



GLOBALSKIN.ORG

International Alliance of
Dermatology Patient
Organizations

Year in Review

2019

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Introduction

People living with dermatological conditions face stigma, shame and other psychosocial challenges in addition to the physical symptoms of their disease. For many patients, this is a lifelong burden. And in many cultures, this can have devastating social impacts. This simply needs to change.

The International Alliance of Dermatology Patient Organizations (IADPO — also known as GlobalSkin) is uniquely positioned to play a leadership role because it serves patient organizations across the full spectrum of dermatological diseases around the world. GlobalSkin is a unique global alliance that is committed to improving the lives of dermatology patients worldwide through research, advocacy and support. GlobalSkin, along with its members and other dermatology stakeholders, is building a global movement to validate what patients know: skin diseases truly impact the lives of those living with them.

Throughout 2019, GlobalSkin’s global reach has continued to grow significantly in the number and diversity of member organizations, in the broader range of its strategic initiatives and as measured by IADPO’s greater impact on the wider dermatology community. This report provides a detailed overview of IADPO’s progress and momentum through 2019.

For general information about the organization visit: globalskin.org.



Building the Movement

Governance/Organizational Effectiveness

The GlobalSkin Board of Directors and Membership approved a new [three-year strategic plan](#) which includes an updated vision and mission and is focused on its Member Community, Awareness and Sustainability. Staff will operationalize the plan with guidance from the Board, taking GlobalSkin into a very promising future.

Strong governance continues to underpin the organization's structure, and in 2019 the Board of Directors was expanded to reflect membership growth in terms of geography and disease representation over the past year.

Following its Annual General Meeting in September, GlobalSkin held an election to fill five Board Director seats. There was great deal of interest from Members resulting in a slate of 13 candidates representing nine countries and 10 different diseases areas. Re-elected was Jean-Marie Meurant (France, Vitiligo); and new Board Directors are Michelle Capon, (Canada, Porphyria), Vlasta Zmazek (Multi-region, Epidermolysis Bullosa), Marc Yale (Multi-region, Pemphigus & Pemphigoid) and Ito Daisuke (Japan, Albinism).

These newly elected Directors will join Cheryl Talent (Australia, Atopic Eczema), Simmie Smith (Canada, Psoriasis), David MacMahon (Ireland, Multi-disease) and Julius Muungano (Tanzania, Albinism) on the Board. Learn more about the [Board of Directors](#).

GlobalSkin has not only seen growth in the Board, but also growth in the staff - 2019 saw staff capacity increase by three. Take a moment to meet the [Staff Team](#) who implement the organization's strategic vision on a day-to-day basis.

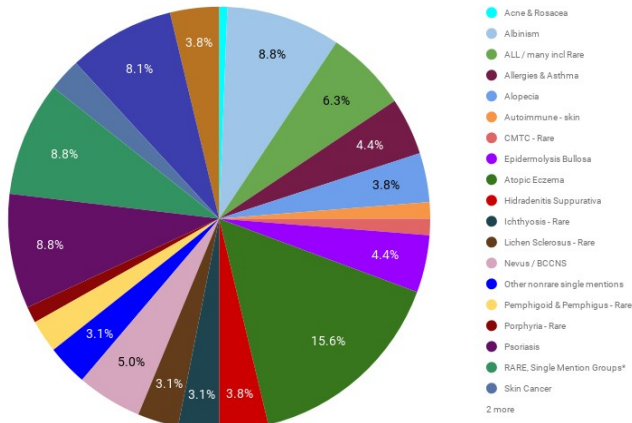
Membership

GlobalSkin membership currently includes 160 dermatology patient groups and organizations located in 50 countries and representing more than 60 disease areas. This demonstrates an impressive 68% year-over-year growth in membership since 2018. GlobalSkin has expanded its geographic representation from 35 to 50 countries – a 39% increase – year-over-year.

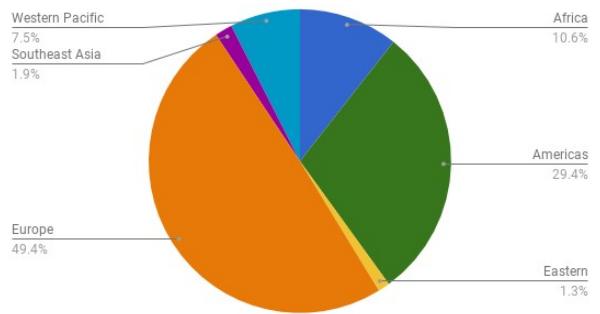
The strength of this global Alliance is found in the community of member organizations that share common challenges and willingly share ideas and resources for the benefit of patients.

GlobalSkin Members are united with a common voice to raise awareness and understanding of the impact of dermatological diseases.

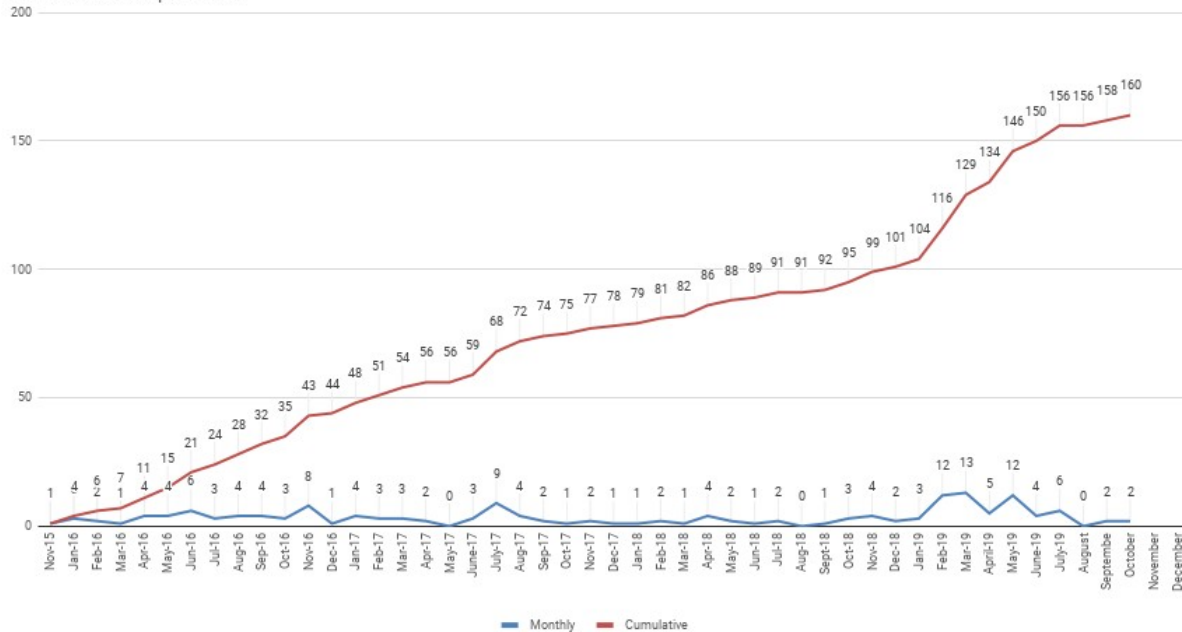
Disease Areas



Regional Representation



IADPO Membership Growth



A complete list of GlobalSkin's Members is available on its [website](#).

GlobalSkin takes pride in connecting patient organizations around the world with one another, bringing attention to the true impact that skin diseases have on the lives of families and individuals, and working to improve access to care and treatment for skin patients.

In 2019, GlobalSkin continued to actively support the dermatology patient organization community through the following activities:

- Led a very successful two and a half day *GlobalSkin 2019* Conference in Milan this past June which brought together 120 leaders of dermatology patient organizations from 35 countries ([read more](#))
- Also, IADPO hosted two disease-specific pre-conference events, *Atopic Eczema Forum* and *RareDERM Forum*. ([read more](#))
- Presented quarterly *Members-only e-Learning Sessions*, led by mentors from among GlobalSkin’s Members, on the following topics:
 - Questionnaire Design—Key to Collecting Useful Survey Data
 - Qualitative Research to Enhance Depth of Understanding
 - Grassroots Advocacy for Skin Diseases
 - Global Research on the Impact of Dermatological Diseases (GRIDD): Why It Matters for GlobalSkin Members and their Patients
- Communicated with Members through four newsletters and five bulletins keeping member representatives informed and involved with all GlobalSkin activities and initiatives.
- Communicated actively through social media channels and regularly updated website content.
- Hosted three *Skin Matters* receptions in 2019: at the American Academy of Dermatology Annual Meeting in March in Washington DC, (co-hosted with the International Federation of Psoriasis Associations), World Congress of Dermatology in June in Milan and European Academy of Dermatology & Venereology in October in Madrid.
- Created an online member collaboration space – *GlobalSkin Workplace* – as a pilot program with two disease communities with the plans to launch to all GlobalSkin Members in 2020.



Community Building

GlobalSkin is actively working to establish a broad global alliance of patient organizations representing as many diseases and countries as possible. At the same time, the need has been identified to establish several patient organization communities representing specific diseases and/or regions.

GlobalSkin's current community-building initiatives are summarized in this section.

Atopic Eczema

GlobalSkin has been working for the past two years to establish a worldwide community of atopic eczema patients and patient organizations. The focus in 2019 has been:

- Hosting the *Atopic Eczema Forum* in June 2019 in Milan, Italy. This event was attended by 25 delegates representing 21 countries and was structured around three components: scientific presentations and the policy and advocacy landscape related to the disease; group discussions around operational and political challenges; and strategies on the future of the atopic eczema community. An *outcome report* has been published.
- A two-day *Advocacy Training Workshop* was held in October with sixteen members from the Atopic Eczema Community. Attendees from 10 countries went home with new skills and a tailored advocacy plan to implement for their patient organization.
- The second *World Atopic Eczema Day* was a great success in 2019 with over 54 atopic eczema patient organizations receiving a new Communications Toolkit and *World Atopic Eczema Day* logo for use in their local campaigns. GlobalSkin offered a *World Atopic Eczema Day Fund* to help offset costs for marketing and event costs for Members. Read about the Day in the [2019 recap report](#).
- [AltogetherEczema.org](#) continues to act as a hub for the atopic eczema patient community.
- Creation of a new *Atopic Eczema Community Advisory Committee*, representing nine patient leaders from five countries. Several planning meetings have taken place including an in-person meeting this fall in Madrid.



- A new three-year *Atopic Eczema Community Strategic Plan* has been developed and will be ratified by the larger atopic eczema community by the end of 2019.

RareDERM

GlobalSkin is working with the rare dermatological diseases community to significantly and measurably improve linkages for patient organization leaders. Key initiatives of 2019 included:

- Hosting a *RareDERM Forum* in June 2019 in Milan, Italy. The Forum, attended by 40 delegates representing 13 countries, gave participants the opportunity to collectively outline broad goals, define challenges and needs; and began developing a strategy to fulfill the vision of a world in which people living with rare dermatological conditions and diseases are able to lead healthy and fulfilling lives. This will ultimately build a cohesive community to:

1. empower patients through knowledge and skills
2. help stimulate research
3. collaborate and influence stakeholders
4. deliver advocacy.



- An *outcomes report* was published following the Forum.
- Creation of the *RareDERM Community Advisory Committee* brought together seven patient organizations from six different countries - providing a wonderful cross-section of viewpoints. Their objective is to develop a three-year *RareDERM Community Strategic Plan*.
- The larger RareDERM Community will ratify the aforementioned plan by the end of 2019.



European Region

More than 40% of GlobalSkin Members are located in Europe. As such this group is another community that will benefit from having GlobalSkin-focused support.

An exploratory meeting was held last year to discuss the challenges and opportunities facing this region and among the key findings was the need for organizational capacity building and advocacy support.



Representatives in this community will have the opportunity to connect further using GlobalSkin's online collaboration tool GlobalSkin Workplace. Hiring of a community manager and strategy development will be the focus in 2020.

GlobalSkin 2019 Conference

The third biennial GlobalSkin Conference was held June 7-9, 2019 in Milan, Italy. This event brought together over 120 skin patient group leaders from 35 countries in Milan for three unique events: the RareDERM Forum, the Atopic Eczema Forum and the *GlobalSkin 2019* Conference.



The RareDERM Forum and Atopic Eczema Forum each spanned two-days and took place just before the *GlobalSkin 2019* Conference. Nearly 40 delegates from 13 countries represented rare and uncommon dermatological disease patient organizations, while 25 delegates from 21 countries represented the atopic eczema community. Participants benefited from formal learning sessions, strategic thinking for their communities and connecting with other patient leaders and dermatology stakeholders.



The *GlobalSkin Conference* is IADPO's signature member-support event, specifically designed for dermatology patient leaders. Participants learned from each other and outside experts during stimulating plenaries, engaging workshops, and small group mentorship opportunities through an impactful interactive living library session.

Delegates also learned from two special keynote speakers and networking opportunities during the One World reception/dinner and a special off-site Patient's First dinner held at a local vineyard. [Photos and highlight videos](#) captured this successful event.

Delegate Feedback:

I enjoyed being able to build cohesive coalitions with other skin diseases; this is important because together we will be louder than we are alone, and hearing of the prospects for the future was encouraging.



I enjoyed the many opportunities there were to network and meet with other patient advocacy group leaders.

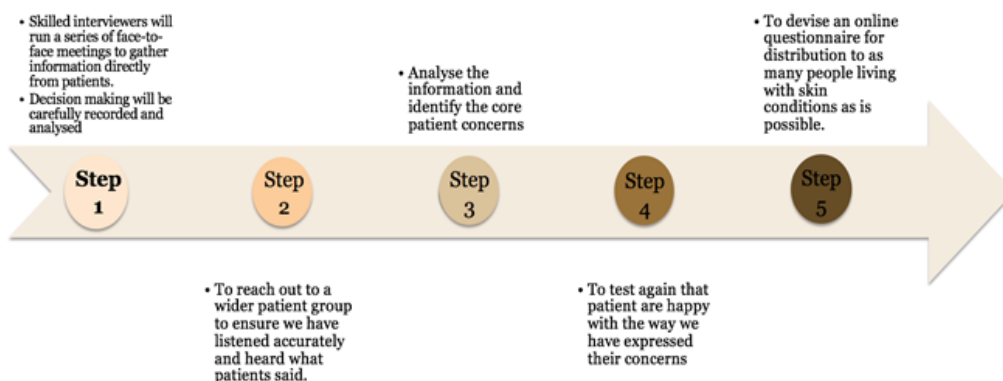
The total vibe, the enthusiasm that was created. There was a good balance in the program between the different kind of sessions. I also liked the collaboration between patient advocates, GlobalSkin, and Pharmaceutical companies. Well done, my compliments.



Global Research on the Impact of Dermatological Diseases (GRIDD)

The Global Research on the Impact of Dermatological Diseases (GRIDD) project has been progressing well throughout 2019. This patient-initiated research project, which will measure the true impact of skin diseases from the patient perspective, is currently in Phase 2 of 5. The project is led by Prof. Dr. Matthias Augustin, Hamburg University and Prof. Chris Bundy, Cardiff University and their teams of dedicated researchers.

- A milestone event took place during the European Academy of Dermatology and Venereology (EADV) Congress this past October where GRIDD researchers presented the findings of the systematic literature review (phase 1 of the project). Rachael Pattison, Cardiff University and Nirohshah Trialonis-Suthakharan, University Medical Center Hamburg-Eppendorf reported the results of the systematic literature review revealing this major finding: ***Based on the gold standard criteria, no dermatology-specific, patient-reported measure can be recommended for use.*** This conclusion proves there is a verifiable need to develop a new dermatology-specific measure for patients by patients.
- These findings have been submitted as a manuscript to a prominent dermatology journal.
- GlobalSkin and the GRIDD research team met during the American Academy of Dermatology Annual Meeting in March and most recently during the EADV Congress in October with the GRIDD Scientific Advisory Board. This impressive group provides guidance and offers support for the project based on their many years of experience in dermatology research. GlobalSkin thanks them all for their dedication to this project.
- Phase 2 of the GRIDD project:



- The prior graphic outlines the process of collecting qualitative information (information that describes people’s opinions and feelings). One round of focus group discussions is complete with another round planned for early-2020. The information gathered will then form the “items” or issues that will become the focus of the GRIDD questionnaire. Phase 2 is expected to conclude in the first half of 2020.
- A presentation on the GRIDD project was recorded in June during the *GlobalSkin 2019* Conference in Milan. This [video](#) is an excellent resource to become further acquainted with the project.
- GlobalSkin will host a GRIDD e-Learning series in 2020. There will be approximately three sessions throughout the year for the purpose of informing, engaging and collaborating with Members regarding this important patient led research project and how they can get their patients involved.



Stakeholder Engagement

Significant strides continue to be made as GlobalSkin’s professional reputation grows amongst its stakeholders. In 2019, GlobalSkin actively worked to improve patient organization involvement at dermatology events like the European Academy of Dermatology and Venerology Congress. Relationships are being formed and nurtured and efforts in demonstrating the value that patient organization leaders bring to the table are being rewarded.

The 2019 EADV Congress saw:

- The second year in a row where patient leaders had access to attend scientific sessions during the Congress as a result of active collaboration between IADPO and the EADV.
- Patient leader representation at the EADV President’s Dinner (which began in 2018).
- GlobalSkin helped to coordinate participation in the Patient Society Village with its European Patient Organization Members and saw 19 Patient Organizations participate this year.
- The third consecutive co-organized session between EADV and IADPO on “*Building the doctor-patient relationship through effective communication*”. Patient organizations were prominently featured in this multidisciplinary program highlighting the importance of positive and open communications between doctors and patients. The session was co-chaired by Jean-Marie Meurant, past President of the IADPO Board of Directors along with representatives from the EADV Patient Working Group and the EADV Psycho-dermatology Task Force.
- GlobalSkin has been invited to sit for a one-year term as the first patient organization representative on the EADV’s Patient Association Working Group.



GlobalSkin on the World Stage

GlobalSkin continued to spread the word about the organization's initiatives, growing member community, and patient needs throughout 2019 by participating in many meetings and conferences.

The organization was represented at the following conferences:

- o **Patient Congress**, Philadelphia, US (Keynote Presentation)
- o **American Academy of Dermatology Annual General Meeting**, Washington, US (Exhibitor)
- o **Harmonizing Outcomes Measured for Eczema meeting**, Tokyo, Japan (Participant)
- o **International Federation of Psoriasis Associations General Assembly/Global Psoriasis Coalition Meeting**, Barcelona, Spain (Presentation on GRIDD, GRIDD poster)
- o **World Congress of Dermatology**, Milan, Italy (Exhibitor)
- o **International Foundation for Dermatology meeting**, London, UK (Presentation and strategic planning participation)
- o **European Academy of Dermatology and Venereology**, Madrid, Spain (Presentation, Exhibitor)
- o **LEO Pharma Hacking Dermatology**, Copenhagen, Denmark (Participant)
- o **European Patients Congress**, Brussels, Belgium (Participant)
- o **Pediatric Dermatology Research Alliance Annual Conference**, Chicago, US (Exhibitor and Presentation)
- o **Internal events** hosted by several of GlobalSkin's members and partners (Presentations)



Relationship building is also an ongoing priority with other organizations not previously mentioned:

- International League of Dermatological Societies (ILDS)
- World Health Organization (WHO)
- Research Scientists, International Investigative Dermatology (IID)
- International Dermatology Outcome Measures (IDEOM)
- Coalition of Skin Diseases (CSD)
- Rare Diseases Europe (EURODIS)
- Canadian Organization for Rare Disorders (CORD)
- National Organization for Rare Diseases (NORD)
- European Patients' Academy (EUPATI)
- International Alliance of Patient Organizations (IAPO)

Partnerships

GlobalSkin is grateful to industry partners for supporting its mission to improve the lives of those affected by dermatological disorders around the world. Stakeholder commitment and generosity has allowed GlobalSkin to undertake many important initiatives this past year, which directly help patient leaders and the patients they serve.

Founding Visionary Partners	LEO Pharma and Celgene
2019 Core Mission Partners	LEO Pharma (Gold) Sanofi Genzyme Regeneron (Bronze) Pfizer (Bronze) Celgene (Bronze) Abbvie (Bronze) Galderma (Contributor) La Roche-Posay (Contributor)
<i>GlobalSkin 2019</i> Conference Partners	LEO Pharma (Platinum) Pfizer (Gold) Sanofi Genzyme Regeneron (Silver) Celgene (Silver) Novartis (Bronze) Galderma (Contributor) Pierre Fabre (Contributor) Almirall (Contributor) Signifly (In-Kind Supporter)
GRIDD Partners	LEO Pharma (Silver) Sanofi Genzyme Regeneron (Silver) Galderma (Bronze) Novartis (Contributor) Pfizer (Contributor) Sun Pharma (Contributor) Pierre Fabre (Supporter) Almirall (Supporter)
Atopic Eczema Community Partners	Sanofi Genzyme Regeneron LEO Pharma Pfizer AbbVie Signifly (in-kind)
RareDERM Partners	LEO Pharma PellePharm Trend Community (in-kind) Signifly (in-kind)

Looking Ahead to 2020



In the coming year, 2020, GlobalSkin will continue to build and mature as an organization. Guided by a new strategic plan, the organization will deliver on key commitments related to its three strategic goals: Member Community, Awareness and Sustainability.

The focus will be on continuing to build and support the expanding membership, advancing priorities in identified disease and regional communities; building capacity for all GlobalSkin Members by developing member programs and planning the *GlobalSkin 2021* Conference; and completing Phase 2 and implementing Phase 3 of the evidence-building GRIDD project.

In order to do all of this, it will be essential for GlobalSkin to continue to: grow its membership base, strengthen its reputation among dermatology stakeholders and broaden awareness about issues that affect people living with dermatological conditions. The organization will also carry on building relationships with the World Health Organization (WHO), at the United Nations (UN), and with key government leaders. GlobalSkin will demonstrate its value proposition as a key patient leader resource; and build internal capacity to manage a growing number of projects and initiatives.

And finally,

A rising tide lifts all boats. By shining a spotlight on the importance of all people suffering with a dermatological condition, GlobalSkin, along with its members, partners and other key stakeholders, will achieve its mission to:

- unite patient voices in dermatology
- empower patient organizations
- stimulate research
- influence decision makers, and
- collaborate with communities of interest.

For more information on Membership, please contact:

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