



International Alliance of  
Dermatology Patient  
Organizations

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Care Imperatives for Atopic Eczema:

***Accelerating Atopic Eczema Care for the Global  
Community***

Atopic eczema is one of the most prevalent skin diseases in the world and also one of the most underrecognized. According to the World Health Organization (WHO) Global Burden of Diseases initiative, more than “230 million people globally” are affected with atopic eczema.<sup>i</sup> And numbers are rising.<sup>ii,iii</sup> Yet because atopic eczema is often dismissed as “just a skin condition,” patients’ needs are not addressed in a supportive and timely manner.

As a [part of a multidimensional effort to address the above-mentioned gap](#), GlobalSkin has conducted a global survey of nearly 500 atopic eczema patients and caregivers from 38 countries on all 6 continents to identify and prioritize what needs to be done to effect a new policy agenda for atopic eczema.

From these findings, GlobalSkin has developed a series of action-oriented imperatives. These imperatives are a charter of definitive needs for the atopic eczema community, from patients to caregivers to healthcare providers to industry, to drive much-needed global change in how atopic eczema is viewed, diagnosed, supported, and treated.

Each of the imperatives within this document is accompanied by a set of potential opportunities for community action. These “opportunities to explore,” offer recommendations to all potential atopic eczema community members and allies on how to best make an impact within a specific care imperative area.

## **THE IMPERATIVES**

### **Imperative 1: Redefine Atopic Eczema Care as Holistic Care**

*A holistic treatment plan and corresponding guidance emerge as top priority and challenge concerning diagnosis of and support for atopic eczema.*

Of all the needs in the atopic eczema community, the one that patients, caregivers, and medical experts agree on is the approach to atopic eczema care needs to be redefined from *just* skin care to a holistic care regimen. Research has shown that those with atopic eczema are more prone to comorbidities like sinus infections, gastroenteritis, and even cardiovascular risk.<sup>iv v vi</sup> Studies also show atopic eczema is more detrimental to patients’ mental health than diabetes or hypertension.<sup>vii</sup>

Patients and caregivers agree that treatment that looks beyond the skin is necessary for better diagnosis and support of atopic eczema. In the survey, 62% of patients and caregivers see a holistic treatment plan that includes consideration of both atopic eczema and other physical and mental health conditions as their number one care priority. Additionally, another top priority for many was receiving lifestyle advice from their healthcare professionals to make better, healthier changes that may improve the state of the disease.

Many patients and caregivers have expressed frustration and confusion at the disagreements between different care providers on the correct plan to manage eczema. 46% of patients and 58% of caregivers have indicated care provider disagreement among their top three issues. By approaching atopic eczema in a holistic way, for instance including considering the links to other physical and mental health conditions and its emerging nature as a systemic disease, care providers can work in a unified and multi-disciplinary way to provide better treatment and support for patients.

### **Opportunities to explore:**

- Produce a peer-reviewed, authoritative list of comorbidities

- Establish holistic treatment guidelines for patients with the intention of global distribution and uptake by care providers across geographies
- Develop a global coalition/movement with a mix of traditional and non-traditional stakeholders to advocate for a broader approach to skin health, including professionals from other disease areas, mental health professionals, inflammatory disease professionals, economists, etc.
- Develop a short report on atopic eczema as more than a skin disease, accompanied by an advocacy campaign
- Initiate a two-tiered advocacy campaign on the importance of holistic care for people living with atopic eczema; the campaign could focus on “treating the whole person,” and ought to include tailored outreach materials for the general public and policymakers
- Using the advocacy campaign as a foundation, seek appropriate private and global organizational partnerships

### **Imperative 2: Connect Primary and Secondary Care by Expanding the Pool of Health Care Providers**

*Primary care is often unconnected with specialty care and ill-equipped to manage the full needs of atopic eczema services and treatment, causing patients and caregivers to consult with many different health care providers.*

Further validating that patients and caregivers acknowledge that atopic eczema affects various areas of physical and mental health, survey results reveal that they are prone to seeing a variety of healthcare professionals. General practitioners (seen by 72% of caregivers and 59% of patients) and dermatologists (seen by 65% of caregivers and 71% of patients) are the most popular health care providers for their atopic eczema care. However, they have also frequently sought out care advice from allergists (seen by 45% of caregivers and 20% of patients) and pharmacists (seen by 21% of caregivers and 18% of patients). Unsurprisingly, 38% of caregivers of children consulted with pediatricians.

Additionally, between 10-12% of patients and caregivers sought out alternative professionals including herbalists, kinesthesiologists, acupuncturists, eczema nurse specialists (for children), and naturopaths – all from high-income countries (HICs). This reveals an income discrepancy of services and knowledge for atopic eczema care.

Despite a National Eczema Association survey showing that more than 30% of Americans with atopic eczema have anxiety and/or depression,<sup>viii</sup> only 4% of GlobalSkin surveyed patients and 6% of surveyed caregivers indicated that they consulted with a mental health professional. These findings reveal that while patients and caregivers are aware about different health conditions associated with atopic eczema, they often don’t receive treatment from specialist healthcare professionals. By improving primary care by expanding the pool of trained health care providers in diagnosis and treatment of atopic eczema and integrating new disciplines, including mental health, into primary care, there can be less confusion and better health outcomes for patients.

#### **Opportunities to explore:**

- Identify opportunities for patients to provide input on atopic eczema care and referral guidelines
- Partner with medical schools and medical associations to ensure that providers across disciplines receive adequate training and continuing medical education on the needs of people living with skin disease

- Encourage health systems to strengthen referral linkages between dermatologists, primary care physicians, and mental health providers.
- Develop a report outlining how each relevant medical discipline fits into the optimum care “equation” for a person living with atopic eczema
- Support patients in advocating for their own care needs through the development of resources on navigating the healthcare landscape and seeking adequate cross-discipline referrals

### **Imperative 3: Broaden Access to Care with a Global Focus**

*Too many patients and caregivers, especially in low-to-middle-income countries, do not have access to basic services at primary care and have to pay out of pocket for basic treatment prescribed by a medical professional.*

Atopic eczema has until recently been classified as a “Western disease,” one that is only pervasive in countries with higher incomes and Western lifestyles. However, various studies conducted in the past 10-20 years have shown that rates of atopic eczema are just as prevalent in low-and-medium income countries (LMICs) as high-income countries (HICs).<sup>ix xxi xii xiii</sup> Results have shown that this slow-to-shift bias against LMICs has detrimental effects: too many patients and caregivers do not have access to basic services at primary care and have to pay out-of-pocket for basic treatment prescribed by a medical professional.

According to GlobalSkin’s survey, patients and caregivers in HICs are eight times as likely to not have to pay for prescribed treatments out-of-pocket. Conversely, patients and caregivers in LMICs are more than twice as likely to have to cover the entire cost of treatment on their own. Of patients and caregivers in HICs, 40% don’t pay anything at all.

Conversely, 66% of patients and 82% of caregivers from LMICs pay out-of-pocket for prescribed treatments; 81% of patients and 88% of caregivers from LMICs pay out-of-pocket for over-the-counter medications; and a concerning 16% don’t use prescriptions at all. While further research is necessary, there is strong evidence to indicate that the reason they don’t use prescriptions is because they can’t afford them. These striking results motivate a significant need to develop a globally focused agenda, inclusive of LMICs in Asia, Africa, and South America, on improving access for services and treatment of atopic eczema.

### **Opportunities to explore:**

- Conduct a landscape analysis to better understand the needs of people living with atopic eczema in underrepresented regions, with a special emphasis on patients and caregivers in LMICs
- Seek to understand the differences and commonalities of patient care across geographical regions and income disparities to support the formation of patient organizations in countries where there are none
- Revisit [The Economist report: “A misunderstood skin disease: Mapping the policy response to atopic dermatitis”](#) with an eye to identifying where the community has made progress, and where care gaps and access barriers may still remain
- Approach global, multilateral organizations (such as APEC, WHO, ILDS) to address both the global lack of eczema awareness, research, and education, and highlighting the particular dearth of atopic eczema-related resources and knowledge in certain regions

- Work alongside global multilaterals to establish updated, appropriate guidelines and standards of care and promote funding for more research in underserved regions, as well as globally

#### **Imperative 4: Bolster Awareness for Patient Empowerment**

*Educational resources are underused by health care providers and patients alike.*

In building towards GlobalSkin’s goal of patient and caregiver support, we identified in our survey that many patients, no matter their income level or geographic region, were not provided with sufficient educational resources by their healthcare provider. In fact, many didn’t even understand the full context of their disease.

According to the GlobalSkin survey, 35% of patients and caregivers did not believe that their atopic eczema care provider clearly explained the condition and only 37% of patients and caregivers agreed or strongly agreed that their atopic eczema care provider recommended useful resources on managing atopic eczema. Moreover, 30% of patients and caregivers indicate that they do not know where to find useful educational resources on managing atopic eczema. The issue that arises is two-fold: firstly, care providers do not have knowledge of or access to helpful educational resources on atopic eczema and secondly, because care providers cannot give these to patients, patients don’t have them either.

Because of this lack of educational support, many patients and caregivers find it difficult to fully understand their disease and how to care for it. In GlobalSkin’s survey, 45% of patients and caregivers see unclear and ineffective guidance on treatment as one of their biggest challenges in getting care. As there is a current wealth of resources for atopic eczema patients, it’s essential that we raise awareness about existing resources that empower people to manage atopic eczema. This will make them easier to find and more accessible to health care providers, patients, and caregivers alike.

#### **Opportunities to explore:**

- Develop an organizational system and repository for housing patient support resources in a way that is readily accessible and easy to navigate
- Educate patients on where to find and how to use available resources
- Identify atopic eczema champions within the health care system to educate care providers on current resources and data
- Connect with patients, healthcare professionals, and advocates to discern if there are any unfilled needs in resources
  - If so, address these needs by working with healthcare professionals to create new patient and caregiver support materials

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<sup>i</sup> Karimkhani C, Dellavalle RP, Coffeng LE, et al. Global Skin Disease Morbidity and Mortality: An Update From the Global Burden of Disease Study 2013. *JAMA Dermatol.* 2017;153(5):406-412. ([link](#))

<sup>ii</sup> Hajar T and Simpson E. “The Rise in Atopic Dermatitis in Young Children: What is the Explanation?” November 2018.

<sup>iii</sup> Odhiambo JA et al. “Global variations in prevalence of eczema symptoms in children from ISAAC Phase Three.” December 2009.

<sup>iv</sup> Serrano L, et al. “Atopic dermatitis associated with extracutaneous infections.” 2019. ([link](#))

<sup>v</sup> Silverberg, J et al. “Childhood atopic dermatitis and warts are also associated with increased risk of infection: a US population-based study.” April 2014. ([link](#))

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<sup>vi</sup> Nahm, DH. "Associations of Atopic Dermatitis With Obesity and Unmarried Status in Young Adults: Evidence for Atopic Dermatitis as a Life-Style Disorder With High Social Impact." *Allergy, Asthma, and Immunology Research*. March 2016. ([link](#))

<sup>vii</sup> Kiebert, G et al. "Atopic Dermatitis is associated with a decrement in health-related quality of life." March 2002.

<sup>viii</sup> Nearly one-third of people with atopic dermatitis report depression/anxiety. National Eczema Association. October 2017. ([link](#))

<sup>ix</sup> Mei-Yen Yong A, Tay YK. Atopic dermatitis: racial and ethnic differences. *Dermatologic Clinics*. July 2017. ([link](#))

<sup>ix</sup> Yuri I Lopez Carrera et al. Epidemiology, Diagnosis, and Treatment of Atopic Dermatitis in the Developing Countries of Asia, Africa, Latin America, and the Middle East: A Review. *Dermatology and Therapy*. October 2019. ([link](#))

<sup>x</sup> Yuri I Lopez Carrera et al. Epidemiology, Diagnosis, and Treatment of Atopic Dermatitis in the Developing Countries of Asia, Africa, Latin America, and the Middle East: A Review. *Dermatology and Therapy*. October 2019. ([link](#))

<sup>xi</sup> Mei-Yen Yong A, Tay YK. Atopic dermatitis: racial and ethnic differences. *Dermatologic Clinics*. July 2017. ([link](#))

<sup>xii</sup> Mallol J, et al. "The International Study of Asthma and Allergies in Childhood (ISAAC) Phase Three: a global synthesis." *Allergologia et Immunopathologia*. April 2013. ([link](#)); Odhiambo JA, et al. "Global variations in prevalence of eczema symptoms in children from ISAAC Phase Three." *Journal of Allergy and Clinical Immunology*. December 2009. ([link](#))

<sup>xiii</sup> Deckers IA, et al. "Investigating international time trends in the incidence and prevalence of atopic eczema 1990-2010: a systematic review of epidemiological studies." *PLoS One*. July 2012. ([link](#))