



Individuals & Families Affected by Eczema Unite to Inform Drug Development

“More Than Skin Deep” initiative seeks to collect and share patient & caregiver experiences

Washington, D.C. – August 1, 2019 – Today, five organizations launch a collaborative effort to inform treatment research and development for atopic dermatitis, the most common form of eczema. For the first time ever, adults and children living with eczema and their family members will share perspectives on what it’s like to live with eczema with U.S. Food and Drug Administration (FDA) regulators, drug and medical device developers, and researchers. The “More Than Skin Deep” initiative will collect and share patient and caregiver experiences as they relate to impacts on daily life, symptom management, and treatment expectations through an online survey and a Sept. 23, 2019, meeting with FDA officials.

More than 33 million Americans of all ages experience eczema, an inflammatory skin disease that results in rashes and patches of itchy, red skin that can appear anywhere on the body, but most commonly occur on the neck, face, hands, feet, and joints. Eczema can vary in severity, yet often leads to diminished quality of life and significant emotional burden in addition to pain, physical discomfort, and sleep disturbance for affected individuals. Despite the high prevalence of this condition, there are limited topical and systemic FDA-approved therapies for eczema, and few patients, especially those with moderate to severe eczema, experience total symptom relief or sustained control of the disease.

This alliance of five patient organizations is the largest to-date to host a patient-focused drug development (PFDD) meeting; there have been approximately 50 held so far under FDA’s program that began in 2013. The five collaborating organizations are: Asthma and Allergy Foundation of America (AAFA), Asthma & Allergy Network (AAN), Global Parents for Eczema Research (GPER), International Topical Steroid Addiction Network (ITSAN), and the National Eczema Association (NEA).

Korey Capozza, director of GPER, sees the meeting as an opportunity to bring the community together to shape development of new treatments. She explained, “Our organization hears daily from parents whose lives are upended by what many people think of as a ‘little rash’ on their child. Existing treatment options are insufficient, especially when you consider they might be used for years in young children. We are excited to work with these four committed patient organizations to highlight the true burden and unmet needs of patients and families impacted by eczema and to attract participation from every corner of the eczema community.”

NEA President and CEO Julie Block describes the immediate and long-term value of this joint effort. “This is an opportunity to unify and empower our community by pulling back the curtain on eczema – a long, silent and underserved disease – and revealing that the disease not only damages the skin, but also breaks apart lives. Scientific advances have ushered in a new era of treatment research, and this meeting will be the start of an ongoing dialogue about what matters most to adults and children with eczema, their parents, and partners,” she stated.

Information shared at the Sept. 23, 2019, meeting and through the survey will be summarized in a written “Voice of the Patient” report as a lasting resource for FDA, life science companies, researchers, the patient community, and the public. Individuals living with or interested in eczema are invited to take part in the meeting and survey.



For more information about the “More Than Skin Deep” initiative, visit www.morethanskindeep-eczema.org.

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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 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 Global Parents for Eczema Research

Global Parents for Eczema Research (GPER) is 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 Addiction Network

The International Topical Steroid Addiction Network (ITSAN) was formed in 2012 to raise awareness about a condition called Topical Steroid Addiction and Withdrawal, also known as Red Skin Syndrome (RSS). ITSAN has grown into a global community of RSS sufferers contributing ideas, funds and inspiration. ITSAN raises awareness of RSS, fosters physician and patient education, and supports affected individuals. Its goals are the prevention, early detection, accurate diagnosis, and proper treatment of RSS. 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.



Asthma and Allergy
Foundation of America

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Media Contact:

Sanaz Eftekhari, Vice President, Corporate Affairs and Research

media@aafa.org

202-974-1225