Voice of the Hyperhidrosis Patient:

Symptoms, Impacts & Treatments:
Insights from Large, Open, FDA-Attended Meeting

Adelaide A. Hebert MD, Dee Anna Glaser MD, Angela M. Ballard RN,
Lisa J. Pieretti MBA, David M. Pariser MD
Disclosures

Adelaide A. Hebert, MD
Allergan, Investigator, Grants, paid to UTH ealth McGovern Medical School, Not relevant to topic
Brickell, Investigator, Grants, paid to UTH ealth McGovern Medical School, Not relevant to topic
Dermira, Advisory Board, Honoraria, paid to UTH ealth McGovern Medical School, Not relevant to topic
Dermira, Investigator, Grants, paid to UTH ealth McGovern Medical School, Not relevant to topic
GSK, Data Safety Monitoring Board, Honoraria, Not relevant to topic
International Hyperhidrosis Society, Board Member, Volunteer

Angela M. Ballard, RN
International Hyperhidrosis Society, Consultant

David M. Pariser, MD
Atacama, Investigator, Grants, Not relevant to topic
Brickell, Investigator, Grants, Not relevant to topic
Dermavant, Investigator, Grants, Not relevant to topic
Dermira, Investigator, Grants, Not relevant to topic
International Hyperhidrosis Society, Board Secretary, Volunteer
TheraVida, Investigator, Grants, Not relevant to topic

Dee Anna Glaser, MD
Allergan, Investigator, Grants, Not relevant to topic
Allergan, Consultant, Grants, Not relevant to topic
Atacama, Investigator, Grants, Not relevant to topic
Brickell, Investigator, Grants, Not relevant to topic
Dermira, Investigator, Grants, Not relevant to topic
Dermira, Speaker, Grants, Not relevant to topic
Evolus, Investigator, Grants, Not relevant to topic
Galderma, Investigator, Grants, Not relevant to topic
International Hyperhidrosis Society, Board President, Volunteer
Revance, Investigator, Grants, Not relevant to topic

Lisa J. Pieretti, MBA
International Hyperhidrosis Society, Staff

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Background:

Hyperhidrosis (Hh) is characterized by extreme sweating beyond what is necessary/expected for thermoregulation, or as a stress reaction. There are ~15.3 million individuals with Hh in the U.S. (prevalence 4.8%).\(^1\) Related discomfort, occupational hindrances, and psychosocial impacts are noted in the literature.\(^2\)\(^-\)\(^4\) Treatment options exist, but patient satisfaction can be low and access challenging.\(^5\)

To add to the understanding of what would constitute patient-centric approaches, the International Hyperhidrosis Society hosted a Patient-Focused Drug Development (PFDD) meeting on Hh as part of the U.S. Food & Drug Administration’s Externally-led PFDD initiative.

Objectives:

To use qualitative methods in the context of an Hh sufferer forum to gather perspectives on disease manifestation, research and treatment. To illuminate condition context and make known sufferers’ care priorities.

References:

Methods:

This PFDD meeting was held November 13, 2017 as a forum for self-identified Hh patients, caregivers and other stakeholders to share insights into disease symptoms, daily impacts that matter most, current research design and treatment approaches. Qualitative results were generated from transcripts of attendee (125) presentations, pre-event poll (150+ responses), live webcast (350 participants) and post-meeting open comment period (100+ comments).

Results:

Insights from individuals on Hh symptoms, impacts, and treatments showed frequent themes including: childhood/adolescent onset and early challenges (in poll, 55% say Hh started at age 10 or younger); indications that Hh has “ruined” life, “controls” life; feelings of self-harm/suicide, anxiety, isolation, depression; limited or “no” treatments for non-axillary Hh; feeling cold and/or painful hands/feet; slips and falls; thoughts of hopelessness with current treatments; frustration at “having tried everything”; desire to get to “root” cause; fear that offspring will “get” Hh; limited access to care; desire for clinicians and regulators to be more informed on Hh.

In poll:

>70% moderately/extremely dissatisfied with clinical Hh knowledge
>75% of Hh sufferers reported asking for medical care for Hh more than 3 times
95% say their Hh is not resolved
Testimonials from Hh Sufferers on Living with Excessive Sweating:

Social, Emotional & Self-Concept Responses

“Always the outcast”
“Doomed”
“Ashamed to be touched”
“Isolating and embarrassing”
“Always anxious”
“Never able to become who I am”
“Very hopeless”
“I feel gross”
“Never, ever able to get home without being on the verge of tears”
“Constantly wet”
“I don’t want people near me. I don’t want to be touched”

Thoughts on Current Clinical Experiences & Treatments

“Overlooked”
“Poorly managed”
“Temporary”
“People with hyperhidrosis are desperate for treatment. We are desperate to find relief”
“Not enough treatments available”
“Expensive”
“Under-treated”
“I would give up both pinky fingers [for effective treatment]”
“Make-do”
“Painful”
“No insurance coverage”
“When the patient is the expert, rather than the doctor, that’s a difficult situation”

Expressed Desires for Future Hh Care

“Better clinical trials”
“Accessible, affordable [treatments]”
“Educate, educate, educate”
“Better treatment options”
“There’s no hope for me. But, I hope there will be for people in the future”

Conclusions:

Sufferers and caregivers offer valuable perspectives on the broader context of Hh, and their experience with care and research. Insights collected from this meeting may be useful during benefit-risk assessments, regulatory review, fit-for-purpose study design, treatments and patient-driven care.

For more information on the International Hyperhidrosis Society’s PFDD meeting results, and to view the full report, visit www.SweatHelp.org/PFDD. #KnowSweat