



YEAR IN REVIEW 2020



International Alliance of
Dermatology Patient
Organizations

GLOBALESKIN.ORG

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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 diseases. These are lifelong burdens for many patients which, in many cultures, can also have devastating social impacts. This simply needs to change. The International Alliance of Dermatology Patient Organizations (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.

This year has been incredibly challenging - full of uncertainty and experiences we could never have imagined when we rang in the New Year in January 2020. Because of COVID-19, priorities shifted, work environments changed, family lives were affected in so many unexpected ways and, sadly, many people lost family members or friends.

Through mutually supportive efforts, the GlobalSkin Community has persevered. This was evident all year long. Member organizations put in place new virtual services for their patient communities as in-person access to healthcare providers was limited for many weeks or months. GlobalSkin launched many responsive programs focused on Members' evolving needs. Our stakeholders and partners stepped up and carried on with critical support which helped bring this all to life throughout 2020.

GlobalSkin celebrated its fifth anniversary as an organization in 2020, and there is so much to be proud of and countless people to thank for being part of this journey. We celebrate this anniversary with our Members, supporters and the entire dermatology patient community!



BUILDING THE MOVEMENT

Organizational Excellence

Strong governance continues to underpin the organizational structure of GlobalSkin led by the globally diverse and multi-dermatological disease representation on the Board of Directors. This year was the organization's second year of its three-year strategic plan which was adopted by the Board of Directors in 2019.

The Board of Directors led the creation of several new Board Committees to further enhance their strategic leadership and oversight. New Board Committees in Finance and Governance were created to complement existing committees - Nominations, Conference and Membership. Each Committee is chaired by a current Board Director and supported by volunteers from the wider GlobalSkin membership as well as a staff representative.

Board elections were held in September 2020 following the Annual General Meeting and two Directors were re-elected: David McMahon, Irish Skin Foundation and Cheryl Talent, Eczema Association of Australasia Inc. Learn more about David, Cheryl and the remaining six Board Directors [here](#).

Our knowledgeable and experienced Board of Directors is an essential contributor in leading GlobalSkin as it builds support for our Member organizations, unifies voices, and helps build a world where people with dermatological conditions can lead healthy lives with timely access to the care and treatment they need.

GlobalSkin's professional staff are also key in effective and timely program delivery to Members and delivering on the Board's vision for the organization. Please see all [staff profiles here](#).

MEMBER ENGAGEMENT

GlobalSkin actively strives to grow its broad global alliance of patient organizations to represent as many dermatological 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.

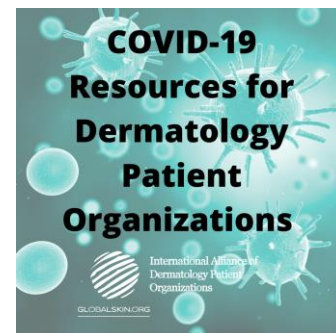
GlobalSkin Membership



GlobalSkin Members are located in 58 countries and represent more than 65 dermatological disease areas. The organization realized 10% year-over-year membership growth, closing out 2020 with 177 Members. GlobalSkin also expanded its geographic representation from 52 to 58 countries.

With the onset of the pandemic, GlobalSkin created a dermatology-focused [COVID-19 Resource page](#) on our website where the most up-to-date information available could be accessed by patient organizations. With over 730 views since April the page was a go-to resource for Members all year long.

Furthermore, GlobalSkin developed a **COVID-19 Townhall Webinar Series** with experts from the International League of Dermatological Societies (ILDS), Cardiff University, Pediatric Dermatology Research Alliance (PeDRA) and the European Academy of Dermatology and Venereology (EADV). These highly informative and well-attended events provided Members with access to dermatology researchers, experts in behavioural medicine and psychodermatology. Both the webinar recordings and resources can be accessed [here](#).



A Members' Needs Assessment survey was conducted in 2020 and found that one of the main needs of GlobalSkin Members is the development of fundraising skills. To help meet this need, GlobalSkin hosted a six-part **Fundraising E-learning Series**, with free tools and resources focused on grassroots fundraising concepts. This learning series was a huge success and is available for continued viewing and reference as a benefit to all Members.

A second program that was launched to further directly assist Members was the **[GlobalSkin Member Impact Fund](#)**. This grant program provides direct financial support to Members by supporting planning and execution of patient-led initiatives in the following categories: Event

Planning, Communications and Marketing, Advocacy, and Organizational Development. In the first year of the program, 24 Members located in 14 countries received funding for their projects. These Members have until June 2021 to complete their projects. GlobalSkin looks forward to sharing inspiring stories about these special projects as these projects are completed.

Recognizing the need to keep GlobalSkin Members engaged and informed about upcoming events, initiatives, and opportunities, a monthly *Members Matter Bulletin* was launched in 2020. In addition to featuring opportunities, a [Meet the Member Spotlight](#) is included where an organization leader is selected and interviewed each month. This brings awareness to their disease community and the work being accomplished in their country and region.



**November 2020
Out Now**

 Check your inbox

A quarterly GlobalSkin Newsletter also provides Members as well as other important stakeholders with an update on GlobalSkin's thought leadership activities and other relevant topics.

GlobalSkin continued to host its online member collaboration space on Workplace (by Facebook) which provides an inclusive space where Members can collaborate privately as a community.

In 2020, GlobalSkin increased its social media presence by posting a steady stream of relevant content on various channels. As a result, the number of followers significantly increased - doubling in size on Twitter from 922 to 1847 and growing impressively by 33% on Facebook taking our audience from 16,500 to 25,000 followers. To further the organization's reach, a new Instagram account was created in September and gained 173 new followers in three short months. GlobalSkin's LinkedIn profile was renewed in 2020, adding a new audience of 324 followers. The GlobalSkin YouTube Channel, where recorded webinar content and informational videos on subjects like GRIDD are housed, also saw more than double the amount of activity. Videos were viewed over 1600 times over the course of the year, up from 717 in 2019.

Community Building

GlobalSkin is actively working to grow its 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 regions.

GlobalSkin's communities include:

Atopic Eczema

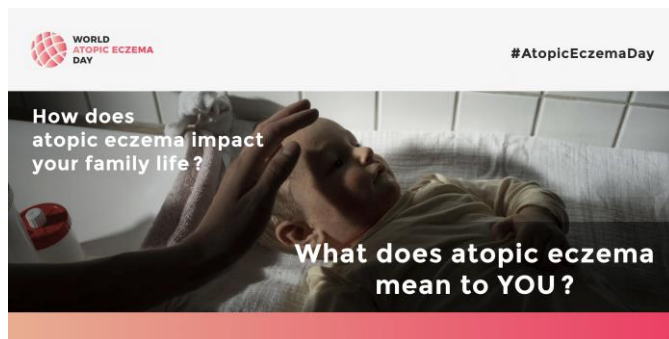
Since 2018, GlobalSkin has engaged a community of atopic eczema patients and patient organizations worldwide and, despite the pandemic, saw a great deal of enthusiasm and connection among members in this community throughout 2020.

GlobalSkin's Atopic Eczema Community developed and approved a [three-year strategy](#) to guide and advance the priorities of patients and the organizations that serve them. Steady progress has been made in 2020 in implementing the year-one activities. An Advisory Committee meets regularly to oversee implementation of the strategy.

In 2020, the Community stayed connected with one another through new quarterly virtual Coffee Chats. These informal meetings allowed for conversations on topics of the day, encouraged peer-to-peer sharing and facilitated connections among our Community Members.

[AltogetherEczema.org](#) continued to act as an information hub for the atopic eczema patient community in 2020.

The third annual [World Atopic Eczema Day](#) was held on September 14. This awareness day initiated by GlobalSkin was a huge success in 2020. The Atopic Eczema Community was not deterred by the pandemic - they were engaged and present globally leading up to and on the day. GlobalSkin, in collaboration with the European Federation of Allergy and Airways Diseases Patient's Associations (EFA), delivered a Campaign Toolkit to Members which was full of communications collateral and was translated into 12 languages. GlobalSkin's own social media awareness day campaign garnered 1.20 million impressions on Facebook and 1.52 million impressions on Twitter.



For the second year in a row, GlobalSkin offered the [World Atopic Eczema Day Grant Program](#). This program offers direct funding to Members for their advocacy and awareness day events and initiatives related to World Atopic Eczema Day. In 2020, 16 GlobalSkin Member organizations from 11 countries benefitted from the program. The impact of this granting program and the full reach of the awareness day campaign can be reviewed in the [World Atopic Eczema Day Report](#).

Throughout September and October, 13 Member organizations participated in a virtual [Atopic Eczema Mobilization Workshop](#). Patient Leaders attended six to eight hours of advocacy training, the learnings of which could be incorporated at their community level. The workshop was offered in two time slots allowing for maximum participation across time zones. Upon completion of the workshop, each participant signed up for a one-on-one coaching session with the facilitator to work on their individual Community Mobilization plans.

GlobalSkin also launched a survey with the purpose of identifying the care priorities, and ongoing care challenges and barriers for people living with atopic eczema as well as for their caregivers.

Over 330 patients took part in the survey. The results are being summarized as an action-oriented set of care imperatives white paper. A landscape analysis and stakeholder mapping exercise of Atopic Eczema also took place in 2020. This analysis will identify policy imperatives along with potential new partnerships and collaboration opportunities with relevant stakeholders.



In December 2020, GlobalSkin hosted an **Atopic Eczema Community Showcase** - an on-demand event that reflected on the Atopic Eczema Community's accomplishments throughout the year. Features included the Community Mobilization Workshop, World Atopic Eczema Day 2020, and reports on community research projects like the Atopic Eczema Landscape Analysis and Care Priorities Survey. Member Organizations hosted virtual booths where

they shared successes from their organizations. The event was specifically for Atopic Eczema Patient Organizations, but was also shared widely with all GlobalSkin Members, stakeholders and partners.

RareDERM



GlobalSkin has been working with the rare dermatological disease community since 2018 to improve linkages significantly and measurably for patient organization leaders.

In early 2020, GlobalSkin's RareDERM Community developed and approved a [three-year strategy](#) to guide and advance the priorities of patients and the organizations that serve them. Considerable progress was made in 2020 in implementing year one activities. The RareDERM Community Advisory Committee met regularly to oversee implementation of the strategy and provided valuable and insightful input along the way.

GlobalSkin undertook an environmental scan of the current RareDERM patient environment including consideration of industry, patient support and government support (orphan drug policies, etc.) in a global context. Phase 1, the qualitative research, was completed in December 2020 and the Report can be viewed [here](#).

In 2020, GlobalSkin CEO Christine Janus was invited to sit on the Chrysalis Project Steering Group led by the IRDiRC which is working towards identifying key factors that lead to research innovation and investment.

Sharing resources and success stories among RareDERM patient organizations was a high priority item in this community in 2020. As such, GlobalSkin developed and created a dedicated landing page on the website for this Community. Visit the [page here](#).

EuropaDERM



With nearly half of GlobalSkin Member organizations located in Europe, this regional group has been prioritized for unique and dedicated GlobalSkin support.

In September 2020, GlobalSkin hired a Senior Advisor for Europe based in Brussels. This was an important turning point for GlobalSkin and its European patient organizations as there is now on-the-ground support for this Community. One-to-one interviews and discussions took place between GlobalSkin and one third of its patient organizations in Europe. Priorities and needs discovered through this outreach provide a starting point for building strategic connections and support for the patient organizations in this region.

An online community event is being planned for early 2021, which will bring together patient leaders in Europe for community priority-setting and identifying common challenges.

GlobalSkin is also planning a multi-stakeholder European roundtable event in 2021 with key dermatology stakeholders to explore best approaches to establishing medical dermatology on the policy agenda. Read more about this Community [here](#).

GlobalSkin 2021 Conference

Planning for the *GlobalSkin 2021* Conference was well underway when the WHO declared a global pandemic in March 2020. This decision effectively halted international travel and the delivery of this event needed to be reconsidered.



Shortly afterwards, GlobalSkin's Board of Directors announced that the 2021 Conference would shift to a virtual format, followed by a continuous learning series to span subsequent months. An in-person conference will now take place in 2022.

GlobalSkin is now planning a meaningful and inspiring event for June 2021 using a highly interactive virtual platform.

AWARENESS

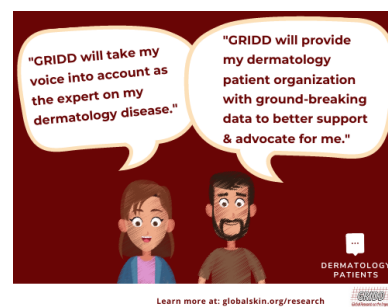
Global Research on the Impact of Dermatological Diseases (GRIDD)



The Global Research on the Impact of Dermatological Diseases (GRIDD) project hit several milestones in 2020. This novel patient-initiated research project, which will measure the true impact of skin diseases from the patient perspective, completed Phase 2 and moved into Phase 3 of 5 this year. The project is co-led by Prof. Dr. Matthias Augustin, Hamburg University, and Prof. Chris Bundy, Cardiff University, and their respective, dedicated researchers.

In 2020, additional Phase 2 quantitative research was undertaken via one-on-one patient interviews. With the help of GlobalSkin Member organizations across several regions of the world, researchers interviewed 28 participants across five disease areas. These interviews further identified the patient items (impacts) and added to the patient impact data collected in focus groups that took place with 72 patients in 2019.

This Phase 2 data will be validated in Phase 3 through a Delphi process that was launched in December 2020 and will end in April 2021. The Phase 3 GRIDD Delphi includes two surveys; Survey #1 invited adult dermatology patients from all regions and as many diseases as possible to take part in the study.



With a minimum target of 1,000 patient participants GlobalSkin called on its membership and network to help ensure that the Delphi had a wide distribution and global awareness. Survey #1 is planned to be open for six weeks, until late January 2021. After the results are analyzed, a second survey will be developed and circulated a month later to the same cohort of participants. In order to capture as wide an audience as possible for the Delphi, the survey was available in six languages including: English, French, Spanish, Arabic, German and Mandarin (Simplified Chinese). GlobalSkin created a Campaign Toolkit, also available in the six languages, to assist Members in spreading the word about the survey to their patient communities.

Following analysis of data from the Phase 3 Delphi, Phase 4 - the drafting of the PRIDD (Patient Reported Impact of Dermatological Diseases) measurement tool - will begin, and by fall of 2021 will undergo standard psychometric testing. It is expected that the PRIDD tool will be ready for global deployment in late 2022.

In 2020, GlobalSkin formed and worked closely with a new Patient Organization Advisory Group to ensure a smooth launch of the Delphi. This group's continued insights will be essential as the project progresses into later phases. The GRIDD Scientific Advisory Board was also an important contributor.

Raising awareness around the research project continued to be a priority for GlobalSkin, and as such, a new dedicated GRIDD section was added to the GlobalSkin website. These pages provide important context and details on the research project; new resources were created to help explain the project including, a video, infographic and pictograph.

HOW GRIDD WILL HELP PATIENTS

"My patient organization has access to data to advocate and fundraise."

"Thanks to great resources and educational materials people in my network now understand my condition!"

"I'm encouraged knowing that the data GRIDD generates has the potential to change the way the world sees dermatology."

GLOBALSKIN.ORG/RESEARCH

GRIDD
Global Research on the Impact of Dermatological Diseases

International Alliance of Dermatology Patient Organizations
GLOBALSKIN.ORG

"My voice is being heard, and I'm finally part of the decision-making process about my care."

"I have an improved quality of life thanks to the support of my patient organization."

"I have better access to specialists, treatments and medications."

The GRIDD Research Team presented abstracts and posters at several key conferences in 2020 including the PeDRA Congress (September), European Academy of Dermatology and Venereology Congress (October) and IDEOM (November). Efforts continued to publish project findings in dermatology journals, however with the onslaught of the pandemic and the multitude of research that was focused on the SARS-CoV-2 coronavirus, it was not possible to secure publication in 2020. The team will continue to pursue options in dermatology journals and research publications in 2021 and hopes that as the global health situation improves, publication about GRIDD will be possible.

We are grateful for our 2020 GRIDD funding partners including: LEO Pharma, Sanofi Genzyme Regeneron, Novartis, Galderma, Pfizer, Bristol Myers Squibb, Pierre Fabre, Sun Pharma, Almirall, and La Roche-Posay.

Thought Leadership

Significant strides continue to be made in building connection and collaboration within the dermatology community. While the pandemic halted travel to conferences and events, GlobalSkin was still able to pursue many opportunities this year to bring the patient perspective to the forefront.

European Academy of Dermatology and Venerology

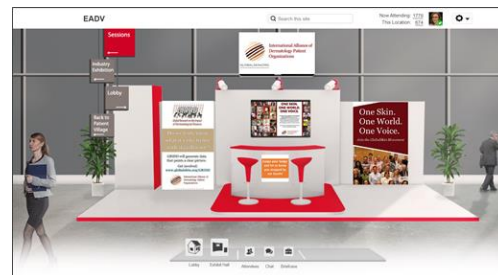
GlobalSkin has been actively working on improving patient organization involvement at the European Academy of Dermatology and Venerology (EADV) Congress for several years. 2020 was considered a break-through year for GlobalSkin, as there were many firsts that came from our ongoing relationship with the EADV. For the first time, a patient organization was invited to sit on the EADV's Patient Association Working Group, and GlobalSkin currently occupies this position.



GlobalSkin also actively and prominently participated in the virtual EADV Congress in October 2020 with another incredible first - Christine Janus, GlobalSkin CEO, gave a plenary presentation to the full EADV Congress. Her presentation, “A Shared Vision - Changing the way the world sees dermatology,” represented the first time a patient advocate had been invited to speak directly to a full congress audience. Over 1600 people viewed Christine’s presentation. Reaching this large and important physician stakeholder group was a noteworthy accomplishment, not only for GlobalSkin, but also for the patient organization members we serve.

Other presentations during the EADV Congress included:

- Plenary Session Presentation by Christine Janus, on Patient Reported Outcomes - “What matters to patients? A Patient’s Perspective”.
- The 4th annual special joint session co-organized by GlobalSkin and the EADV Patient Group on “Improving Your Patient Reviews Through Patient Satisfaction”. This multi-disciplinary event featured four patient organization leaders, clinicians, psychologists and a dermatology nurse association representative.
- GRIDD scientific poster - an audio presentation of the latest phase of GRIDD was available in the e-poster area.
- GlobalSkin Booth - a 3D virtual booth was created as part of the Patient Village at the EADV Congress.



GlobalSkin on the World Stage

GlobalSkin Senior Leadership, including CEO Christine Janus and Executive Director Jennifer Austin, took part in many other events in 2020 including:

- Global Albinism Alliance Exploratory Meeting (Participant, Presenter), Paris
- Patients as Partners in Europe (Presentation), London
- Supporting the Future of Rare Disease Product Development Public Meeting (Participant), Online
- Next Pharma Summit (Presenter), Online
- Patient Partners Leadership Training - Canadian Organization for Rare Disorders (Presenter), Online
- Pharma 4 Change (Presenter), Online
- European Patient Innovation Summit (Participant), Online
- PeDRA Congress (Presenter), Online
- Sanofi Genzyme Regeneron Type 2 Inflammation Event (Presenter), Online
- Dermatology Drug Development Summit (Plenary Presenter), Online
- Rare Disease International Roundtable (Participant), Online
- Geneva Health Forum (Presenter), Online
- La Roche-Posay Live Derm Class (Presenter), Online

Strategic Relationship Building

In 2020, GlobalSkin partnered with the International League of Dermatological Societies (ILDS) on several initiatives including co-hosting webinars for GlobalSkin Members, bringing topics related to COVID-19 to the forefront and coordinating access to key subject matter experts.

GlobalSkin continues work with a large stakeholder group including the following organizations:

- American Academy of Dermatology (AAD)
- Research Scientists, IID, IDEOM, PeDRA
- World Health Organization (WHO)
- IRDiRC, EURODIS, CORD, RDI, Global Genes, NORD
- SFD, IFPA, IPPF, EUPATI, OAC, IAPO
- Our Member organizations - see searchable list [here](#).

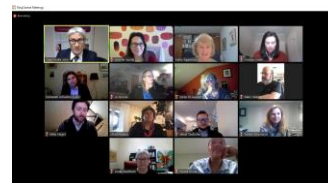
As part of GlobalSkin's reach and expertise, representatives have been invited to sit on several key committees, working groups and task forces:

- EADV Patient Association Working Group
- ILDS Patient Organizations Working Group
- World Congress of Dermatology Scientific Programme Committee
- IRDiRC Task Force - Chrysalis
- EFPIA Patient Think Tank
- PSO Protect/PSO Protect Me Steering/Communications Committee (COVID-19 registry)
- RDI--WHO Collaborative Global Network for Rare Diseases Programme (CGN4RD)
- Global Psoriasis Coalition and Task Forces

COVID-19 Roundtable

GlobalSkin assembled a multi-stakeholder roundtable event in December 2020 to explore collaborative priorities in achieving a better coordinated, multi-stakeholder global leadership agenda to raise the profile of dermatology - now and beyond the current global health crisis.

The group was comprised of patient leaders, researchers, clinicians and nurses and examined challenges that affect dermatology in general, and as exacerbated by the COVID-19 pandemic in particular.



Next steps will be to discuss in more detail a shared set of priorities that will lay the foundation for a roadmap towards improved care for patients.

PARTNERSHIPS

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

Founding Visionary Partners	LEO Pharma and Celgene
2020 Core Mission Partners	Abbvie (Bronze) Almirall (Bronze) Amgen (Bronze) LEO Pharma (Bronze) Pfizer (Bronze) Sanofi Genzyme Regeneron (Bronze) UCB (Bronze) Dermira (Contributor) Galderma (Contributor)
<i>GlobalSkin 2021</i> Conference Partners	Pfizer (Gold) Beiersdorf (Supporter)
GRIDD Partners	LEO Pharma (Silver) Sanofi Genzyme Regeneron (Silver) Galderma (Bronze) Novartis (Bronze) Bristol Myers Squibb (Contributor) La Roche-Posay (Contributor) Pierre Fabre (Contributor) Pfizer (Contributor) Sun Pharma (Contributor) Almirall (Supporter)
Atopic Eczema Community Partners	AbbVie LEO Pharma Pfizer Sanofi Genzyme Regeneron Pierre Fabre Eczema Foundation (in-kind)
RareDERM Partners	LEO Pharma
EuropaDERM Partners	LEO Pharma Pfizer
COVID-19 Roundtable Partners	Pfizer Sanofi Genzyme Regeneron

LOOKING AHEAD TO 2021

At a time when the world is in a state of uncertainty and change, GlobalSkin remains committed to reaching its goals. Dermatology patients' need for support is greater than ever and so is our resolve to support them in meaningful ways. Given the very challenging global reality, we must develop new understanding, new skills, and new approaches to engaging patient organizations and making vital connections to assist in gaining better access to care and treatment for the patients we all serve.

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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To explore partnership opportunities, please contact:

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