



International Alliance of
Dermatology Patient
Organizations

GLOBALSKIN.ORG

Year in Review 2022

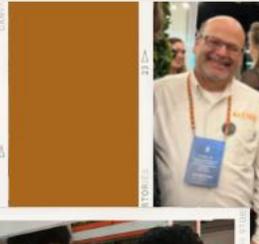
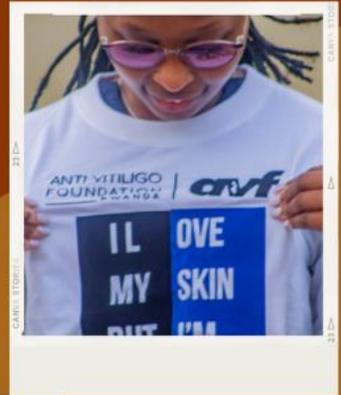


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LETTER FROM OUR BOARD PRESIDENT

Dear Members and Stakeholders,

As 2022 comes to an end, I can't help but reflect on how much positive change has happened this year and how much GlobalSkin has grown. This year we have actively supported our 209 members and encouraged the continued growth of our alliance. We have managed to overcome many challenges during the pandemic, which is deemed to be one of the most difficult and uncertain times in a generation. We are so proud of our accomplishments, which were undertaken with flexibility, agility, thoughtfulness, and grace during unprecedented times. Through it all, we actively engaged our partners and received continued support from our community thanks to all of you!



The 2020-2022 Strategic Plan is concluding, and we will soon begin a new chapter in the evolution of our organization. We began working on a new Strategic Plan in 2021 at the direction of GlobalSkin's Board of Directors. It was decided that this plan would cover a five-year period (2023-2027), providing the organization with a longer period of focus and direction. I would like to thank the GlobalSkin Strategic Plan Working Group who helped guide this important work. Our members were also vital to this process which culminated with a live townhall event immediately following our Annual General Meeting in June. Much gratitude to everyone who participated in this journey. We are thrilled to have a new [Strategic Plan 2023-2027](#) that will guide GlobalSkin in all that it does for the coming five years.

Our vision is creating a world where people with dermatological conditions are healthy and fulfilled. We will accomplish this through four areas of focus:

- Strategic Objective #1 - Elevate - Amplify the voice of the dermatology patient community globally
- Strategic Objective #2 - Champion - Ensure a strong and representative global voice for people affected by dermatological conditions
- Strategic Objective #3 - Unite - Change the way the world perceives dermatological conditions
- And no strategic plan would be complete without building a strong, inclusive, and impactful organization.

As your Board President, I am excited that we have a new roadmap with which to start the new year and feel very confident that it will lead us to continued growth, maturity and success. Most importantly, it will serve to broaden and deepen the support we provide to **YOU**, our members, and will amplify our collective voice supporting dermatology patients worldwide.

Gratefully,

Marc Yale
Board President

LETTER FROM OUR CHIEF EXECUTIVE OFFICER

Dear Members and Stakeholders,

GlobalSkin experienced a year of exceptional growth and in-person connection with our community in 2022. Like everyone else, this followed a virtual existence that began in March 2020. While the pandemic is not over, our organization is learning to live with it, along with the rest of the world. With vaccines and other protective measures in place, we were able to start attending conferences and other events this year, allowing us to expand key collaborations, build even stronger relationships and share GlobalSkin's priorities and successes with the wider dermatology community.



I'm particularly proud of our member organizations' resilience during the past several years and their willingness to participate in important 2022 events with renewed vigor and commitment. It was incredible to see so many of you this year - whether it was at the World Health Assembly side event that we hosted in Geneva in May, the first-ever World Congress on Rare Skin Diseases in Paris in June, in Milan during the European Academy of Dermatology and Venerology Congress in September, or the World Skin Summit in Peru in October. And I can't wait to see you all in Brussels when we host GlobalSkin's Conference - Elevate 2023 in June!

We have a lot to celebrate when we come together next year for our first in-person conference since 2019. We will be launching our much-anticipated global study using the new Patient-Reported Impact of Dermatological Diseases (PRIDD) measure which nearly 2500 of your patients participated in creating. We will all be empowered to do evidence-based advocacy by the data and insights that come from that study. We will recognize incredible patient-support projects that GlobalSkin has been helping to financially support through the Impact Fund. And we will be discussing the newly formed Global Dermatology Coalition, which GlobalSkin helped to found, and how we can all participate in a global awareness campaign in 2024 that communicates the challenges of living with dermatological conditions.

As not-for-profit organizations we all have challenges - whether it's raising funds, recruiting volunteers, or helping others with our limited resources. But we are all also stronger working together by sharing experiences and best practices, learning as a group from experts, and using our collective voice to speak for patients globally.

I am pleased that we can conclude 2022 on such a positive note and look forward to continuing our growth and progress together in 2023. Congratulations to our Members and Partners on all that you do to support people living with dermatological diseases in every corner of the world. I'm honoured to work alongside you.

Warm regards,

Jennifer Austin
Chief Executive Officer

GLOBALSKIN'S VISION & STRATEGIC PRIORITIES 2020-2022

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

1. Member Engagement

Building a supported, engaged and inclusive member community

2. Awareness

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

3. Sustainability

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

2020-2022 GlobalSkin Highlights Include

- ✓ **GRIDD**: Cognitive & Delphi Study (1100+ patients)
- ✓ **Fundraising** Education Program for Members launched
- ✓ **Member Impact Fund** launched



- ✓ **Global Documentary** on Atopic Eczema launched
- ✓ **Global Dermatology Coalition** announced
- ✓ **Participated** in WCRSD, EADV Congress, World Skin Summit
- ✓ **GRIDD**: PRIDD measure complete

2020

2021

2022



- ✓ Jennifer Austin becomes **CEO**
- ✓ **GlobalSkin-Europe Community** launched
- ✓ **GRIDD**: Psychometric testing began
- ✓ Virtual 2021 **GlobalSkin Conference**



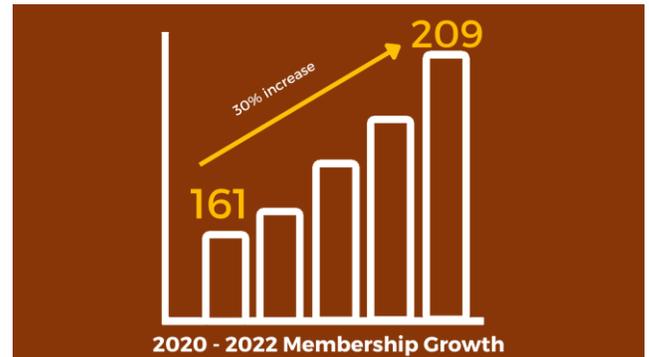
MEMBER ENGAGEMENT

GlobalSkin Membership

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

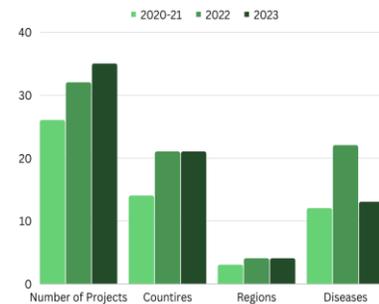
We reached a substantial milestone in 2022 in growing to **200+ Members**. GlobalSkin Members are located in **67 countries** across the world, covering all continents and supporting patients in **57 dermatological disease areas**.

In 2022, 23 new organizations joined our alliance to grow our membership to 209 patient organizations. Geographic reach increased this year as we welcomed new patient organization Members from five new countries including: El Salvador, Uganda, Pakistan, Philippines and Zambia.



Supporting our Members

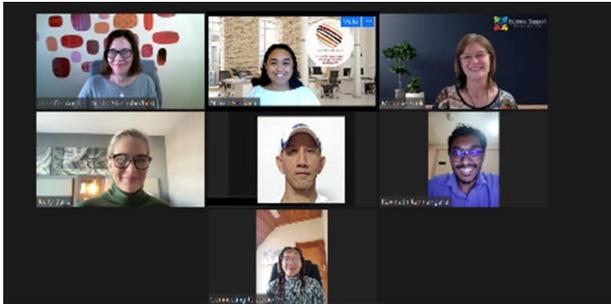
GlobalSkin Member Impact Fund - Our most popular program provides direct financial support to Members in planning and executing their patient-led initiatives. In 2022, the second year of the micro funding grant program, GlobalSkin supported 32 projects from 21 countries and representing 22 diseases. Projects ranged from conferences and events to creating disease awareness materials, advocacy projects and in-person patient screening with dermatologists.



Amount of GlobalSkin Funding Support 2020-23

Seeing these projects come to life around the world has been very powerful as they have meaningful impact in their local patient communities. As projects are completed, they are showcased on the [Impact Fund webpage](#). The 2023 Member Impact Fund application intake period took place in November and once again was a success with 35 applications for projects in 21 countries representing 13 disease areas. We look forward to supporting our largest number of projects to date next year.

Patient Expert Scholarship: GlobalSkin has expanded our Patient Expert Program with the European Patients' Academy on Therapeutic Innovation ([EUPATI](#)). We offer our patient leaders a financial scholarship as they work to enhance their skills as patient advocates. In 2022, five patient leaders were awarded \$4000 CAD each which will be used to cover their course fees enroute to becoming a EUPATI Fellow along with travel expenses to attend graduation. The EUPATI training expands a patient advocate's knowledge and understanding of medicines research and development, along with clinical trials development. GlobalSkin is pleased to support our patient leaders in this endeavour. Jennifer Austin, GlobalSkin CEO, is taking part in the 2023 cohort and leads a learning group with the Scholarship recipients.



"I got quite excited! I'm not based in Europe, so when I saw the application, this is an opportunity for me to have a broader understanding of [research and development in medicine]. I'm Definitely excited and learning new things!"

Gaone Matewa - Beyond Vitiligo

Workshops:

To support patient leaders in 2022, GlobalSkin launched an exciting new workshop series called, "**Practical Solutions to Strengthen Your Organization**", co-hosted with IFPA. This workshop series was dedicated to supporting GlobalSkin and IFPA Members in a collaborative and productive setting. Three workshops were held, led by patient leaders on topics related to strategic planning, community development and working with volunteers.

Practical Solutions to Strengthen Your Organization
A GlobalSkin & IFPA Workshop Series

WORKSHOP #1

"Strategic Planning"

With guest speaker Murray Turner, Chief Executive Officer at Psoriasis Australia and GlobalSkin Finance and Risk Board Committee Member

IFPA International Alliance of Dermatology Patient Organizations

Webinars:

In 2022, GlobalSkin held several webinars for Members on important topics of interest.

- Neil Bertelsen, an expert in patient involvement in [Health Technology Assessment \(HTA\)](#), reviewed the original decision-making processes from several leading HTA bodies when the first new Atopic Eczema biologics were being assessed for reimbursement. To share his findings and learn about different stakeholder perspectives, GlobalSkin hosted a **Virtual Panel Event: Health Technology Assessment Case Study**. Jennifer Austin, GlobalSkin CEO, Rachael Manion, Executive Director at the Canadian Skin Patient Alliance, and Lindsey Smith of Sanofi, on behalf of Sanofi Regeneron, participated as panelists.
- GlobalSkin co-hosted an event with the International League of Dermatology Societies (ILDS) on **Effects of Sunlight on the Skin, and Public Education on Sun Protection**. This highly attended and engaging webinar was led by Dr. Henry Lim, USA. [Watch here](#).

- In October, we held a webinar about our research project: **The Power of GRIDD's Verifiable Data in Your Patient Advocacy**. Dr. Rachel Pattinson, Cardiff University, and GlobalSkin's CEO Jennifer Austin presented the final testing step of developing the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure. Global insights derived from the GRIDD Delphi Study completed last year were also shared as part of the presentation.
- To launch the 2023 Member Impact Fund, a webinar was hosted to provide an opportunity for Members to hear about the successes and learnings from three 2022 Impact Fund recipients. **Elevating our Communities through the Impact Fund** included presentations from Joseph Harerimana - *Anti Vitiligo Rwanda Foundation*, Mateja Krznar - *DEBRA Croatia*, Ajith Kannangara - *Skin Sri Lanka*. Webinar participants had the opportunity to ask questions and learn about the application process.



Members can access webinars and all Member-only programming in the GlobalSkin Members-Only area on [our website](#).

Regional Meetings

In 2022, GlobalSkin focused on diversity, equity, inclusion, and belonging initiatives and hosted three special regional meetings with Members.

On September 23, GlobalSkin co-hosted the latest session with Board Director Gaylord Inena Wa Inena (CORBETTA RDC) for our Members in Africa where the focus was on the experiences and needs of patient leaders in that region. This meeting followed others held for Members in Latin America with Board Director Guillermo Gutierrez (Fundapso) in May, and for Members in Asia co-hosted with Board Director Ritu Jain (Debra International) in June.



We are grateful to our Members for their input during these region-specific meetings as it allows GlobalSkin leadership to plan for the most inclusive and equitable Member programs and support possible. We look forward to more regional meetings in 2023.

Connecting with our Members

GlobalSkin connected with Members in numerous ways and on several platforms in 2022 to ensure that we fostered an engaged and informed community. The **GlobalSkin website** (globalskin.org) is the primary source of information and is frequently updated with new programming, organization news and events. This year, website traffic increased by **199%** over 2021 with a **233%** 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

also showcased our Members in a weekly #FollowFriday social media post on Facebook, Twitter, Instagram and LinkedIn, where we brought awareness to the organization, their disease community and the work being accomplished in their country and region.

The **GlobalSkin Newsletter**, distributed quarterly, provides Members and other important stakeholders with updates on our thought leadership activities and collaborations. GlobalSkin continued to utilize **social media** to reach our Members along with prospective new members by posting a steady stream of relevant content. In 2022, we grew our presence on all online platforms and channels over the previous year. The visibility and reach of all GlobalSkin social media channels (Facebook, Instagram, LinkedIn, Twitter) grew by 46% from the previous year. Our reach on Facebook and Instagram saw an increase of 55% and we doubled our country reach in 2022. The GlobalSkin YouTube channel, which houses recorded content such as webinars on subjects like GRIDD, community workshops and our new Atopic Eczema Documentary, has increased activity by 60% and subscribers by 43%.

GlobalSkin Conference ELEVATE 2023

After several years of only hosting virtual events, GlobalSkin is pleased to share that plans are well underway for the GlobalSkin Conference ELEVATE 2023 in Brussels, Belgium. The conference will take place June 1-4, 2023, at the Brussels Crown Plaza Airport hotel.

We look forward to bringing our patient organization leaders together for several days of learning, sharing and networking. Registration for the event is now open and we are currently building the conference program.

Special thanks to the Conference Committee for their time and expertise as we plan this exciting event.

We are supporting Members' travel and accommodation to attend ELEVATE 2023. A Travel Bursary Program has been launched to assist Members as we hope to have many of our member organizations represented in Brussels. [Learn more and register today.](#)



Community Building

GlobalSkin has in recent years expanded its principal work of uniting and providing support for all dermatology patient organizations by focusing 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](#) has grown to 48 patient organizations, located in 28 countries. In the final year of their three-year community [strategy](#), great strides were made in meeting the priorities of patients and the organizations that serve them. The Atopic Eczema Community

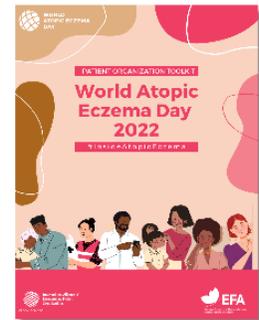
Advisory Committee continued to meet regularly throughout the year as they oversaw implementation of the strategy.

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 the spring, Members met for a two-part workshop series to reflect on accomplishments of the past three years and choose the Community's priorities for the next three to five years.

The GlobalSkin Atopic Eczema Community took on a significant project this year producing a ten-minute documentary, [Skin Our Barrier to the World](#) as told by six patients living with the condition - each from different regions of the world. We connected with and captured stories from patients in the United States, New Zealand, Colombia, Slovenia, Kenya, and Hong Kong SAR, China who shared the burdens that Atopic Eczema presents in their daily lives. We thank our patient organizations in these countries who supported the creation of this documentary and connected us with these amazing patients who so bravely shared their story with the world. [Please watch and share the film.](#)



World Atopic Eczema Day 2022 took place on September 14 – the fifth 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 #InsideAtopicEczema. A big thank you to all GlobalSkin Members and Partners who took part in this year's campaign.



For the fourth year, GlobalSkin offered the **World Atopic Eczema Day Fund** which provides direct funding to Members for their advocacy and awareness day events and initiatives related to World Atopic Eczema Day. The Fund included a new category of Digital Advocacy which increased the amount of funding to almost \$4000 CAD to members in support of their awareness day activities. GlobalSkin supported 22 Member organizations located in 17 countries through the 2022 World Atopic Eczema Day Fund.

For full campaign analytics and grant recipient stories we invite you to read our [World Atopic Eczema Day 2022 Report](#).



DOWNLOADS

- Campaign Toolkit - 1068
- Social Cards - 358
- Blank Social Cards - 261
- Translated Social Cards - 339



GlobalSkin staff attended the **International Society of Atopic Dermatitis (ISAD) Symposium** in Montreal in October. Ten Members of the Atopic Eczema Community were also present through the support of a GlobalSkin travel bursary. Along with attending the Symposium, Members participated in a Community Member Workshop where patient leaders explored the many facets of digital advocacy and reflected on how to use it within their own organizations.



GlobalSkin co-hosted a luncheon with ISAD and the Global Parents for Eczema Research (GPER) / The Global Initiative to Improve Eczema Care. The 70 attendees included healthcare professionals, patient organization leaders, and researchers and explored areas of intersection, alignment, and potential collaboration around research priorities in atopic eczema. Also, GlobalSkin had a booth in the exhibition hall where staff promoted the initiatives of the GlobalSkin Atopic Eczema Community and the GRIDD project.

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 between patient organizations.

In 2022, GlobalSkin's RareDERM Community included 98 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 and the RareDERM Community participated in **Rare Disease Day 2022** 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. The 2022 campaign centred on the theme #MySkinIsRare.

**MY SKIN IS
RARE**



The RareDERM Community took a deeper dive into different sections of the Environmental Scan, starting with relationships between rare dermatological diseases comorbidities. The RareDERM Community's virtual event "**Amplify Your Voice for Rare Skin Disease**" gave attendees an opportunity to hear presentations on findings of the RareDERM Community environmental scan and insights from the GRIDD Delphi study related to rare dermatological conditions. A facilitated discussion led attendees to share their observations about the two sets of data and then generate ideas around ways to work together to improve care for patients with rare dermatological diseases.

World Congress of Rare Skin Diseases: GlobalSkin staff and Members of the GlobalSkin RareDERM Community were in Paris in early June for the first-ever World Congress on Rare Skin Diseases, organized by the European Reference Network (ERN) Skin and La Fondation René Touraine (FRT).



GlobalSkin with the ERN-Skin European Patient Advisory Group, co-hosted a patient-focused panel session - **Building Global Innovative Collaboration for Improved Quality of Life for Patients** - to open the event. In their capacity as members of the ERN-Skin European Patient Advisory Group Working, GlobalSkin Members Antoine Gliksohn (Genespoir - association française des albinismes) and Marie-Claude Boiteux (Cutis Laxa Internationale) collaborated with GlobalSkin to organize and co-host the event.



A robust program, featuring multi-stakeholder presentations and a panel discussion showcased patient collaboration successes to a full room of healthcare professionals. We were honoured to have Durhane Wong-Reiger, Chair, Rare Diseases International, thoughtfully guide us through the session as our moderator.



As we continue to grow GlobalSkin's RareDERM Community, we are grateful for the opportunity to collaborate with ERN Skin and look forward to participating in the World Congress on Rare Skin Diseases 2024.

We continue to stay connected with Rare Diseases International by supporting the UN Resolution on Persons Living with a Rare Disease and their Families (led by RDI, EURORDIS, and the NGO Committee for Rare Diseases), which was formally adopted by the UN General Assembly in December 2021. We support campaigns like #Act4Rare to increase visibility and call for action on the resolution and encourage our Members to do the same.

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, [GlobalSkin-Europe](#) took their Community to the next level in 2022. Working closely with a Community Advisory Committee, this group of 91 patient organizations, located in 28 countries and representing 21 dermatological diseases, had a successful year.

The **GlobalSkin-Europe Forum - Mobilizing for the Future** took place on January 27, 2022. The event was well attended by 20 Members from 13 countries. The event included the first presentation of GRIDD Delphi data (from the European patient perspective), followed by a multi-stakeholder discussion and consultation on the [Community Engagement Plan for 2022-2024](#).

Following this event, the Community worked to finalize a community engagement plan that will guide their efforts for the next two years.

This Plan is empowering the community to unite with a single voice when advocating to health policy-makers in Europe. The Plan’s two main pillars – community building and advocacy – work alongside three building blocks: Action, Build, Collaborate. Initiatives undertaken must have an actionable outcome, insights, and measurements, which must build awareness, and must encompass collaboration among partners.



In 2022, GlobalSkin became quite active in the European health policy and advocacy space ensuring that the voice of dermatology patients is heard and opportunities for input are pursued. Highlights include:

- Achieving “patients’ and consumers” status with the European Medicines Agency, allowing GlobalSkin to be involved in the agency’s activities
- Being active on the European Health Policy Platform by establishing the Dermatology Patients Advocacy Network
- Joining the European Patients Forum Working Group on Universal Access to Healthcare where we inform and support EPF’s work on Universal Health Coverage and Access to healthcare from both a strategic and content perspective



We look forward to continuing to expand our connections at European policy tables in 2023.

Opportunities for in-person connection for the GlobalSkin-Europe Community were facilitated at the European Academy of Dermatology and Venerology (EADV) Congress in Milan in 2022.

Not only did Members attend the EADV Congress and take part in the Patient Advocacy Village, the EADV’s Patient Task Force, and GlobalSkin’s Reception, they also attended the GlobalSkin-Europe Member Event - Pitching the Next Great Idea.



GlobalSkin brought together patient leaders to present initiatives and projects being undertaken in their regions. After a long separation due to the pandemic, this event provided great connection and engagement among those who attended.



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 2022 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 Nirohshah Trialonis-Suthakharan and Dr. Rachael Pattinson.

The GRIDD team actively engaged patients around the world to complete two phases of psychometric testing, a key step in developing the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure. Phase One (Q4 2021/Q1-2 2022), involving 486 patients, tested the validity and structure of the measure. Phase Two (Q3-4 2022) tested the measurement properties including stability and interpretability and involved test/retest surveys. Over 500 people participated in Survey One (test) and 260 took part in Survey Two, (re-test). Data from results of the psychometric testing have been analyzed by the researchers and final edits were made to the PRIDD measure. By the end of 2022, we will have the final PRIDD - a 16-question measure!

We could not have done this without the support of our Member Community at every stage of this project.

This image showcases patient involvement in GRIDD over the last three years.



Planning is well underway for translation and cultural adaptation of PRIDD into 16 languages. In 2022, we engaged with the GlobalSkin Patient Organization Advisory Committee to create a strategy to launch the GRIDD Study using the PRIDD measure in 2023. Recruitment of dermatology patients across the world will be paramount to the success of the GRIDD Study. It is our intention to reach 10,000 patients. We know that our Members will be key to this success and with this in mind we are creating resources and tools to assist in engaging their patient communities.

In 2022, GlobalSkin also continued to work with the GRIDD Scientific Advisory Board as they help to guide and provide strategic advice throughout the research process. We are very appreciative of our esteemed colleagues and their important contributions to our project.

Publishing & Presenting

Publishing about the GRIDD project continues to be a priority for the GRIDD Team. For the second time, the GRIDD project has been published in the *ActaDV Journal*. This publication is about *Phase 2: A Qualitative Concept Elicitation Study*. Please see the link to the [paper here](#).

The Team is pursuing several other journal publications including *Frontiers in Medicine*, *British Journal of Dermatology* and the *JEADV*.



The GRIDD Research Team continued to present abstracts and posters at key conferences in 2022 including the American Academy of Dermatology Congress (March), ISPOR 2022 (May), SPIN Conference (July), ISAD Conference (September), European Academy of Dermatology and Venereology Congress (September), ILDS' World Skin Summit (November), and Digital Skin Summit (December).

Raising awareness about 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 to explain the project and how meaningful it will be in patient advocacy and how important it is that they participate in the data collection.

We are grateful for our 2022 GRIDD funding partners including: Sanofi Regeneron, LEO Pharma, Novartis, Galderma, Pfizer, Bristol Myers Squibb, Pierre Fabre, La Roche-Posay, Beiersdorf, Sun Pharma, Boehringer Ingelheim and Almirall.

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.

Recognizing that our partnership with the International League of Dermatological Societies (ILDS) is important and is valued by both organizations, a Memorandum of Understanding was signed in March 2021. In 2022, GlobalSkin and the ILDS continued to grow and mature this important relationship.



International League
of Dermatological Societies
Skin Health for the World

GlobalSkin attended the **ILDS' World Skin Summit** which took place in Lima, Peru, October 13-15. This was a special and unique global event that brought together ILDS Members - leaders of national dermatology societies - and Partner organizations like GlobalSkin. GlobalSkin was part of the event organizing committee and assembled a delegation of patient organization leaders to participate in the Summit including GlobalSkin's Board President Marc Yale (IPPF), Board Director Tran Hong Truong

(Vietnam Psoriasis Network (PSORVIET)), and GlobalSkin CEO Jennifer Austin. They were joined by GlobalSkin Members Antoine Gliksohn (International Albinism Network), Martin Petroco, (Asociación Civil para el Enfermo de Psoriasis and Asociacion Civil de Dermatitis Atopica Argentina), Carolina Huaman and Maria del Pilar Arinabar (Asociación de psoriasis y artritis psoriásica - Perú - APAPSO PERÚ).

Jennifer Austin had the privilege of presenting to participants on GRIDD as well as on the importance of Patient Organizations and how they can be partners to health care professionals in supporting dermatology patients.



GlobalSkin has also been participating as a member of the World Congress of Dermatology (WCD) 2023 Scientific Programme Committee and has worked to ensure that several patient organization leaders have been invited to present at the event, including GlobalSkin's Board President Marc Yale who will be 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
- PeDRA Patient Advisory Committee
- RDI-WHO Collaborative Global Network for Rare Diseases Programme (CGN4RD)
- Global Psoriasis Coalition

Global Dermatology Coalition

Following a nearly two-year dialogue with the dermatology community led by GlobalSkin, a patient-led multi-stakeholder group of 22 like-minded organizations - including dermatology patient organizations, health care professionals (dermatologists and dermatology nurses), researchers, and industry - announced the formation of the Global Dermatology Coalition. This announcement took place on May 25 during the 75th World Health Assembly in Geneva as a first step in changing perceptions about the often-severe impacts of these diseases and elevating their prioritization in health policy both at global and national levels.



The Global Dermatology Coalition's mission is to harness its collective power to raise awareness about the global impact of dermatological diseases/conditions and increase their health policy prioritization.

The Coalition has been making steady progress since its formation. GlobalSkin as the Coalition Secretariat continues to coordinate the activities of the Coalition. Coalition Partners met in October to set strategic goals and identify initiatives to be undertaken to achieve the objective of raising the prioritization of dermatology on the global health agenda. One of the first initiatives being undertaken is the development of a global awareness campaign. The strategy will be complete by the end of 2022. 2023 will be focused on planning the campaign implementation, and 2024 will see the launch of the campaign which will be open to participation by dermatology patient organizations and other stakeholders.



Thought Leadership

With international travel possible again, GlobalSkin made great progress throughout 2022 in building connections and collaboration within the dermatology community. These are important opportunities to ensure that the patient voice is heard by key stakeholders throughout the wider dermatology community.

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 2020-2022 strategic plan concluded. GlobalSkin developed and approved a new five-year Strategic Plan for 2023-2027.

Board of Directors

On June 22, the GlobalSkin Board Election concluded and results were announced during the Annual General Meeting. Marc Yale (International Pemphigus and Pemphigoid Foundation) and Michelle Capon (Canadian Association for Porphyria) were re-elected; Tran Hong Truong (PSORVIET) was newly elected. 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

Thank You

Executive Committee

Directors

Marc Yale – President



Cheryl Talent – Vice President



Michelle Capon – Board Director



Guillermo Gutierrez - Board Director



David McMahon – Treasurer



Gaylord Inena Wa Inena - Secretary



Ritu Jain - Board Director



Tran Hong Truong - Board Director



Special appreciation goes out to Jean-Marie Meurant, GlobalSkin’s Founding Board President and longest-serving Director, for his many years of service to the Board and our organization - particularly during its formative years. Thank you also to Vlasta Zmazek and Ito Daisuke for their important contributions to the GlobalSkin Board during their terms.

Board Committees

In 2022, GlobalSkin's Board Committees provided strategic leadership and oversight in a number of important areas, including Nominations, Finance and Risk, Membership, and Conference, along with the Governance Committee which concluded its work in 2022. We thank all Board volunteers for their time and for sharing their expertise with us.

GlobalSkin Board Committees

Finance & Risk Committee

- **Marc Yale, Chair**
International Pemphigus
Pemphigoid Foundation
USA
- **Michelle Capon**
Canadian Association for
Porphyria
Canada
- **Gary Lai**
Hong Kong Psoriasis Patients
Association
Hong Kong
- **Rachel Ogola**
Eczema Society of Kenya
Kenya
- **Susan Thornton**
Cutaneous Lymphoma
Foundation
USA
- **Murray Turner**
Psoriasis Australia
Australia

Membership Committee

- **Truong Tran, Chair**
PsorViet
Vietnam
- **Gaylord Inena Wa Inena**
CORBETTA/RDC
Democratic Republic of the Congo
- **Špela Novak**
Društvo Atopijski Dermatitisi
Slovenia
- **Jorge Perez**
Vitiligo Support and Research Group
Cuba
- **Cheryl Talent**
Eczema Association of Australasia
Australia
- **Susan Thornton**
Cutaneous Lymphoma Foundation
USA

Conference Committee

- **Michelle Capon, Chair**
Canadian Association for
Porphyria
Canada
- **Julie Block**
National Eczema Association
USA
- **Guillermo Gutierrez**
Fundapso Colombia
Colombia
- **Susana Palkonen**
European Federation of
Allergy and Airways Diseases
Patients' Associations (EFA)
Belgium

Nominations Committee

- **Michelle Capon, Chair**
Canadian Association for
Porphyria
Canada
- **Ritu Jain**
DEBRA Singapore
Singapore
- **Ogo Maduewesi**
Vitiligo Support and
Awareness Foundation
(Nigeria)
Nigeria

THANK YOU
FOR EVERYTHING!

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 to build a world where people with dermatological conditions can lead healthy lives and can be provided with timely access to the care and treatment that they need.

We thank and acknowledge the many volunteers who help to guide our Communities through the Atopic Eczema, RareDERM and GlobalSkin-Europe Steering Committees, and the patient leaders who were on the Strategic Planning Working Group. We appreciate all Members who take the time to be part of our organization's leadership. [Learn about them here.](#)

GlobalSkin's professional staff are also key in delivering effective and timely programming to Members and in implementing the Board's vision for the organization.

Please see all [staff profiles here.](#)



Partnerships

GlobalSkin is grateful to our 2022 industry partners for supporting the organization's 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 year, which directly helped patient organizations and the patients that they serve.

Founding Visionary Partners	Celgene LEO Pharma	
Core Mission	Abbvie (Bronze) Amgen (Bronze) Boehringer Ingelheim (Bronze) Bristol Myers Squibb (Bronze) LEO Pharma (Bronze)	Pfizer (Bronze) Sanofi Regeneron (Bronze) Galderma (Contributor) La Roche-Posay (Contributor)
GlobalSkin Conference ELEVATE 2023	AbbVie Amgen Beiersdorf Novartis	Pfizer Pierre Fabre Sanofi Regeneron
GRIDD	Sanofi Regeneron (Gold) LEO Pharma (Silver) Novartis (Silver) Galderma (Bronze) Pfizer (Bronze) Bristol Myers Squibb (Bronze)	La Roche-Posay (Contributor) Pierre Fabre (Contributor) Sun Pharma (Contributor) Beiersdorf (Contributor) Boehringer Ingelheim (Contributor) Almirall (Supporter)
Atopic Eczema Community	AbbVie Bristol Myers Squibb Sanofi Regeneron	Pierre Fabre Eczema Foundation LEO Pharma
RareDERM Community	Boehringer Ingelheim Galderma Sanofi Regeneron	
GlobalSkin-Europe Community	Boehringer Ingelheim Sanofi Regeneron	
Global Dermatology Coalition	Bristol Myers Squibb La Roche-Posay LEO Pharma	Pfizer Pierre Fabre Eczema Foundation Sanofi Regeneron

LOOKING AHEAD TO 2023

GlobalSkin's new five-year Strategic Plan is based on four important strategic objectives which support our vision of creating a world where people with dermatological conditions are healthy and fulfilled:

- Strategic Objective #1: Elevate - Amplify the voice of the dermatology patient community globally
- Strategic Objective #2: Champion - Ensure a strong and representative global voice for people affected by dermatological conditions
- Strategic Objective #3: Unite - Change the way the world perceives dermatological conditions
- Strategic Objective #4: Build a strong, inclusive and impactful organization.

GlobalSkin has a strong and clear roadmap to follow for the next five years that will lead to continued growth, maturity and success. And this will serve to broaden and deepen the support that we provide to members. If 2022 was a year of assessing progress in achieving its outgoing Strategic Plan while also planning for the coming five years, then 2023 will be a year of stretching to meet new challenges and looking beyond the visible horizon to a world where our global network of dermatology patient organizations is empowered to speak with one voice for transformative changes in support of dermatology patients worldwide.

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:

- **Elevate** the voice of the global dermatology patient community
- **Champion** the common interests of people affected by dermatological conditions globally
- **Unite** global dermatology stakeholders to bring about transformative change for patients.



For more information on membership, please contact:

Nicole Sudiagal, Members Services Manager Nicole.Sudiagal@globalskin.org

To explore partnership opportunities, please contact:

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