



ATOPIIC ECZEMA FORUM 2019 OUTCOMES REPORT



International Alliance of
Dermatology Patient
Organizations

Milan, Italy

5 - 6 JUNE 2019

**Atopic Eczema Forum 2019:
Mobilizing the Global Community to Improve the Lives of Those
Living with Atopic Eczema**
5-6 June, 2019 | Milan, Italy

In June 2019, over 25 patient association leaders came together in Milan, Italy to continue work that began in 2018 to build a cohesive global movement on atopic eczema. The two-day forum leveraged the diverse experiences of the community attendees from around the world to identify avenues for pushing the atopic eczema agenda forward, with the aim of ultimately improving the lives of people living with the disease. The forum was structured around three components: informational and scientific presentations on atopic eczema and the policy and advocacy landscape related to the disease, group discussion on common operational and political pain-points, and brainstorming activities on the future of the atopic eczema movement.

On the first day of the meeting, presentations and discussion centered on education and capacity-building. The forum began with a presentation on the landscape of atopic eczema today—the disease’s burden and impact, the media and social media engagement on the topic, and an overview of the World Health Organization’s evolving interest in dermatological conditions. Participants then had the chance to preview the community’s 2019 World Atopic Eczema Day campaign resources, including a new logo and shareable communications toolkit. Following a scientific presentation from Australia-based Dr. John Su, the group reconvened in the afternoon for a series of capacity-building modules. These modules included resources on goal setting, key message development, and stakeholder outreach. The first day closed with two member presentations—representatives from the National Eczema Association and the Malta Eczema Society shared success stories with the group to serve as food for thought in informing future local-level community mobilization efforts.

The second day of the forum shifted the focus of conversation away from capacity-building and informational presentations and towards an engaged group conversation on the future of the atopic eczema movement. Patient leaders shared local challenges in running an effective patient organization, vetted existing policy drivers as identified through past patient community convenings, and provided their perspectives on what they would like to see the community accomplish in the next twelve months.

This outcomes document highlights those key takeaways, themes, and insights which surfaced over the two-days of conversation, along with providing an outline of a recommended path forward for the atopic eczema community over the next twelve months as informed by the group’s conversation. Ultimately, patient association leaders agreed that the atopic eczema community must align around a shared three-, five-, and seven-year vision for action underpinned by a collective set of policy and advocacy goals. The suggested workplan elements defined in this document ought to serve as the foundation for establishing and advancing that longer-term community vision.

Key Takeaways:

The negative impact of atopic eczema on patients’ mental health and quality of life is difficult to overstate.

Throughout the two days of conversations, patient leaders consistently reiterated the devastating impact that atopic eczema can have on patients’ quality of life. During the first day of conversation, participants had the chance to react to some of the key existing advocacy messages related to atopic eczema—messages related to co-morbidities, infection, immune responses, quality of life, and the economic toll atopic eczema exacts on patients. Overwhelmingly,

participants pointed to the messages around quality of life and mental health. Patient leaders expanded on the topic and pushed it further, noting that atopic eczema also negatively impacts intimate and family relationships in ways that can be damaging for both the patient and their loved ones. Participants explained that atopic eczema is “claustrophobic” in the way that intense pain and itching are unpredictable and restrict patients’ ability to fully participate in the activities of everyday life.

Young people suffering from atopic eczema deserve special attention.

Discussions during the forum revealed that patient leaders are concerned about atopic eczema’s impact on children’s educational attainment, mental health, sleep quality, and overall well-being. Attendees shared stories of children experiencing anxiety, depression, and even suicidal thoughts as a result of living with atopic eczema, and particularly emphasized the role that stigma plays in leading to poorer educational experiences for children with atopic eczema. Both teachers and student peers need to be better educated on the disease. School-based awareness programs and interventions aimed at cultivating teacher and school administration understanding of atopic eczema were identified as potentially promising initiatives.

Patients are frequently confounded by lack of- and mis-information on atopic eczema, and face barriers in obtaining timely diagnosis and treatment initiation.

Patient leaders shared personal stories of primary care physicians—and even dermatologists—being ill equipped to adequately diagnose and treat atopic eczema. Care is fragmented, and patients often face multiple appointments with several dermatologists before receiving a definitive diagnosis. This challenge is compounded by the volume of misinformation and atopic eczema “myths” presented online and in the media. There is also a sense that primary care physicians, in particular, may not take atopic eczema seriously enough.

Generating public awareness of atopic eczema, and a public recognition of the serious nature of the disease, are perennial challenges for patient associations of all sizes.

Participants shared frustrations that the public thinks of atopic eczema as “just a skin disease.” Further, because of the stigma associated with skin conditions in general, and atopic eczema, in

“Speaking with patients one-on-one they speak eloquently about their condition. But there is an image problem with the condition itself and how people perceive that they will be perceived by others—it makes patients more reluctant to share publicly or over social media. And, the condition is discounted amongst policymakers because it’s not deadly.”- *an Atopic Eczema Forum participant*

particular, patients are often reluctant to speak up and publicly associate themselves with the disease. The repercussions of the lack of public awareness are multifold—for example, atopic eczema is not sufficiently prioritized by policymakers, leaving some treatments under- or un-available in health systems, and employers do not offer adequate sick-leave for people living with atopic eczema.

The patient association landscape is diverse and is marked by a number of newly created associations, particularly across Europe.

While some atopic eczema patient organizations in attendance have existed for over 40 years, others have just launched within the past 18 months. This highlights the recent traction that atopic eczema has gained in the public sphere—research on the topic has increased significantly in the past five years, and the patient community is beginning to mobilize as never before. For example, the Harmonized Outcomes Measures for Eczema Initiative is a multisectoral, first-of-its-kind project to develop a consensus-based core outcome set for clinical trials and clinical practice in atopic eczema. Patient leaders bring a diversity of experiences to the atopic eczema community and there is much to be gained by finding further opportunities for community interactions. Participants expressed a specific interest in ensuring that future convenings and working groups focus on bringing together representatives from newer associations as well as more established organizations.

Many patient associations, especially those that have been recently established, struggle with financial, staff, and tactical capacity constraints.

Associations of all sizes stated that while industry support is invaluable for running specific campaigns or hosting events, many still struggle to achieve long-term financial sustainability.

Further, smaller associations struggle to prioritize government advocacy activities because they often do not have the staff capacity to devote towards policy work. It can also be difficult to engage with patient volunteers because of the nature of atopic eczema—examples were shared wherein patient volunteers were unable to provide support for hosting events because of atopic eczema flares or related symptoms.

One patient association cautioned against undertaking events or other activities without consulting the local patient community first: it is critical to understand local patient needs and then build a workplan and objectives around those local realities. Finally, newer associations especially expressed a desire for robust tactical support to build internal capacity to craft advocacy messages, build web presences and online brands, and undertake community mobilization activities.

“How can we inspire parents to engage in advocacy and longer-term goals when they have more immediate concerns like taking care of their kids or finding a treatment that works?” – *an Atopic Eczema Forum Participant*

There is an appetite in the atopic eczema community for increased collaboration: with health care professionals, with industry members, with researchers, and with patient association and advocacy groups representing other related disease areas.

Several more established patient associations already partner closely with health care providers—some issue health care provider-specific newsletters providing educational information to boost awareness of atopic eczema. Other associations have created continuing medical education programs to educate physicians in primary care on atopic eczema clinical guidelines. The group agreed that health care providers represent two valuable partnership opportunities: one, an opportunity to work with health care providers to improve atopic eczema care in clinical practice; and two, to leverage the voices and credibility of medical professional societies to help advance conversations with governments and policymakers. One participant noted that their association is in the process of developing an advisory board, led by patients and caregivers and involving medical professional organizations from all disciplines related to atopic eczema (including disciplines such as nutrition and psychology). Participants also concurred that partnerships with other disease areas of relevance to atopic eczema could be a useful approach for generating momentum and gaining traction with policymakers—they pointed to existing relationships with asthma and allergy organizations as a promising starting point, and suggested expanding collaboration considerations to organizations focusing on type 2 inflammatory and immune conditions.

While patient leaders are thrilled with recent innovations in atopic eczema treatment, they see access barriers and would also like a louder patient voice all along the innovation pipeline, from clinical trials to discussions on incorporating new treatments in clinical guidelines.

Across the room at the forum, it was clear that patient access to treatments and therapies is

“Now is a time of unprecedented innovation in the atopic eczema space. However, innovation without access breeds frustration. As a community, we have a lot of hope surrounding innovation, but we need to get those things to the right patients at the right time.” – *an Atopic Eczema Forum participant*

uneven—participants gave examples of challenges related to reimbursements for new treatments. One representative shared a story of influencing the government to now include one of these new treatments within national insurance schemes, a true bright spot for the community demonstrating that advocacy efforts aimed to securing treatment access can enjoy success. Participants noted that patients ought to be more involved in shaping clinical trials

for new atopic eczema therapies, and that governments should provide resources to patient groups

to enable their enhanced participation in policymaking circles and in conversations on national clinical guideline development for atopic eczema.

Patient leaders are eager for more and better data and evidence around atopic eczema to improve treatment options for patients, better coordinate care models, and equip advocates with the proof-points necessary to influence health system stakeholders, policymakers, and the general public.

The forum’s scientific presenter frequently spoke to the lack of concrete evidence on specific associations between atopic eczema and other conditions, along with a lack of clarity on the efficacy of different treatment approaches. This is a frustrating care landscape for patients to navigate, and they often rely on patient associations to translate the complexity of scientific evidence on atopic eczema into concrete guidance. Unfortunately, the lack of a robust and longitudinal evidence-base means that absolute guidance is difficult to come by. From an advocacy perspective, there are several patient organizations taking the lead to gather the necessary evidence. However, there are still significant gaps leaving patient leaders particularly hungry for two types of data: one, proof-points demonstrating the economic impact of atopic eczema; and, two, quantitative data-sets detailing the burden that atopic eczema places on patients in terms of out-of-pocket costs, and, crucially, quality of life and well-being. Patient leader participants were almost universally willing to spearhead data-collection efforts in their local markets aimed at surveying atopic eczema patient experiences and perspectives.

Charting a Path Forward:

In looking ahead to the future of the atopic eczema movement, patient association leaders agreed that the community must define long-term strategic goals, potentially at a three-, five-, and seven-year interval. The group also validated three central global challenges for atopic eczema care, along with a related three policy drivers. These priorities were identified through previous community consultations led by GlobalSkin, and the group indicated that they remain relevant and top-of-mind:

Identified Challenges & Policy Drivers

Challenges



Atopic eczema is widely misunderstood



Patients experience difficulties in accessing timely and appropriate care



Patients experience difficulties in accessing treatments

Policy Interventions



Empower patients



Quantifying impact through evidence



Policy positions

In group discussions on community workplan priorities, recommendations covered two types of activities: *strategic initiatives* related to the further development of a set of community advocacy objectives and *operational initiatives* related to boosting the everyday capacity of atopic eczema patient organizations. And, crucially, the group agreed that the future successes of the community—both strategic and operational—will rely on the development of further opportunities for ongoing interactions between patient groups and the fostering of a true community identity for the atopic eczema movement.

Strategic Initiatives

The group agreed to the development of an advisory group, comprising representatives from both new and established groups, and ideally maintaining some representation from patient leaders who previously served on the Steering Committee, to drive the community's strategic planning efforts forward over the next twelve months. Further, forum participants suggested that the advisory group endeavor to include representation from at least one researcher and one policy expert. The advisory group would be responsible for taking forward the workplan's strategic priority elements. While forum participants identified several items for potential inclusion in the advisory group's scope, the list would likely require prioritization to maintain feasibility:

- ❖ Official group consensus on strategic priorities for the atopic eczema movement, as indicatively developed by the advisory group. This effort ultimately must be paired with an operational plan, informed by those policy drivers validated by the group at the atopic eczema forum—patient empowerment, position papers, and quantifying impact through evidence.
- ❖ Exploration of opportunities to collaborate across disease areas to advance political action. Allergy and asthma groups have historically been allies for the atopic eczema community, and there is new enthusiasm for exploring engagement with patient groups related to immune dysregulation, type 2 inflammatory conditions, or common atopic eczema co-morbidities.
- ❖ Identification of globally relevant proof-points on atopic eczema to unify advocacy messages with the aim of raising awareness. While the core policy priorities underpinning the messages ought to be universal, local associations will have the opportunity to adapt the messages and proof-points for ultimate relevance within local communities. One idea involved the development of a global patient survey to be designed centrally and implemented locally. This could take different forms: the group discussed the production of a white paper utilizing data collected by each local group or the development of an international study capturing patient and public perceptions of atopic eczema. Forum participants stated that the research effort could be straightforward—the development of three questions on the burden of disease.
- ❖ Either global or local initiatives to identify atopic eczema champions, particularly within clinical and policy communities. Participants stated that the cultivation of health care provider champions, for both global and local advocacy efforts, will be especially critical.

Operational Initiatives

The group also aligned around a number of operational elements that they would like to see realized through a tactical community workplan over the next several months. Resoundingly, the patient association leaders called for a community platform to continue and enhance interactions amongst leaders of the atopic eczema community. Ideally, the platform would both house capacity-building resources along with providing a forum for real-time group and one-on-one interactions among the patient association community. The group identified the following specific deliverables related to the day-to-day operations of the patient association community:

- ❖ Facilitation of further and more meaningful interactions between patient association leaders. Forum participants noted that tools like quarterly calls, online forums, newsletters, and “speed dating” type events to connect patient associations for one-on-one conversations. It was suggested that an online forum could provide a venue for quarterly webinar convenings wherein members are selected to share “bright spots” and best practices to catalyze cross-fertilization of successful community mobilization initiatives.

- ❖ Development of “marketing” materials on common atopic eczema co-morbidities. This is an example of the type of resource where GlobalSkin could facilitate the provision of globally relevant proof-points and messages, and then local associations could augment the materials with national-level statistics and economic arguments.
- ❖ Dissemination of toolkits, best practices, and “how-to” guides on various topics in community mobilization and advocacy. Patient associations, especially those associations that were recently established, expressed a strong interest in further tactical support and guidance. Specific requests included: advocacy collateral, especially videos and photo libraries, case studies, and resources and tools that are specifically tailored for interventions such as school-based awareness initiatives and meetings with government officials. Other patient associations are also interested in “public relations”-type support, wherein an online resource provides recommendations on topics such as branding, online presence, and social media campaign management.
- ❖ Centralized leadership in undertaking outreach to potential global partners such as the International Eczema Council. The International Eczema Council represents a promising partner for future research efforts, as the Council has a global footprint and are focused heavily on research. Patient leaders expressed an interest in identifying ways to collaborate with the Council in the future.



STRATEGIC INITIATIVES

Composition & launch of an advisory group tasked with defining the community’s long-term ambitions

Group consensus on strategic priorities for the movement

Exploration of opportunities to collaborate across disease areas to advance political action

Identification of globally relevant proof-points on atopic eczema to unify advocacy messages, including perception survey

Either global or local initiatives to identify atopic eczema champions, particularly within the clinical and policy communities



OPERATIONAL INITIATIVES

Facilitation of further and more meaningful interactions between patient association leaders: quarterly calls, online forums, newsletters, shared online resources

Development of “marketing” materials on common atopic eczema co-morbidities

Dissemination of toolkits, best practices, and “how-to” guides on various topics in community mobilization and advocacy

Centralized leadership in undertaking outreach to the International Eczema Council

Next Steps:

In recognition of the value of convening as a community for two days of networking and conversations, the group prioritized the following action items:

- The development of a virtual community forum to facilitate ongoing relationship-building and knowledge-sharing among members of the atopic eczema movement worldwide. Immediate next steps for this effort include: the distribution of a community survey, gauging patient leader interest in different types of online engagement options. Based on community feedback and research, GlobalSkin will launch an online community platform.

- World Atopic Eczema Day on 14 September will be the next major milestone for the atopic eczema community. Patient leaders are encouraged to leverage the [Patient Association Communications Toolkit](#), developed in partnership between GlobalSkin and the European Federation of Allergy and Airways Diseases Patients' Associations, to guide and inform their World Atopic Eczema Day campaign efforts.
- Community Strategy – Significant progress was made at the Forum in identifying shared challenges and opportunities for the global atopic eczema community. An Advisory Committee – comprising a diverse set of patient leaders representing patient groups with various levels of maturity – is being established to clearly define a set of measurable short- and long-term objectives for the atopic eczema community. The Advisory Committee will also oversee the development of a community workplan aimed at executing against the established strategic and policy goals identified by forum participants.

Endnote

We gratefully acknowledge and thank our industry partners for their support of the Atopic Eczema Forum: AbbVie, LEO Pharma, Pfizer and Sanofi Genzyme Regeneron. Thanks as well to in-kind supporter Signify Digital Agency.

Appendix A

Atopic Eczema Forum 2019 Patient Organization Participants			
First	Last	Organization	Country
Kelly	Barta	ITSAN	United States
Julie	Block	National Eczema Association	United States
Shulamit	Burstein	The Israeli Association for Atopic Dermatitis	Israel
Lisa	Butler	National Eczema Association	United States
Joana	Camilo	ADERMAP	Portugal
Helen	Crawford	Canadian Skin Patient Alliance	Canada
Amanda	Cresswell-Melville	Eczema Society of Canada	Canada
Kristin	Grossouw	Dutch Association for People with Atopic Dermatitis	Netherlands
Erhard	Hackler	Deutsche Haut- und Allergiehilfe e.V.	Germany
Karin	Hafner	Haut Info	Austria
Paul	Herriott	Irish Skin Foundation	Ireland
Henrique	Ishii	AADA	Brazil
Africa	Luca de Tena	AADA	Spain
Tina	Mesaric (Dr.)	Zavod Atopika	Slovenia
Olesya	Mishina	Skin and Allergic Diseases	Russian Federation
Lynda	Mitchell	Global Parents for Eczema Research	United States
Spela	Novak	Drusto Za Pomoc Osebam Z Atopijskim Dermatitidom	Slovenia
Susanna	Palkonen	European Federation of Allergy and Airways Diseases Patients' Associations	Belgium
Sandra	Plowright	Eczema Association of Australasia	Australia
Josef	Pohunek	Psoriatic and Atopic Eczema Association	Czech Republic
Christine	Roxburgh	Eczema Outreach Support	United Kingdom
Povilas	Sid	Atopinio Dermatito Pacientų Asociacija	Lithuania
Snezana	Sundic-Vardic	Allergy and Me	Serbia
Cheryl	Talent	Eczema Association of Australasia	Australia
Tonya	Winders	Allergy and Asthma Network	United States
Maggie	Young	Allergy UK	United Kingdom
Melissa	Zarb	Malta Eczema Society	Malta