



# Policy Drivers in Atopic Eczema: Patient Leader Dialogue Report 2018

*Atopic Eczema patient organization leaders from eight countries worked together in defining the three most impactful policy drivers needed to establish atopic eczema as a priority amongst healthcare decision-makers.*



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International Alliance of  
Dermatology Patient  
Organizations

## Executive Summary

Atopic Eczema patient organization leaders from eight countries worked together in defining the three most impactful policy drivers needed to establish atopic eczema as a priority amongst healthcare decision-makers:

1. Empowering patients and patient organizations
2. Quantifying impact of disease
3. Developing position papers on key topics.

## Background

International Alliance of Dermatological Patient Organizations (IADPO, also known as GlobalSkin) hosted a Patient Leader Dialogue Workshop on atopic eczema on September 13, 2018 in Paris, France. Moderated by Christine Janus, GlobalSkin's CEO, the workshop was attended by patient advocates and leaders of patient organizations who work to support patients suffering from eczema and atopic dermatitis around the world. The goal of the workshop was to look at challenges and recommend policy drivers that could positively influence the prioritization of atopic eczema among healthcare decision-makers. A list of participants is provided at the end of this report. This published paper is a result of the dialogue that took place during that workshop.

## Approach

To determine the most effective policy drivers, participants first needed to examine the challenges and impediments that currently exist for this disease, including perceived barriers to the adoption of policies that could support improved access to care and treatment. Following that discussion, three key policy drivers were identified that could assist in prioritizing atopic eczema among healthcare decision-makers.

Participants identified and discussed the current challenges in supporting patients with atopic eczema, past successes they have had in working with decision-makers and approaches for a way forward. While participants raised many challenges in driving policy for patients with atopic eczema, the main themes that emerged from the discussions were:

- Atopic eczema is widely misunderstood
- Difficulties in accessing timely and appropriate care
- Difficulties in accessing treatments

## Challenges

### **Atopic eczema is widely misunderstood**

The perception amongst the public and decision-makers is that atopic eczema is *not* a serious chronic skin disease but *rather* “just a rash”. Unfortunately, the reality is that dermatology in general is not a policy priority for most governments, particularly when compared to heart disease and stroke or cancer – all of which are considered priority diseases.

In some corners, the disease is considered merely a “childhood condition” and it is erroneously believed that it will resolve in early adulthood. Sadly, this is not the case for at least 50% of the atopic eczema population. This creates a gap in care, leaving patients underserved. To remedy this situation, atopic



eczema needs to be recognized as a serious medical condition that is in fact extremely heterogenous.

Raising awareness of the true impact of atopic eczema is key. To do so, it is important to engage and inspire patients and caregivers to tell their stories. There are several challenges in doing so, however. Firstly, they need help in overcoming the dual impact of both stigmatization and minimization of atopic eczema (and skin diseases in general), which keeps many sufferers from speaking out. Also, their daily treatment regimes are often onerous, and parents of young children are frequently sleep-deprived and exhausted, and the psychosocial effects can be overwhelming. And finally, those who are grappling with the disease may believe that no one is interested in their suffering.

Patient organizations are an essential support in making it possible, and even desirable, to affect basic 'word of mouth' awareness-raising, as well as inspire willingness among patients and caregivers to stand up and share their stories with decision-makers.

### **Difficulties in accessing timely and appropriate care**

Patients globally are looking for and deserve proper care. Patients, caregivers and patient leaders report insufficient access to dermatological care. Participants from every country represented agreed that there is an ongoing shortage of trained healthcare professionals who can provide up-to-date dermatological care for their patients. This includes all healthcare providers: general practitioners, nurse practitioners, and even many dermatologists.

It would seem that there is also a shortage of skilled primary health care professionals with enough knowledge of dermatology which results in poor access to timely diagnosis and ineffective care and management. In some countries, primary-care physicians receive only one week of dermatology training during their entire family-practice residency. Difficulty in accessing appropriate care is further exacerbated by a shortage of trained dermatology specialists. Because of significant ongoing advances in the understanding of the disease, there is also a critical need for many current dermatologists to receive ongoing training on atopic eczema so that they can stay up-to-date as they diagnose the disease and provide treatment options.

### **Difficulties accessing treatments**

Participants indicated that there is a need for equal and fair access to treatments and therapies for atopic eczema patients across all world regions. In some regions, there is a lack of access to medications; in others there are challenges related to reimbursements for new treatments. Some healthcare systems have been known to impede timely treatment by demanding that all patients follow a stepped access to treatment protocol, even though in some cases their doctors know that the basic levels of treatment will not alleviate their symptoms. This effectively takes the treatment prescribing decision out of the hands of physicians working directly with patients and, gives it to bureaucrats.

## Policy drivers and interventions

### The Goal: Making atopic eczema a priority among healthcare decision-makers.

Influencing decision-makers to change, update and develop policy related to healthcare for patients is an ongoing challenge for patient advocates and specifically, the atopic eczema community. Participants outlined many ways in which they currently engage with policy-makers in their regions and while some tactics are more successful than others the end goal has been the same: to improve the lives of patients suffering with this disease.

In order to drive change amongst decision-makers, the following three priority policy drivers emerged from the discussion:

### 1. Empowering Patients

Sharing information and tools with skin patients to help them engage with healthcare professionals, provide support as they live with their disease, and the acknowledgement that they are not alone in their journey are just a few of the approaches that are currently being undertaken to empower patients. Additional opportunities also exist in the following areas:

- Engage in public awareness/information campaigns – locally and regionally to alter current misconceptions that exist about atopic eczema.
  - Patient organizations are already working to educate decision-makers, physicians, nurses, patients and the general public on the impact of atopic eczema on patients and their families through targeted awareness and education programs. These programs are definitely helping, but much more is needed.
  - Utilizing the media to circulate information to address the public misperceptions of atopic eczema is one tactic that has proven effective and inexpensive.
  - Develop and share consistent messaging across countries which can assist in changing the perception of the disease locally and globally.
  - Engage in grassroots advocacy to raise awareness and influence policy decisions.
- Strengthen patient organizations so they may provide key support to patients and caregivers to fill the gaps in patient care left unaddressed by medical systems.
  - Patient organizations are an essential support in making it possible, and even desirable to affect basic ‘word of mouth’ awareness-raising as well as inspire willingness among patients and caregivers to stand up and share their stories with decision-makers.
  - IADPO is building its capacity to play a bigger role in supporting atopic eczema patient organizations, not only in advocacy but also in skills development, resource sharing, networking and collaboration.
  - As medical systems currently fall short, there is a critical need for developing mechanisms to support both the patient and their caregivers (families) at home, the workplace and at school. Patient organizations are often tapped to take on these roles, despite inadequate funding and support for these functions. If the gaps that are being filled by these patient organizations were quantified, local governments could better understand the value they provide.
  - Patient organizations can support patients by providing doctor mapping – locating where patients can find dermatologists and doctors who have expertise in treating atopic eczema.

- In some cases, patient organizations are working with dermatologists and other healthcare professionals to create reports that can be presented directly to decision-makers.
- Global campaigns can be built by patient organizations collectively to present a united voice, to achieve better awareness for atopic eczema and thereby influence the policy agenda.
  - By building on existing country-specific campaigns and sharing that information globally, or creating a cohesive new campaign, there is an opportunity to create consistent messaging for the atopic eczema patient movement.
  - There is currently no global atopic eczema patient Bill of Rights. Creating this Bill of Rights with patients and building a global campaign around it could drive attention to the disease and empower patients themselves to speak up for timely and appropriate treatment; access to care; safe school and work environments; and the right to work or school settings free of discrimination.
  - Building on World Atopic Eczema Day for 2019, encourage the sharing of patient stories and sharing data. Use of the AltogetherEczema.org platform to gather issues and then use them to inform global and regional campaigns is a means to calibrate and consolidate messaging for use in multiple fora.
  - By leveraging relationships with other stakeholders – notably researchers, dermatologists, nurses and primary care physicians – to speak with a unified global voice that atopic dermatitis profoundly affects lives, patient organizations can amplify these key messages to policy makers.

## 2. Quantifying Impact through Evidence

Data is a key input in the rubrics of decision-makers in any field. Patient organizations that have access to or collect relevant data about patients and/or their disease are able to make a much more compelling case as they are able to speak the relevant “language”. Research that can provide data in the following areas will help quantify the impact of atopic eczema on the patient, their family and society and empower patient organizations to bring a compelling message to decision-makers:

- Health Economics
  - Relative costs of care and treatment
  - Economic implications (e.g. absenteeism, presenteeism, and other costs of inadequate or non-treatment)
- Prevalence
  - Demonstrate that the disease is not just a “childhood disease” and has long-term symptoms and quality of life impact for many patients
  - Country-specific data along with global data to illustrate who the disease affects
- Impact on Patients

Demonstrating the impact of the disease quantitatively and qualitatively on patients is key to moving the yardstick with decision-makers. The key is to engage patients to involve them in research, to share stories and to help validate how serious this skin disease is to them and how it affects their daily lives.

- Impact research from the patient perspective (e.g. Global Research on the Impact of Dermatological Diseases)
  - Utilizing data from quality-of-life surveys – like the research done by the Eczema Society of Canada or the one by the European Federation of Allergy and Airways Diseases Patients’ Associations (EFA) – can inform educational and advocacy campaigns surveys undertaken to showcase the ongoing challenges of patients and caregivers
  - Conducting practical research on diagnosis and treatment options can show where there are gaps in treatment options, and draw attention for policy makers to areas critically needing attention
  - Research into the psychological effects experienced by the patient and/or the family are needed to illustrate the impact that atopic eczema has beyond the skin
  - Establishing a credible evidence base through a collaborative research agenda one that is responsive to the needs of patients and their families
  - Research on the comorbidities associated with atopic eczema, asthma, allergies, allergic rhinitis, cardiovascular disease, and possibly others is needed.
- Documentary Evidence: Pictures, videos and stories illustrating skin diseases can make a big impression on policy makers. While some decision-makers claim they will not allow themselves to be swayed by stories or pictures of obvious pain and misery, and some even suggest that they will only respond to data, qualitative information can play a key role in bringing out the atopic eczema message.

### 3. Position Papers

The development of coordinated Position Papers built on patient organization consensus can drive policy change. Collecting knowledge and experience locally, regionally and across countries creates a globally unified voice for patients. Employing this united voice when approaching global healthcare decision-makers is invaluable. Empowering them to inform local or regional decision-makers can be equally helpful.

Some topics that the group felt might impact patient access to care and treatment include:

- Expanding Healthcare Professional Training  
Patients would receive better care if healthcare professionals, including general practitioners and nurses had more training in, and therefore better knowledge and understanding of, the most prevalent dermatological diseases, including atopic eczema.
  - Additional training for healthcare practitioners would ensure patients are receiving at least some level of primary treatment while they wait to see a specialist. Because of shortages, wait times can exceed a year.
  - Knowledgeable primary healthcare professionals can also direct where the patient might more quickly seek secondary and tertiary care for treatment of this disease. Patients with dermatological conditions have the same right to up-to-date care, as do the other patients in their jurisdictions with other types of diseases.
  - Patient organizations are working with their local doctors, colleges of physicians, nurses and researchers to support various kinds of education for healthcare providers so that they can be better educated in dermatological care related to atopic eczema. Training

that provides accreditation/certification is being offered in a number of countries. Most patient organizations, however, don't have the resources to be providing training programs; so, in those countries where there is a lack of updated atopic eczema knowledge amongst healthcare providers, patients and their families pay the price.

- Increasing Number of Specialists

In order to drive policy on this issue, it would seem that a coordinated campaign potentially led by dermatology and family practice professional associations, with input from patient organizations, could speak to the importance of:

- Increasing dermatological training base levels in medical schools and residency programs at a local level, and/or
- Creating or building upon existing credit courses on dermatological diseases – like atopic eczema, psoriasis, vitiligo and alopecia areata – where new scientific findings are changing treatment paradigms.

- Establishing Best Practices and Treatment Guidelines

There is a lack of consensus globally on best practices and treatment guidelines for atopic eczema.

- There are currently no globally-accepted guidelines for treatment approaches for any of the populations affected by atopic eczema.
- Guidelines are critically needed because the standard of care varies not just from country to country, but from one doctor's office to another – an obvious manifestation of there being no consensus on care.
- Because there have been significant advances in the medical understanding of atopic eczema and subsequently new treatment, patient care needs to change to adapt to this new knowledge.
- Global clinical guidelines could help usher in new understanding for physicians who are not able to attend dermatology conferences for the latest updates
- The development and distribution of clinical guidelines is also a tactic that can raise awareness, not only within the medical community, but can show policy makers that knowledgeable physicians/researchers see the need for a different treatment protocol than what has existed in the past.
- Given the proliferation of treatment guidelines for a great many diseases, it would seem that the documentation of accepted standards of care would also act as validation of the importance of the disease.

- Healthcare Professional Coordination

There is a lack of coordinated care among family physicians and specialists – all of whom may make up the care team for the atopic eczema patient.

- Given the link between atopic eczema, asthma and allergy and the growing understanding that patients often have additional comorbidities and concomitant conditions, care delivered in silos hampers optimal care for patients. Coordination is critically needed in these cases between specialties like dermatologists and allergists.
- Participants indicated that their members are increasingly embracing and stating a preference for a holistic treatment of the patient and the family.
- Coordinated communication is needed between physicians and pharmacists filling

prescriptions. Too frequently, patients or parents of children with atopic eczema, who are already struggling with the physical and psycho-social issues that the disease brings, are left trying to communicate information from one care provider to the next, adding stress and complexity to lives that are already overwhelmed.

- Policy makers are already receiving the call from the entire spectrum of diseases to improve communication across specialities, form cross-specialty working groups and put the patient at the centre of the system – rather than force the patients to try and navigate unwieldy systems. By bringing the needs of atopic eczema patients to this dialogue via a position paper, this ensures that atopic eczema is represented, and patients’ unique needs are taken into consideration.

## Conclusions

Patient advocates and patient organizations are tirelessly working to support patients with atopic eczema, and they continue to encounter a wide range of challenges as identified in the workshop. There is much complexity behind the issues that were raised, and that complexity is more fully revealed as one considers the differences in medical systems, geographical challenges and a very wide range of socio-economic conditions. This disease continues to be greatly misunderstood – not only across the healthcare spectrum, and among healthcare professionals, but also by the general public and even amongst patients themselves. Atopic eczema, like most skin diseases, suffers from inattention from policy-makers because it is perceived as “just a skin disease” despite widely available research data to the contrary. Patients deserve access to current, modern and up-to-date care along with unfettered access to the appropriate treatment and therapies.

While the challenges outlined are not new to patient advocates, they universally appreciate opportunities to share with and educate others about the challenges that patients face daily. Evolving policy is rarely easy, but the challenges presented can also be viewed as opportunities. Bringing together patient leaders within the atopic eczema community for this dialogue session is considered an important step in addressing these opportunities.

To bring about meaningful change in the policy environment that addresses the needs of those living with atopic eczema, it would seem the pervasive dismissive attitude towards skin diseases in general needs to evolve. Patient organization leaders pointed to empowering patients and patient organizations, quantifying impact of disease and the development of position papers on key topics, as drivers that could contribute towards the goal of making atopic eczema a priority amongst healthcare decision-makers.

## Endnote

GlobalSkin is actively engaged in growing the global atopic eczema community and working to bring together patient organizations to create a global voice for atopic eczema patients worldwide. As part of this work, GlobalSkin launched World Atopic Eczema day in September 2018, as well as an issues-based website for the global community found at [AltogetherEczema.org](http://AltogetherEczema.org). In June 2019, GlobalSkin plans to host a Forum for leaders from atopic eczema support and advocacy organizations from around the world in Milan, Italy, to develop a strategic plan to drive positive policy development and awareness-raising both at the national and global levels.



We wish to express gratitude to the very engaged patient organization leaders (listed below) who shared their knowledge and experience and to LEO Pharma for providing an educational grant to cover the costs associated with this highly informative session.

Attendees (listed in alphabetical order by organization):

- Carla Jones, Allergy UK
- Stephanie Merhand, Association Française de l'Eczéma
- Erhard Hackler - Deutsche Haut-und Allergiehilfe e. V. (German Skin and Allergy Association)
- Cheryl Talent, Eczema Association of Australasia
- Amanda Cresswell-Melville, Eczema Society of Canada
- Korey Capozza, Global Parents for Eczema Research
- David McMahon, Irish Skin Foundation
- Alice Visintin – National Association of Atopic Dermatitis (ANDeA) (Italy)
- Julie Block, National Eczema Association (USA)

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