

GRIDD
Global Research on the Impact
of Dermatological Diseases

Do we truly know
it's like to live
disease?

generate data
clear picture.

Involved:
globalskin.org/GRIDD

International Alliance of
Dermatology Patient
Organizations

International Alliance of
Dermatology Patient
Organizations

One Skin.

AltogetherEczema
The Global Network for Eczema & Atopic Dermatitis

A new global movement for the eczema &
atopic dermatitis community, dedicated to
identifying critical issues and improving
access to care and treatment.

Join us in advocating for change
AltogetherEczema.org

Project of
International Alliance of
Dermatology Patient
Organizations



GLOBSKIN.ORG
International Alliance of
Dermatology Patient
Organizations

Year in Review 2018

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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) has been 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 those living with them.

Throughout 2018, GlobalSkin has made significant progress in implementing its highly-focused strategic plan centred on research, advocacy and support.

Meet GlobalSkin's [Board and Staff](#) and find out more about the organization at globalskin.org.



Building the Movement

Membership

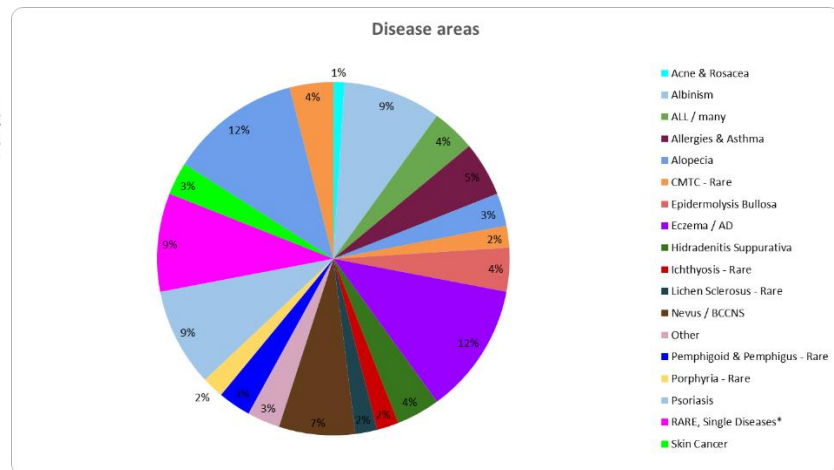
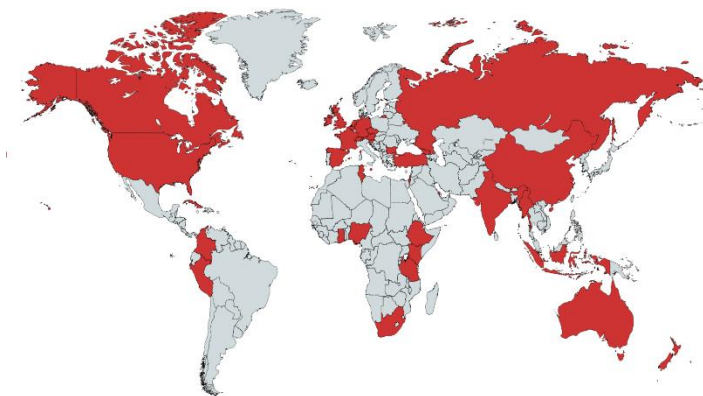
On December 10, 2019, GlobalSkin welcomed a very special new member - its 100th! The honour of helping achieve this important milestone went to the Eczema Association of New Zealand.

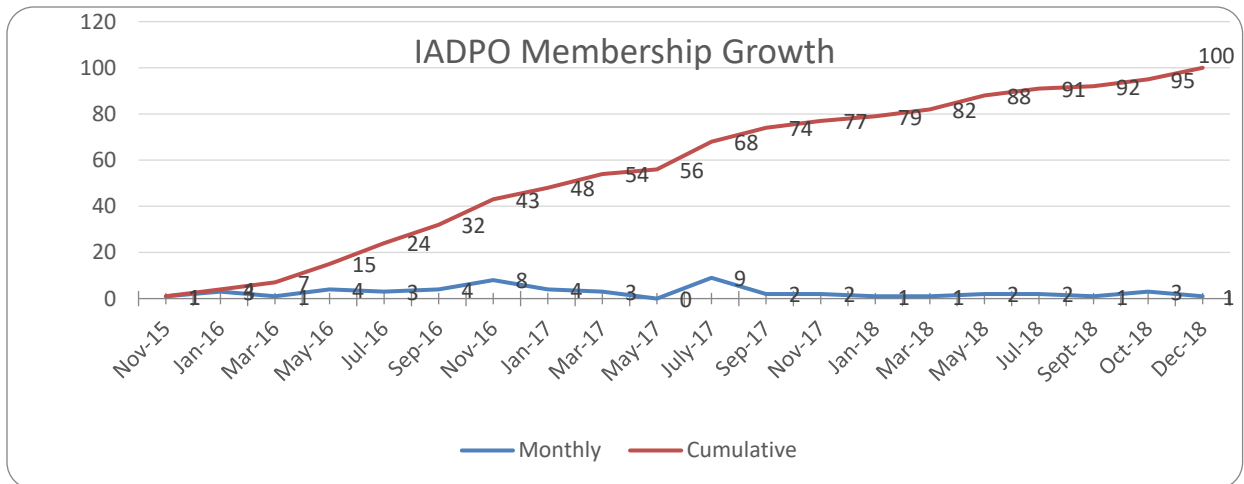
GlobalSkin's 100 members represents 37 countries worldwide, and over 36 skin disease areas. The strength of the Alliance is found in its community of members who contribute their wisdom and understanding of their organizations' skin diseases; their ideas; and most importantly their time.

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

GlobalSkin achieved 28% year-over-year membership growth in 2018.

GlobalSkin has expanded its membership over the past year, increasing the number of countries represented by 9% with continued growth of the number of disease areas.





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 2018, GlobalSkin continued to actively support the dermatology patient organization community through the following activities:

- Presented quarterly members-only e-learning sessions, led by mentors from among GlobalSkin’s members, on the following topics:
 - Fundraising Tools & Methods
 - Effective Communications and Outreach Strategies
 - Key Components of Successful Websites
 - Strategies for Enhancing & Leveraging our Relationships with local Dermatologists
 - Power of Patient-led Research
- Redesigned the globalskin.org website for a better user experience for members, partners and other stakeholders.
- Communicated with Members via quarterly newsletters and via social media channels.
- Published two position papers that were developed through Members’ input at the *GlobalSkin 2017* Conference:



- [Empowering and Advocating for Dermatology Patients](#) (January 2018)
- [Supporting Patients in the Digital Age](#) (January 2018)
- Connected members with each other through a mentorship initiative. Members who have skills to share or who are looking for help are matched with each other through the members-only website.
- Hosted two Skin Matters receptions: one at the American Academy of Dermatology (AAD) Annual Meeting in March and one at the European Academy of Dermatology & Venereology (EADV) Congress in September.
- Continued expanding 700+ dermatology patient organization database.



Following the Annual General Meeting in October, GlobalSkin held a Board election to fill two Director seats. There was great deal of interest from Members resulting in a slate of eight candidates representing five regions and six different diseases. New Board Directors are Julius Muungano, from Promotion of Education Link Organization (Tanzania) and Simmie Smith, from the Canadian Psoriasis Network.

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 established a worldwide community of atopic eczema patients and patient groups in 2018, working in cooperation with many eczema and atopic dermatitis organizations from around the world. Projects include the launches of [AltogetherEczema.org](#), and World Atopic Eczema Day, as well as the release of a co-sponsored report on atopic dermatitis with the Economist

Intelligence Unit. The lessons learned from this community building will be very helpful in building more disease- and region-specific communities.

GlobalSkin either led or were participants in a number of publications and events about Atopic Eczema in 2018:

- [*IADPO Position Paper: Atopic Dermatitis: A Collective Global Voice for Improving Care*](#) (February 2018)
- Launch of World Atopic Eczema Day (September 2018) — What is it really like living with atopic eczema? On September 14, 2018, GlobalSkin gave patients and their caregivers an opportunity to answer that exact question on this new interactive online community.
- [*Economist Intelligence Unit: A misunderstood skin disease: Mapping the policy response to atopic dermatitis*](#) (co-sponsored with Pfizer) (October 2018)
- [*The Economist webinar on Atopic Dermatitis, with GlobalSkin CEO, Christine Janus*](#) (co-sponsored with Pfizer) (October 2018)
- [*Policy Drivers in Atopic Eczema: Patient Leader Dialogue Report*](#) (November 2018)



European Region

GlobalSkin hosted a European Patient Organizations Community meeting in September 2018 in Paris, bringing together patient leaders from across Europe to discuss challenges and opportunities currently faced in this region.

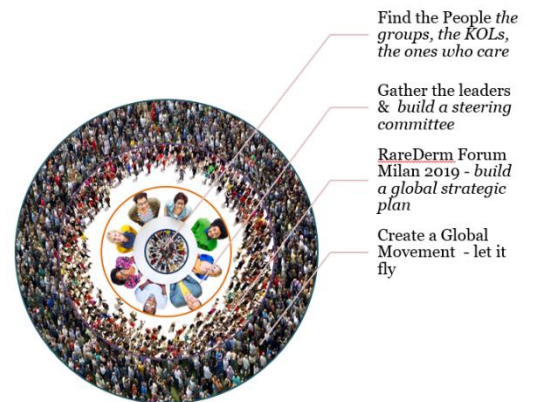
As 40% of IADPO Members are located in Europe, the objective was to have an open discussion on where opportunities exist to improve advocacy for skin patients in Europe. All European dermatology patient organizations are invited to connect with GlobalSkin as it continues to build support programs for its Member Organizations from that region.



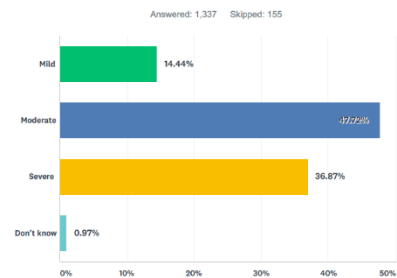
RareDERM

GlobalSkin is working with the rare/uncommon and neglected dermatological diseases community to significantly and measurably improve linkages for patient organization leaders. The goals are to build capacity and coordination of a synchronized strategic approach to improve access to care; stimulate critical research; disseminate critical information; and improve treatment options for patients living with neglected, rare or uncommon diseases. One of the key initiatives will be hosting a RareDERM Summit in June 2019 in Milan, Italy.

GlobalSkin kicked off this initiative by conducting a disease experience survey of nearly 1,500 Lichen Sclerosus (LS) patients. The findings of this research can be found on the [RareDERM](#) web page.



Q37 How would you categorize the severity of your LS condition, based on how it affects your life – the whole you?



Hidradenitis suppurativa (HS)

Patient organizations that provide support to people living with Hidradenitis Suppurativa (HS) provide essential services, support, access to information, opportunities to link with other patients and to become empowered to speak up for access to care and treatment. This is a disease where patient organizations are currently under-resourced and not well connected to each other. As such, GlobalSkin is working with this broader community to significantly and measurably improve linkages for patient organization leaders to build capacity and coordination of a synchronized strategic approach to improve access to care, critical information and treatment options for patients.

As GlobalSkin builds its experience in developing communities, it will be considering branching into other diseases and regions going forward.

Stakeholder Engagement

Significant strides have been made as the dermatology community has gotten to know GlobalSkin and its commitment to professionalism. In fact, this year's European Academy of Dermatology and Venereology (EADV) Congress was an inflection point for GlobalSkin – a point at which progress jumped from steady to significant!

GlobalSkin has been actively working to improve patient organization involvement at the EADV for several years. Through close collaboration, some excellent results were achieved at the Paris congress in September 2018:

- Enhanced Patient Organization Village which was located in a very prominent space at the conference venue.
- Patient Leaders had access to attend scientific sessions during the Congress – for the first time ever!
- And another first...patient leader representation at the EADV President's Dinner where the importance of the involvement of patients was endorsed by the outgoing EADV president – for all to hear.
- Co-organized session – for the second year in the row – on the psycho-social impact of skin diseases. The event brought together patients and healthcare professionals for an interactive and dynamic dialogue. Outgoing EADV President Luca Borradori took the podium and spoke passionately about the need for patient involvement during the congress. An article published in Medscape quoted Professor Borradori as saying, "You can't do anything without understanding your patients, which are the reason for your existence. This is one of the best sessions I have attended in many years of the EADV, and one of the most important."



Incoming EADV President



Outgoing EADV President

- GlobalSkin’s CEO Christine Janus travelled extensively this year to spread the word about the organization and mission. She participated in the following conferences:

- 10th Georg Rajka International Symposium on Atopic Dermatitis and Harmonized Outcomes Measures for Eczema meeting, Utrecht, NL (observer)
- Economist Roundtable on Atopic Dermatitis, London, UK (observer)
- IAPO Global Patients Conference, Miami, US (presenter and poster session on GRIDD)
- Vitiligo International Patient Organizations Conference, Paris, FR (presenter)
- EADV, Paris, FR (presenter and poster session on GRIDD)
- Rethinking Healthcare Systems in Europe: how to incorporate the patient perspective – hosted by Permanent Representation of Denmark to the European Union, Brussels, BE (presenter)
- Eye for Pharma, Philadelphia, US (presenter)
- Internal events hosted by several of GlobalSkin’s partners (presenter)
- [The Economist webinar on Atopic Dermatitis](#), London, UK (presenter)



Brussels Seminar

- Relationship building is also an ongoing priority with the following organizations:

- International League of Dermatological Societies (ILDS)
- World Congress of Dermatology (WCD)
- American Academy of Dermatology (AAD)
- Research Scientists, IID
- World Health Organization (WHO)
- EURODIS, CORD, RDI
- SFD, IFPA, IPPF, EUPATI, OAC



GlobalSkin & ILDS Presidents

GlobalSkin 2019 Conference

Plans are well underway for the biennial *GlobalSkin 2019* Conference which will take place June 7-9, 2019 — just before the World Congress of Dermatology — at the Hilton Garden Inn Milan Malpensa in Milan, Italy.



The conference is GlobalSkin’s signature member-support event, specifically designed for dermatology patient leaders. *GlobalSkin 2019* will deliver a life and career enhancing experience — for both new and experienced patient leaders — by providing networking opportunities as well as skill building and mentorship. It will attract over 100 delegates from around the world representing a wide cross-section of serious skin diseases.

The Conference Steering Committee, chaired by Board Vice President, Cheryl Talent (Australia), consulted directly with GlobalSkin member organizations in the spring on their learning priorities. The conference program focuses on advocacy, science and research, and building strong, resilient organizations. Delegates will share experiences and skills each other while also attending plenaries, workshops and “living library” sessions.

Additional special events being planned around the *GlobalSkin 2019* Conference include:

- RareDERM Forum — an event that will bring together patient leaders from around the world who serve people living with rare/uncommon and neglected dermatological diseases
- Atopic Eczema Forum — an event that will bring together the atopic eczema community for continued collaboration.

The *GlobalSkin 2019* Conference program can be found on the newly launched [Conference website](#).



Global Research on the Impact of Dermatological Diseases (GRIDD)

It has been a very successful year for the Global Research on the Impact of Dermatological Diseases (GRIDD) project – the first patient-initiated and patient-led impact global research study in dermatology.

The research team, led by Professor Matthias Augustin, University of Hamburg and Professor Christine Bundy, Cardiff University, in conjunction with GlobalSkin's leadership has achieved the following:

- The GRIDD methodology was completed in the final quarter of 2017.
- Poster sessions:
 - 5th World Psoriasis & Psoriatic Arthritis, Stockholm, SE
 - IAPO Global Patients Conference, Miami, US
 - EADV, Paris, FR
- Scientific Advisory Board recruitment is ongoing to ensure regional diversity. Several members are confirmed with the remainder to be confirmed over the next several months so that their first meeting can take place at the American Academy of Dermatology AGM in March 2019.
- Stakeholder Advisory Committee meetings were held twice in 2018 – at the AAD in February and at the EADV in September.
- The Systematic Literature Review will be complete by the end of 2018. The protocol has been published on [Prospero](#).



Do we truly know what it's like to live with skin disease?

GRIDD will generate data that paints a clear picture.

Get involved:
www.globalskin.org/GRIDD



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 helps patient leaders and the patients they serve.

Founding Visionary Partners	LEO Pharma and Celgene
2018 Core Mission Partners	LEO Pharma (Platinum) Sanofi Genzyme Regeneron (Gold) Pfizer (Gold) Galderma (Bronze) Celgene (Bronze)
<i>GlobalSkin 2019</i> Conference Partners	LEO Pharma (Platinum) Sanofi Genzyme & Regeneron (Gold) Pfizer (Gold) Novartis (Bronze) Galderma (Contributor) Pierre Fabre (Contributor)
GRIDD Partners	LEO Pharma (Silver) Sanofi Genzyme Regeneron (Bronze) Galderma (Contributor) Novartis (Contributor) Sun Pharma (Contributor) Pierre Fabre (Supporter)

Looking Ahead to 2019



In the coming year, 2019, GlobalSkin will continue to build and mature as an organization as it delivers on key commitments related to its three strategic pillars: research, advocacy and support. The focus will be on continuing to build and support membership, hosting the *GlobalSkin 2019* Conference in Milan, Italy; and undertaking Phase 2 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 which affect people living with dermatological diseases. The organization will continue to build relationships with the World Health Organization (WHO), at the United Nations (UN), and with key government leaders. GlobalSkin will continue to demonstrate its value proposition as a key patient leader resource; and build capacity to manage a growing number of projects and initiatives.

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 and the dermatology community, will improve the likelihood that decision-makers see the claims made by people living with a particular dermatological condition as valid and worth supporting.

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