



# UNDERSTANDING THE LIVED EXPERIENCE OF ECZEMA

Overview of the “Voice of the Patient” Report on the Eczema Patient-Focused Drug Development Meeting

On September 23, 2019, hundreds of members of the eczema community gathered in person and by live webcast to share their experiences at the **More Than Skin Deep** patient-focused drug development (PFDD) meeting held in Silver Spring, MD. This meeting and a contemporaneous web-based survey was the first initiative of its kind for eczema. It was hosted by five organizations serving the eczema community (Allergy & Asthma Network, Asthma and Allergy Foundation of America, Global Parents for Eczema Research, International Topical Steroid Awareness Network, and National Eczema Association) in collaboration with the U.S. Food and Drug Administration (FDA).

The meeting and survey addressed the burdens of symptoms and impacts of eczema, as well as ways in which individuals were treating and managing eczema. The 100-page report – available as a free download – compiles the important learnings from both sources. It features survey and live polling data and direct quotations from adults and teens with eczema, parents of children with eczema, and spouses and other family caregivers.

**The burden of itch went far beyond a simple sensation. It contributes to long-lasting physical, mental, emotional, social, and financial tolls on the individual and family.**

the second-place symptom, “red, inflamed skin.” The torturous effects of itch echoed throughout the meeting, appearing 143 times in the transcript; itch was mentioned 629 times in open text survey responses. The burden of itch went far beyond a simple sensation. It was described as contributing to skin damage and physical harm, shame, difficulty with mood and attention,

The report reflects a broad range of experiences offered by 160 participants who attended in person, hundreds more who contributed via the live webcast, and 1,508 individuals from the U.S. and 57 other countries who completed the 32-item survey.

## HEAVY BURDENS

Across all methods of gathering perspectives, itch was identified as the most problematic symptom; 79% of survey respondents placed it in their top three; it received more than twice the number of votes in live polling compared to

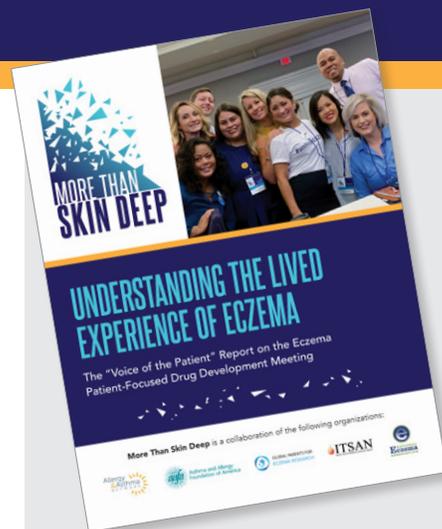
negative effects on social and intimate relationships, poor school and work performance, negative self-image, depression, and anxiety.

The effect of eczema on the condition and appearance of the skin was the second-most burdensome symptom, also leading to numerous negative impacts on daily life including discomfort and pain, low mood, poor self-image, and lack of confidence.

Each of the panelists who spoke at the meeting displayed photos documenting severe damage caused by eczema to the body's largest organ; many of their photos are included in the report.

Sleep was badly disrupted among children and adults with eczema, as well as parents of children with eczema. Depression, frequent infections, and co-occurring atopic conditions were other burdensome aspects of eczema that levied heavy physical, mental, emotional, social, and financial impacts.

One of the clear findings emerging from this initiative is the extent to which parents of children with eczema are personally affected by their child's condition and the care it requires. Personal accounts offered at the meeting illustrated their intertwined experiences and survey data provided quantified evidence. Responses to a question about the global impact of eczema over the past month from adult eczema patients and caregivers of children showed an identical response pattern. Extreme feelings of helplessness, guilt, anxiety, and depression; strains on marital, family, and interpersonal relationships; and negative influences on work performance, career attainment, and family dynamics were among the many ways in which parents reported their own lives were affected by eczema.



Download the comprehensive “Voice of the Patient” report at [bit.ly/eczema-report](https://bit.ly/eczema-report)



**89%**  
of patients and caregivers  
report limited effectiveness  
of available treatments.



## CHALLENGING TREATMENT & MANAGEMENT

The burdens of treating eczema were almost as great as the burdens associated with the disease itself. Although there are numerous approaches to treating eczema, the most widely used treatment was topical corticosteroids as measured by live polling and with 97% of survey respondents reporting current (55%) or past (42%) use. Oral corticosteroids (such as prednisone) was the next-most-often reported treatment, with 54% reporting past use and 4% currently taking this medication (generally prescribed for short-term use only). There was relatively limited use of other systemic treatments; the first biologic therapy approved for use in treating eczema, dupilumab (or Dupixent), was reported to be used currently by 10% of survey respondents – the most of any systemic therapy (aside from prednisone). There was a wide variety of adjunctive or complementary approaches pursued, with lifestyle and dietary modifications each reported as currently used by 55% of survey respondents.

Patients and caregivers shared their approaches to treatment, describing the array of treatments considered, tried, and sometimes stopped. They spoke to difficult benefit-risk assessments they make and time-consuming regimens they follow. They also reported on harms they experienced, including from use of and the process of withdrawing from use of topical steroids. In spite of these challenges, some people reported achieving benefits from single therapies including dupilumab; from a compounded formulation of corticosteroids, antibiotics, and moisturizer known as the “Aron Regimen”; phototherapy; and/or complex customized protocols painstakingly calibrated over time through trial and error and with persistent care and attention. Overall, a vast majority – 89% – of meeting participants and survey respondents reported limited treatment effectiveness and/or harms from current therapies. Survey results show a correlation between the level of control achieved with current therapies and self-assessed disease severity; more severe patients reported less satisfactory control.

## LOOKING AHEAD

The meeting and survey underscored the large number of unmet medical needs among people affected by eczema, and both concluded with questions about attributes of the ideal therapy and experience with clinical trials. When asked about the ideal treatment benefit, “immediate and sustained relief from itch” received the greatest number of responses by polling and was selected by 51% of survey respondents. The second most-widely endorsed treatment benefit was, “increased ability to go about daily life,” with 15% of survey respondents selecting it.

At the meeting, many people expressed a desire for more targeted approaches to therapy based on biomarkers, clinical features, and/or treatment goals and a need for more evidence to inform treatment decisions, especially for children. Recognizing the key to more effective and safer therapies is research and clinical trials, there is great opportunity to engage more patients in these endeavors. Two-thirds of those who participated in the survey reported never having been asked to participate in a clinical trial; just 8% had participated in the past or were currently enrolled in a clinical trial for eczema.

The five host organizations offer their perspectives on the meeting and how they’ll incorporate the learnings in future mission-based efforts in a “Reflections” article included within the report. The **More Than Skin Deep** report will be submitted to the FDA as an evergreen resource for agency staff, life science companies, researchers, healthcare professionals, the eczema community, and the public.

**Participants described a wide array of treatments considered and tried. They spoke to difficult benefit-risk assessments, time-consuming regimens, and harms experienced – all in pursuit of relief.**

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

