

# The Voice of the Hyperhidrosis Sufferer

A report from the International Hyperhidrosis Society's  
Externally-led Patient-Focused Drug Development Initiative

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Hello and thank-you for taking the time to listen to, via this report, the important voices of hyperhidrosis sufferers — voices that for too long have been silent, or dismissed.

As Executive Director and one of the Co-founders of the International Hyperhidrosis Society, I have, over the last 15 years, had the honor and privilege to know a community of brave, determined and beautiful individuals (hyperhidrosis sufferers, their loved ones; distinguished, compassionate healthcare providers, and many others) including all of the people who took part in our 2017 Externally-led Patient-Focused Drug Development (PFDD) meeting on hyperhidrosis (summarized here). Many of these extraordinary people I have been blessed to have known for over a decade and through major life moments.

This PFDD meeting was another of those major moments and I am grateful from the bottom of my heart that it provided a platform for an outpouring of support, honesty, commitment, compassion, empowerment, and shared effort.

To commemorate the day, every attendee was gifted a stone. The stone was to signify something that is a weight when held by one person, but becomes a structure when we all contribute to a common goal. Thus, in collaboration, we can transform a burden into progress.

The hyperhidrosis PFDD was an inspiration and it was the start of a transformation – by hearing the voices of those represented here in this report, the voices of the hyperhidrosis community, we can understand where the road ahead must lead.

As you read the pages that follow, know that all personally-affected hyperhidrosis sufferers (we call them “experts” and “advocates”) were encouraged to contribute to the dialogue – whether they were seated on stage, in the audience, or at home participating via webcast.

Discussion focused on hyperhidrosis impacts, treatments and research with an emphasis on constructive, forward-thinking conversation and information sharing.

The views expressed were personal; the stories shared were intimate. Members of the hyperhidrosis community participated with bravery and candor to teach. FDA regulators listened, and industry innovators learned. The meeting, the comment period afterwards, the creation and dissemination of this report, the road that unfolds now ahead of us; each is part of the process to move us forward.

The conversation continues and the voices captured in the ensuing pages echo with bravery and dignity. Their words and struggles must remain top of mind to guide us in building a better future. We must succeed so that their lights can shine brightly, without the burden of hyperhidrosis. They—we—deserve that.

In appreciation,

*Lisa J. Pieretti, MBA*  
Executive Director, Co-founder  
International Hyperhidrosis Society

## **Authors/Contributors and Disclosures:**

By Angela Ballard, RN, Communications Director, International Hyperhidrosis Society and Lisa Pieretti, MBA, Executive Director, International Hyperhidrosis Society

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For more information contact: Angela Ballard at [AngelaRN@SweatHelp.org](mailto:AngelaRN@SweatHelp.org)

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## Introduction

On November 13, 2017, the International Hyperhidrosis Society held a public meeting and live webcast to hear perspectives from hyperhidrosis (Hh) sufferers, caregivers and other involved parties. Discussion focused on:

- 1) The most significant effects of hyperhidrosis and
- 2) Currently available therapies to treat the condition.

The International Hyperhidrosis Society conducted the meeting as part of the U.S. Food & Drug Administration's (FDA's) Externally-led Patient-Focused Drug Development initiative (PFDD). PFDDs, both externally-led and FDA-led, help to systematically gather first-person perspectives on a particular medical condition and currently-available therapies to treat or manage that condition. Such perspectives help key decision-makers and innovators to understand the context of the condition and priorities for care. In other words, PFDD meetings give the FDA, healthcare professionals, and industry representatives an opportunity to hear directly from individuals experiencing a condition, their advocates, and caretakers about the symptoms that matter most to them, the impact the disease has on daily life, and experiences with therapeutic options. This input can inform decisions and oversight both during drug/device development and during review of marketing applications.

More information on Externally-led Patient Focused Drug Development meetings can be found by visiting: <https://www.fda.gov/forindustry/userfees/prescriptiondruguserfee/ucm453856.htm>

## Overview of Hyperhidrosis

Based on data published in 2016, there are approximately 15.3 million individuals living with hyperhidrosis (Hh) in the U.S.<sup>1</sup> Many of these patients are likely children and adolescents as Hh typically first manifests in youth, but there are also large numbers of older adults still suffering after a lifelong struggle with the disorder – which is chronic and, research shows, does not lessen in severity with age.<sup>3</sup>

As readers may know, primary idiopathic Hh (sometimes called “excessive sweating” or simply “hyperhidrosis”) is a disorder of uncontrollable, extreme, episodic, unexpected sweating beyond what’s “normal” or necessary

to regulate temperature or as a reaction to stress. Individuals with Hh may sweat four or five times more than what's considered "average"<sup>15</sup> with damaging effects on daily living, well-being, and self-actualization.

Primary Hh is typically focal in nature with sufferers sweating excessively from specific, symmetrical, localized regions of the body such as the palms of the hands (palmar Hh), the soles of the feet (plantar), the underarms (axillary), the face and/or scalp (cranial/facial), under the breasts, on the back, or in the groin. Other focal areas of sweating may also be seen. Often, combinations of focal areas of sweating are experienced such that many people with Hh have "multifocal" sweating. For example, research published in 2016 found that 81% of axillary hyperhidrosis sufferers indicate that they sweat excessively from three or more additional focal areas.<sup>3</sup>

*(Please note that there is another type of Hh known as secondary generalized Hh. This form of Hh is caused by a separate underlying medical condition or as a side effect of a medication and it is not the focus of this report nor was it the topic of the PFDD discussed here. Secondary generalized Hh is treated - if possible - by addressing the underlying medical condition or by adjusting the medication involved. In this report, all references to Hh are to indicate primary Hh.)*

Studies have shown that hyperhidrosis' impact on quality of life is equal to or greater than that of psoriasis, severe acne, Darier's disease, Hailey-Hailey disease, vitiligo, and chronic pruritus.<sup>2</sup>

As mentioned above, hyperhidrosis usually begins in childhood or adolescence<sup>3</sup>, which means it can potentially impact school success and emotional well-being during key developmental stages. Indeed, reported psychosocial ramifications of hyperhidrosis include decreased confidence and depression.<sup>4</sup> A 2016 study in more than 2,000 participants found that the prevalence of anxiety and depression was significantly higher in those with Hh than those without Hh (21.3% vs 7.5% and 27.2% vs 9.7%, respectively).<sup>11</sup>

It can be argued that, in the past 10 years, the burden and impact of Hh has grown significantly in developed nations due to changes in culture and technology that make excessive sweating more visible and embarrassing as well as more of a functional impediment. Examples include:

1. Security checkpoints at airports that require travelers to remove shoes and jackets and raise their arms in scanners (exposing sweating that might otherwise be hidden).
2. Touchscreens like smartphones, tablets, and other devices in day to day life (banking, shopping, etc.) and touch identification that may not work with sweaty hands and that can be damaged due to wetness. According to one recent study, 20% of hyperhidrosis sufferers report problems using computer keyboards, a computer mouse, mobile phones, and touch screens.<sup>16</sup>

Fingerprinting for employment can also present a challenge for those with palmar Hh, while social media use among young people has made cyberbullying a growing problem -- teenagers with Hh can be particularly vulnerable to teasing.

Workplace issues with Hh are of particular concern because the condition seems to disproportionately affect individuals between the ages of 18 and 39: one study recently put prevalence among this age group at 8.8%.<sup>1</sup> Challenges at work due to hyperhidrosis include: needing to change clothes frequently,<sup>4</sup> the embarrassment of sweat "stains," and avoidance of otherwise desirable careers, especially those requiring frequent public speaking.<sup>5</sup> Hyperhidrosis sufferers have been known to damage paperwork due to sweating and have difficulty gripping tools, playing musical instruments, and using electronic devices (as mentioned above).<sup>6,7</sup> Indeed, 80% of Hh sufferers say they are dissatisfied with their abilities at work,<sup>17</sup> 42% say that Hh prevents them from following a particular career path,<sup>18</sup> and 30% say they become frustrated with daily activities.<sup>17</sup> Safety can also be an issue as hyperhidrosis sufferers can drop objects and experience electric shocks<sup>8,9</sup> or may slip and fall due to sweaty feet.

General health consequences exist, as well. Research shows that:

- Hh sufferers have a 300% greater risk of skin infections<sup>19</sup>
- 60% of Hh sufferers report negative impacts on general health<sup>1</sup>
- 40% of Hh sufferers report physical discomfort<sup>16</sup>
- 5% of Hh sufferers indicate they take antidepressants or anti-anxiety medications due to their sweating.<sup>17</sup>

Economic burdens are also an issue as excessive sweating can stain and destroy apparel, requiring items to be frequently replaced at personal cost.<sup>7</sup> It's been noted that patients may spend thousands of dollars dry-cleaning and purchasing new items.<sup>10</sup> Police, military, and construction boots and uniforms are particularly susceptible to sweat damage and are expensive to replace. Patients also spend significant out-of-pocket money trying a range of over-the-counter antiperspirants, powders, and sweat-management supplies in an attempt to find relief. Additional costs also include co-pays for multiple physician visits including specialists and treatments that are not covered by health insurance (more discussion of treatment costs to come).

Data published in Archives of Dermatological Research shows 4.8% of the population suffers from hyperhidrosis – that's almost twice as many people as previously believed.<sup>1</sup> This makes Hh more common than autism,<sup>20</sup> melanoma,<sup>12</sup> psoriasis,<sup>13</sup> and peanut allergies.<sup>14</sup> According to this same research, not only is hyperhidrosis more prevalent, it's also more severe and socially debilitating than previously reported with 75% of those with excessive sweating saying the condition has had negative impacts on their social life, sense of well-being, and emotional and mental health and 35% saying they sacrifice many important things in their lives because of excessive sweating.<sup>1</sup>

Meanwhile, the condition remains underdiagnosed and undertreated. Most sufferers, due to lack of condition awareness, embarrassment, believe that there are no treatments, and other reasons delay discussing Hh with a healthcare professional (HCP) for years: 85% waiting 3+ years and 50% waiting more 10+ years to do so.<sup>21</sup> In other research, 27% were never diagnosed.<sup>1</sup>

For those who do receive a diagnosis, treatment options are often: off-label (botulinum toxin [Botox/Dysport etc.] injections for any area *other* than underarms, prescription oral medications) and invasive (surgery, injections), require frequent retreatment (injections, iontophoresis, over-the-counter and prescription antiperspirants), have treatment-limiting side effects (current oral options, may occur with antiperspirants or iontophoresis), and inadequately address the multiple body areas affected (thermolysis [miraDry] of the sweat glands is only available for underarms, for example, and there is no approved treatment for all the body parts affected by hyperhidrosis).

Exposing a disconnect between frequently-prescribed treatments and actual sufferer satisfaction, survey participants in a recent study indicated they were most satisfied with botulinum toxin injections (Botox) for their excessive sweating and least satisfied with antiperspirants (both over-the-counter and prescription varieties). Yet, antiperspirants are among the most commonly-prescribed treatments for excessive sweating and injections can be very difficult for patients to access. Among respondents who had not received any hyperhidrosis treatment, 38.5% were not sure why not, 32% reported they couldn't afford their recommended treatment, and 23.1% did not like their recommended treatment.<sup>21</sup>

The International Hyperhidrosis Society often hears of patients having medications compounded (off-label and with no oversight or regulation) or concocting their own treatments and medical devices using YouTube videos as guidance. Aside from prescription antiperspirants (which often provide inadequate relief and result in skin irritation), the only FDA-approved hyperhidrosis treatment is botulinum toxin (Botox, Dysport, etc.) for just axillary hyperhidrosis. The only FDA-cleared medical devices for hyperhidrosis are a thermolysis device (miraDry) for underarms, and iontophoresis for palms/soles. These options leave face/scalp, groin, back, submammary, and multifocal hyperhidrosis sufferers without effective FDA-sanctioned options.

Because many Hh treatments are off-label, it follows that they have not been extensively studied for the Hh population. An additional concern is that, given the chronic nature of Hh and that the condition often begins early in life and does not necessarily lessen with age,<sup>3</sup> Hh sufferers may be exposed to therapies lacking long-term safety data and inaccurate or incomplete labeling. For most treatments, there's also a dearth of research regarding childhood or adolescent use.

# Meeting Overview

As mentioned, the International Hyperhidrosis Society's Externally-led PFDD meeting provided attendees the opportunity to hear directly from individuals living with Hh, caregivers, and other sufferer representatives about their experiences with hyperhidrosis and its treatments.

The discussion focused on two key topics: (1) disease symptoms and daily impacts of hyperhidrosis that matter most to sufferers and (2) individual perspectives on current approaches to treating/managing hyperhidrosis. A discussion outline (Appendix 1) was published in advance of the meeting via the International Hyperhidrosis Society's website ([www.SweatHelp.org](http://www.SweatHelp.org)) and email communications as well as through links provided on social media.

For each topic, a panel of six sufferers (12 panelists total) shared comments to begin the dialogue. Panelist presentations were followed by large-group facilitated discussions inviting input from those in the audience. An International Hyperhidrosis Society facilitator led the discussion and asked follow-up questions. Participants who joined the meeting via the live webcast were also able to contribute comments. These are summarized later in this report and available in full on the International Hyperhidrosis Society's website ([www.SweatHelp.org](http://www.SweatHelp.org)).

In addition, prior to the meeting, the International Hyperhidrosis Society informally polled those who would be attending in-person or via webcast (the goal of 150+ responses was achieved the day the poll opened). An overview of poll results is found in Appendix 2. The results provide a sense of how many participants shared a particular perspective on a given topic, but data is not represented as scientific research.

Approximately 125 hyperhidrosis sufferers or sufferer representatives attended the meeting in-person while 350 people attended the meeting through the live webcast. According to the 150+ responses to the pre-event polling questions, these participants represented a spectrum of the hyperhidrosis patient population.

(Recognizing that PFDD registrants do not necessarily represent a random sample or the demographics of a broader population, the results of this survey not considered scientific data but rather to provide valuable insights into the hyperhidrosis community that participated in the PFDD.)

- 85% U.S. residents, 4.5% Canadian residents.
- 11 other countries represented.
- 72% female, 28% male.
- Age ranged from less than 17 to over 60.
- 69% between the ages of 21 to 49.
- 55% reported that their Hh started before the age of 10.
- 19% reported Hh onset between the ages of 11 and 13.

To supplement the input gathered at the meeting, hyperhidrosis sufferers and others were encouraged to submit comments via email. The comment period was open until Jan. 13, 2018. More than 100 comments were submitted, the majority by individual patients and caregivers. A summary of public comments can be found in this report.

More information, including the archived webcast, photographs, meeting transcript, webcast transcript, and complete public comments, is available on the meeting page of the International Hyperhidrosis Society's website:

<https://www.sweathelp.org/taking-action/patient-focused-drug-development.html>

# Topic 1: Disease Symptoms and Daily Impacts That Matter Most to Hh Sufferers

The first discussion topic focused on Hh sufferers' experiences with their hyperhidrosis symptoms and how these symptoms affect their daily lives. The International Hyperhidrosis Society and other attendees were particularly interested in hearing participants describe specific symptoms in their own words. The International Hyperhidrosis Society was also interested in learning about the activities that patients can no longer do at all, or as fully as they would like because of their condition.

Six panelists provided comments to start the dialogue. Due to the embarrassment and sensitivity many hyperhidrosis sufferers have expressed regarding public perceptions of and reactions to their condition and visible sweating, names of panelists and audience participants are being kept confidential, but summaries and key take-aways are provided:

1) A 37-year-old woman who reported living with palmar (hand), plantar (foot) and axillary (underarm) hyperhidrosis. Her first memories of hyperhidrosis date back to second grade when she would wipe her palms on her school uniform, use her sleeves to hide sweat dripping from her fingertips, and watch her academic papers curl as they got wet from her hands. She noted: feeling that her sweating was "out of control," feelings of "shame," being "ashamed to be touched," turning inwards as a result, and developing creative "hacks" to get by in daily life and on special occasions (such as on her wedding day). These hacks include: never wearing high heels, wearing women's dress shoes with socks, wrapping her wedding bouquet in an absorbent towel, covering her steering wheel in fabric, and putting a towel between her hands and the skin or clothing of her friends' babies when holding them. Most significantly, however, she discussed her fear of giving herself necessary self-injections for another medical condition and the risk of not being able to give herself the medication properly due to her sweaty hands as well as the potential of dropping her (expensive) dosage. She called for "better clinical trials, better treatment options, and better lives" for hyperhidrosis sufferers, like herself.

2) A 27-year-old man with palmar hyperhidrosis who described living with the condition as "incarceration." He explained that he first realized his sweaty hands were not "normal" when he was in high school. At this time, he felt "doomed" and had experiences that led him to believe that healthcare professionals did not have "true" knowledge or experience with the condition. Describing his days he said, "From the moment I woke up, to the moment I went to sleep, I was constantly trying to dry my hands" and he compared his sweaty hands to "washing your hands under running water and not drying your palms." Emotionally he relayed "extreme embarrassment," not wanting to go to school, and avoiding people. Socially he felt that hyperhidrosis both prevented and sabotaged romantic relationships. At school he had difficulty using touch screens and taking tests. Professionally, he said he based job choices on those that did not involve shaking hands and has developed "tactics" to avoid handshakes with co-workers and supervisors. He is a paramedic and noted that donning gloves for patient care can be difficult and slow and that his gloves fill with sweat that leaks out at the wrist. He feels hyperhidrosis is "overlooked, under-treated and poorly managed." To manage his sweating, he utilizes iontophoresis via a machine he built himself after watching a YouTube video.

3) A woman with hyperhidrosis of her hands, feet and "other areas." She described her sweat experience as being "constantly wet all of the time and it never goes away." She first remembers noticing her sweaty hands in fifth grade and her parents telling her to "deal with it" and that it "wasn't a problem." In terms of current treatment options, she said that they are "too expensive" for something that is a "temporary fix... so I just kind of deal with it." She, too, mentioned avoiding handshakes and becoming a "master manipulator." She also said that she "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 ... even at church." Daily life for her includes changing clothes multiple times, "not being able to have a good quality of life," and "battling everyday just to do normal things."

4) A man who is a college professor and experiences difficulties being close to students, working with documents and being taken seriously due to his axillary hyperhidrosis. He described the challenges this way: "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.” He said his students ask him if he is having a heart attack. He mentioned throwing shirts and nice suit jackets in the trash because they become ruined by his sweating. He described a desire to understand hyperhidrosis

5) A 30-year-old woman who is a flutist and music teacher. She has palmar and plantar hyperhidrosis. While she noted personal memories of excessive sweating in elementary school (“No one wanted to hold my hand in dance class,” she said) she also reported her mother’s memories of her learning to walk and leaving sweaty footprints on the floor. “Hyperhidrosis,” she said, “makes ordinary tasks a struggle.” Examples included holding a newspaper and having ink come off on her hands, not being able to use the fingerprint technology on her smartphone, trouble turning doorknobs, and needing to always carry a towel. As a flutist she says sweat runs down from her hands to her elbows as she plays, it rusts her instrument, and slows down her fingers. As a youngster, to help limit her sweating so she could practice her flute, she filled her bathtub with “ice cold water” and stood in it while playing. She added that hyperhidrosis has prevented her from networking and it makes her “always anxious,” “uncomfortable in my own skin,” and “not fully able to enjoy activities and be myself.” “I don’t like the feel of the touch of my own hands,” she said and reminded everyone that hyperhidrosis affects patients “physically, socially, and emotionally.”

6) A 25-year-old man who said he was 7 or 8 when he first noticed his hyperhidrosis. His feet were dripping sweat despite being in an air-conditioned room. To get by at school he continually wiped his palms on his shorts or else risked his assignments “turning into an illegible mess of sweat and lead smudge.” At a school dance, he noticed he was sweating so much in his underarms that he went to the bathroom and stuffed his shirt with paper towels. After that he began to wear only black clothing. He noted frustration with the unpredictable nature of his sweating episodes and that while he had certain “triggers” (social anxiety and extreme heat), excessive sweating also occurred at random. Sweating caused him to give up guitar lessons and become a “master” in disguise. Having tried antiperspirants with minimal effect, he joined a clinical trial for a medical device that uses thermolysis to destroy the sweat glands of the hands [miraDry]. He showed pictures of the “painful” blisters he developed afterwards. “My hands took three weeks to recover,” he said. “At one point the pain of one of the blisters became so severe and unbearable that I had to resort to draining them myself...” The treatment, he added, was only partially effective. He called for “safe and minimally invasive treatments.”

The panelists’ statements provided a vivid description of the burden of daily and prolonged living with hyperhidrosis. They described the day-to-day limitations of living with hyperhidrosis, and in particular embarrassment, shame, extreme daily inconvenience, feeling misunderstood, and physical difficulties. Their stories provided rich insight into the practical, emotional and social impacts of the condition. In the large-group facilitated discussion that followed the panel discussion, the majority of the sufferers and caregivers in the audience indicated by a show of hands that their own experiences (or those of their loved ones) were reflected in the panelists’ comments.

## **Summary of Open Discussion on Topic 1: Disease Symptoms and Daily Impacts That Matter Most to Hh Sufferers**

In our open discussion on hyperhidrosis symptoms and daily impacts, several key themes emerged:

- Childhood or adolescent onset. A hyperhidrosis sufferer in the audience remembered the nuns at her school hitting her because she had a tissue in her hands (she used it to dry her hands.). She also remembered that the game Ring Around the Rosey was traumatic because “I never had any friends... I was always the outcast... Nobody wanted to hold my hand.”

- Hyperhidrosis and its impacts on emotional/mental wellbeing (feelings of self-harm/suicide, anxiety, isolation, depression). One hyperhidrosis sufferer in the audience noted needing “social anxiety and anxiety meds, depression meds...” Another said “I have gone through like this mental craziness...” Other related comments included: “Depression aspect, yes, I’m medicated,” and “I never, ever get home without being on the verge of tears.”

- Different body locations of excessive sweating that audience members felt are underserved and/or under-recognized (including: craniofacial sweating, wet hair, and sweating of the legs and groin).
- Related difficulties at school and with educational and/or professional achievement. An audience member said, “It has impaired my ability to be able to communicate and to have people take me seriously... I begin to be shunned.” Another said, “In high school I withdrew myself from school and I was at the top of my class... My plan was to get a PhD, but I ended up finding another path.” One audience member said she had been an internal medicine physician but needed to change her career due to her sweating and related difficulties examining patients.
- Sweat/wetness leading to feeling very cold and/or painful hands/feet. One hyperhidrosis sufferer remarked, “My fingers get very, very cold. Like ice cold.” Another said “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 my body.”
- Slips and falls due to sweaty feet. One participant said, “Yoga is not possible because I slip off the mat.” Another added, “I’ve twisted, sprained, darn new broke my ankles from trying to wear regular shoes, trying to be barefoot in my house... I don’t feel safe being barefoot. Or I don’t feel safe wearing shoes.”
- Family members also having hyperhidrosis and fears that children in the family will develop it.
- Difficulty enrolling in clinical trials including due to older age.

## Topic 2: Perspectives on Treatments for Hyperhidrosis

The second discussion topic focused on sufferers’ experiences with hyperhidrosis therapies and desires for future therapies. The International Hyperhidrosis Society and other attendees were particularly interested in hearing participants describe therapy upsides and downsides and hopes for the future of hyperhidrosis treatment in their own words.

Six panelists provided comments to start the dialogue. Below are summaries and key points:

1) A young woman who has suffered from hyperhidrosis her whole life. After years of feeling misunderstood and trial-and-error with numerous treatments, she said she’s finally managing her hyperhidrosis so that it’s tolerable. As part of her treatment journey, she noted having tried topical aluminum chloride products [antiperspirants], iontophoresis, oral anticholinergics, and herbal remedies but said that “ultimately, none of these was effective.” In addition to frustration with inadequate treatments, she recalled how time consuming it was to see specialists, to wait for results when trying a new treatment, and to figure out how to pay for treatments (while working through her health insurance plan). Currently she travels from New York to Virginia to receive botulinum toxin [Botox] injections for her hands, feet, and underarms from a physician she knows can get good results. This is critical for her because, she said “I saw many physicians who administered this treatment, but the results were less than satisfactory.” For her, downsides of “unsatisfactory” treatment with Botox injections have included severe muscle weakness and pain. But while Botox injections provide this patient with hyperhidrosis management, she reminded the audience that it’s “not a cure, and its effect wore off after several months.” To extend the life of her treatment, she has added an anticholinergic (oral medication) to her regimen. “I am dry,” she said. But downsides to the oral anticholinergic include: “constant and severe dry mouth, difficulty urinating, and more.” She added that she feels uncertain about the long-term effects of her treatments and that if she stops treatment, “the sweat will come back.”

2) A young man who is a fourth-year medical student. He has craniofacial hyperhidrosis. He experimented with treating it with topical wipes obtained from Canada and he has tried antiperspirants but said that, since he sweats from his head, he can't apply topical products adequately due to his hair and that the antiperspirants and wipes "helped maybe a little bit." In order to obtain botulinum toxin [Botox] treatment, he drove six hours to see a physician. Downsides to the Botox treatment, he said, included the distance he needed to travel, the number of injections (100), and the cost ("a few thousand dollars"). Botox was, however, successful for him in that he "finally felt normal." The results lasted 4.5 months but then, he said "I found myself right back where I was before. Why can't I just go get another treatment? Oh yeah, the closest doctor is a six-hour drive so it's not very accessible and it costs a few thousand dollars because it's paid out-of-pocket since insurance doesn't cover it." This doctor-to-be now uses an anticholinergic (oral medication) instead, the drawback he says "is that it dries you out globally." For the future, he said he hopes there will be a treatment as effective as Botox, but without the repeated needle sticks. "Something that doesn't require daily application... and doesn't have systemic side effects... something that all hyperhidrosis patients can use in their variable applications, not just treatments focused on underarms." He also indicated he'd like treatments to be covered by insurance, widely accessible, and affordable.

3) A woman who is a litigation attorney and has palmar, plantar as well as axillary hyperhidrosis. In her journey to find hyperhidrosis treatment, she said she has experienced much ignorance from physicians about the condition. To illustrate, she said, "When the patient is the expert rather than the doctor, that's a difficult situation." She added, "People with hyperhidrosis are desperate for treatment. We are desperate to find relief." To illustrate that desperation, she remarked that she had asked fellow hyperhidrosis sufferers if they would give up a finger for a cure and "dozens of people would be willing to give up a finger to find a treatment." As a call to action for treatment developers she said, "There are not enough treatments available, there is no insurance coverage available." She described current treatment options as forcing hyperhidrosis sufferers to "make do." She described Botox injections as "temporary," "painful," and "expensive." She described iontophoresis as time-consuming and inconvenient. Other treatment and "make-do" options she indicated she'd tried include: wearing white cotton gloves as a child while doing homework, "all sorts of topical creams and ointments," "waiting to 'grow out of it'" as per a doctor's instructions, Botox, two miraDry treatments for underarms (resulting in an 80% reduction in her underarm sweating), and dehydrating herself (she got a kidney stone). She concluded with, "Please, please help us find solutions to manage this condition."

4) A woman who is a nurse and experiences palmar, plantar and axillary hyperhidrosis. As part of her presentation, this hyperhidrosis sufferer focused on the need for treatments to help hyperhidrosis patients achieve the necessary self-confidence to "develop as human beings, "to have feelings of control over our own bodies," and to "actualize." She went on to describe how, due to her hyperhidrosis, she is unable hold objects for any length of time and that this has severely impacted her career as a nurse, and these impacts, she said, have been inextricably linked to her treatment difficulties. She said she has tried Botox injections, systemic anticholinergic medications, and topical medications. Botox injections were, she said, the most effective for her but that getting access to Botox and having it covered by insurance was an obstacle. Moving forward, she would like to see more research into treatments for body locations beyond the underarms and she would like Botox for non-axillary areas to transition from off-label to on-label designation (to improve insurance coverage and therefore affordability and accessibility.)

5) A woman who has been experiencing hyperhidrosis since kindergarten. Describing her journey to diagnosis she said, "I can't tell you how many doctor's offices I walked into... and I was blown off. I was dismissed." Her first treatment attempt was a prescription topical antiperspirant, but it caused her to develop hives. Next, she tried iontophoresis, but she could not travel with the device, found the routine impractical, and the therapy resulted in minimal sweat-reduction. She tried Botox injections and received 100 injections in each hand and 30 under each arm. When her insurance changed she could no longer afford this Botox regimen every six months as it cost her \$4,000 out-of-pocket. She is now on an oral anticholinergic medication. "It dries you out," she said. "It also dries out 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... I can't remember the last time I had a good night's sleep..." but, she added, "I'm sweat-free." She felt this was a good example of the trade-offs hyperhidrosis sufferers make to achieve relief from sweating.

6) The final panelist of the day was a woman from Virginia. She is an educator and a small business owner who has been suffering from and hiding hyperhidrosis her whole life. Describing why she has hid her condition

for so long she said, “It’s a horrible feeling inside to know that you gross someone out.” Most painful for her, she said was when her son was a newborn, it was winter and her hands were still so sweaty they would soak through his baby blankets when she held him. This meant that she was afraid to take him out in the cold weather. As a result, she and her son stayed home. “I was really happy when summer came around and I could go out and leave the house,” she remembered. Finally a physician diagnosed her with hyperhidrosis and she tried a prescription topical antiperspirant. “It didn’t do much for me... it was small change but nothing significant,” she recalled. Next, she tried an oral anticholinergic medication, but she got “dry mouth” and “still had sweaty hands.” She also tried Botox injections, which, she said, worked very well but were too expensive for her. So, she said, “I currently manage with iontophoresis.” At first she had to perform iontophoresis treatments three times per week (for three weeks), but now her maintenance regimen is once per week. “My issue,” she said, “is the time that it takes, the discomfort... and good luck traveling with that thing in your suitcase.” For the future she said she would like treatment that is “accessible, affordable, just like everyone else, that’s safe and that’s a little more permanent to help us manage our conditions.”

## Summary of Open Discussion on Topic 2: Perspectives on Treatments for Hyperhidrosis

In our open discussion on hyperhidrosis treatment the following themes emerged:

- Hyperhidrosis sufferers believe that healthcare professionals need to be more informed of and educated about hyperhidrosis and its treatment. For example, an audience member said: “Educate, educate, educate.”
- Desperation and lack of hope. Demonstratively, an audience member said, “There’s no hope for me. But, I hope there will be for people in the future.”
- Feelings of frustration at “having tried everything.” An indicative comment that emerged was, “I’ve tried everything except surgery and nothing works for me.”
- A desire to get to the “root” of the cause of hyperhidrosis and wondering whether Hh is related to “something in the brain.” One participant said, “I wonder if there’s anything coming that would be more of an internal treatment. Something that’s in our brain...”
- Fear that the children of hyperhidrosis patients will also develop the condition. For example, one audience member said, “My concern today is my little boy, eight months, and I just don’t want him to have to suffer through this like everyone else here today.”
- A desire for treatments that help patients mentally and physically and that help address excessive sweating on numerous body areas.

Please note that due to time constraints, the open discussion period for topic 2 was limited. Extensive feedback regarding treatments for hyperhidrosis was, however, provided post-meeting via public comments. These are summarized below and are provided in full on [www.SweatHelp.org](http://www.SweatHelp.org).

## Summary of Public Comments

There were 100+ comments submitted via email to the International Hyperhidrosis Society that supplemented the Externally-led Patient-Focused Drug Development public meeting on hyperhidrosis. Nearly all the comments were submitted by individuals identifying themselves as sufferers of hyperhidrosis. Overall, the comments received reflected the experiences and perspectives shared during the November 2017 public meeting, but also add valuable different insights particularly into:

- Downsides of current treatments
- Lack of healthcare provider awareness and education on hyperhidrosis
- Desire for more focus on cranial/facial Hh, palmar Hh, generalized Hh, and groin Hh
- Requests for specific areas of focus for future treatment development and research.

The following is a collection of key comments, with particular focus on experiences or perspectives that were not raised or addressed in detail at the actual meeting.

## Public comments on most significant symptoms

A number of comments mentioned pain, tingling, and swelling of the hands and feet associated with hyperhidrosis episodes. Others mentioned having to deal with being cold all the time due to frequently being wet or damp (“chilled to the bone”.) For example one comment was: “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. Sometimes 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 is very uncomfortable and makes it hard to do things.”

Safety issues came up multiple times with one person writing: “being barefoot... will slip and fall. I actually broke my arm falling down the stairs because I lost my balance...” A woman told a story of slipping out of her mother’s hands as a child and being seriously injured as a result.

Related to cranial/facial sweating, there was a comment that it can be “blinding.”

## Overall impact of hyperhidrosis on daily life

Many submitting comments noted the pervasiveness of hyperhidrosis intrusion into their lives and the many years they have been living with the condition with indicative phrases being:

- “my entire life”
- “all my life”
- “as long as I can remember”
- “since I was young”
- “began in middle school”
- “began during puberty”
- “...since I was about 5 years old”
- “diagnosed at the age of 6”

Many respondents indicated that hyperhidrosis has “ruined” their lives or has “negatively affected every aspect of my life,” “this condition controls my life,” “debilitating” ...

Childhood experiences recounted included hyperhidrosis impacting test-taking abilities, a child at 5 years old “filling my little purse with tissues as a way to hide and wipe my sweat,” in middle school going to class in mittens to hide sweat, being teased, learning to hide, wearing dark clothes, teachers thinking a child is cheating when really he is drying his hands, and never holding hands or dancing with someone.

Feelings evoked by hyperhidrosis were described in comments as: humiliation, embarrassment, shame, anxiety and social anxiety, depression, inferiority, feeling like an outcast, stress, “uncomfortable in my own skin,” panic, hopelessness, fear of passing the condition on to offspring, feeling “dirty,” feeling (and actions) of self-harm, low self-esteem, isolation, loneliness, disdain, disgust, “drowning in my own sweat.”

Daily hurdles mentioned include an inability to: write on paper, use touch screens, open jars, hold onto a steering wheel, wear makeup or style hair. “I cannot even type this email properly...” wrote one individual.

Other related problems mentioned include: job interviews and the inability to obtain and retain employment, recurring fungal infections, odor problems, avoiding certain careers, avoiding relationships and intimacy,

related development of drug and alcohol problems.

## **Perspectives on current treatments**

A common refrain in the comments is “I’ve tried everything” and lists of all the different treatments that have been tried with little success or other reasons why treatments were not continued (downsides, finances, or a lack of access, for example.)

### **Treatment downsides**

#### ***Topical treatments (antiperspirants over-the-counter and prescription)***

Many of those discussing treatment options in the public comments noted that antiperspirants either never worked for them or stopped working after a period of use, or worked only on certain body areas (leaving other body areas untreated.) Others discussed downsides such as skin irritation. A repeated frustration noted was that antiperspirants are meant to be applied to dry skin, but hyperhidrosis skin may never be dry (resulting in improper application and subsequent irritation). Other downsides to antiperspirants mentioned include: “expensive,” “leaves a rash and burning sensation,” “very temporary,” requires an additional cream to “counteract the stinging and burning,” “was not able to sleep the entire night because it was so unbearably uncomfortable,” “made my hands extremely itchy – I found myself scratching my hands raw at one point they itched so bad,” reddening of the skin, and “makes my underarms burn.”

#### ***Iontophoresis***

Reflections on iontophoresis included the following observations: Difficulty finding a doctor to prescribe an anticholinergic to go in the water, expensive, time-consuming, painful, “burnt my skin,” “hasse to use,” “logistically difficult to use,” “only kinda worked,” “extremely painful,” “very complicated, tricky, and sometimes even painful... incredibly time consuming and inconvenient... I feel chained to this treatment regimen as it is impossible to follow while on the go,” and “burned my skin at the water level, even on the lowest setting and didn’t produce results.”

#### ***Botulinum toxin injections (Botox/Dysport etc.)***

Comments on botulinum toxin injections (Botox/Dysport etc.) included the following reactions, descriptions and phrases: Expensive, not covered by insurance, painful, “lackluster results not lasting more than a few months,” “puts me out of work for a few days” (palmar injections), “changed my life but it was only temporary (can’t afford retreatment),” not an option for children, “my job requires a lot of dexterity and I can’t risk a lost in dexterity with Botox,” “doctor won’t do it on my hands and feet,” “cost is prohibitive,” “I do Botox treatment on my hands every 4-6 months which has helped significantly. It also affects the strength in my hands though,” “bruising for a week following and it is quite painful,” and “Botox in my palms left me with extreme compensatory sweating in my feet and groin for several months and only minimally dried my palms.”

#### ***Oral medications***

Downsides to oral medications (anticholinergics, typically) are noted as: severe headaches, very bad dry mouth, no saliva, stomach cramps, “side effects are taking over my life,” “fatty deposits under my eyes,” urinary problems, uncomfortable dry nose and ears, “dries up my body as a whole,” “does not work well for me,” “slight relief but dried everything out, felt like my eyeballs were going to pop out and my tongue felt like a cactus; so dry,” “no insurance coverage or at least the drug is still fairly expensive,” “I sometimes get food jammed in my esophagus, and it is beyond excruciating... I believe it is in relation to the anticholinergic effects on smooth muscle contraction,” “creates more problems,” “made my mouth and throat uncomfortably dry and didn’t stop the sweating,” and “controls my sweat-

ing when I am at rest... has little or no effect when I am physically active (walking or vacuuming) or under any kind of stress.”

### ***Thermolysis of underarm sweat glands (miraDry)***

Reflections on thermolysis of underarm sweat glands (miraDry) include the following: Only for underarms (repeated desire for miraDry for other body areas), and “after miraDry I started sweating, a lot, on my groin area and buttocks. I was getting a lot of bacterial vaginosis” [now on an antibiotic for vaginosis].

### ***Endoscopic thoracic sympathectomy (ETS) surgery***

In terms of endoscopic thoracic sympathectomy (ETS) surgery, public comments included: “ETS should be banned,” “makes it a million times worse,” “compensatory sweating!!!!,” and “the sweating I had before is nothing compared to my present [compensatory] sweating.”

### ***Alternative therapies***

Public comments related to alternative therapies note the following treatments tried: Relaxation techniques, medicinal marijuana (with some success), herbs/supplements, acupuncture, Chinese herbs, restricting liquid intake (leading to muscle cramps and dizziness), buying a topical Robinul spray obtained from Canada, and carrying ice packs or frozen water bottles.

## Summary of Live Webcast Participants' Comments

In addition to the hyperhidrosis sufferers who shared their experiences as patient panelists at the live meeting and those sufferers and their loved ones who contributed to the discussion in the room, there were 350 registrants for the live webcast (not all of these registrants necessarily logged in and watched the webcast, however.) Webcast participants may have included hyperhidrosis sufferers as well as non-hyperhidrosis sufferers.

Comments via the webcast platform had themes that both reflected those in the meeting room and also took on their own directions.

### **Hyperhidrosis Age of Onset**

Many web participants chose to share the age at which they remember their hyperhidrosis/excessive sweating symptoms first manifesting, summarized as follows:

- “...born with it...”
- “...had [Hh] since I was 5 years old...”
- “...since 8 years old”
- “... first noticed around 3<sup>rd</sup> grade...”
- “...suffered since age 12...”
- “...since my very early teens...”
- “...started at age 62...” (another person mentioned that Hh began in his/her 50s and multiple mentioned compensatory sweating manifesting after ETS surgery)

### Emotional Impacts of Hyperhidrosis

Common discussion points included the emotions and potential mental health issues related to hyperhidrosis

and the perception of being “alone,” “distracted,” and “on edge.” Other words brought up included “humiliation,” “shame,” “depression,” “anxiety,” “anger,” and “hiding.” Thoughts of self-harm were mentioned along with individuals feeling “defective” and “like a freak” while others said:

- “Sweating makes me feel less feminine and like a slob.”
- “I feel gross.”
- “...such a miserable condition... no one talks about it...”
- “...feeling very hopeless...”
- “...very isolating and embarrassing...”
- “Tears over this are part of daily life.”
- “Don’t want people near me, don’t want to be touched.”
- “This [Hh] ruins my life.”
- “[Hh] doesn’t ruin my life but it certainly controls it.”
- Fear of passing hyperhidrosis on to offspring was mentioned by multiple webcast participants, as well.
- Hearing others discuss experiences with hyperhidrosis, for some, did appear to provide a sense of support:
- “Getting emotional being here with people who understand my struggle...”
- “...tearing up...”

### **Practical Impairments and Adaptations related to Hyperhidrosis**

In addition to the emotions webcast participants shared, many also discussed the practical, day-to-day implications of excessive sweating and adaptations required to manage sweating. One participant noted his/her belief that hyperhidrosis is a “functional” problem. Another used the word “debilitating” while many others gave examples of daily functioning impacts or adjustments including:

- Inability to wear make-up
- Hair that “smells like sweat”
- Showering five times per day
- “Feeling sticky and smelly”
- Needing to sew pads into clothing and to wear gloves for typing
- “Purposefully stay[ing] in workout clothes because it’s more acceptable to sweat in them”
- Dreading or avoiding handshakes
- “Missing out on a lot of things” including relationships and important events (like weddings)
- Cancelling events
- Ruining wedding photos due to visible sweating
- Needing to wear loose clothes
- Not being “able” to wear pants
- Wearing only dark clothing
- Needing to “go on disability”
- Wet school papers
- Wet money
- Feeling the need to work from home
- “Needing” to cut hair short
- “Always apologizing for appearance”
- “I sweat through my winter coat”
- “I don’t go anywhere without paper towels
- “[Hh] is time consuming”
- Avoiding hugs and physical contact
- Avoiding public speaking
- Wearing a portable fan
- “All my clothing choices are based on what will keep me from sweating”
- Avoiding situations that require a uniform
- “Puddles”
- “Slippery” shoes
- Inability due to facial sweating to “make a living”
- Feeling like one “can’t” get a massage,



- “Soaking” the exam table at the doctor’s office
- Not getting call-backs after interviews
- High electric bills due to running the air conditioning to keep the home cold
- Wearing extra undergarments to absorb sweat

Related physical aspects discussed by web participants included: hands and feet swelling and turning red, increased sweating with alcohol consumption and with stress, hands that “get ice cold” and “Raynauds.”

## Treatment Options

When the topic of treatments came up in the meeting, those participating in the webcast shared their experiences in seeking medical care. In doing so, individuals noted a lack of “informed” healthcare providers in “small towns” and that physicians “do not understand.” One participant relayed an experience of being “laughed at” by a physician. Another participant mentioned that physicians had told him/her that “nothing” could be done and that he/she found himself/herself needing to “educate” healthcare providers. Another mentioned that while “Botox worked wonders... [I am] having trouble finding doctors to do it.”

The expense of treatment came up numerous times, particularly around botulinum toxin injections:

- “Botox worked but now too expensive for me.”
- “Botox was great but unrealistic to keep up due to cost.”
- One participant expressed desire for “insurance coverage” of miraDry.

Downsides of current treatment options were discussed including one participant saying “No pain, no gain.”

In regards to topicals, the downsides listed by webcasters were:

“Some success,” “lumps in skin,” and (specifically related to Drysol) “irritated” skin, “grit my teeth and bear it,” and “cracked skin.” One participant said, in terms of topicals, that he/she had found “nothing that works” for hands/feet.

Related to iontophoresis, one webcast participant noted his/her experience was a “success,” another noted that iontophoresis “helped A TON” but one needs to “stay on a routine,” another said it was “time consuming” and “stopped working.” Someone else added that iontophoresis was “painful” and “takes hours” per week.

For oral medications, downsides mentioned included “severe dry mouth, headaches” and:

With Glycopyrrolate – “decreased urination, dry throat, scratchy voice, headaches and muscle cramps when exercising” and “horrible leg cramps.”

With oxybutynin – “ending up in hospital for 3 days.”

Downsides of botulinum toxin (Botox/Dysport etc) (in addition to cost concerns mentioned above) were noted as: “uncomfortable” and “painful” in hands and feet, and after injections for palmar hyperhidrosis, a web participant noted he/she “could barely hold a pen or keys afterwards ‘til it wore off.” Another mentioned loss of “grip strength.” For future Botox options, a participant said, “Botox wipes would be amazing.”

Additional attempts to control sweating included diet modifications, calorie restrictions and avoiding certain foods.

For the future, an interest in miraDry for other body areas (aside from underarms) was mentioned as were “options” for compensatory sweating (after ETS). More broadly, a webcast participant said, “I would give up both pinky fingers [for effective treatment]” and another noted a desire for treatments to address a “root cause of Hh.” Others said: “I have tried everything and nothing really works,” and “I’ve done it all.” A fear expressed was that of “treatments that stop working.”

# Conclusion

This Externally-led Patient-Focused Drug Development meeting on hyperhidrosis provided the International Hyperhidrosis Society as well as representatives from the FDA, the healthcare profession, and industry the opportunity to hear directly from sufferers and caregivers about the significant and debilitating impacts that hyperhidrosis has on their lives. The International Hyperhidrosis Society recognizes that sufferers have a unique ability to contribute to understanding of the broader context of this chronic disease, which is critical to the drug development process.

## **As key participants noted after the meeting:**

*"I would 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... 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."*

– Dr. Kendall Marcus, Director, Division of Dermatology and Dental Products, FDA

*"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... 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, Analyst at FDA's Center for Drug Evaluation and Research

*"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."*

– Panelist

*"This weekend had such a huge impact on my life and I feel so empowered because of it."*

– Audience participant

*"Thank you for giving me hope after 47 years!"*

– Webcast participant

*"I haven't received any treatment yet, but I feel like the healing has begun."*

– Audience participant

The International Hyperhidrosis Society is grateful to all who so thoughtfully, generously, and courageously shared their personal stories of living with hyperhidrosis. Through this meeting, all those in attendance learned more about what matters most to sufferers and caregivers regarding symptoms, impacts, and aspects of hyperhidrosis treatments. The participants' sense of community and their desire to advocate for current and future generations at risk for hyperhidrosis were clear. The International Hyperhidrosis Society is committed to helping to further the development of new safe and effective therapies to treat hyperhidrosis.

The imperative is clear and our work is cut out for us.

95% of PFDD participants say their hyperhidrosis is not resolved  
and

70% are DISsatisfied with healthcare provider knowledge of Hh.

Reading this report is a great first step towards changing those statistics. Thank you for doing so. We hope you will now take what you have learned and make it work for the future of hyperhidrosis care.

*The International Hyperhidrosis Society thanks the generous support of [Dermira](#), [RA Fischer](#), [Brickell Biotech](#), [Hidrex USA](#), and private [donors](#) for making this landmark hyperhidrosis Externally-led PFDD initiative possible.*

## **Appendix 1**

### **Summary of Meeting Agenda and Discussion Topics**

#### **Topic 1 with expert, personally-affected panel: Hyperhidrosis symptoms and impacts**

##### **Open Discussion Topic 1: SYMPTOMS and IMPACTS, including:**

1. Overall impact of Hh on daily life. Burden on daily living and burden of prolonged/chronic nature of hyperhidrosis.
2. Activities/choices affected by hyperhidrosis.
3. Limitations in daily life (focus, concentration, work, school, hobbies) and relationships.
4. Embarrassment or social stigma/discrimination due to Hh.
5. Pediatric perspective including impacts on daily life/school, social ramifications, emotions, and development.
6. Healthcare journey: interactions with providers, access to care, and diagnosis.

#### **Topic 2 with expert, personally-affected panel: Hyperhidrosis treatments and research**

##### **Open Discussion Topic 2: Treatments and research, including:**

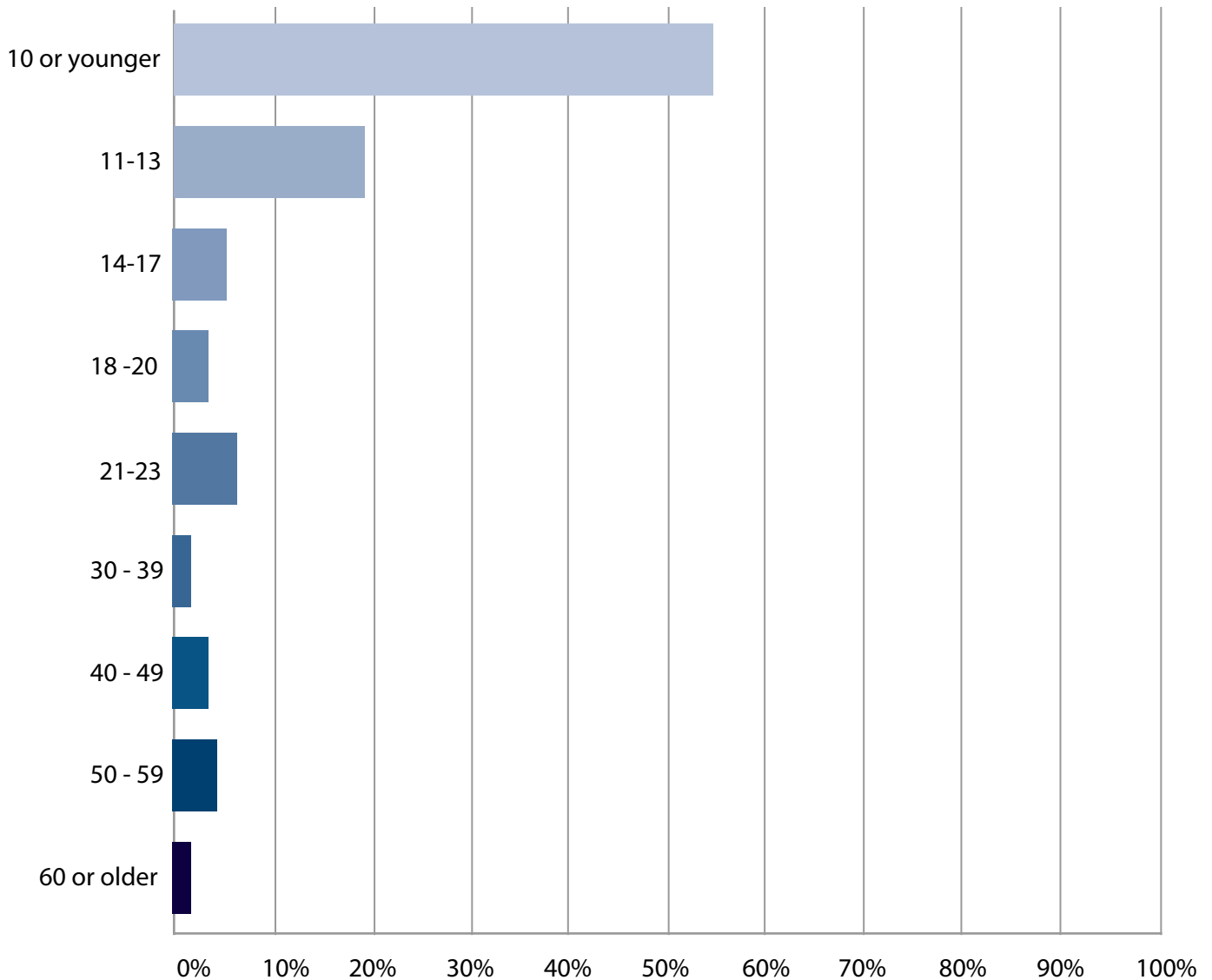
1. Treatments currently used or tried in the past.
2. Effectiveness of treatments, downsides, and unmet treatment needs.
3. Details of current regimens.
4. Experiences with participation in clinical research.
5. Goals and expectations for treatment, aside from a cure.
6. Key considerations when choosing a treatment and most meaningful endpoints.
7. Financial experiences including out-of-pocket expenses, insurance coverage/reimbursement, co-pays, and travel for treatment.

## Appendix 2 Pre-meeting Polling Results

On October 31, 2017, approximately two weeks prior to the Externally-led PFDD on hyperhidrosis, the International Hyperhidrosis Society dispatched an email invitation to registered PFDD attendees to participate in an informal survey. Within hours, more than 150 individuals had completed the survey and maximum responses were received. Recognizing that PFDD registrants do not necessarily represent a random sample or the demographics of a broader population, the results of this survey are not considered scientific data but do provide valuable insights into the hyperhidrosis community that participated in the PFDD. Polling results follow here:

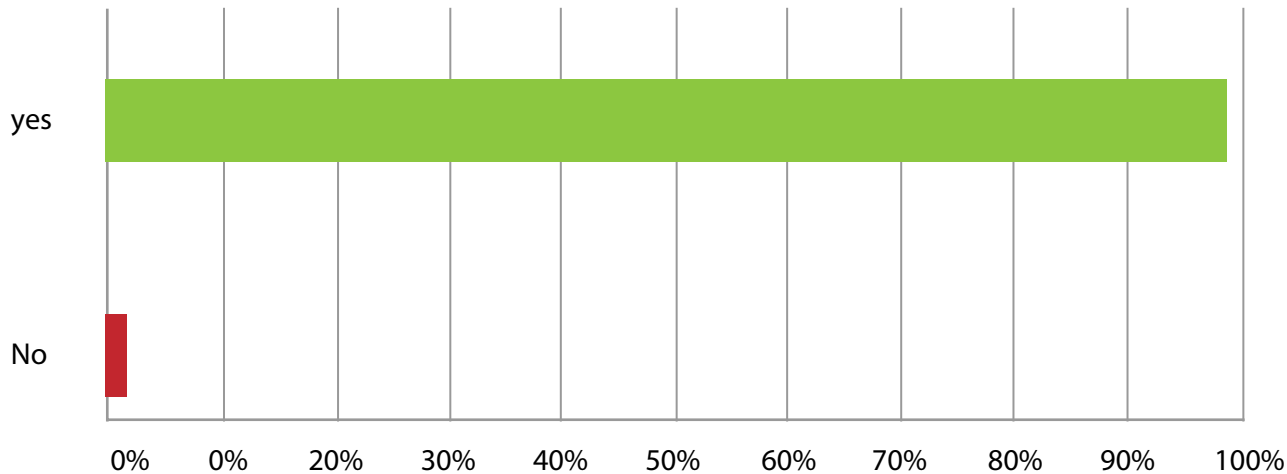
### What age were you when your hyperhidrosis started?

Answered: 156 Skipped: 0



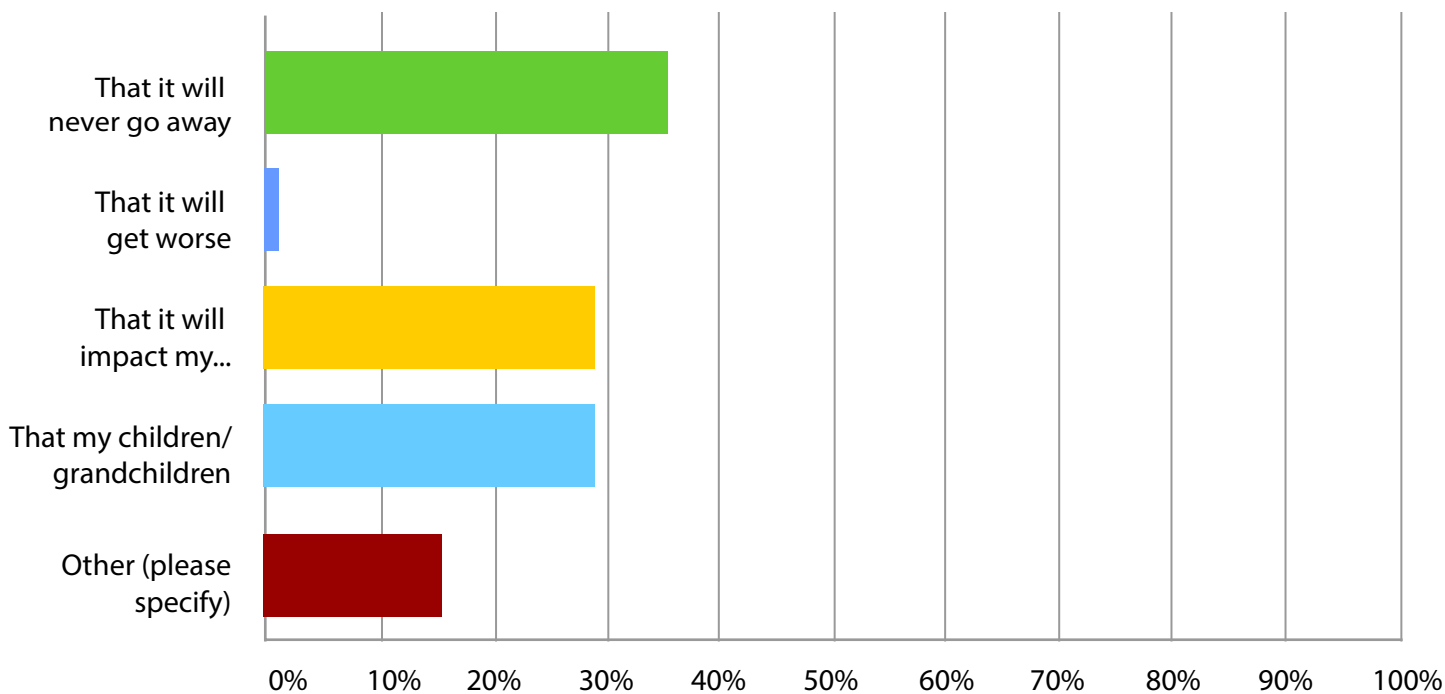
# Did hyperhidrosis impact your actions, planning, wardrobe, and/or activities in the past week?

Answered: 156 Skipped: 0



# What worries you most about hyperhidrosis

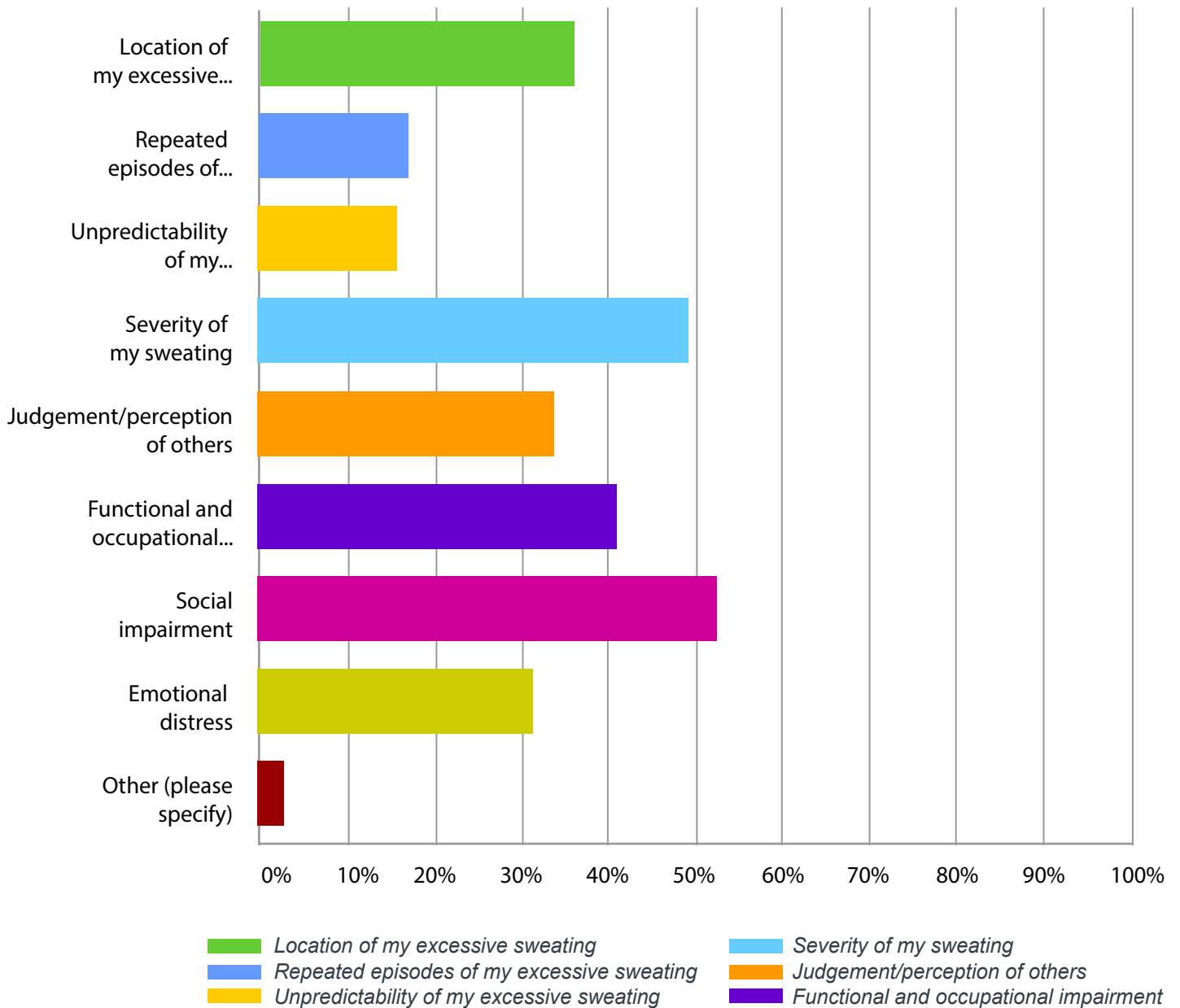
Answered: 156 Skipped: 0



■ That it will impact my happiness or success  
■ That my children/grandchildren may have it

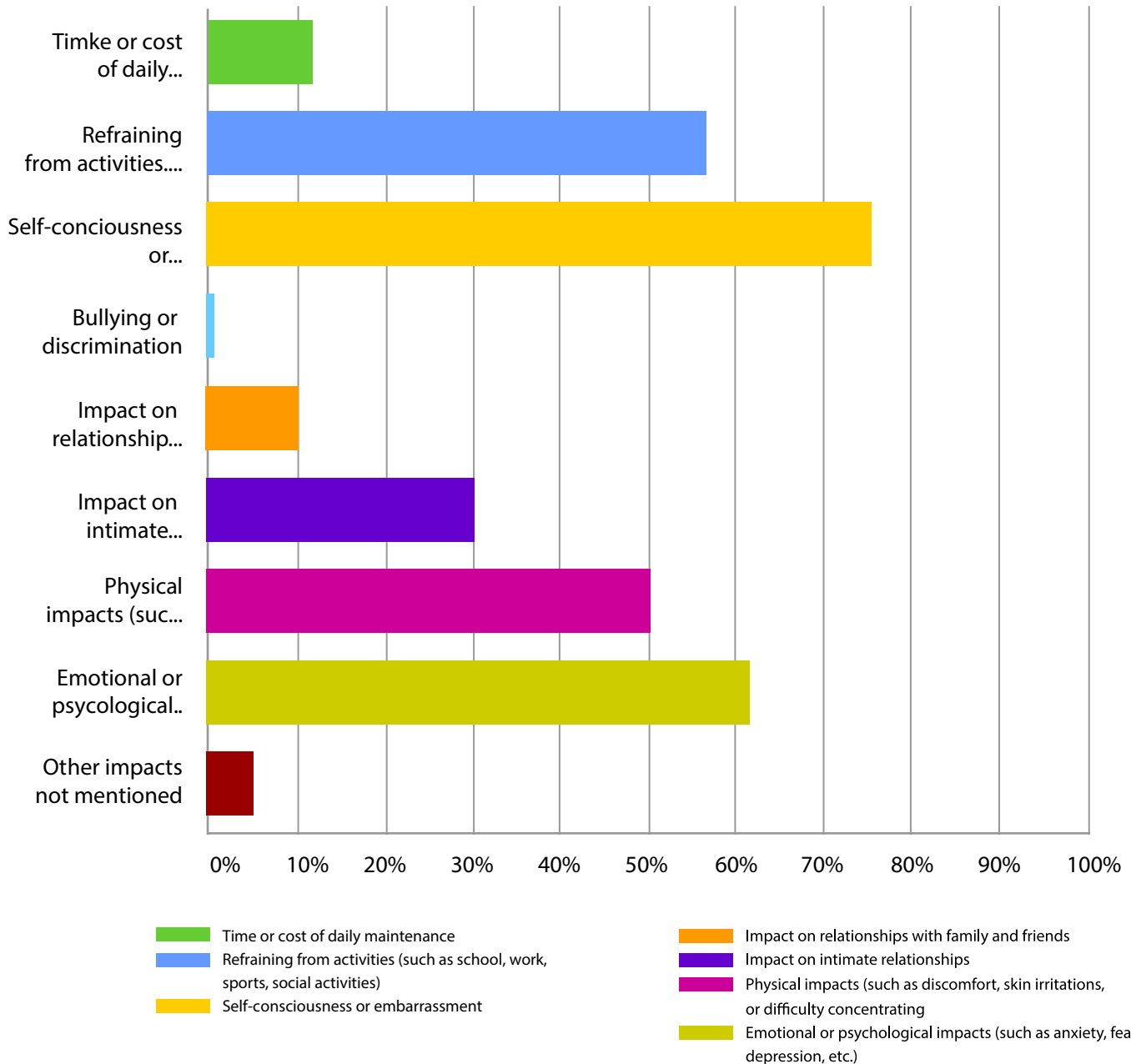
# What aspects of your hyperhidrosis is most bothersome to you? (choose up to three)

Answered: 156 Skipped: 0



# What do you find to be the most bothersome impacts of hyperhidrosis on your daily life? Please choose up to three answers.

Answered: 156 Skipped: 0



# What items, tasks, events, and moments cause you distress because of your Hyperhidrosis?

*Open-ended question. Responses below:*

"I had ETS so now it's compensatory sweating and sweating through clothes. As a child holding a woman's hand...square dancing...very embarrassing with hand sweat."

"Meeting people, relationships, work."

"When I meet with clients and have to shake their hand. Taking of my shoes somewhere else besides my own home because of the smell caused by excessive sweating."

"I don't hang out with my friends. I plan my outings around places I can refresh myself before important events. Gym activities are awful."

"Hyperhidrosis has ruled my life since I can remember. I noticed in elementary school that I sweat WAY more than my classmates. I had a jacket that I wore every single day, no matter the season or temperature. Regardless to say, I was always hot. I would never ever raise my hand in class because of my armpit sweat. When we had to 'take a paper and pass it back' I was terrified that everyone would see our smell me. My papers were always soaked. I never wanted to be in a new relationship, because I'd have to explain my weirdness... So I just settled. When it came time to choose a career, I knew healthcare was absolutely out of the question. I'd tried (and failed) to put on a pair of latex gloves. Even if I did get them on without ripping, I would have sweat literally pouring out when I removed them. So... I decided on a desk job. The horror when someone would use my computer after me! They'd ask why my keyboard and mouse pad were soaked. I remember being at a party when I was younger and I'd sat in the floor in my knees for an extended period of time. I was wearing khaki shorts, and when I stood up, my entire seam was wet. Someone called me out in front of everyone and I was embarrassed the entire night. I constantly have to explain to people why my face is dripping sweat in the middle of winter. These are just a few of the moments where hyperhidrosis has ruled my life, but only a tip of the iceberg."

"When it is humid or temperature above 65 degrees and or I will be doing physical activity that will start the sweating process. What I can and cannot wear (types of material and clothing) because it will be worse. The yucky feeling of cold sweat."

"Deodorant shopping, wearing mostly black and sleeveless clothing, constant drying of hands, personal adjustments for writing."

"Not being able to wear certain things. Always feeling like someone is going to notice my sweating. Feeling uncomfortable in wet clothes/shoes. Hindering my performance in work and sports."

"Anything social."

"Physical activity, when breathing/heart rate speed up, anxious situations"

"Any type of movement like walking through a shopping mall or a store, temperatures above 70 degrees and the thought of others witnessing my sweating exacerbates my current state of excessive sweating."

"Social situations, especially in the summer and when drinking alcohol."

"Shaking hands and meeting new people. Avoiding church or socializing because of my profuse sweating."

"Any kind of exertion triggers sweating. Stressful situations can also trigger it. What bothers me the most is that absolutely NOTHING can be going on (such as sitting in church) and excessive sweating will start!"

"Socializing, outdoor events."

"I am distressed on various occasions throughout my day. I sweat on my hands, feet, face, and underarms excessively with no correlation to the current temperature. Even when it's cold I am sweating on either all or a few of the locations mentioned. I try to avoid situations when I am expected to meet new people because I know the introduction usually involves shaking hands. It has impacted my career choices and social interactions. When I shop I only use credit or debit cards so I don't have to exchange wet money or reach my dripping hand out for the change. I have to use a towel to plug



electronics in the wall. I had to be very careful handling my son when he was a baby. If my hands are sweaty opening a door knob is close to impossible. Typing on a keyboard is hard because it gets drenched with sweat. The list is never ending.”

“My Hyperhidrosis has a ‘switch.’ When I wear socks or footwear, it triggers it. To answer your question, any moment when I have to wear socks and footwear causes my distress.”

“Visiting my home country where the weather is extremely humid causing serious swelling of hands and feet.”

“Networking events, meeting new people in a social setting. Handshakes cause me a lot of anxiety which perpetuates the sweating.”

“Someone seeing my excessive sweat and the feeling of being unclean it brings.”

“When I go to work and doing sport exercises.”

“Being around people not knowing if I am going to have a sweating episode.”

“In indoor places with a lot of people especially during the summer, for example buses, or high heating during the winter, when I’m nervous, when I work out.”

“Shaking Hands and wearing sandals.”

“Everything.”

“Physical intimacy, public/group speaking, sewing, cake decorating, book reading, note taking, holding my son’s hand, shaking hands, hugging friends.”

“Any job meetings or interviews, any minor stressful situation would cause the sweating to start and only make it more stressful.”

“I am in my last year of medical school and sometimes my hands are so sweaty that I can not write on patients’ files or put on sterile gloves so I find it really frustrating and embarrassing.”

“DANCING, TALKING IN FRONT OF PEOPLE.”

“Meetings.”

“When around strangers, my girlfriend, when I am about to begin doing a task.”

“My job, sports, social interaction (shaking hands), not being able to wear sandals - affects my wardrobe and where I live/visit.”

“Going out to places where it’s a lot of people and I worry if I do sweat will someone smell the sweat or see me sweating?”

“Any social or professional interaction that requires handshakes.”

“Sharing keyboard/mouse/phone with co-workers; living in Florida (need I say more?), the amount of time it takes to get ready to go out, limited choice of shoes and clothes, incidence of eczema and limited treatment due to sweating hands.”

“Needing to always think about my environment and how prepared I am for it to handle the sweating.”

“Work, social gatherings”

“Just going outside.”

“Holding hands for prayer. Shaking hands. Touching others to show compassion. Preparing food. Driving. Any social setting.”

“Closely working with other colleagues, socializing at social events with friends, meeting new people, handshakes,

tolerating computer work such as typing, writing, etc.”

“Eating spicy foods. Shoes. Meetings. Shaking hands. Sitting on vinyl. Written forms. Walking barefoot. Yoga.”

“Meeting people (shaking hands) typing, writing by hand, driving (holding steering wheel), clothing choices.”

“Work related: notarizing documents, signing contracts or other official documents. Church/personal: shaking hands, holding someone’s hand, laying a hand on them in prayer. Interviews. Ceremonies or public events where people might see it.”

“Shaking hands during introductions. Fearful of casual contact with hands.”

“Shaking hands in any sort of business/social setting, any sort of touching of objects, people or things that would expose others to the condition - both professional and personal - particularly, I have to use others workstations for training and it’s awful to leave sweat on their keyboards/mouse. Anytime I hold someone else’s child, the kid’s clothing/blanket becomes so wet it seems like the child’s diaper leaked - very embarrassing.”

“Touching any person; touching & holding documents, electronics, delicate/porous items; occupational tasks (nursing); creating art or jewelry.”

“I am a meeting planner and I have a huge event in January. Many handshakes will take place at this event. It causes me a lot of stress and money for Botox shots to help my palms from sweating.”

“Any situation where I am unable to control the temperature of my environment.”

“Being around other people and public speaking.”

“Insecure about everything.”

“Being able to shake hands at interviews, high five’s, or hold hands without my hands sweating uncontrollably.”

“When I wear a suit, if I leave the jacket on indoors, I will sweat like a pig.”

“Use of technology, iPhone touch, laptop soaking at work, not being able to hold my loved one’s hand, my clothes wet from wiping my hands.”

“Summer and what shoes I can’t wear.”

“Being limited in my ability to do things that anyone can do. Just yesterday I declined an invitation from my girlfriend to join her somewhere after work because I had been sweating too much. In a few days a group of people is going for a walk and picnic, and I’m already struggling not knowing what to do with the fact that I can’t sit in the picnic because of the amount of sweat that I will produce during the walk.”

“Being in front of people, Knowing that I have to greet people in meetings, socializing and people asking ‘Why is your hand wet and cold?’ Interviews, exams etc.”

“Wearing sandals, shorts or dresses, using a pen, pencil, marker etc., doing a craft. Holding my husband’s or children’s hands, and being around people I don’t know.”

“Shaking hands, first impressions, writing, using a computer/phone or other electronic device, comments from strangers about the color of my hands or feet, playing sports, productivity in work and school, etc.”

“Shaking hands with colleagues and superiors at work. Passing the phone to someone with a moist palm print on the phone receiver. Holding the metal poles on subways and busses.”

“Very restricted clothing due to sweat. Massages. Flip flops or sandals. Getting ready after showering. Ruins clothing.”

“Social events. Family gatherings. Everyday tasks.”

“Everyday life.”

“Writing, typing, putting on gloves (nurse), dating, meetings, presentations, driving.”

“When I have to speak in public. Trying to write letters.”

“Having to stay the evening at someone else’s home, hotel as all the bedding will be soggy and smelly.”

“Shaking hands, working closely with others who might notice the sweat on my hands, sweat seeping through my clothes and making wet marks that others can see, not being able to walk in my shoes when my feet sweat, leaving steam marks or wet spots on chairs. I could go on and on. These are just a few off the top of my head.”

“I feel like I have very limited wardrobe options, hyperhidrosis causes a great deal of stress at work or having to speak at events. My back, butt, underarm, inner thighs, hands and feet just break out in a major sweat. I’ve missed parties, weddings and major events because of the sweating. It affects intimacy, work, and it controls my day to day actions especially if it’s hot. My scalp sweats, the back of my thighs and feet are getting worse. I damage a lot of shoes, I throw away lots of clothing and I’m constantly showering. Hyperhidrosis controls my life.”

“Social situations, my work, everyday life.”

“Shaking hands or holding hands.”

“The total discomfort and persistent sweating that is unbearable once it starts.”

“Having work lunches outside with colleagues, walking around outside, anything involving other people where the temperature isn’t controlled.”

“Shaking hands, holding hands, not being able to go barefoot because my feet will leave puddles, my hands leaving sweat puddles on electronic items or books and ruining them, worrying about what type of pants/shorts to wear and if I’m going to sweat a lot that day, when my shoes make squishy noises because of the sweat, ruining crafts that I try to work on because my hands sweat, any time I don’t have a place to wipe my hands, having smelly feet because of the sweat.”

“Socially.”

“Being in public.”

“Face to face conversations, shaking hands, accommodating my attire to hide the sweat.”

“Work, wearing open toed shoes, taking notes.”

“Work, cooking, relationships, clothing, electronics, dehydration, social activities.”

“Giving presentations, going to social gatherings, any stress related activities even if the stress is mild.”

“At work, church, school, family/friends outing, handshake, writing, holding my significant other.”

“Sometimes I wear the wrong thing in a social situation and the wetness shows on my clothes.”

“It’s constant. I always have to choose loose clothing, in dark colours. Anything other than cotton causes my underarm odour to be unbeatable after just a couple of hours. I refrain from any form of physical intimacy because I’m too embarrassed.”

“Doing physical exams on patients, procedures in the hospital, shaking people’s hands.”

“Hand shakes, becoming emotionally involved with social interactions, advancing in a religious calling.”

“Having to change clothes because of groin sweating, high maintenance for iontophoresis, shaking hands.”

“Wearing shoes, and keeping shoes for longer than the ‘expiry’ time, work events. This question is too tough to answer as my Hh affects all aspects of my life. So everything is causing me distress.”

“Speaking in public, shaking hands, typing on computer, ability to wear clothing without distress, holding hands.”

“Shaking hands, events wearing business attire (not sweat friendly materials), wearing gloves, handling sensitive

materials.”

“Social situations where I know I am going to have to shake someone’s hand.’

“Going to gym, using colorful clothes.”

“I have craniofacial hyperhidrosis which is very noticeable. I no longer like to go out in public at all, have lost most of my relationships with friends, am unable to find a job, and have an overall feeling of hopelessness that my life will never improve.”

“Literally everything!! I have horrible anxiety because of this condition and social situations are dreaded.”

“You never know when it will strike. Working with children.”

“Everything. It can be triggered by anything. And gets worse with embarrassment of an episode.”

“First impressions, handshakes, handling papers, writing on paper/whiteboards, summer, networking events, dating, travel, explaining my condition.”

“Everything. Literally, everything.”

“Anything that involves using my hands.”

“The compensatory sweating I have after ETS surgery causes anxiety, emotional distress, and isolation.”

“Social interaction. Relationships. Job stressful situations.”

“Meeting somebody, dancing, exchanging money at cash register, handing my baby to somebody, giving a hug and putting my hand on somebody’s back, showing others my ring/nails/etc., getting my nails done, giving any kind of massage, partner work in yoga, yoga in general (my passion), putting my hand on something I know will leave a sweat mark (glass, dark surfaces, etc.), going to Dr. and needing to be touched by Dr. or nurse, TOO MANY TO LIST!!!!”

“EVERY day, every moment, except when resting.”

“Using my phone and computer, writing on paper, holding hands, shooting guns, taking test at school, being in social situations etc.”

“I am a media student and I have to work mostly in groups and because of my hands sweating I just sit in silence at the side. I always wear big hoodies because of my underarm sweating and refuse to go to the counter of any shop because of my hands sweating.”

“I can’t do anything physical... I can’t go on vacation anywhere the weather is warm... also I am no longer employed.”

“I have facial hyperhidrosis. Meeting new people/getting to know someone new is always challenging. My anxiety increases in these situations, and when it does, the sweat comes with it. Then it’s an avalanche of nervousness and embarrassment because all I can concentrate on is how they perceive the excessive sweating issuing from my forehead and I end up just aching to escape the situation.”

“Everything. I sweat from head, face, neck. I always look like I just got out of the shower.”

“If I am moving any part of my body I am sweating everywhere except my face and scalp. Being soaking wet all day is exhausting. My top is 4 hours in one stretch.”

“Shaking hands at business events, holding hands, especially at church, sweat marks on brown leather shoes - so typically wears black shoes, unable to wear sandals and open toe shoes without inserts - use paper towel in closed shoes, wet marks on clothes at event from sweating in groin area, sweating episode when working in team.”

“The excessive sweating causes me to not do activities that I used to love.”

“Any task that would make me overheat i.e. - my work as a dance teacher / performer, social gatherings, wearing certain

clothes / fabrics / colours, lying on a beach in a hot country, etc.”

:Anything to do with physical contact, hands and feet mostly, footwear.”

“Social gatherings because my face is dripping wet and people stare and wonder what’s going on with me.”

“Getting ready to go out, dancing and just meeting with people.”

“Going to mass (sign of peace, holding hands for Lord’s prayer), any business or social interactions where I have to shake hands, holding my children as infants or holding their hands in parking lots or areas where it is unsafe (otherwise I don’t generally hold their hands), taking tests in school as the paper would get soaked and rip, finding clothes and shoes that don’t show the sweat (I wear black and closed-toe shoes all the time!)”

“When I’m going to a concert, or having a meeting at work, or even just going out for dinner. I can’t drink when I go out because it makes it worse.”

“Shaking hands, having to explain/justify the condition.”

“Everything, every day.”

“Meeting presentations.”

“Any outside events.”

“Walking with someone else; cocktail parties (alcohol induced Hh); almost any social activity that is active.”

“Holding Hands, dancing, interacting with others and most importantly at work.”

“All daily activities.”

“When I am out in public and my face just sweats and drips off my face. The back of my hair is usually soaked and this is in the winter.”

“Social, networking activities. Also dancing where it is customary to hold hands. Playing music. Taking change. Writing with pen and paper. Hand shaking.”

“Don’t like to exercise in public. Don’t like to be outside when it’s hot or humid. Don’t like to socialize outside or where there is no air conditioning.”

“Giving presentations, going to parties, meeting new people, meeting clients, going somewhere hot, going out in the summer.”

“Most activity will cause me to sweat from my head & face before the rest of my body will sweat. Humid weather is the worst thing for me here in Florida. I have to have a towel with me at all times & have to clean my glasses from sweat dripping on them. In FACT in part this cost me a job years ago.”

“Writing, sitting (I have compensatory after a failed sympathectomy), anything requiring a tight grip as things slip, having to wear socks or I slip and fall from wet feet, social/job interactions are the worst!”

“Fingerprinting , shaking hands, doing presentations in front of people.”

“Certain color clothes. I have to wear black all the time and especially during summer. Can’t get hair cut or nails because sweat to much. And sad I can’t afford treatments and never can do anything because of sweating.”

“Taking my shoes off.”

“Networking events were people shake hands often. Holding hands with a relationship partner for the first time and having to explain that my hands are always like that.”

“Anytime my feet are visible (sandals) and my hands when I have to shake hands or type or present in front of people.”

"Anything that involves my hands. So, everything. I don't like holding hands, I ripple paper when I touch it, I have to bring a rag everywhere with me, my sweaty hands inform everything I do."

"Clothing discoloration and wetness. Visible sweating that is uncontrollable when dealing with people. Odor. Maintenance of hair style."

"Can't do much of anything of fear of the hyperhidrosis. The smell it causes affect my daily life."

"As a medical student, direct patient interactions can often be embarrassing for myself when my hands sweat uncontrollably and unpredictably."

"Being in public! People assume I'm on drugs, having a heart attack, or in poor physical condition. I can't wear makeup because I just sweat it off, so as 48 yo single female, I don't feel as attractive. Also, people assume I'm sweating because I'm nervous. I think it's the other way around! I used to think I had social anxiety...now I think it's just sweat anxiety."

"Constantly suffering from this disease. It stops me from doing things. It worries me. It brings me sadness to my life. Suffering in silence. I worry about my children. One of them has this problem and I knew from his childhood. It can get worst for him. Lots many reasons of this discomfort and problem."

"Public speaking. Outdoor activities. Physical activities. Social settings. Work."

"Public speaking Job interviews Shaking hands. Holding a coffee mug without a handle due to slippage. Self-injecting medication with dripping hands. Holding file folders and worrying the color will leak onto my hands. Networking meetings. Going to church and having to shake hands and/or join hands in prayer. Going to the doctor and sticking to/tearing the exam table paper. Being absolutely mortified of groin sweating during a gynecological exam Wearing sandals and having my feet slip and slide. Ruining nice clothing with underarm stains and pitting out. Slicing vegetables with a sharp knife + onion skin sticking to hands. Holding someone's baby and getting them wet. Walking barefoot on wood or tile floors and leaving prints Blow drying hair and having it stick to my feet. Standing in lines. The list is never ending!"

"Shaking hands is the worst, typing on the computer, writing on paper."

"Everything I do is impacted. I have a very severe case and it is a component of every decision I make."

"I'm a banker, so going to work every day is a huge mental struggle. I can't wear sandals AT ALL. I throw away shoes all the time. My relationship is difficult at times. My social anxiety is HORRIBLE. I declined going to college because of this. I finished high school in an alternative school with only online classes because of this. I never went to prom, homecoming, got my nails done, played sports, etc. I've had breakdowns countless times. depression some days. Anxiety every day. Social anxiety the most. I avoid people, public places, being outside, shaking hands. I can go on and on."

"Life. Everyday of my life is affected by hyperhidrosis. It affects the clothes I choose to wear, my activities for the day. It's affected jobs I've applied for (no uniforms). I'm worried my kids will inherit it. It's one of the hardest conversations I've had to have with past significant others. It keeps me from doing extra activities. My favorite way to help people is to help them move because it's physical labor and it's ok to sweat."

"My hyperhidrosis is magnified with warm weather. This strictly impacts the clothing I can wear, the events I can attend and the activities I can do. I am most nervous in social gatherings or when meeting people for the first time. Anytime that a physical interaction has to take place, I am constantly thinking about sweating."

"Romantic relationships, social events, wearing open toe shoes, wearing certain materials such as silk or the color white."

"Driving, what shoes I wear, holding my son, making food, using the computer etc."

"I have to be conscious of what I wear all the time, and have to choose darker colors or clothing that masks my sweat. Exercise, public speaking (with my job), interacting with friends and my spouse - are all stressful because of my underarm, hand and foot sweat."

"Work especially wearing safety gear. Recreation outdoors and indoors. Any detail oriented tasks. Dating."

"Meeting someone for the first time is tricky. After our handshake I'm always worried about what they think of me. I feel like I have to try extra hard to prove I'm balanced, trustworthy, normal, etc. It's exhausting. Also using computers, touch

screens, around others like in a job atmosphere is very challenging and embarrassing. Thinking about my two kids having this with no really good treatment or cure is probably the thing that bothers me the most. I can sort of deal with the embarrassments, the misunderstandings, the withdrawing from certain events, job losses, etc. but when it comes to my kids having to deal with it it really gnaws at me.”

“Tests, events that require me to rely on my hands, how it affects my piano playing.”

“Church (shaking or touching others hands), cash transactions, meeting new people, if I ever have to remove my shoes & socks in front of anyone, going anywhere when it is hot and my clothing is saturated and wet.”

“Social events, hot weather.”

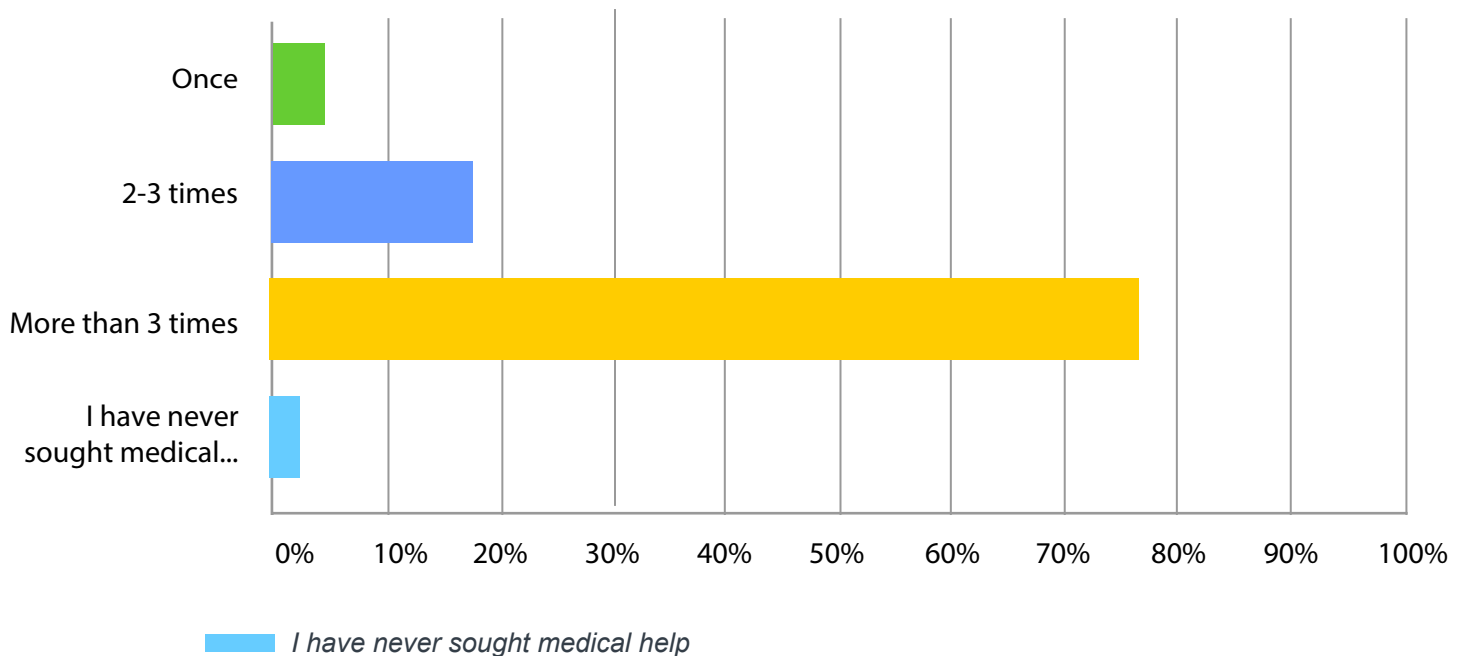
“Virtually everything after waking. Lightest exertion.”

“Being inside...in a hot room. Heavy humidity.”

“Any activity involving people.”

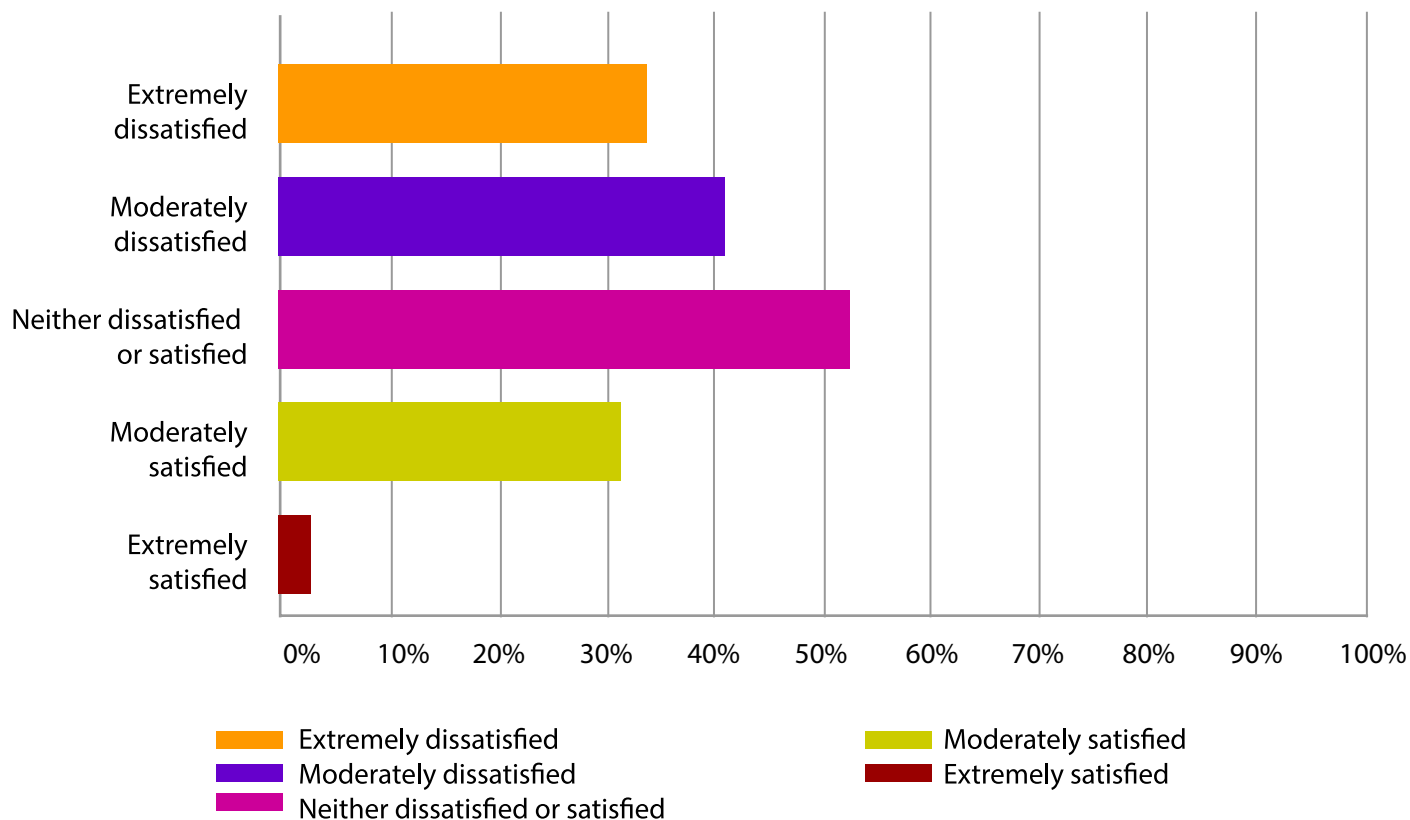
## How many times have you asked for medical care for your hyperhidrosis?

Answered: 156 Skipped: 0



# With the exception in the physicians participating in this PFDD event, how satisfied or dissatisfied are you with healthcare provider knowledge about hyperhidrosis

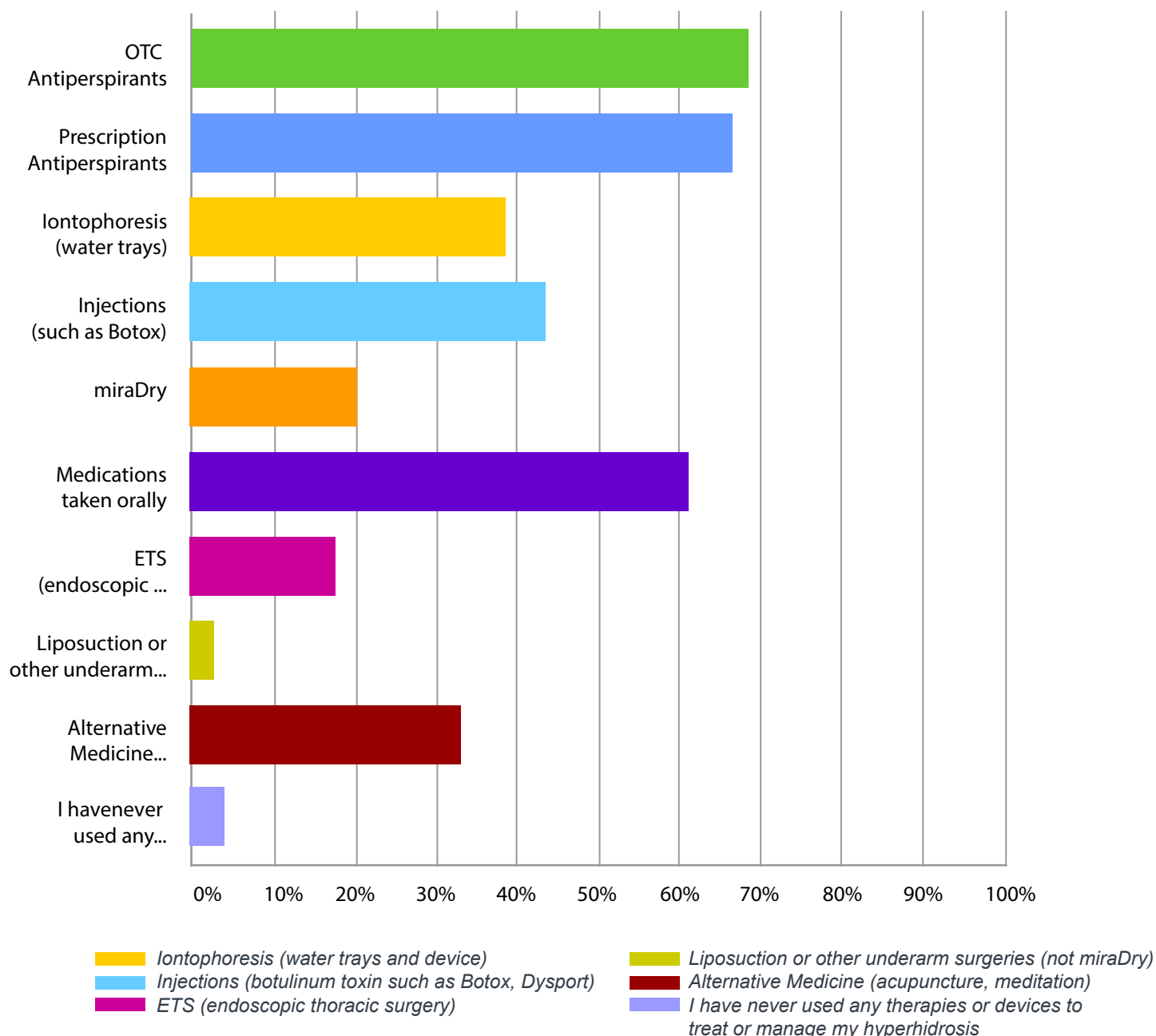
Answered: 156 Skipped: 0





# Have you ever used any of the following drug therapies or medical devices to treat your Hyperhidrosis? Check all that apply.

Answered: 156 Skipped: 0



For the therapies you use, what do you consider to be the most burdensome downsides? Please choose up to three answers.

How the medication is administered (such as a topical cream or an injection)	16.67%
Difficulty in accessing treatment (for example, physician knowledge)	29.49%
Treatment only provides minimal benefit	43.59%
Treatment is effective only for a short time	44.23%
Bothersome side effects of the treatment	39.74%
Concern about serious risks of the treatment	14.74%
Uncertainty about the long-term side effects of the treatment	25.64%
Cost of the treatment	28.21%
I do't use any therapies	8.33%

Besides the therapies mentioned previously, what else are you doing to manage any symptoms or manifestations you experience because of your Hyperhidrosis? Check all that apply.

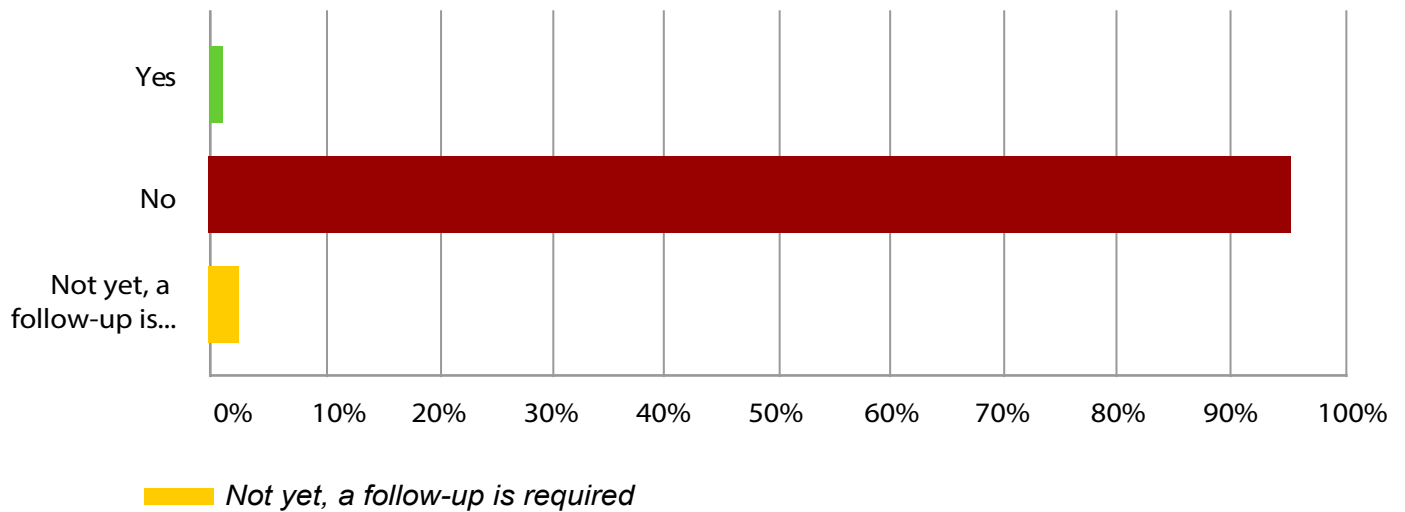
Dietary and herbal supplements	16.03%
Diet modifications	19.87%
Complementary or alternative therapies	10.90%
I am not doing or taking any therapies to treat my Hyperhidrosis	53.21%
Other therapies not mentioned (please specify)	24.36%

Responses

“Other” included: “Looking into microwave spot treatment,” “I’ve tried a lot of things, don’t know what else to try,” “I constantly carry a portable fan with me at all times,” “I’m taking a beta blocker,” “Supplementation with L-theanine,” “stay immobile, out of heat, wear absorbent clothing and pads, bath often, change clothing often,” “Meeting with a psychologist,” “biofeedback,” “I have done all the above without success. And currently doing nothing,” “Currently I have taken a break from my therapies to treat hyperhidrosis due to cost and pain,” “Secluding myself,” “Meditation and acceptance,” “taking a medication which has a side effect that helps my HH but has lead to other health complications,” “have to wear a plastic sauna suit under my clothes.”

# Is your hyperhidrosis resolved?

Answered: 156 Skipped: 0



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