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# Atopic Eczema Community 3-Year Strategic Plan

2020-2022  
GLOBALSKIN

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International Alliance of  
Dermatology Patient  
Organizations

**Background and Context:** 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.

During the workshop, community members emphasized the need for two types of activities for inclusion in future strategic planning efforts: *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. To pursue these aims, 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.

We would like to offer a special acknowledgment and thank you to the original Atopic Eczema Steering Committee for shaping this community's foundation and growth.

- ❖ **Cheryl Talent**, Eczema Association of Australasia
- ❖ **Tonya Winders**, Allergy and Asthma Network (US)
- ❖ **Susanna Palkonen**, European Foundation of Allergy and Airways Disease Patients Assc.
- ❖ **Julie Block**, National Eczema Association (US)
- ❖ **Amanda Cresswell-Melville**, Eczema Society of Canada

In September 2019, the Atopic Eczema Community Policy & Advisory Committee was launched and tasked with the following mandate: to contribute to the development of the GlobalSkin global strategy and plan of action to increase the profile of atopic eczema on the global health agenda. Complementarily to its primary mission, the Committee could help GlobalSkin ongoing processes by informing its *strategic positioning on prioritized or urgent policy issues related to atopic eczema and advising on opportunities to advance patient engagement in relevant international fora.*

**Atopic Eczema Community Policy & Advisory Committee:** The Committee comprises the following representatives from diverse patient associations across the GlobalSkin community:

- ❖ Tonya Winders, Allergy Asthma Network (USA)
- ❖ Maggie Young, Allergy UK (UK)
- ❖ Tina Mesaric, Atopika (Slovenia)
- ❖ Spela Novak, Drustvo Atopijski Dermatitisi (Slovenia)
- ❖ Rachel Ogola, Eczema Society of Kenya (Kenya)
- ❖ Melanie Funk, Eczema Support Australia (Australia)
- ❖ Panagiotic Chaslaridis, European Federation of Allergy and Airways Diseases Patients’ Associations (Belgium)
- ❖ Kelly Barta, National Eczema Association (USA)
- ❖ Korey Cappa, Parents for Eczema Research (USA)

This Committee first came together on 25 September, 2019, via videoconference to align on a Committee workplan and set of priorities. Committee members also used this first conversation as an opportunity to share their national experiences in atopic eczema community building and put forward their individual perspectives<sup>1</sup> on the future of the movement. Finally, the Committee convened in-person on 8 October, 2019 alongside the European Academy of Dermatology & Venerology Annual Conference in Madrid, Spain for a half-day strategic workshop. During the course of the workshop, Committee members developed a vision statement to guide the atopic eczema community’s efforts moving forward, and identified the key strategic and operational elements to inform the community’s three-year

strategic plan. The strategy detailed within this document represents the outcomes of the Committee’s deliberations throughout September and October 2019, and has been complemented by priorities and suggested activities surfaced during the Atopic Eczema Forum in June.

**Framing the Community’s Ambitions:** In order to realize the ambitions of the atopic eczema community wherein people living with atopic eczema live fulfilling and healthy lives, the community’s strategic plan is centered on supporting two complementary strategic pillars: building community capacity and galvanizing global action. The driving philosophy of the roadmap is that the community must simultaneously maintain a focus on strengthening its internal processes and linkages as it looks to drive its message outwards and engage with the broader global health and policy community. Four strategic objectives underpin the strategic roadmap, and these objectives have also been designed to reflect a spectrum of activities that range from exclusively internally focused, to heavily externally focused. Specific activities to drive each strategic objective forward are detailed within the community workplan milestones table later in this document.



At the end of this 3-year plan, GlobalSkin will be a recognized leader in the atopic eczema community, having achieved advances in critical areas including in ensuring a sustainable backbone to its operations through building a solid community of members and partners; affirming thought leadership, through advancing the positioning of atopic eczema as a relevant health issue and launching the GRIDD project among others; and scaling advocacy to the next level, by involving the community in a journey towards coherent international recognition of atopic eczema, either via a WHO engagement plan or through other institutional outreach.

Community workplan milestones are captured in tables below.



**Strategic Pillar: Building Community Capacity**

*This pillar acknowledges the centrality of a strong and cohesive atopic eczema community as a prerequisite for effective global action on atopic eczema, and as a core resource for people living with atopic eczema. This strategic pillar is home to many of the operational and capacity-building efforts identified as necessary by members of the atopic eczema community during the June 2019 Forum. The first objective in this pillar, “To build a strong and united voice on atopic eczema by aligning atopic eczema community members around a shared set of capacity-building resources” is fully internally focused and is marked by capacity-building and community development milestones. The second objective, “To collaborate with and influence other stakeholder groups of relevance to boosting the visibility of atopic eczema in national, regional, and global policy fora,” takes community development to a next-level by growing in scope to also include adding new stakeholders to the atopic eczema community’s network and sphere of influence.*

Objective	Q1-2 2020	Q3-4 2020	Q1-2 2021	Q3-4 2021	Q1-2 2022	Q3-4 2022
1) To build a strong and united voice on atopic eczema by aligning atopic eczema community members around a shared set of capacity-building resources	<p>Socialize and introduce the advocacy toolkit</p> <p>In-person capacity building activity for convening the atopic eczema community, the “Atopic Eczema Community Mobilization Workshop”</p> <p>Continue to identify and engage patient organizations with the goal of encouraging three new</p>	<p>Unified World Atopic Eczema Day campaign for all atopic eczema patient organizations, globally</p> <p>Launch of a “virtual coffee &amp; conversation” series on the Atopic Eczema Community online platform, with the aim of conducting one virtual convening per quarter</p>	<p>Centralized patient care guide (customizable by patient associations) that will:</p> <p>provide list of existing external resources that support patients in seeking care for atopic eczema and its associated comorbidities, along with recommendations for guiding conversations with care-providers.</p>	<p>Unified World Atopic Eczema Day campaign for all atopic eczema patient organizations, globally</p>	<p>Key messages document (inclusive of talking points and press release) capturing the most salient insights from the GRIDD project</p>	<p>Unified World Atopic Eczema Day campaign for all atopic eczema patient organizations, globally</p> <p>and</p> <p>In-person meeting of the atopic eczema community</p>



	patient associations to participate in the next in-person convening of the community					
2) To collaborate with and influence other stakeholder groups of relevance to boosting the visibility of atopic eczema in national, regional, and global policy fora	Landscape analysis and stakeholder mapping capturing issues and stakeholder groups of relevance to boosting the visibility of atopic eczema in national, regional, and global policy fora.	Narrative establishing atopic eczema as significant within the frame of one of the issues identified through the stakeholder mapping exercise and landscape analysis (for example: establishing atopic eczema as a type-2 inflammatory condition, or an “all-skin” resolution)		In-person meeting of patient leaders within the atopic eczema community to align on an approach for engaging with key stakeholders, regional, and global policymakers; these efforts would be informed by the outcomes of the stakeholder mapping and narrative-development exercise	Implementation of World Health Organization outreach and engagement, in line with the outcomes of the Q3-4 2021 community convening	Event alongside World Health Organization Assembly showcasing the results of the GRIDD project, to be executed and presented in partnership with a global organization representing another health area (i.e. mental health)



**Strategic Pillar:** Galvanizing Global Action

*Alongside community development and capacity-building objectives, the atopic eczema community has also prioritized galvanizing global action on atopic eczema with the dual aims of improving access to high-quality care and enhancing awareness about the impact of the condition on peoples' lives. These two objectives are core to the community's vision and will require ongoing work from 2020 through 2022. In order to support and catalyze global action on atopic eczema, the community will focus on gathering evidence and then leveraging these enhanced evidence-sets and investment cases to make a persuasive argument for action with global stakeholders such as the World Health Organization. However, in recognition of the community's responsibility to provide concrete support to patients, activities within this pillar will also focus on improving the lives of people living with atopic eczema through the provision of patient and health care provider tools and resources.*

Objective	Q1-2 2020	Q3-4 2020	Q1-2 2021	Q3-4 2021	Q1-2 2022	Q3-4 2022
3) To ensure access to high-quality, coordinated, and innovative care for people living with atopic eczema.	Survey for national patient organizations aiming to define patient-centered care for atopic eczema. The survey results would be analyzed with an eye to identifying the 3-4 hallmarks or "must-haves" for patient-centered care.	Start the planning process for a specialist roundtable conversation alongside the American Academy of Dermatology or European Academy of Dermatology & Venerology, 2021 welcoming a selection of diverse specialists relevant to the care of people living with atopic eczema. The roundtable could open with a session on "patient stories"	Compendium of patient-centered best practices and guidelines for informing high-quality atopic eczema care	Development of patient-centered-guidelines-based approaches broken down into plain language, accessible materials	Launch of the patient care support guide (with nationally-tailored versions made available in at least 15-20 countries), delivered through local patient associations	Healthcare provider education campaign in partnership with WHO ( <i>dependent on outcome of objective 2 milestones</i> )



		and would introduce the community's imperatives for care coordination				
4) To raise awareness of atopic eczema, its impact on patients' lives, and the needs of the patient community, among healthcare providers, policymakers, and the general public.		Compilation of existing data and evidence on atopic eczema, sourced from credible experts within the atopic eczema community (i.e. health product suppliers, medical associations, and patient groups) and gap-analysis identifying further research needs; for example, the community has frequently noted a lack of data on atopic eczema prevalence		Comprehensive policymaker briefing document, inclusive of relevant evidence and data-sets, along with concrete policy and national plan "asks," vetted by atopic eczema community leaders	Development of a documentary capturing atopic eczema's impact of patient quality of life; the documentary ought to include findings from the GRIDD project	Documentary launch, accompanied by screening events hosted by national patient organizations