermoregulation-please do more research into the correlation between body temperatures, and the ability to regulate them and how they relate to HH. Also the effects and intensities of HH and its treatments in different climates such as hotter areas opposed to colder areas, as I found being in the humid Hawaiian climate made my condition even worse.

I would also like treatment options to be accessible and affordable, (I will never be able to afford Botox every 6 months for example). I also want Doctors to start being educated about Hyperhidrosis and for that to be as routine as any other condition that's covered in medical school. And insurance companies need to start taking us seriously and covering our treatments. My insurance would not even cover my \$7 Drysol. If they can cover someone with eczema (rash on skin), then they can cover my sweat on skin. I would love to be able to have some kind of therapy for hands like Miradry, which unfortunately is only for arm pits at the moment.

I have tried Drysol, Certain Dry, and am currently using Carpe Lotion. As stated above, the Drysol and Certain dry did not work and the Drysol made my hands extremely itchy-I found myself scratching my hands raw at one point they itched so bad. Also the fact that someone with hyperhidrosis was asked to apply it to dry hands is kind of ironic and made it nearly impossible. I haven't been using Carpe Lotion long enough to know for sure, but after a month it is not lessening my sweat. I would say that a meaningful degree of sweat reduction would be 80%. To the degree that I sweat-cutting it by half would still get me nowhere near a functional level of sweating. I need my degree of sweating to be cut almost completely to have a meaningful impact on the quality of my life and simple daily tasks.

I would also ask if possible for treatments that are not painful and are non-invasive wherever possible. The thought of undergoing hundreds of needle punctures on one of the most sensitive parts of my body every few months for the rest of my life just isn't good enough for me. Not only that-I cannot afford that. I don't want to trade one horror for another and ideally treatment will not risk compensatory sweating such as the surgery. I don't want to trade sweating from one source to another. Back to the topic of pain, I would be willing to undergo a certain amount of pain if it was a PERMANENT solution...such as a one-time treatment. Not a regular recurrent painful treatment like Botox injections.

For example I hear that Miradry can be somewhat painful, but that it's effects are permanent. Unfortunately currently they are only treating excess sweating of the armpit with Miradry. Also side effects are important...with treatments like anticholinergics you may not be able to pee, may have extremely dry eyes and a dry mouth which can create all new ailments on their own. Reiterating the fact that I don't want to trade one ailment for another.

I feel like if there was a one-and-done process that all my dreams would come true. Like if there was a Miradry solution for all areas of the body. Daily treatments can accidentally be missed, leaving you untreated and suffering. I just want to have a procedure and move forward with my life leaving hyperhidrosis behind forever. Is that too much to ask? Hopefully not. If there is any hope at all I have faith that I am in the right hands. And soon, hopefully, the right hands will be on me J

Now just to wrap up about the multiple areas I sweat from: hands, feet, groin, arm pits and the rest of my body more than normal. But none are as debilitating as the sweating from the hands and none are as bad or as frequent. I sweat from my hands all day, every day. My feet are a close second, but never has it *really* been an issue. Because I can always put on socks and shoes and it's never got to the point where it would seep through my shoes. My groin is probably the 3rd worst and luckily that doesn't happen every day or bad enough to seep through my clothes, but if I get too warm things down there will get damp. 4th in intensity is my arm pits...I feel this is the least annoying one, because it's easiest to hide for me and again never as intense or frequent as the sweating of my hands. Now in situations like when I had to use the phone at the car dealership, when I went into a full-on panic after the lady saw my hand sweating on her desk my legs and face and arms started to sweat along with my other main areas...but this rarely if ever happens. I notice my legs, face and arms only join the party when I am hot and in an extreme panic of fear. If I were able to rid myself of palmar hyperhidrosis, I would be willing to live with the sweating I already have in other areas. Again, that is not to say I would want to trade the level that my hands sweat for that level of sweating in another area...but no other site of sweating is effecting my ability to live my life like my palmar hyperhidrosis is.

Having said that, I want to again thank everyone from IHHS, from the bottom of my heart-you truly have no idea how much of a beacon of hope your organization is for people like me. Please again, if you need anything, do not hesitate to ask. I am ready.

-Commenter

I suffer from plantar and palmar hyperhidrosis as well as having some effects in my underarms and crotch area. During the Hh summit, many people shared their experiences with Hh and how it has affected their lives. One thing that wasn't mentioned very much is the pain and physical discomfort it causes, which is what I want to focus on in my comments.

As I write this, my body is in conflict with itself. My head, core, arms, and legs are perfectly comfortable and dry while my hands and feet are ice cold and wet. If parts of my body were just sweaty, that would be uncomfortable, but the tips of my fingers and toes actually hurt from being cold for long periods of time. The pain is like an ache coming from inside my fingers and toes. Some times my fingers will be so sore from being cold for hours that it hurts to type or do other tasks that require fine motor skills.

Conversely, if I am warm while sweating, my hands become swollen, which, while not painful, is still very uncomfortable and makes it hard to do things like clasping a necklace or threading a needle. My feet will also swell from sweating to the point where my shoes become tight and my toes feel crushed. Tight shoes seem to encourage the sweating which makes the cycle get worse throughout the day until I can get home and remove my shoes.

I have tried many treatments for Hh through the years: Drysol, Botox injections, Iontophoresis, and Robinul Forte (orally and crushed in the water of my iontophoresis machine). None of these treatments produced any lasting results for me and, in fact, caused very unpleasant side effects. The smallest amount of Drysol in a tiny cut or on dry skin stings terribly and doesn't work for me. Botox in my palms

left me with extreme compensatory sweating in my feet and groin for several months and only minimally dried my palms. Iontophoresis burned my skin at the water level, even on the lowest setting, and didn't produce results. Robinul made my mouth and throat uncomfortably dry and didn't stop the sweating.

My biggest hope for treating Hh is that a treatment can be developed that can stop the sweating and not produce unwanted side effects. Thank you to everyone who is working on this project to find a solution and thank you for giving those of us with Hh renewed hope. Your efforts are appreciated more than you know.

-Commenter

I was a normal active person until 2012 when I got the first of 3 pneumonias. I never really recovered - something happened and no doctor knows what.

I have symptoms similar to chronic fatigue (mostly fatigue) but by far my WORST symptom is sweating — all over my body, almost all the time.

I have to bring extra clothes with me all the time; often have to change clothes and, if possible, put my soaking wet clothes in the dryer.

There seem to be no good treatments and I am desperate after several years.

MY LIFE HAS BASICALLY BEEN RUINED B/C OF HYPERHYDROSIS. We need some effective treatments to deal with this.

-Commenter

I noticed something was off about my body around my sophomore year in high school. I was always a little shy, but even more shy because i noticed i would sweat more than usual. I never talked to anyone about it either. I started to research some things and found out i can use clinical strength deodorants by Secret, Dove and many others. I started to use them and they worked. I found out shortly after that they would only work for a short period of time and the odor and sweating would come back full force. I continued to use this option until I graduated high school.

After i graduated high school i went to the dermatologist and tried Drysol and it worked for a while and then stopped working. I also used Clindamycin for odor which didn't seem to help me, but I still used it because i didn't have any other options. It has gotten worse since I've gotten older. It started under my arms and eventually started in my groin and under my breasts and it's so embarrassing and stressful. I avoid most social events and i truly believe i stayed in an unhealthy relationship for longer than i should have due to me not wanting to start over with someone knowing i have sweating and odor issues. Everyone in my family is very social and outgoing and i know i would be the same way if it wasn't for hyperhidrosis.

I'm looking into botox for my groin area and Mira Dry for my underarms and I'm hope it works for me. I know botox is temporary, but it seems like something that can help me. I really don't know what I'll do about under my breast, but i hope there's a successful and permanent treatment for them all thats safe for me or anyone else suffering.

I'm currently 25 years old, trying to be confident and live a better life for myself and my two daughters. I would like to see permanent treatment options for all my sweat areas or affordable temporary options until the permanent ones are available. I would be happy with at least an 80% reduction in sweat. Drysol (or Hypercare) makes my underarms burn and I haven't used it in about 2 years. Anti perspirants do not work for me! I'm currently trying out sweat block and since its my first time it has been working the last 3 days or so, but i have no doubt that around a month from now it won't work at all. It seems like everything thats new and wears off eventually.

I've been using anti perspirants since high school on and off and i used drysol (and hypercare) for about 3 years. I shower twice a day put anti perspirant on at night and in the morning or deodorant. I use dial

antibacterial soap or body wash. I'm saving up to be able to afford mira dry and/or botox for my sweat areas. I know new treatments will take a while to get approved, but I'm praying it happens sooner than I think because this affects my life everyday negatively. I'm getting older and I would like to live the way I want not the way hyperhidrosis wants me to. I also spend more money on deodorant than the average person unfortunately.

I haven't been dating since my last relationship and I don't want to because I would be so embarrassed if someone asks me about my sweat. I got a gym membership, but I never go because I will sweat so much and smell in all sweaty areas. Most doctors in Wisconsin don't offer botox in the groin or under the breast. Out of 30 offices I called I found one doctor who does injections in the groin. It shouldn't be this way. My dermatologist knows I have hyperhidrosis, but she will only help me with my underarms. I would like to be the best version of me. I want to be happy, smiling, and motivated for my kids because and myself. Please help me and others who struggle with hyperhidrosis. Thank you!

-Commenter

I am 33 years old and I'm from Liberia, west coast of Africa.

I am suffering from hyperhidrosis, affected areas are hands and feet.

Those of us who're suffering from hyperhidrosis faces a lots of embarrassment and shame every single day of our lives with our educations, dreams and talents all fading away leaving tears in our eyes.

Here's what I want the future of hyperhidrosis treatment to be: Though we're face with all these trouble but you gives us a vision of being the best fully integrated, Africa and global hyperhidrosis freed.

And God sent this organization on such a great mission to efficiently provides sustainable and superior quality solutions and services to create values for all hyperhidrosis patients globally.

I think the organization should involved stakeholders and other humanitarian organization around the globe in the fight against hyperhidrosis.

That will gives us hope in restoring back our culture with these values as our foundation, and the essence of our culture will demonstrates itself in four (4) ways:

- * performance to deliver outstanding results.
- * ownership to do what is good for the organization and stakeholders.
- * collaboration to work as a team and target a brighter future.
- * people, we realized our people's potential and create room for advancement.

Thanks for acknowledging our hurt and I hope for change in our lives.

-Commenter

I am now 58 years of age and I have suffered from Generalized Hyperhidrosis since the age of 14, approximately. I sought help from family physicians as a teenager but received only the advice to "sweat it out." The problem was chronic and serious enough that it severely damaged my emotional & social development at a vulnerable age. Years later I was prescribed Pro-banthine (Propantheline) and, later, Robinul (glycopyrrolate) which I have taken for many years.

Robinul successfully controls my sweating when I am at rest. However it has little or no effect when I am physically active or under *any* kind of stress, no matter how insignificant it might seem. By physical activity I mean things such as walking several city blocks or vacuuming a carpet.

I would like to make 3 suggestions:

1. Make an anticholinergic like Robinul that works more powerfully, that works even when a sufferer like me is not at rest. I can take higher doses of Robinul, of course, but the side-effects affecting my eyes and stomach become onerous.
2. Alert more physicians to the existence of Generalized Hyperhidrosis. Many seem to be unaware of it and consequently dismissive about it. They are much more likely to be aware of localized (e.g., palmar) hyperhidrosis.

3. Please do more research on the subject of Generalized Hyperhidrosis. Even now, it seems that localized hyperhidrosis gets all the attention, probably because a number of treatment options already exist that can be tested and refined.

-Commenter

Hyperhidrosis controls my life. But not for the better. Throughout my life, I smelled of sweat. It is awful, it controls your life. You are looked at so differently.

I grew up poor, did not realize what was happening to me. Finally when I grew up and had medical insurance through my job. Doctors I visited did not know what my problem was. They would actually say, you do not smell. Even as I was describing my situation, they seem confused.

Years later, and still single, I found a doctor in an article I read about extreme sweating under the arms. I learned of Botox. I went and got several pricks on my underarms, and my sweat went away for 4 months. At a cost of \$1000.00. For 4 months, I felt alive. Just like that waitress, who comes to your table, and has no odor what so ever. I wanted that so badly. After four months it all went away. It took me many years later to get it again. As I needed to save another \$1000.00.

Still, doctors I went to, did not know what I was going thru. And thought the Botox was great. Another bad day, I was upset, and went back to the computer, and typed in Hyperhidrosis. An ad came up, miraDry. I went, they said it will cost, \$2500.00, all my saving, but I was desperate.

It was two sessions, I did it, was extremely excited. Will I be like that waitress?

My underarms, do not sweat like before, but I do sweat, the doctor said that I might need another session, for another \$2500.00.

I used to slather Secret Clinical Strength deodorant, after miraDry, I still put on Secret Clinical Strength deodorant. Regular deodorant, does not stop the odor.

I asked this doctor, if miraDry will stop my bromhidrosis. He did not know that word, and called the company, miraDry, about bromhidrosis. The doctor came back and said yes, that miraDry also controls bromhidrosis. It did not. I don't know if this is the right term - compensatory sweating. But what happen to me, after miraDry, was that I started sweating, a lot, on my groin area, and buttocks. I was getting a lot of bacterial vaginosis. My Obgyn, who is very understanding, and knows about hyperhidrosis, is giving me antibiotic, Metronidazole.

I am always worried about losing my job. Always upset, when people look or say something about my smell. I hope that one day, Pediatricians, Medical Doctors, and now these new offices - Urgent Care Clinics - are aware of Hyperhidrosis. And that all will be able to help those affected with this. It is so important that people do not get sent away. That there is an avenue to go to.

-Commenter

Hyperhidrosis has devastated our family. I have a son and a son-in-law as well as two young grandchildren who are affected by this. My son and son-in-law had severe palmar hyperhidrosis which impacted everything in their lives. They were unable use computers, which they did for their work, and it greatly impacted their abilities to have relationships with others. They were both so desperate that each had the ETS surgery, one at 15 years of age and one at 21 years of age. When my 21 year old son woke up from his surgery, he cried with relief that his hands were dry. This was cruel because he has since been devastated by crippling compensatory sweating and gustatory sweating. He is constantly wet from his waist up. He tries to eat only one time a day due to the impact of gustatory sweating. He is now working at home and is starting to be more and more isolated. My son in-law succumbed to many many Botox shots over his feet and body in desperation to stop his compensatory sweating. This did not help him. Perception drugs are of very little help, and have significant side effects. My boys have little hope and have psychological issues facing a future in which there is nothing out there to help compensatory sweating. Millions of people have had ETS surgery and are impacted by this. Please, please, take this to the forefront as it's impact is so, so devastating and there is nothing out there to help. There is so many people who suffer so much more than the area of focus which seems to get so much more attention...axillary hyperhidrosis. I am constantly looking for new help for them and I don't see anything on the horizon. Please help us to have hope, as I have two young beautiful grandchildren who are also going to have the same problem.

-Commenter