



MORE THAN SKIN DEEP


UNDERSTANDING THE
LIVED EXPERIENCE OF ECZEMA

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#ECZEMA

#MORETHANSKINDEEP


#PFDD



THE ECZEMA PATIENT- FOCUSED DRUG DEVELOPMENT MEETING

September 23, 2019
9:00 a.m. – 3:30 p.m.

College Park Marriott Hotel &
Conference Center
Hyattsville, Maryland



More Than Skin Deep is a collaboration of the following organizations:





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THE MORE THAN SKIN DEEP INITIATIVE

In 2013, the U.S. Food and Drug Administration (FDA) began holding a series of meetings to hear directly from patients, caregivers, advocates, and other key community stakeholders about what it's like to live with various medical conditions and how well available treatments are meeting patients' needs. This meeting series, called the "Patient-Focused Drug Development" initiative or PFDD, has now been expanded to enable patient organizations to host PFDD meetings in collaboration with FDA. (See <http://bit.ly/FDA-PFDDinfo>)

The eczema community was approved to hold a meeting and five organizations serving the eczema community have joined together to host the **More Than Skin Deep** PFDD initiative: 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). This is the largest coalition of organizations to collaborate for a PFDD initiative.

The purpose of PFDD meetings in general and the **More Than Skin Deep** eczema PFDD meeting is for FDA staff, researchers, and developers of drugs and medical devices to understand more fully the burdens of living with a particular medical condition, as well as what patients most value in terms of treatment benefits and the risks and side effects they are willing to tolerate. An example of how PFDD can benefit people living with eczema is to deepen understanding about all the ways in which eczema impacts people's lives – beyond the discomfort of having red, itchy skin that is so often the sole focus. Your active participation during this meeting will help depict the full range of experiences with eczema and will show these key audiences that eczema is "more than skin deep."

*Learn more about the five organizations that have created the **More Than Skin Deep** initiative beginning on page 11 of this program.*

ATOPIC DERMATITIS – THE MOST PREVALENT FORM OF ECZEMA

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.

MORE THAN SKIN DEEP | ECZEMA PFDD MEETING AGENDA | SEPTEMBER 23, 2019

8:00 – 9:00 am	Registration and Continental Breakfast
9:00 – 9:15 am	Welcome and Opening Remarks Julie Block – President & CEO, National Eczema Association (NEA) Korey Capozza – Founder, Global Parents for Eczema Research (GPER)
9:15 – 9:35 am	Patient-Focused Drug Development at the U.S. Food and Drug Administration (FDA) Jill Lindstrom, MD – Deputy Director, Division of Dermatology and Dental Products, FDA
9:35 – 9:55 am	Clinical and Epidemiological Overview of Atopic Dermatitis Jonathan Silverberg, MD, PhD, MPH – Associate Professor, Feinberg School of Medicine, Northwestern University
9:55 – 10:05 am	Introduction of Moderator & Overview of Meeting Format and Live Polling Process Kelly Barta – President & CEO, International Topical Steroid Awareness Network (ITSAN) James Valentine, JD, MHS – Meeting Moderator
10:05 am – 12:00 pm	Session 1: Symptoms and Daily Impacts That Matter Most to Patients Key Questions: <ul style="list-style-type: none">• Of all the symptoms that you experience because of your condition, which 1-3 symptoms have the most significant impact on your life?• Are there specific activities that are important to you but that you cannot do at all or as fully as you would like because of your condition?• How has your condition and its symptoms changed over time?• What worries you most about your condition? Panel: Kelly Barta; Raelle Brown; Brianna Cox; Joseph Cutaran; Keri Kelley; Sarah Pry Live Polling (On-site & Webcast Participants) Moderated Discussion Among All Meeting Participants (On-site & Webcast Participants)
12:00 – 12:05 pm	Morning Wrap-Up and Invitation to Lunch Tonya Winders – President & CEO, Allergy & Asthma Network (AAN)
12:05 – 12:55 pm	Networking Lunch
1:00 – 3:15 pm	Session 2: Current and Future Approaches to Treatments Key Questions: <ul style="list-style-type: none">• What are you currently doing to help treat your condition or its symptoms?• How well does your current treatment regimen treat the most significant symptoms of your disease?• What are the most significant downsides to your current treatments, and how do they affect your daily life?• Assuming there is no complete cure for your condition, what specific things would you look for in an ideal treatment for your condition? Parent/Caregiver Panel: Lynell Doyle; Ashley Ellis; Angela Fox; Heather Sullivan; Kathryn Tullos Adult Panel: Tyler Berryman; Lisa Choy; Pamela Friedman; Steve Gawron; Lindsay Swire Jones Live Polling (On-site & Webcast Participants) Moderated Discussion Among All Meeting Participants (On-site & Webcast Participants)
3:15 - 3:30 pm	Summary and Closing Remarks Kenneth Mendez – President & CEO, Asthma and Allergy Foundation of America (AAFA)

MEET THE PANELISTS

The purpose of today's meeting is to better understand the experience of children, teens, and adults living with eczema. The FDA's Patient-Focused Drug Development initiative has elevated the level of respect and credence accorded to first-person accounts. The host organizations extend their deepest gratitude to every person who contributes to today's **More Than Skin Deep** meeting discussion.

The panelists have dedicated additional time to speak to the challenges, expectations, and hopes of the community as a way of inviting an even broader range of experiences through the moderated discussion. We deeply appreciate their courage and dedication to the success of this initiative.

Kelly Barta – Lawrenceville, GA

Tyler Berryman – Sunnyvale, CA

Raelle Brown – Philadelphia, PA

Lisa Choy – Corte Madera, CA

Brianna Cox – Memphis, MI

Joseph Cutaran – Fort Worth, TX

Lynell Doyle – Pontiac, MI

Ashley Ellis – Olive Branch, MS

Angela Fox – New Braunfels, TX

Pamela Friedman – Orinda, CA

Stephen Gawron – Long Island, NY

Keri Kelley – Yukon, OK

Sarah Pry – Crossville, TN

Heather Sullivan – Spokane, WA

Lindsay Swire Jones – Chicago, IL

Kathryn Tullos – Houston, TX

MEET THE SPEAKERS

KELLY BARTA

Ms. Barta began as a volunteer with the International Topical Steroid Awareness Network (ITSAN), helping raise awareness and conduct advocacy activities, after personally experiencing severe effects of steroid withdrawal in 2012. Kelly served on ITSAN's Board of Directors and became its President and CEO in 2018.

JULIE BLOCK

Ms. Block held a number of leadership positions in the non-profit sector before being named President and CEO of the National Eczema Association (NEA) in 2010. In 2014, she led a process to develop a Roadmap to Advocacy for NEA to deepen the organization's impact and capitalize on a coming sea change in the treatment of eczema.

KOREY CAPOZZA, MPH

In 2015, Ms. Capozza's lived experience as the parent of a child with eczema, coupled with her professional experience in health policy and community-based research led her to found Global Parents for Eczema Research (GPER) with a "Pipeline to Proposal" award from the Patient-Centered Outcomes Research Institute (PCORI).

JILL LINDSTROM, MD, FAAD

Dr. Lindstrom serves as Deputy Director of the Division of Dermatology and Dental Products in the Center for Drug Evaluation and Research at the FDA. She is certified in dermatology by the American Board of Dermatology and is a Fellow of the American Academy of Dermatology.

KENNETH MENDEZ

Mr. Mendez was appointed to serve as the Allergy and Asthma Foundation of America's President and CEO in January 2018, building on his prior experience in the non-profit sector as well as 12 years at AdvaMed, the world's largest medical technology association. He has two children affected by allergies and asthma.

JONATHAN I. SILVERBERG, MD, PHD, MPH

Dr. Silverberg is Associate Professor of Dermatology, Medical Social Sciences and Preventive Medicine at the Feinberg School of Medicine, Northwestern University. His research interests include the patient- and population-based burden of atopic dermatitis and other chronic inflammatory skin diseases.

JAMES E. VALENTINE, JD, MHS

Mr. Valentine is an associate at the law firm of Hyman, Phelps & McNamara, P.C. where he assists medical product industry and patient advocacy organization clients in a wide range of regulatory matters, including new drug and biologic development and approval issues. He previously worked at the FDA.

TONYA WINDERS, MBA

Ms. Winders' association with the Allergy & Asthma Network (AAN) began as a strategic partner through her work for industry. Her husband and children have atopic conditions and she also became a volunteer for the organization. In 2013 she succeeded AAN's founder as President and CEO, a position she holds today.

MEET THE PROJECT TEAM

Working on behalf of their organizations and collectively as a cohesive team, these women have contributed their skills, talents, and boundless energy to planning and delivering the **More Than Skin Deep** initiative:



KELLY BARTA

President & CEO
International Topical Steroid Awareness Network



LISA BUTLER

Vice President, Strategic Partnerships & Programs
National Eczema Association



KOREY CAPOZZA

Founder
Global Parents for Eczema Research



SANAZ EFTEKHARI

Vice President, Corporate Affairs and Research
Asthma and Allergy Foundation of America



KERI KELLEY

Parent Member
Global Parents for Eczema Research



CARA KRAFT

Director of Research
Allergy & Asthma Network



WENDY SMITH BEGOLKA, MBS

Director of Research
National Eczema Association



KATHRYN TULLOS, RN

Volunteer
International Topical Steroid Awareness Network



TONYA A. WINDERS

President & CEO
Allergy & Asthma Network



ELISA ZIZZA

Grants Manager
Asthma and Allergy Foundation of America

ACKNOWLEDGEMENTS

With gratitude for the following individuals who have enhanced the **More Than Skin Deep** initiative:

Meghana Chalasani of the FDA's Office of Strategic Initiatives, Center for Drug Evaluation and Research for providing counsel and encouragement throughout the entire planning process.

John Dudley & Eric Quigley of Dudley Digital Works for creative and technical services to broadcast today's meeting to a live remote audience and preserve it for later on-demand viewing.

Kim McCleary of the Kith Collective for strategic, communications, survey development, and outreach support in preparation for today's meeting. Kim will write the "Voice of the Patient" report to summarize today's discussion and the final survey results.

Julie Rathjens of Hello Brand for design of the More Than Skin Deep logo and production of other creative materials, including this program booklet.

James Valentine of Hyman, Phelps & McNamara, PC for strategic counsel about PFDD, preparing panelists to convey their experiences, and moderating today's meeting.

CORPORATE SPONSORS

Thank you to these generous sponsors for their unrestricted educational grants in support of the **More Than Skin Deep** initiative:

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INTERIM RESULTS OF THE MORE THAN SKIN DEEP PATIENT & CAREGIVER SURVEY

In preparation for the September 23, 2019 **More Than Skin Deep** meeting, host organizations fielded a survey to capture a broad set of experiences. As of September 10, 2019, the 32-item survey attracted responses from 1,131 people. Seventy-one percent (71%) of responses were from individuals speaking to their own experience with eczema; 26 percent responded on behalf of one or more children under the age of 18 who have eczema; 3 percent replied on behalf of an adult child, spouse, partner, or parent with eczema.

Demographics: Nearly three-quarters of respondents (72%) indicated the person with eczema identifies as being female. Seventy percent (70%) reported having one member of the household with eczema; 21 percent have two affected household members and 6 percent report having three or more people in the household.

Respondents were well distributed across the U.S.; 18 percent of responses came from outside the U.S. Slightly more than a quarter (27%) of responses were provided for children under age 18, with 12 percent under the age of 5. One-third (36%) were reporting on an individual between the ages of 35-64. Almost half (47%) reported the onset of symptoms before age 2; nearly three-quarters (71%) reported symptom onset before age 18.

SURVEY COMMENTS ON DIAGNOSIS

“A diagnosis was predicted by our GP but then we needed to wait several months to see a dermatologist to confirm.”

“At first [our daughter was] diagnosed with infant acne and mostly dismissed by the pediatrician. As it spread to more of her body, she was diagnosed with eczema.”

“I was misdiagnosed by two dermatologists and a primary care provider who just kept saying I had acne or rosacea and giving an array of meds, both topical and pill form, and sent on my way. It was over five years going through this, which I now have scars to remind me daily, until I found a doctor who actually listened, communicated, and got me testing and a proper diagnosis.”

Diagnosis & Severity: Nearly all – 99 percent – of respondents were reporting on behalf of someone diagnosed by a physician; nearly two-thirds (61%) received a diagnosis within 12 months of symptom presentation. Just 15 percent reported the diagnostic process taking more than two years; however, the open comments in the survey contain many descriptions of having to see multiple providers (primary care providers and specialists) before a proper diagnosis was made.

At its worst point, 79 percent of respondents indicated that the condition was severe. At present, responses were more spread across the spectrum of severity, with 28 percent reporting severe symptoms, 46 percent reporting moderate symptoms, and 26 percent reporting mild symptoms. Compared to the time of symptom onset, nearly half of respondents (46%) indicated that the symptom severity had worsened; 42 percent stated that it was less severe than at onset. Nearly two-thirds report that more areas or different areas are affected; almost half indicate that the frequency of flares was worse than at onset.

When separated by the current age of the person with eczema, experience was similar among children and adults, with 76 percent of parents rating their child's symptoms as “severe” at the worst point, and 80 percent of adults indicating the same. At present, the severity was rated “moderate” by 49 percent of caregivers for children and 44 percent of adults.

Most Problematic Symptoms: Asked about which three symptoms have been the most problematic the person with eczema has experienced, three symptoms were selected by more than 25 percent of all respondents: itching (81%); red, inflamed skin (47%); and sleep disturbance (30%). Sleep disturbance was more problematic for children (46%) compared to adults (23%).

Comorbidities were common among all respondents. Five conditions were present in more than 20 percent of all respondents: allergic rhinitis (47%); food allergy (43% overall; 64% among children and 35% among adults); asthma (35%); anxiety (26%); and depression (22% overall; 8% among children and 27% among adults). When asked directly about symptoms of depression at the present time, 8 percent rated this as a “severe” symptom and 29 percent rated it as currently “moderate.” At the worst point of their eczema, 52 percent rated depression as “severe” and 27 percent rated it as “moderate.”

The impact of eczema on identity and self-confidence was rated as “significant” (27%) or “high” (22%) by nearly half of all respondents. Among adult patients it was even higher, with 55 percent indicating it had a “significant” or “high” impact, compared to 31 percent for children.

The impact of sleep was “significant” for 32% and “high” for 21%. There was considerable variability in responses on the impact of symptoms on dimensions such as ability to concentrate and/or think, diet, physical activity, intimate relationships, work/education, family-related responsibilities, the ability to handle stress and/or recover from stressful events, participation in leisure activities, social relationships, and life events. More

INTERIM RESULTS OF THE MORE THAN SKIN DEEP PATIENT & CAREGIVER SURVEY

subgroup analysis and examination of open-ended responses will be needed to better understand how different groups may be affected by or experiencing these effects of eczema.

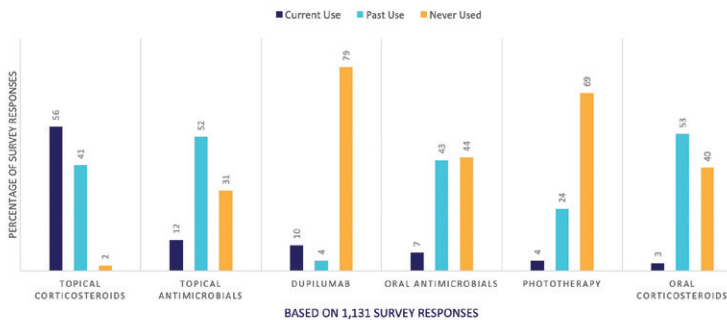
Management: A large number of approaches to treatment are being used at present or have been used in the past, combining medications, medical devices, and supportive therapies. While 51 percent spend less than five hours per week managing their eczema, of the remaining portion, 26 percent spend 5-10 hours; 12 percent spend 11-20 hours; and 11 percent spend 21 or more hours each week on a combination of tasks related to managing the condition.

The most widely utilized treatment – both at present and in the past – is topical corticosteroids (56% at present and 41% in the past (but not at present)). Among those who have used topical steroids, 70 percent reported they had some relief for a period of time; 40 percent had limited or no relief; 34 percent had a severe or long-lasting flare after stopping use; and 26 percent reported that symptoms worsened on topical steroids.

There was less experience with other topicals. Antimicrobials have been used in the past by 52 percent, but are in current use by only 12 percent. For specific topicals including tacrolimus, pimecrolimus, and crisaborole, all have been used in the past by more than use them at present, but nearly half or more of all survey respondents have never used them. Phototherapy has been used by 24 percent in the past and just 4 percent at present; 69 percent have never tried it.

Among the systemic medications taken orally or by injection, there was more experience with corticosteroids than other medications. Oral corticosteroids had been used by 53 percent in the past, but only 3 percent reported current use; injectable corticosteroids were used by 22 percent in the past and just 1 percent at present. Other oral medications have been tried by even fewer survey respondents. Ten percent (10%) report current use of dupilumab.

USE OF PRESCRIPTION THERAPIES



There is heavy use of over-the-counter treatment products by survey respondents, with just 13 percent indicating no use and nearly two-thirds (62%) indicating use of 3 or more products at present.

The most highly reported adjunctive/complementary/alternative therapy in current use is bathing modifications (55% current; 30% past), followed closely by lifestyle adjustments (such as controlling exposures or activity) with 54 percent current use (21% past), and dietary modifications currently used by 39 percent (27% past). Approaches with more past than current use include wet wraps (34% past; 6% current); bleach baths (26% past; 9% current); the “Aron Regimen” (17% past; 13% current); and traditional Chinese medicine (18% past; 4% current). Topical steroid withdrawal, as a therapy, has been used in the past by 25 percent of respondents and is in current use by 23 percent.

SURVEY COMMENTS ON IMPACT

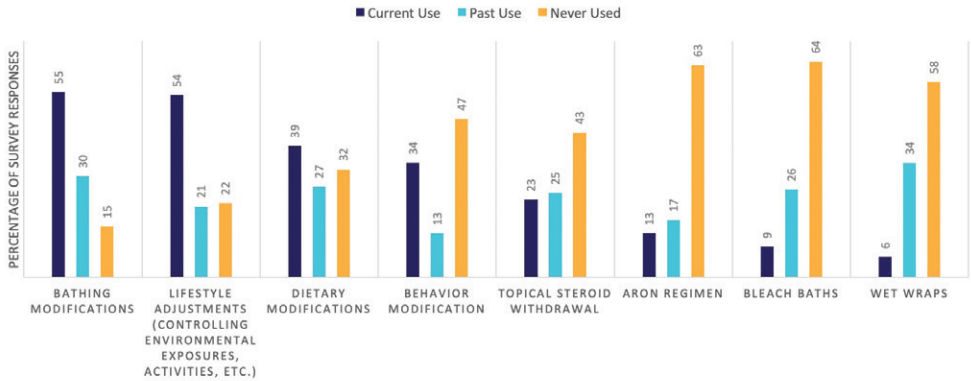
“During my worst flare ups, I’ve been unable to properly walk due to the skin at the bottom of my foot splitting open and my arms have oozed.”

“Eczema at its worst is painful constantly and completely demoralizing. Imagine your entire suit of skin on fire. Scratching provides [immense] relief but is humiliating. Social interaction is difficult and embarrassing. Sleeping is a precious commodity, but when you wake up and the sheets are crusted to your wounds the reminder of the difficulty of life begins. It’s nonstop. It’s life consuming. It’s hell.”

“My child has been in tears many days after being left out of activities at school because others don’t want to touch her. Her skin is very dry and flaky, covering the inside of her clothes each night when she takes them off. Some topical lotions and creams burn her skin when applied, and she will cry in pain. The constant itching keeps her awake at night, often making it harder for her to get up for school in the morning. She worries about not being able to fall asleep, being too tired at school, and being an outcast because of the way that she looks.”

INTERIM RESULTS OF THE MORE THAN SKIN DEEP PATIENT & CAREGIVER SURVEY

USE OF ADJUNCTIVE OR COMPLEMENTARY/ALTERNATIVE THERAPY APPROACHES



BASED ON 1,131 SURVEY RESPONSES

Treatment Satisfaction: Overall, 38 percent of respondents indicate that their eczema is moderately well-controlled using therapies available to them; however, a similar proportion (32%) expressed that the condition was “poorly controlled, but better than nothing.” At the ends of the spectrum, 13 percent reported their eczema is “very well-controlled” and 12 percent responded that their symptoms were “not controlled at all/no sustained relief.”

Overall, 59 percent indicate that they have experienced mixed response to available therapies. There was fairly even distribution among the other three responses: 15 percent indicated no sustained relief, and 15 percent report having been harmed by existing therapies; 12 percent are very satisfied with available therapies.

In response to a question about the most challenging areas of the body to treat, the hands were rated as most challenging by 47 percent, closely followed by face with 46 percent. Other areas that were identified as challenging by at least one-fourth of respondents are: arms (36%); fingers (33%); neck (32%); knees – front and/or back (30%); and scalp (28%).

Barriers to Treatment: There are a large number of barriers to therapy, led by “concerns about long-term use” (54%) and “treatment being ineffective” (53%). Other barriers that were indicated by at least 25 percent of respondents include: “treatment is not beneficial” (36%); “too many side effects” (33%); “financial barriers” (32%, including lack of insurance, lack of coverage, or high out-of-pocket costs); “hard to use/accommodate in the school/workplace (27%), and “inconvenient” (25%).

Close to half of respondents (43%) reported having to discontinue prescribed medications for eczema. When this group was asked the reason(s) for stopping prescribed medications, three answers were chosen most often: “it was ineffective” (63%), “negative side effects” (62%), and “concern over long-term use” (62%). Twenty-nine percent (29%) indicated a desire to pursue non-prescription approaches.

Looking Ahead: The most important result that a treatment could provide was “immediate and sustained reduction in itch and pain” for 51 percent of respondents. Another 24 percent sought to experience a reduction in frequency of flares and 10 percent sought “increased ability to go about their daily life.”

Two-thirds have never been asked to participate in a clinical trial; 14 percent have considered participating, but did not, whether due to failure to qualify or for some other reason. Overall, just 6 percent have participated in a clinical trial in the past. Among adults, 7 percent reported clinical trial participation.

The Patient & Caregiver Survey will remain open until October 11, 2019; a link to it can be found at <http://bit.ly/mtsd-survey>. Final results will be tallied and included in the “Voice of the Patient” report that will summarize the meeting and survey for submission to the FDA and as a lasting resource for the eczema community, researchers, and sponsors of clinical trials.

ALLERGY & ASTHMA NETWORK (AAN)

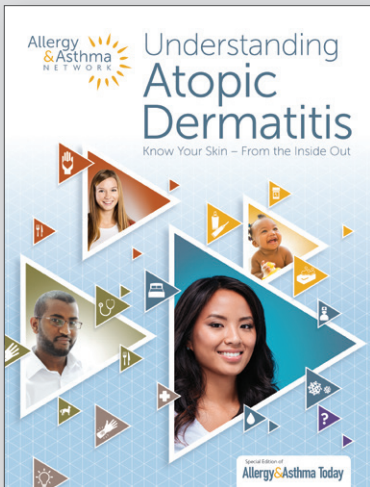


OUR MISSION

To end needless death and suffering due to asthma, allergies, and related conditions through outreach, education, advocacy, and research.

Allergy & Asthma Network is the leading nonprofit patient outreach, education, advocacy and research organization for people with asthma, allergies, and related conditions. Our patient-centered network unites individuals, families, healthcare professionals, industry leaders, and government decision-makers to improve health and quality of life for millions of people affected by the conditions.

An innovator in encouraging family participation in treatment plans, Allergy & Asthma Network specializes in making accurate medical information relevant and understandable to all while promoting standards of care that are proven to work. We believe that integrating prevention with treatment helps reduce emergency healthcare visits, keep children in school and adults at work, and allow participation in sports and other activities of daily life.



PROGRAM HIGHLIGHTS

UNDERSTANDING ATOPIC DERMATITIS GUIDE

Atopic dermatitis is a lifelong condition that involves skin symptoms, often when you least expect them. Get to know your skin – from the inside out – with our comprehensive guide. It addresses diagnosis, symptoms, treatment, and prevention and details the latest innovative medications that can help keep severe atopic dermatitis in check.

ALTOGETHER ECZEMA AWARENESS CAMPAIGN

A microsite (altogethereczema.org) launched by GlobalSkin to allow the global eczema and atopic dermatitis community to directly share experiences of life with eczema or AD; interact with content and features to explore key issues; and use tools to campaign for changes that will improve the lives of those living with eczema and AD.

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ASTHMA AND ALLERGY FOUNDATION OF AMERICA (AAFA)



Asthma and Allergy Foundation of America

OUR MISSION

To save lives and reduce the burden of disease for people with asthma and atopic diseases through support, advocacy, education, and research.

Founded in 1953, the Asthma and Allergy Foundation of America (AAFA) is the oldest and largest asthma and allergy-focused patient advocacy organization in the world. Through our education and support programs, AAFA empowers people living with chronic conditions like eczema, asthma, and allergies to take charge of their health. Because these conditions are often connected in a progression known as the “atopic march,” AAFA provides resources and support to people and families managing these overlapping conditions. Through our advocacy initiatives, AAFA continues to fight for patient rights and advocates to bring the patient voice to policy discussions. Our patient-centered research works to elevate patient insights and improve health outcomes for people with atopic conditions.



AAFA'S ONLINE COMMUNITY FOR PATIENTS AND FAMILIES

Living with chronic diseases like eczema, asthma, and allergies can be overwhelming because they can affect many aspects of everyday life. Sometimes, it just helps to know you're not alone. AAFA's online community provides a safe and supportive place to connect with others who have experienced similar challenges in living with these conditions.

Our online community offers evidence-based information and expert advice, but also provides peer-to-peer support for the less visible impact of chronic conditions—such as the emotional toll and burden. It offers a platform to connect with others who understand that sometimes symptoms can make you feel defeated, helpless, anxious, or isolated.

By joining the community, you can access science-based, age-by-age, stage-by-stage support for atopic conditions. Our trained staff and volunteers monitor the online community to share resources and respond directly to questions. The community is comprised of patients and caregivers at various stages throughout the patient journey who can support and give advice regardless of wherever you happen to be in your personal journey.

We're here to help you overcome obstacles at any stage in your journey. AAFA's online community is a place for encouragement, inspiration, understanding, and support. Join us at [aafa.org/join](https://www.aafa.org/join).

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GLOBAL PARENTS FOR ECZEMA RESEARCH (GPER)



GLOBAL PARENTS FOR ECZEMA RESEARCH

OUR MISSION

To dramatically improve quality of life for children living with eczema by advancing research that fills critical knowledge gaps from the patient and family perspective.

Global Parents for Eczema Research (GPER) is an international coalition of parents of children with eczema comprised of and led by parents. GPER formed in 2015 to address the critical need for research that answers questions of importance to children and families, and was selected by the Patient-Centered Outcomes Research Institute (PCORI) for a three-year award to pursue that purpose.

GPER is uniquely focused on bringing the patient and family perspective to the research and innovation process and policy discussions – and on sharing critical research that pertains to the treatment and management of eczema with families.

GPER engages in four strategic areas: influencing research, conducting research, engaging in public policy, and sharing evidence-based information with families.



The full “Burden of Eczema on Children and Families” video can viewed at www.parentsforeczemaresearch.org

PROGRAM HIGHLIGHTS

ASSESSING AND COMMUNICATING THE BURDEN AND UNMET NEEDS OF ECZEMA

In 2019, a team of GPER parent members and researchers conducted a survey that assessed burden and unmet needs among children with moderate to severe atopic dermatitis and their families. The results have been translated into an animated video and shared via a social media campaign. Please visit www.parentsforeczemaresearch.org and share with your networks, too. Findings will also be published in a peer-reviewed journal.

PARENT INSIGHTS ON MEDICATION ADHERENCE: RATIONALE FOR CHANGING PRESCRIBED MEDICATIONS

Recognizing a gap in knowledge related to prevalence of and reasons for medication non-adherence among parents of children with eczema, GPER initiated a study in 2018 to examine these issues. That work was recently published in the journal *Pediatric Dermatology*. Capozza, K, Schwartz, A. Does it work and is it safe? Parents’ perspectives on adherence to medication for atopic dermatitis. *Pediatr Dermatol*. 2019; 00: 1–4. <https://doi.org/10.1111/pde.13991>

CONTACT US

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INTERNATIONAL TOPICAL STEROID AWARENESS NETWORK (ITSAN)



OUR MISSION

To raise awareness about Topical Steroid Withdrawal Syndrome (TSW) (also known as Red Skin Syndrome (RSS), or Topical Steroid Addiction (TSA)) and to support affected individuals.

ITSAN is the only non-profit serving the global TSW community as a resource for the individual, the caregiver, and the healthcare provider. From its origin as a small support group, ITSAN has evolved into a vast network of thousands of RSS sufferers around the world who comfort, share, and encourage one another. Today ITSAN conducts outreach and member engagement through webinars, newsletters, social media, and moderated online support groups. We also participate in numerous national and international coalitions and advocacy initiatives to advance our mission.

TSW Syndrome is a debilitating condition that can arise from the use of topical corticosteroids to treat a skin problem, such as eczema.

Characterized by red, itchy, burning skin that can appear after ceasing topical steroid treatments, or even between treatments. The original problem escalates as it spreads to new areas of the body. This “progression” is often mistaken for worsening eczema. Treatment becomes less effective, even with increased potency and strict adherence.

RSS is an iatrogenic condition, which means it is a condition caused inadvertently by a medical treatment. Not everyone who uses topical corticosteroids will develop TSW syndrome.

Symptoms: Inflamed skin, constant itching, stinging, burning, edema, lymphadenopathy, altered thermoregulation, hair loss, insomnia, profound limitations on mobility, and relentless skin desquamation. Symptoms are severe and protracted, often lasting months to years.

More than skin deep: The sufferer may also endure depression, anxiety, job loss, financial burdens, delays in education or other life plans, and changes in family dynamics or romantic relationships.

CONTACT US

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Facebook: @InternationalTopicalSteroidAddictionNetworkitsan/
Facebook Support group: @groups/ITSANSupport/

LOOKING AHEAD:

ITSAN is a small non-profit with very big plans!

- TSW Awareness Campaign: Plans include regional informational sessions for the medical community, highlighting diagnostic criteria for TSW vs. eczema, non-steroidal treatment options, and patient data collected by ITSAN.
- Patient registry: In support of research efforts and making the first estimate of TSW prevalence.
- Physician registry: Connecting our patients with doctors who understand how to diagnose and treat TSW is a top priority.

NATIONAL ECZEMA ASSOCIATION (NEA)



NATIONAL
Eczema
ASSOCIATION



Research



Support



Education



Advocacy



Awareness

We're here because you're here. We are the voice, the resource, and the hub for the more than 30 million Americans and their families who are living with all forms of eczema.

The National Eczema Association (NEA) is a non-profit, 501(c)(3) organization with a mission to improve the health and quality of life for individuals with eczema through research, support, and education.

This means that day in and day out, NEA provides people with eczema the information they need to best manage their condition, while fast-tracking research towards better treatments and a cure.

NEA has an aggressive strategic plan with the goal of improving the health and well-being of people with eczema. NEA's strategic plan promises the following key impacts:

- Eczema will be better understood as the serious disease it is – driven by expanded research and the contributions of empowered community members.
- Patients will increasingly be active partners in their own care.
- People with eczema will be more connected to the community and the support they need and deserve.
- NEA's commitment to people living with eczema will improve lives.

IT'S A BIG CHALLENGE,
BUT WE'VE GOT MILLIONS ON OUR SIDE.



NATIONAL
Eczema
ASSOCIATION

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INVITING YOUR ACTIVE PARTICIPATION!

We invite all participants with experience living with eczema – as a person diagnosed with eczema or as someone who cares for or about someone diagnosed with eczema – to contribute your views and perspectives to today's dialogue. Each panel session will be followed by a moderated discussion to build on topics that panel speakers introduce. **The meeting format is specifically designed to engage as broad an array of experiences and perspectives as possible.** If you are not a person with lived experience, we encourage you to be in attentive listening mode throughout the meeting.

Use this worksheet to make notes about statements that resonate with you, ways in which your experience might be different from one described by a panelist, subtleties that you feel are overlooked about ways eczema affects your life or the lives of those around you, treatment experiences you have had – good and bad – and what you hope the next era of research and development will lead to for more and better treatment options.

**Your active participation will enrich the dialogue
and ensure the success of the More Than Skin Deep initiative!**

SESSION 1: SYMPTOMS AND DAILY IMPACTS

WHAT I HEARD	WHAT I'D LIKE TO ADD

SESSION 2: CURRENT AND FUTURE APPROACHES TO TREATMENTS

WHAT I HEARD	WHAT I'D LIKE TO ADD