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New Eczema Report Depicts Enormous Burdens and Huge Unmet Medical Needs

“More Than Skin Deep” meeting and survey results deepen understanding of patient and caregiver experiences

Washington, D.C. – March 18, 2020 – Today, five organizations jointly release the “More Than Skin Deep” Voice of the Patient report summarizing outcomes from a September 2019 patient-focused drug development meeting – a novel effort to understand and share the lived experience of patients and caregivers affected by atopic dermatitis, the most common form of eczema. For the first time ever, adults and children living with eczema and their family members shared riveting descriptions of symptom burdens, challenges managing the disease, and treatment expectations with U.S. Food and Drug Administration (FDA) regulators, drug developers, and researchers. This comprehensive, full-color report shares testimony, data, and photos from the 160 in-person participants, 1,508 respondents to the companion survey, and thousands of virtual attendees participating via webcast. The survey is one of the largest surveys of the eczema community to date.

More than 33 million Americans of all ages experience eczema, an inflammatory skin disease that results in rashes and patches of itchy, red skin. Eczema can vary in severity, yet, as patients and caregivers confirmed in sharing their lived experiences with the disease, it frequently leads to diminished quality of life and significant emotional burden in addition to intense itch, skin damage, sleep disturbance, pain and other physical discomforts. The vast majority – 89% – of survey respondents reported dissatisfaction and/or harms with their current treatment options. “Immediate and sustained relief from itch” was the most sought-after treatment benefit as measured by polling at the meeting and among survey respondents.

This alliance of five patient organizations is the largest to-date to host a patient-focused drug development (PFDD) meeting; there have been approximately 55 held so far under FDA’s program that began in 2013. The five collaborating organizations are: Allergy & Asthma Network (AAN), Asthma and Allergy Foundation of America (AAFA), Global Parents for Eczema Research (GPER), International Topical Steroid Awareness Network (ITSAN), and the National Eczema Association (NEA).

Kenneth Mendez, President & CEO of the Asthma and Allergy Foundation of America, remarked on the huge unmet need for safer, more effective treatments this initiative revealed. “Only 2% of meeting participants were satisfied with current therapies, yet the survey showed newer therapy options are not reaching most patients. This meeting, the survey, and the report released today mark a new beginning for the work we collectively have ahead of us on behalf of eczema patients everywhere,” Kenneth stated. Survey results indicate that fewer than 10% of patients are currently being treated with non-steroidal systemic therapies.



Meeting participants, many of whom are quoted directly in the report, expressed a desire for more targeted approaches to therapy. “We must continue to push the envelope to better understand phenotypes and underlying immunology in eczema to ensure that we get the right treatment to the right patient in the most timely and effective manner,” urged Tonya Winders, President & CEO of the Allergy & Asthma Network.

Through its PFDD initiative, FDA has recognized that patients’ chief complaints often are not factored into drug development plans. Kathy Tullos, President & CEO of the International Topical Steroid Awareness Network, further emphasized the potential impact of engaging patients and caregivers in eczema medical product development: “This initiative gave voice to the voiceless. Patients and caregivers are pioneers on a new frontier. Future eczema patients will have better, safer, more effective options because people courageously shared their experiences at the meeting and through the survey.”

The “More Than Skin Deep” Voice of the Patient report will inform the plans and programs of each of the five host organizations and sponsors developing new eczema therapies, as described in a special “Reflections” section. The report has been submitted to FDA and will serve as a lasting resource for regulators, life science companies, researchers, the patient community, and the public.

To read the report and learn more about the “More Than Skin Deep” initiative, visit www.morethanskindeep-eczema.org.

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About the Allergy & Asthma Network

Allergy & Asthma Network is the leading nonprofit patient education and advocacy organization for people with asthma, allergies and related conditions. Our patient-centered network unites individuals, families, healthcare professionals, industry and government decision makers to improve health and quality of life for Americans with asthma and allergies. We specialize in making accurate medical information relevant and understandable to all while promoting evidence-based standards of care. Learn more at allergyasthmanetwork.org.

About the Asthma and Allergy Foundation of America

Founded in 1953, the Asthma and Allergy Foundation of America (AAFA) is the oldest and largest non-profit patient organization dedicated to improving the quality of life for people with asthma, allergies and related conditions through research, education, advocacy and support. AAFA provides practical information and community-based services through its digital communities and network of chapters and support groups. AAFA is a member of the National Health Council. Learn more at aafa.org.

About Global Parents for Eczema Research

Global Parents for Eczema Research (GPER) is a grassroots, parent-led nonprofit organization focused on improving our knowledge of how to treat and manage eczema through research and innovation. GPER’s mission is to improve quality of life for children living with moderate to severe eczema. GPER achieves its goals by influencing research, conducting research, engaging in public policy, and disseminating research to patients and families. Learn more at parentsforeczemaresearch.org



About the International Topical Steroid Awareness Network

The International Topical Steroid Awareness Network (ITSAN) is a US-based nonprofit formed in 2012 to provide support and raise awareness about a condition called Topical Steroid Withdrawal Syndrome (TSW Syndrome), also known as Topical Steroid Addiction or Red Skin Syndrome. ITSAN has grown into a global support network and educational resource for individuals, caregivers, and healthcare providers. Its main goals are prevention, early detection, accurate diagnosis, and proper treatment for all TSW Syndrome patients worldwide. Learn more at itsan.org.

About the National Eczema Association

Founded in 1988, the National Eczema Association (NEA) works to improve the health and quality of life for individuals with eczema through research, support, and education. Specifically, NEA seeks to break through negative stereotypes to promote understanding of eczema and reduce burden of disease; equip medical practices for a new era in eczema care; promote new models of care; support high-value/high-yield research projects; and, advocate for accessible and affordable treatments for all eczema patients. Learn more at nationaleczema.org.