

Atopic Dermatitis: A Collective Global Voice for Improving Care

Working in a coordinated, strategic manner—via an alliance of patient organizations, together with key stakeholders—will provide the best chance of bringing about positive change for eczema.

BY CHRISTINE JANUS

Atopic dermatitis (AD) is the most common form of eczema. It is currently an incurable, chronic immune-mediated systemic disease with a debilitating effect on individuals and families worldwide. Atopic dermatitis is more than “just a skin condition.” People living with atopic dermatitis feel its effects—both on their skin (with a relentless itch, redness, swelling, and lesions) and on their well-being (linked to sleep deprivation, social isolation, anxiety, depression, and an overall reduced quality of life). Patients with inadequately controlled atopic dermatitis face the devastating and unpredictable physical and psychosocial impact of the disease, every day.

Earlier this year, the International Alliance of Dermatology Patient Organizations (IADPO, also known as GlobalSkin) published a position paper entitled “Atopic Dermatitis: A Collective Global Voice for Improving Care.” It was the result of a roundtable meeting of clinicians, researchers, and patient leaders from national and global organizations—all known to be key opinion leaders in the international AD/Eczema community—that was held in Ferney-Voltaire, France in September 2017. The roundtable was organized and hosted by GlobalSkin and supported by a joint unrestricted educational grant from Sanofi Genzyme and Regeneron.

The goals of the meeting were to discuss the issues affecting patients and the AD community; to better understand the gaps in care; to identify advocacy priorities where the community can collaborate to drive change for patients and families locally and globally; and to bring together a united, international voice to help support patients with AD.

The position paper identifies the gaps and challenges in atopic dermatitis and offers up incentive for the gathering

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of evidence and collaboration among stakeholders to positively impact quality of life for those living daily with AD. GlobalSkin believes it is important to share the results of this work with the dermatology community, including physicians who are so integral to the care of patients with this chronic disease.

A HEALTHCARE PRIORITY

Atopic dermatitis is currently not considered a priority for health systems and therefore is universally poorly resourced. This has a number of negative consequences for the quality of care for patients.

Patients with AD experience a complex range of challenges in their daily lives that go above and beyond the painful and visible manifestations of their disease. Symptoms can be extremely debilitating and difficult to control. The reasons for this vary from patient to patient and depend to some extent on the resources available to them.

Currently, accessing effective treatments is a challenge for many patients, even if those treatments are available in their country. Frequently, associated side-effects and time-consuming protocols can act as a deterrent to prescribing by the physician and adherence among patients.



Participants of the Atopic Dermatitis Roundtable meeting in September 2017.

Mental health challenges are also part of the experience for patients with moderate to severe cases of the disease. Patients face stigma in society, social isolation, and can even have a clinical diagnosis of depression and anxiety. The inability to control their disease brings an additional burden, as frustration grows over the lack of control. Personal relationships can be strained, and caregivers themselves can carry a heavy practical and psychological burden.

In general, patients with AD can have difficulty navigating their care system and are often not able to see a specialist in a timely manner, delaying treatment and optimized outcomes. Clinicians acknowledge there are often gaps in care and currently no universal agreement on management of the disease.

Sub-optimal interaction between patients and their doctors can also limit the opportunity for improved patient outcomes. A lack of self-esteem can inhibit patients' communication with their doctors, and they can often find it difficult to explain the intensity of their symptoms or the impact AD has on their sleep, ability to conduct daily activities, its long-term impact on intimacy and life choices, and their overall quality of life. Patients sometimes report that their doctors do not listen to them properly. Physicians recognize that adult patients tend to "over cope" with the disease, which also inhibits optimal conversations and access to timely and appropriate care.

Patients with AD often grapple with other associated conditions. However, they report that the healthcare professionals they see in different specialties generally do not share their medical information with each other nor collaborate and this adds to the frustration with treatment. Treatment is taking place in silos rather than holistically which may undermine patient outcomes.

In many countries, general practitioners receive very little dermatological training. This can result in inappropriate treatment, delayed referral to specialist care, and a lack of recognition of the importance of AD in healthcare provision. In addition, in many countries payment and incentive systems for physicians tend to discourage any kind of focus on skin conditions.

A SEVEN-STEP PLAN

Our Position Paper sets out the above challenges facing the AD community as well as the barriers to securing greater policy attention. These include a lack of data on the burden of disease and low public awareness. The assembled roundtable participants recommended a seven-step plan to address this challenging and disheartening picture for patients, with the goal of securing greater attention to this disease among all stakeholders and ultimately better outcomes for patients. In brief, these steps include:

1. Call for international collaboration among all stakeholders, led by patient leaders and GlobalSkin
2. Generation of credible evidence on prevalence, economic costs and impact of disease
3. A global campaign to raise awareness of the disease and its true impact
4. Empowerment of patients via improved access to information and support, as well as tools to help in consultations with their physicians
5. Improved care for patients from both family doctors and specialists so that care is holistic, accessible and includes access to psychological support
6. Sharing of best practices and guidelines to improve quality of care universally
7. Continued investment into and timely access to innovative solutions and treatments for disease control.

TOWARD BETTER OUTCOMES

This important roundtable discussion has provided insight into the challenges facing the AD patient community. There is a shortfall in resources devoted by governments to this disease; AD does not feature in any health system's priorities. There are many consequences of this: inadequate training and awareness among healthcare professionals and a lack of capacity to fully support patients who face debilitating physical and psychosocial problems. Many effective treatments currently available for AD have side effects or do not work at all; as a result, the disease is often not well-managed. Fortunately, new treatments offer hope.

Collaboration between all stakeholders in the AD community, alongside determined advocacy, and broad communication will be needed in order to ensure patients are able to achieve better outcomes in the future. GlobalSkin believes adoption of the strategies presented above will help deliver this, alongside the following key recommendations made at the roundtable meeting:

1. Potential collaboration between stakeholders in AD

- Create an alliance or formalized supported global community of national patient organizations in atopic dermatitis.
- Develop a shared strategy to address current access challenges for patients with AD.
- Advocate additional investment and research in new therapies to treat AD.
- Compile new data to evidence the value of therapeutic interventions.
- Include patients and caregivers in the development of care guidelines.
- Develop a common language for AD that both patients and physicians understand.

- Establish a global AD awareness day.
- Drive more public awareness of the condition.

2. Health system improvements that will support better care for patients with AD

- Identify obstacles in patient pathways at a national level and take steps to enable the introduction of fast-tracking of patients to specialist.
- Formulate guidelines for the organization of dermatological services that are truly patient-centric in design.

3. Clinical management of AD

- Improve training of health professionals in AD.
- Develop tools for patients that will improve communication with doctors about their signs, symptoms, and burden of disease.

4. Patient empowerment

- Establish a team of patient coaches and care navigators to enable patients to secure optimum care in their health systems.
- Provide patients with resources to support optimal interaction with the specialist.

While there are a great many challenges facing the AD community, it is clear that working in a coordinated, strategic manner—via an alliance of patient organizations, together with key stakeholders—will provide the best chance of bringing about positive change. Physicians are key partners in this journey. ■

Read the Position Paper: <https://globalskin.org/images/Publications/AtopicDermatitis.pdf>

To learn more about GlobalSkin, visit globalskin.org. GlobalSkin is leading the Global Research on the Impact of Dermatological Diseases (GRIDD) project which will produce data on atopic dermatitis and many other skin diseases: globalskin.org/GRIDD

Christine Janus is CEO of the International Alliance of Dermatology Patient Organizations (IADPO) and has held that role since 2015. She has a proven track record as a strong patient advocate and was instrumental in founding IADPO and conceiving of the organization's ground-breaking Global Research on the Impact of Dermatological Diseases (GRIDD) project. It has long been Christine's view that people living with dermatological conditions around the world deserve much better access to care and treatment, and that by working together with like-minded stakeholders, this goal is achievable.

