



International Alliance of
Dermatology Patient
Organizations

GLOBSKIN.ORG

Year in Review 2021



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LETTER FROM OUR BOARD PRESIDENT

Dear Members and Stakeholders,

It is with great honor that I write my first letter as the new International Alliance of Dermatology Patient Organizations (GlobalSkin) Board President. On behalf of the Board, I extend great thanks and gratitude to outgoing Board President Simmie Smith for her passion, dedication, and commitment to the organization. Her leadership has enabled us to become stronger as she helped us navigate both challenges and successes.



Over the past several years I have had the opportunity to watch GlobalSkin grow to 187 members and represent you on the Executive Committee as Treasurer while working with my Board colleagues, leadership, and staff. It has been exciting to watch and to be part of an organization that is so dedicated to empowering all of us to lead our patient communities by uniting as one voice.

2021 was a challenging but successful year for GlobalSkin. We saw continued growth of membership, patient organization leaders leveraging their expertise and experience to guide us and new partnerships for our organization. The GlobalSkin team provided us with valuable programming like the Impact Fund, Fundraising On-Demand Series and Continuous Learning Series.

As we move into 2022, I look forward to working with the Members, staff, Board of Directors, and Executive Committee in developing a new five-year strategic plan. This plan will help us achieve our mission of leading a global movement to shift the perception of society, decision-makers and researchers to serve all those affected by dermatological conditions. You are the stewards of your communities, and your participation is key. After all, our patient leaders are in over 50 countries, representing the diverse spectrum of over 60 dermatological disease areas.

GlobalSkin is here to support you and your patient communities, and I believe that 2022 holds great things for us all.

Gratefully,

Marc Yale
Board President

LETTER FROM OUR CHIEF EXECUTIVE OFFICER

Dear Members and Stakeholders,

The International Alliance of Dermatology Patient Organizations (GlobalSkin) began 2021 with a change of leadership with the retirement of our founding CEO Christine Janus in January. After being selected to take on the role as interim CEO for several months, the Board announced my formal appointment as CEO in October. I am humbled and grateful to have the support of the Board to take on this unique and fulfilling opportunity. As I collaborate closely with our Board to lead GlobalSkin into the future, our Members will always be our guiding light. They are firmly at the centre of our alliance's strategic vision.



While the pandemic was still very much a reality this year, causing suffering for people all around the world, GlobalSkin and its Members worked hard to adapt and innovate for the benefit of dermatology patients. I'm proud of our live and on-demand virtual programming which provided a sense of connection for our global membership. Highlights in this *2021 Year in Review* include our popular micro-funding programs - the GlobalSkin Member Impact Fund and the World Atopic Eczema Day Fund - as well as the organizational capacity building programming we offer Members like the Continuous Learning Series, On-Demand Fundraising Series and our virtual Patient Leader Conference.

The Global Research on the Impact of Dermatological Diseases (GRIDD) project made great progress this year in finalizing and testing the pilot version of our new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure. We are grateful to our Members for their ongoing support of this project, because without them and their patient community participation, this would not be possible. And no less groundbreaking is the work that GlobalSkin has undertaken in 2021 with the wider dermatology community to form the new Global Dermatology Coalition to prioritize medical dermatology on the global health agenda.

In sharing our 2021 accomplishments with you, we salute our Members and the incredible contribution they make in supporting dermatology patients worldwide. We are so proud of the role they play in raising awareness about the burden and true impact of skin diseases and supporting patients on their difficult journeys. It's an honour to work alongside you in advocating for a world in which people with dermatological conditions lead healthy and fulfilling lives.

Warm regards,

Jennifer Austin
Chief Executive Officer

GLOBALSKIN'S VISION & STRATEGIC PRIORITIES

Our Vision

A world where people with dermatological conditions lead healthy and fulfilling lives.

Our Mission

To lead a global movement for people living with dermatological conditions by:

- uniting patient voices
- empowering patient organizations
- stimulating research
- influencing decision makers
- collaborating with communities of interest

Our Strategic Goals

Member Engagement

- Building a supported, engaged and inclusive member community

Awareness

- Raising society's awareness and understanding of the full impact of dermatological conditions through outreach, collaboration and evidence-based advocacy

Sustainability

- Building a diverse and sustainable organization, positioned for growth with varied funding streams, strong governance and best management practices



MEMBER ENGAGEMENT

GlobalSkin Membership

GlobalSkin is a diverse and broad alliance of dermatology patient organizations that we support and engage with in many different ways. We actively strive to grow our Membership in regional and dermatological representation, while at the same time endeavouring to support our diverse Members and their shared and specialized organizational needs.

GlobalSkin Members are located in 62 countries across the world, covering all continents and supporting patients in 54* dermatological disease areas. In 2021, 10 new organizations joined our alliance to grow our membership to 187 patient organizations. Geographic reach increased this past year by 7% as we welcomed new patient organization members from countries including: Democratic Republic of Congo, Greece, Rwanda and Vietnam.

**Disease areas number changed in 2021 (from 65 to 54) due to a disease area re-classification.*



Supporting our Members

GlobalSkin Member Impact Fund - This micro-funding program provides direct financial support to Members in planning and executing their patient-led initiatives. In 2021, the first year of the program, GlobalSkin supported 24 projects from 14 countries and 12 diseases. Projects ranged from conferences and events to creating disease awareness materials, advocacy projects and in-person patient screening with dermatologists. Seeing these projects come to life around the world has been very powerful as they positively impact patients in their local communities. As projects are completed, their stories are showcased on the [Impact Fund webpage](#). The 2022 Member Impact Fund application intake was a great success and we look forward to sharing the inspiring stories about these special projects as they are completed next year.



"People are more informed, phone calls to our offices have increased, a remarkable number of people are now aware of eczema, and stigma is reducing. We have more volunteers on board, more children in schools are more aware of eczema and what bullying means, also more champions have emerged."

Rachel Ogola, Eczema Society of Kenya
Funded Project: Advocacy campaign to stop stigma in the community and raise awareness about eczema and its impact on patients and caregivers.

On-Demand Fundraising Series: This six-part Fundraising Series was available to all Members this year as an on-demand program with free tools and resources focused on grassroots fundraising concepts. Upon completion of each module, digital badges were awarded and a certificate of completion provided at the end of the program. Since the launch of the program in 2020, 70 Members have benefitted from this series and are on their way to fundraising success for their organizations.

Continuous Learning Series: In 2021, GlobalSkin partnered with the European Patients' Academy on Therapeutic Innovation (EUPATI) to offer our patient leaders a new program to enhance their skills as patient advocates. Patient leaders may take part in the Open Classroom Training to expand their knowledge and understanding of medicines research development, and clinical trials development. This training develops expertise in critical areas and can be tailored to each leader's personal learning goals. GlobalSkin has supported nearly a dozen patient leaders since the program was launched in June by covering the costs of certification for each of the training modules. We look forward to supporting more leaders in 2022.

"I am honoured to receive support from GlobalSkin for the EUPATI training as I am studying hard to become a EUPATI Fellow. These courses will help me learn a lot to improve my patient advocacy work."

Annemarie Sluijmers, LUPUS Europe

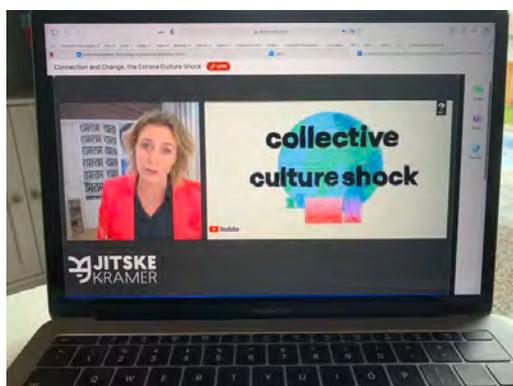
Webinar Series: For the second consecutive year, GlobalSkin partnered with the International League of Dermatological Societies (ILDS) to deliver webinars to our Members. Sessions included: *"Creating a Movement for Rare Disease," "Lessons Learned about the Integrated Care Management of Skin Patients Through the Lens of Atopic Dermatitis," "The Global Psoriasis Atlas Model: Bringing Data to Life"* and *"Changing the Way the World Sees Dermatology Through the GRIDD Project."* These highly informative events connected Members with dermatologists, nurse practitioners and researchers. Members can access webinars and all Member-only programming in the GlobalSkin Members Portal found on our website.



GlobalSkin 2021 Virtual Conference

On June 3, 2021, GlobalSkin brought together 91 dermatology patient group leaders and stakeholders from all regions of the world for a virtual half-day conference. While the coronavirus pandemic forced our biennial conference to take place in a virtual format, the event was designed to create synergies, inspire hope, strengthen connections and provide opportunities to collaborate and network.





The *Thrive 2021* Conference Program included informational and interactive sessions, which offered opportunities to network with other participants and the chance to connect directly with speakers for an intimate question and answer session. Collaborative sessions brought together participants to discuss how and which opportunities can be leveraged to elevate the importance of medical dermatology globally. Participants ideated and prioritized the need for a multi-stakeholder consortium which should clearly define what the dermatology community wishes to do together.

The virtual Conference hosted 23 exhibit booths from patient organization and partners, each with its own virtual booth space with downloadable materials for attendees.

During the event, GlobalSkin offered a Thrive Engagement Game. Participants were encouraged to complete several activities – like attend sessions, visit exhibitors and engage with other event participants – and were awarded points for each completion. Winners chose prizes from the [GlobalSkin Shop](#).

GlobalSkin was pleased to organize this virtual event for our Members and was very proud to have received a 4.6 / 5 satisfaction score from attendees. We look forward to bringing dermatology patient leaders together again - hopefully, in person in 2023! We thank all attendees, event sponsors, and the Conference Committee for making the event a success!

"This is the best run conference I've attended during the pandemic. It has the closest feel to an in-person event which is really great after months of virtual events."

Event Attendee

Connecting with our Members

GlobalSkin connected with Members in numerous ways and on numerous platforms in 2021 to ensure that we had an engaged and informed community. The [GlobalSkin website \(globalskin.org\)](#) is the primary source of information and is frequently updated with new programming, organizational news and events. This year, website traffic increased by 124% over 2020 with a 130% increase in users.

Members received a monthly **Members Matter Bulletin**, providing them with highlights of upcoming events, initiatives and development opportunities. In addition to sharing news about programming, we introduce a new Member through a [Meet the Member Spotlight](#) that features an interview with a patient leader who has just joined our Community. Members are also recognized and showcased in a weekly #FollowFriday social media post on Facebook, Twitter, Instagram and LinkedIn, where



we bring awareness to the organization, their disease community and the work being accomplished in their country and region.

The **GlobalSkin Newsletter** provides Members and other important stakeholders with updates on our thought leadership activities and collaborations. Members had the opportunity to connect on the **GlobalSkin Workplace** (by Facebook) platform.

GlobalSkin continued to utilize social media to reach our Members along with prospective new members by posting a steady stream of relevant content. In 2021, we grew our presence on all platforms and channels over the previous year. Followers on Twitter increased by 73% and grew impressively on Facebook taking our audience from 25,000 to 30,360. On Instagram our followers grew by 52% and GlobalSkin's LinkedIn profile has expanded its reach – increasing from 324 connections to 521. The GlobalSkin YouTube Channel, which houses recorded webinar content and informational videos on subjects like GRIDD, more than quadrupled its activity. Over the last year, our subscribers increased by 260%, views have increased by over 500%, and watch time increased by more than 700%.

Community Building

GlobalSkin has in recent years expanded its principal work of uniting and providing support for all dermatology patient organizations by focusing in on 'communities' of interest and building their capacity. You can learn more about GlobalSkin's Atopic Eczema, Rare Dermatological Diseases, and European Region Communities by clicking [here](#).

Atopic Eczema Community



GlobalSkin's Atopic Eczema Community is an engaged group of 40 patient organizations, located in 28 countries. The Community is in year two of a [three-year strategy](#), which guides and advances the priorities of patients and the organizations that serve them. Steady progress was made in 2021 on community activities, despite not being able to meet in person. The Advisory Committee continued to meet regularly throughout the year as they oversaw implementation of the strategy.

Members stayed connected through quarterly virtual Coffee Chats - a series of informal meetings that facilitate conversations on topics of the day, peer-to-peer sharing and connections among our Community Members.

In October, 15 community members located in 11 countries took part in an Advocacy Alignment Program workshop which stimulated a productive conversation about how GlobalSkin and its Members can best work together to further our collective goals as a Community. The

overarching outcomes of this discussion were a desire for the Community to focus on access to approved medicines, a holistic and standardized approach to care and improved access to better-educated healthcare professionals. These themes will inform a Policymaker Briefing Paper which will be developed by the end of the year and which prompted a landscape analysis into Health Technology Assessment (HTA) guidelines in relation to approving treatments for atopic eczema. The learning from this landscape analysis will provide the discussion topics for a multi-stakeholder panel session in early 2022.

World Atopic Eczema Day 2021 took place on September 14 – the fourth consecutive year of this global awareness campaign. GlobalSkin once again partnered with the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) to create a Campaign Toolkit that contained messaging, social cards and event ideas to mark the day with a theme of #UniteForAtopicEczema. Social cards and key messages were available for download in six languages: English, French, Finnish, Slovenian, Spanish and Turkish which contributed greatly to global engagement and campaign reach. The toolkit was downloaded 426 times from GlobalSkin's website and we are thrilled to see so many patient organizations and dermatology stakeholders participate in this year's campaign.



Each year GlobalSkin contributes to World Atopic Eczema Day by running our own social media campaign and we saw an impressive 5.29 million total impressions across our social channels (Twitter, Facebook, Instagram, LinkedIn) which represents a 94% increase from 2020. Our paid posts also reached 40 countries, a 60% increase from last year.

GlobalSkin offered the **World Atopic Eczema Day Fund** for the third year in a row which provides direct funding to Members for their advocacy and awareness day events and initiatives related to World Atopic Eczema Day. The Fund supported 21 Member organizations in 16 different countries with grants of \$2,400 CAD each in support of their awareness day events in 2021. This represents a 50% increase in the number of projects supported over 2020.



“World Atopic Eczema Day contributes 100% to our goals as it is a perfect way to give eczema the much-needed attention.”

Gunter van Dyke, Allergienet vzw, Belgium

For full campaign analytics and grant recipient stories we invite you to read our [2021 World Atopic Eczema Day Report](#).

RareDERM Community



Over half of GlobalSkin's Member organizations represent patients living with rare dermatological diseases; because of this, we have been working with the rare dermatological disease community to improve linkages significantly and measurably for patient organizations.

In 2021, GlobalSkin's RareDERM Community included 96 patient organizations in 33 countries representing over 29 rare dermatological diseases. This Community continued to implement its three-year strategy advancing the priorities of patients and the organizations that serve them. 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 important and extensive environmental scan with Members of the RareDERM Community in late 2020 and early 2021. GlobalSkin continues to explore insights and opportunities from results of Environmental Scan 2.0. We are planning programming for the RareDERM community in 2022 that will take a deeper dive into different sections of the Environmental Scan, starting with the relationships between rare dermatological comorbidities.

GlobalSkin and the RareDERM Community participated in Rare Disease Day 2021 on February 28 by raising awareness for rare dermatological diseases. Patient organization campaigns were boosted by social media cards and messaging developed by GlobalSkin. These resources were designed to help bring attention to the large number of rare diseases in dermatology. Members were encouraged to use the hashtag #RareDERM in their social posts. We look forward to participating again in 2022 and further evolving our tools, resources and campaign.



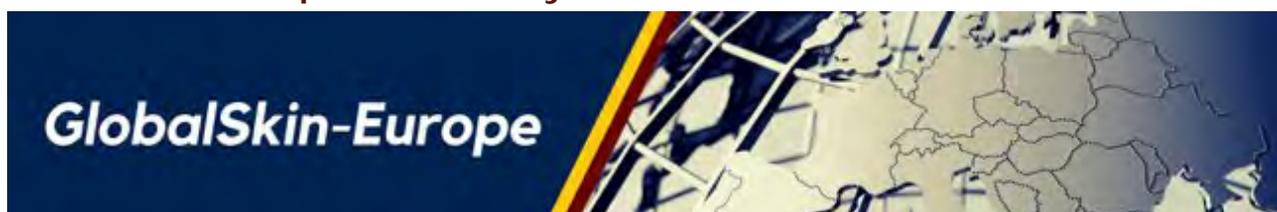
This year, GlobalSkin encouraged the RareDERM community to support and help propel the campaign to establish a UN Resolution on Persons Living with a Rare Disease and their Families (led by RDI, EURORDIS, and the NGO Committee for Rare Diseases). On Thursday, December 16, 2021, the UN General Assembly (UNGA) formally adopted the first-ever UNGA Resolution on "*Addressing the Challenges of Persons Living with a Rare Disease and their Families.*"

GlobalSkin continues to participate in the IRDiRC - Chrysalis Project Task Force which is identifying criteria for making rare disease research more attractive to industry for research and development. GlobalSkin Board President Marc Yale represents the organization on the Panel

of Experts for Rare Disease International to inform the [WHO Collaborative Global Network](#) for Rare Diseases. GlobalSkin has also been invited to help coordinate a patient session at the World Congress on Rare Skin Diseases taking place in 2022.

GlobalSkin continues to share all relevant community information - visit the webpage [here](#).

GlobalSkin-Europe Community



With nearly half of GlobalSkin Member organizations located in Europe, the opportunity arose for GlobalSkin to support the work of this regional group by formalizing as an official community.

GlobalSkin held two meetings with European patient organization leaders in January and March 2021, where it was determined that sharing resources and working together as a European regional community was not only desirable, but critical if access to treatment and care issues are to be effectively addressed and solved.

Following the initial meetings, the GlobalSkin-Europe Advisory Committee was established and has been engaged in developing the parameters of this community initiative. GlobalSkin has strengthened its commitment to building and sustaining this regional community through the presence of a GlobalSkin European Advisor located in Brussels.

In 2021, this Community, comprised of 90 patient organizations, located in 28 countries and representing 21 dermatological diseases, worked towards developing a roadmap which will include key milestones following a four-dimensional approach of community building—identifying, engaging, empowering and mobilizing. The GlobalSkin-Europe Community will build symbiotic relationships with patient organizations, policymakers, industry and researchers to achieve their goals.

In early 2022, all European Members are encouraged to participate in a Community Mobilization Forum which will formalize the objectives and goals for 2022.

Read more about this Community [here](#).

AWARENESS



Global Research on the Impact of Dermatological Diseases (GRIDD)

The Global Research on the Impact of Dermatological Diseases (GRIDD) project made exciting progress in 2021 in its ambition to develop a new measure which will quantify the true impact of skin diseases from the patient perspective. The project is co-led by Prof. Matthias Augustin, Hamburg University, and Prof. Chris Bundy, Cardiff University, and their respective, dedicated researchers.

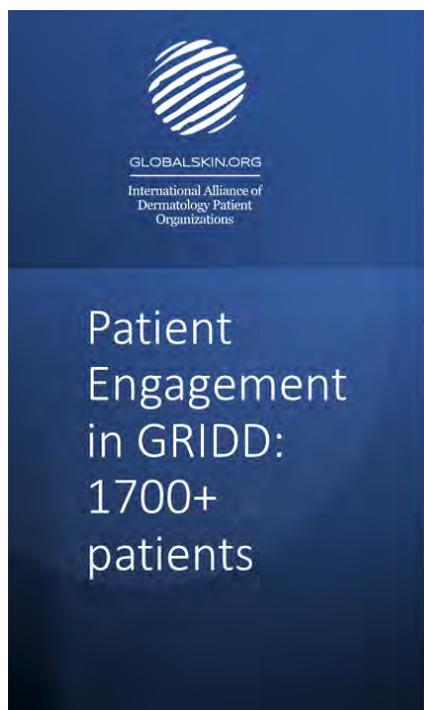
The GRIDD team actively engaged patients around the world to complete a Delphi process, a key step in developing the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure. The GRIDD Delphi was comprised of two consecutive surveys that targeted adults diagnosed with a dermatological condition. The surveys were available in several languages: English, French, Spanish, German, Mandarin (simplified Chinese) and Arabic.

Delphi #1 took place in December and January and saw 1154 patients from 61 countries representing 90 diseases complete 263 questions about the impact of their dermatological diseases. In Delphi #2, which took place in May and June, 493 of the original respondents completed the significantly refined and reduced 76-question survey. Researchers then reduced the items further to 33 items following the analysis of data from the Delphi.



In July and August, GlobalSkin engaged 12 patients representing six dermatological conditions and four countries in Cognitive Interviews to test the comprehensibility, relevance, comprehensiveness, acceptability, and feasibility of PRIDD. Researchers continued their refinement of the measure based on the findings during the interviews. In November, GlobalSkin, with crucial involvement of our Members, launched the Psychometric Testing phase of the pilot version of PRIDD. The survey, now comprised of 26 items, was shared globally and we saw 486 dermatology participants located in 31 countries, representing 49 dermatological diseases take part.

At every stage of this project, we are so grateful to our Members for their active participation and interest in helping us to develop and refine the PRIDD measure. Without their help the project would not be possible. GlobalSkin is very proud to have engaged dermatology patients in every phase of this project. The image below showcases patient involvement over the last three years.



Item Gathering: 2019-2020

- Workshop: **37** patients in **16** countries and **14** diseases
- Patient interviews: **28** patients in **11** countries and **5** diseases
- Outcome: 263 items

Delphi Surveys: 2020-2021

- **1154** patients in **61** countries and **90** diseases
- Outcome: 27 items

Cognitive Interviews: 2021

- **12** patients in **4** countries and **6** diseases
- Outcome: 26 items

Psychometrics Surveys: 2021-2022

- Survey #1: 486 patients (Complete Dec. 1, 2021)
- Survey #2: 500 patients (2022)



In 2021, GlobalSkin continued to work with the [GRIDD Scientific Advisory Board](#) as they help guide and provide strategic advice during the research. We are very appreciative of our esteemed colleagues and their important contributions to our project.

Publishing & Presenting

One of the most exciting milestones achieved this year for the project was the publication of the GRIDD systematic literature review manuscript in the *Acta Dermato-Venerologica* Journal. The article was even selected as editor's choice in October – it is available to view [here](#).

Raising awareness around the research project continued to be a priority for GlobalSkin, and the dedicated GRIDD area on the [GlobalSkin website](#) is regularly updated providing important context and details on this research project. New videos and resources are created to help explain the project and how meaningful it will be to patients and how important it is that they participate in the data collection.

The GRIDD Research Team continued to present abstracts and posters at key conferences in 2021 including the European Society for Dermatology and Psychiatry Congress (June), IFPA Congress (July), European Health Psychology Society Congress (August), PeDRA Congress (September), European Academy of Dermatology and Venereology Congress (October) and IDEOM (November) and is pursuing other journal publication opportunities.

We are grateful for our 2021 GRIDD funding partners including: Sanofi Genzyme Regeneron, LEO Pharma, Novartis, Galderma, Pfizer, Bristol Myers Squibb, Pierre Fabre, La Roche-Posay, and Beiersdorf.

Strategic Relationship Building

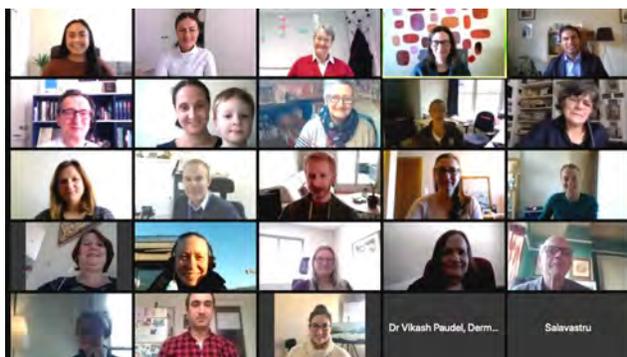
A key component of GlobalSkin's mission is to build connections and opportunities for strategic collaboration within the dermatology community – and bringing the patient perspective to the forefront is always top of mind.

In 2021, GlobalSkin continued to expand our relationship with the International League of Dermatological Societies (ILDS). Recognizing that our partnership with the ILDS was important and valued by both organizations, a Memorandum of Understanding was signed in



International League
of Dermatological Societies
Skin Health for the World

March 2021. This MoU enhances our collective efforts - now and in the future - to improve the lives of dermatology patients through better access to care and treatment, and to address stigmatization, persecution, or economic disadvantages due to their conditions.



In 2021 we co-hosted webinars for both GlobalSkin and ILDS Members focusing on topics related to dermatology and coordinating access to key subject matter experts. GlobalSkin continues to sit on the ILDS Patient Organisation Working Group. GlobalSkin also participates as a member of the World Congress of Dermatology (WCD) 2023 Scientific Programme Committee. As

planning is underway for the WCD having a seat at this planning table is key to including patient representation in the scientific programme and as a keynote speaker.

GlobalSkin continues to work with many stakeholder groups including the following organizations:

- EADV
- EFPIA
- ESDR
- EUPATI
- European Dermatology Forum
- European Medicines Agency
- European Patients' Forum
- Global Genes
- Global Psoriasis Coalition
- GLODERM
- IAPO
- IDEOM
- IFPA
- ILDS
- IRDiRC - Chrysalis
- PeDRA
- PhRMA
- PSO Protect
- Rare Diseases International
- World Congress of Dermatology
- World Patients Alliance

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

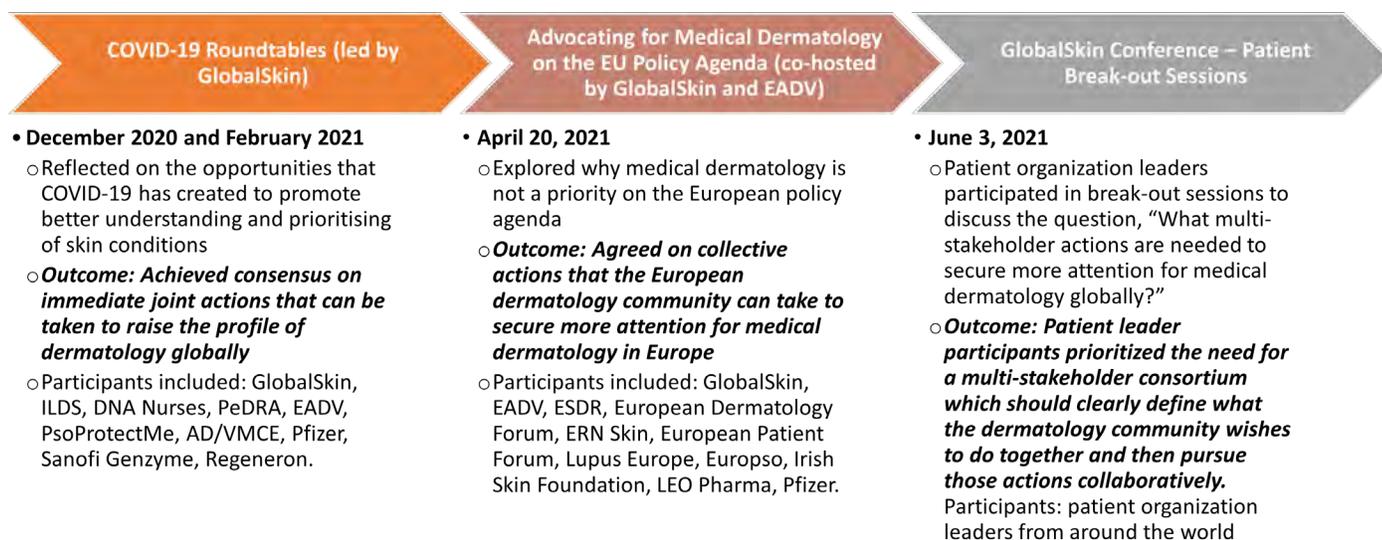
- EADV Patient Association Working Group
- EADV Advocacy Working Group
- ILDS Patient Organisations Working Group
- World Congress of Dermatology Scientific Programme Committee
- IRDiRC Task Force - Chrysalis
- EFPIA Patient Think Tank
- PSO Protect Me Steering/Communications Committee (COVID-19 registry)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

Global Dermatology Coalition

GlobalSkin brought together dermatology stakeholders for a series of multi-stakeholder roundtable discussions in 2020 and 2021. The purpose of these sessions was to explore the challenges and priorities of dermatology patients and the community that serves them. Participants – representing patient organizations, dermatologists, nurses, researchers and industry – were aligned in their perspectives that dermatological diseases are not well-understood and their impacts are underestimated. As a result, patients are underserved and stigmatized, research is under-prioritized and under-funded and access to specialist care is relatively poor.

The shared ambition coming out of these discussions is to improve patient outcomes globally by raising awareness of the impact of dermatological diseases and increasing the healthcare prioritization of these conditions.

Following is a summary of the roundtable process and outcomes:



Following analysis of this multi-stakeholder input, GlobalSkin brought participants back together in October 2021 to discuss how to achieve broad community collaboration that would elevate the profile and understanding of dermatological diseases.

The formation of a Global Dermatology Coalition was explored with feedback collected on how best to establish a forum for ideas, collaboration and joint actions that fulfills on the following agreed-to values:

- An informal multi-stakeholder collaboration between independent organizations, societies, groups, networks, institutions and companies
- It will not be registered or a legal entity
- Patient-led with GlobalSkin as coordinator (i.e. secretariat)
- Democratically run with equal representation and simple majority rule at all levels of decision making
- Transparency and agility in operations and decision making
- Feasible, incremental, efficient, tangible, impactful actions
- Collaborative approach with each member committing to contributing through co-creation (conceptualizing, planning, implementing), people hours, and/or financial resources
- Inclusive and global in focus
- High ethical standards whereby members are equal and do not unduly influence decisions and outcomes – adherence to the Consensus Framework for Ethical Collaboration

GlobalSkin has responded to input and has shared a final coalition framework to key dermatology stakeholders along with an invitation for these organizations to become founding partners in the coalition. Several organizations have already formally signed on and a meeting of these founding partners will take place in January 2022. GlobalSkin is proud to be taking a leadership role in this initiative and, together with stakeholders and funders, is committed to improving patient outcomes globally by raising awareness of the impact of dermatological diseases and increasing the healthcare prioritization of these conditions.

Thought Leadership

GlobalSkin continued to make significant strides in building connections and collaboration within the dermatology community in 2021 – even though the pandemic prevented travel to conferences and events. GlobalSkin was still able to actively pursue many opportunities this year to bring the patient perspective to the forefront.

European Academy of Dermatology and Venerology

GlobalSkin continued to collaborate with the European Academy of Dermatology and Venerology (EADV) and actively work towards expanding patient organization involvement at the 2021 EADV Congress.



The 30th EADV Congress was held as a virtual event in October 2021 and GlobalSkin planned and co-hosted a special joint session with the EADV Patient Working Group. This was the fifth consecutive year for this special joint session between patients and specialists. The session took place on October 2 and was entitled, “*Physical and Emotional Pain of Dermatological Conditions: Helping You Support Your Patients*”. Patient advocates played a prominent role presenting on two important topics: *Minimizing Pain During Treatments and The Physical and Emotional Impact of Living with Severe Itch*.



Also featured at the Congress was the GRIDD research project with a scientific poster and an audio presentation. GlobalSkin also reached participants through a profile created as part of the Patient Village.

GlobalSkin continued to sit on the EADV’s Patient Association Working Group as the patient representative and participated in the EADV’s Advocacy Working Group.

Virtual Conferences and Presentations

Despite the pandemic preventing GlobalSkin staff from travelling to events and conferences in 2021, GlobalSkin CEO Jennifer Austin took part in several virtual events:

- Tioga Research’s “Topical Science Talk” Series, “*Integrating patient experiences at all stages of the topical drug product development process*”
- Atopic Dermatitis Summit (Argentina), A Multi-stakeholder Approach to Achieving Shared International Objectives, (Panelist)
- World Patient Alliance Webinar, GRIDD (Presenter)
- EUPATI AGM, (Presenter)
- PeDRA Congress (Workshop Leader)
- EADV Panel - Addressing skin cancer prevention across the European Union (Presenter)
- La Roche-Posay DermLIVE Skin Health Summit (Presenter)



9th PeDRA Annual Conference



SUSTAINABILITY

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, implementation of the 2019-2022 strategic plan continued.

Board of Directors

Board elections were held in September 2021 following the Annual General Meeting. This year, three new Directors were acclaimed as the Board passed a motion to increase the number of Board Positions from nine to 10. With that change we welcomed Guillermo Gutierrez (Colombia), Gaylord Inena Wa Inena (Democratic Republic of Congo) and Ritu Jain (Singapore) who joined the remaining seven Directors. We are very grateful to all Directors who serve on our Board. To read their profiles and learn more about them, please visit [our website](#).

GlobalSkin Board of Directors 2021-2022

Executive Committee

Marc Yale – President



Cheryl Talent – Vice President



David McMahon – Treasurer



Gaylord Inena Wa Inena - Secretary



Board Directors

Michelle Capon – Board Director



Ito Daisuke – Board Director



Guillermo Gutierrez - Board Director



Ritu Jain - Board Director



Jean-Marie Meurant – Board Director



Vlasta Zmazek – Board Director



Board Committees

In 2021 GlobalSkin's Board Committees provided their strategic leadership and oversight in a number of important areas, including Nominations, Governance, Finance and Risk, Membership and Conference.

GlobalSkin Board Committees

Nominations Committee

- **Vlasta Zmazek, Chair**
DEBRA International
Croatia
- **Cheryl Talent**
Eczema Association of Australasia
Australia
- **Julius Muungano**
Promotion of Education Link
Organization
Tanzania
- **Ogo Maduwesi**
Vitiligo Support and Awareness
Foundation (Nigeria)
Nigeria

Conference Committee

- **Michelle Capon, Chair**
Canadian Association for Porphyria
Canada
- **Vlasta Zmazek**
DEBRA International
Croatia

Governance Committee

- **David McMahon, Chair**
Irish Skin Foundation
Ireland
- **Rachel Ogola**
Eczema Society of Kenya
Kenya
- **Rachael Manion**
Canadian Skin Patient Alliance
Canada
- **Julie Block**
National Eczema Association
USA

- **Oliver Warui**
Vitiligo Group Kenya
Kenya
- **Thea Chassin**
Bald Girls Do Lunch
USA

Finance & Risk Committee

- **Marc Yale, Chair**
International Pemphigus Pemphigoid
Foundation
USA
- **Susan Thornton**
Cutaneous Lymphoma Foundation
USA
- **Gary Lai**
Hong Kong Psoriasis Patients
Association
Hong Kong
- **Murray Turner**
Psoriasis Australia
Australia

Membership Committee

- **Cheryl Talent, Chair**
Eczema Association of Australasia
Australia
- **Jean-Marie Meurant**
Vitiligo International Patient
Organizations Committee
France
- **Susan Thornton**
Cutaneous Lymphoma Foundation
USA
- **Jorge Perez**
Vitiligo Support and Research Group
Cuba
- **Špela Novak**
Društvo Atopijski Dermatitis
Slovenia



Our knowledgeable and experienced Board of Directors and Board Committee Members are essential contributors 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.

We thank and acknowledge the volunteers who help guide our Communities through the Atopic Eczema, RareDERM and GlobalSkin-Europe Steering Committees, and the patient leaders who are on the Strategic Planning Working Group. We appreciate all Members who take the time to be part of our organization's leadership.

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



Partnerships

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

Founding Visionary Partners	LEO Pharma and Celgene
2021 Core Mission Partners	UCB (Silver) Abbvie (Bronze) Amgen (Bronze) Arena Pharmaceuticals (Bronze) Boehringer Ingelheim (Bronze) Eli Lilly & Co (Bronze) LEO Pharma (Bronze) Pfizer (Bronze) Sanofi Genzyme Regeneron (Bronze) Bristol Myers Squibb (Contributor) Galderma (Contributor)
GlobalSkin 2021 Conference Partners	Pfizer (Gold) Sanofi Genzyme Regeneron (Silver) Amgen (Bronze) La Roche-Posay (Bronze) Beiersdorf (Supporter) Pierre Fabre (Supporter)
GRIDD Partners	Sanofi Genzyme Regeneron (Gold) LEO Pharma (Silver) Galderma (Bronze) Novartis (Bronze) Pfizer (Bronze) Bristol Myers Squibb (Contributor) La Roche-Posay (Contributor) Pierre Fabre (Contributor) Sun Pharma (Contributor) Beiersdorf (Supporter) Almirall (Supporter)
Atopic Eczema Community Partners	AbbVie Eli Lilly & Co Pfizer Sanofi Genzyme Regeneron Pierre Fabre Eczema Foundation
RareDERM Partners	LEO Pharma Sanofi Genzyme Regeneron

GlobalSkin-Europe Partners	LEO Pharma Pfizer Sanofi Genzyme Regeneron
Global Dermatology Coalition Founding Partners	La Roche-Posay Pfizer Sanofi Genzyme Regeneron

LOOKING AHEAD TO 2022

Throughout 2021, GlobalSkin's outlook remained positive despite unprecedented challenges facing the world. The organization and its Members have demonstrated resilience and a continued commitment to reaching GlobalSkin's strategic objectives. The need among dermatology patients for support is greater than ever and so is our resolve to support them in meaningful ways. As has been the reality for the last few years, we must continue to 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
- collaborate with communities of interest



For more information on Membership, please contact:

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To explore partnership opportunities, please contact:

Jakub Sadocha, Strategic Partnerships Manager Jakub.Sadocha@globalskin.org