GlobalSkin
Year in Review
2023
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Letter from Board President, Marc Yale

Dear GlobalSkin Members and Stakeholders,

As 2023 ends soon, I am reflecting on how much has been accomplished this year. Our vision of creating a world where people with dermatological conditions are healthy and fulfilled has advanced through our strategic objectives to:

- **Elevate** - Amplify the voice of the dermatology patient community globally
- **Champion** - Ensure a strong and representative global voice for people affected by dermatological conditions
- **Unite** - Change the way the world perceives dermatological conditions
- **Build a strong, inclusive, and impactful organisation**

We **Elevated** our Members at the GlobalSkin Conference in Brussels, we provided funding for 35 projects for Member organizations in 21 countries representing 13 disease areas through the 2023 Member Impact Fund, and we financially supported five patient leaders by awarding Patient Expert Scholarships that allowed them to take part in the *European Patients' Academy of Therapeutic Innovation* (EUPATI) Patient Expert Training Program.

GlobalSkin **Championed** the patient voice at the United Nations (UN), the World Health Organization (WHO), the European Commission (EC) and at the World Congress of Dermatology (WCD).

We **United** our patient advocacy organisations through the Global Research on the Impact of Dermatological Diseases (GRIDD) Study, worked with the World Skin Health Coalition (WSHC) and our many alliance partners in dermatology including the International League of Dermatological Societies (ILDS) and the European Academy of Dermatology and Venereology (EADV) to bring the patient perspective to the forefront.

As your Board President, I am looking forward to all that 2024 has in store. We will continue to amplify your voices wherever you are in the world to have your conditions taken seriously, ensure strong representation through global advocacy, and help to raise visibility by providing critical validation of the often-immense impact of dermatological diseases.

I would like to thank all of **YOU** for your engagement, participation, and support in 2023. As GlobalSkin membership continues to grow with 256 participating organisations from 70 countries representing 58 disease areas, together we are moving closer to creating a world where people with dermatological conditions are healthy and fulfilled.

On behalf of the GlobalSkin Board and staff, I would like to wish you all a happy holiday season and look forward to our collective success in the new year!

Gratefully,

Marc Yale

GlobalSkin Board President
GlobalSkin CEO Jennifer Austin reflects on the organization’s 2023 accomplishments

https://www.youtube.com/watch?v=1o5HQQwXRmc
2023 Executive Summary: Activities

- Rare Disease Day
- WHO Skin NTD Meeting
- Youth Engagement Webinar
- Digital Advocacy Campaign Workshop
- 2023 ELEVATE Conference in Brussels
- Atopic Eczema Forum
- RareDERM Forum
- Regional Meetings
- GRIDD Study launched

Q1

- UN HLM UHC
- WHO Resolution work
- Expanded EUPATI scholarships
- World Atopic Eczema Day & Fund
- #ShareTheBurden Campaign
- WCD – Plenary Presentation by GlobalSkin President!

Q2

- Impact Fund launch
- GRIDD Study to close
- New Member Welcome Call
- First GlobalSkin EUPATI class to graduate
- Rare Disease Day Fund
2023 Membership Summary

January 2023 – December 2023
47 new members
= 22.5% growth

Regional Representation

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<td>Western Pacific</td>
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</tbody>
</table>

TOTAL # OF ORGANIZATIONS: 256
GlobalSkin’s Strategic Plan 2023-2027

**Vision and Mission**

**Vision:** Create a world where people with dermatological conditions are healthy and fulfilled

**Strategic objective #1**

**ELEVATE:**
Amplify the voice of the dermatology patient community globally

![Diagram of people helping each other]

**Strategic objective #2**

**CHAMPION:**
Ensure a strong and representative global voice for people affected by dermatological conditions

![Diagram of a castle]

**Strategic objective #3**

**UNITE:**
Change the way the world perceives dermatological conditions

![Diagram of four hands holding a heart]
In 2023, we ELEVATED our Members.

Capacity Building
- **GlobalSkin ELEVATE 2023 Conference** - We welcomed 200 participants including 142 patient leaders from 124 organizations across 53 countries. ([More details](#))
- **GlobalSkin Youth Engagement Initiative** launched with 10 youth patient leaders agreeing to participate.
- **Training** offered through webinars on Youth Engagement and Digital Advocacy available on GlobalSkin’s YouTube Channel.

Member Impact Fund
- Micro-funding grants provided to 35 patient organizations in 21 countries for 2023 impact projects. ([More details](#))
- Project application intake for 2024 completed -- 40 new projects will be funded next year with special Skin Cancer Awareness category offered.

Patient Expert Scholarship Program
- Scholarships provided to five patient leaders to become EUPATI Fellows (Patient Expert Training Programme – medicines development process.)
- Program expanded in 2023 to 13 participants who will graduate in 2024. ([More information](#))

Regional/Disease Collaboration
- Convened regional meetings to discuss needs/priorities
- Developed campaigns/initiatives to support Atopic Eczema Community, RareDERM Community and Europe Community
GlobalSkin Conference 2023

Achievements:

- **Grew knowledge and built expertise** of patient leaders
- **Launched the GRIDD Study** to support and augment a global movement on the serious impact of dermatological diseases
- **Celebrated the achievements** of our Members with the first-ever Patient Leader Awards
- **Strategized** about the needs and priorities of Members by region
- **Fostered excellence in advocacy** with expert-led presentations and workshops expanding the capacities of dermatology patient organizations
- **Expanded and strengthened our cohesive community** of dermatology patient organizations through networking and information exchange

Feedback from Members

“The workshops and the exercises in the workshops were great; they got us out of our seats, connecting with others, and applying our knowledge in real-time.”

“Inspirational, elevating, good for networking: meeting and talking to many people in person.”

“Inclusive, interactive, unforgettable.”

96% Rated the 2023 Conference as Very Good/Excellent

Read the full Report!
2023 Recap: Atopic Eczema Community

- Steering Committee Meetings
- Mapping of International Care Guidelines
- In-Person Forum: Shared Decision Making. Path to Better Treatment and Care
- Expanded Reach of WAED and Documentary #Share the Burden Campaign
- Environmental Scan of Health Equity Issues in Atopic Eczema
- Partner in Global Atopic Dermatitis Atlas (GADA) Project
- Attendance at International Society of Atopic Dermatitis (ISAD) Annual Meeting, Poland

Read the full details!
RareDERM Forum – The Path Forward: RareDERM Community Priorities and Aspirations

New Community Value Proposition

Rare Disease Day Awareness Campaign

White Paper To Be Posted in 2024 – Living with a Rare Dermatological Disease: A Global Perspective on Impact and Action

Webinar on New Approaches to Rare Skin Disease Drug Discovery

Advisory Committee meetings and Community expansion

Membership and participation in IRDiRC and RDI

Planning for World Congress on Rare Skin Diseases (WCRSD) 2024

Read the full details!
Regional Meeting in October to Identify Needs and Priorities

Advisory Committee Meetings and Coffee Chats

Met with Stella Kyriakides, EU Commissioner for Health and Food Security

In-Person Event at EADV – Building Stronger Bonds: Fostering Effective Partnerships between Patient Organizations and Pharma Industry

Signatory to EADV Call to Action on Chronic Inflammatory Skin Disease & Participated in Burden of Skin Diseases event at European Parliament

Participated in the European Medicines Agency (EMA) Patients and Consumers Working Party

EU Pharmaceutical Legislation Working Group, EPF Working Groups on Universal Health Care

Read the full details!
In 2023, we CHAMPIONED the patient voice.

Dermatology Conferences *(details)*
- Patient Villages (AAD, WCD, EADV)
- Presented in scientific sessions (WCD, EADV)
- Hosted side events (AAD, EADV, WCD)

Awareness Days
- World Atopic Eczema Day 2023 *(report)*
- Rare Disease Day 2023 *(report)*

Global Advocacy *(details)*
- World Health Organization
- United Nations
- European Union
Global & Regional Advocacy

**World Health Organization**
- Began working with dermatology stakeholders to develop a WHO All-Skin Resolution for as early as 2025
- Invited to be a member of the new WHO Civil Society Commission
- WHO’s First Global Meeting on Skin NTDs
- Meetings with ILDS and various WHO departments: Non-Communicable Diseases, ICD-11, Neglected Tropical Diseases, Essential Medicines

**United Nations**
- High-Level Meeting on Universal Health Coverage
- Multi-Stakeholder Hearing on Universal Health Coverage
- Supporting Rare Disease Resolution led by Rare Disease International

**European Union**
- Participated in Burden of Skin Diseases event at European Parliament
- Occupational Skin Cancer Event co-hosted with EADV and ILDS
- Meeting with EU Commissioner of Health

Read the full details!
In 2023, we UNITED to change perceptions.

**Strategic Alliances** *(more details)*
- Co-creation
- Advise on the patient perspective
- Thought leadership

**GRIDD Project** *(more details)*
- Completed validation of PRIDD - new patient-led measure in dermatology
- Collected verifiable data for evidence-based advocacy through GRIDD Study

**World Skin Health Coalition** *(more details)*
- Multi-stakeholder group of 27 organizations
- Built Awareness campaign for March 2024
GRIDD Project

**PHASE 1**
Initiation: Literature Review

**PHASE 2**
Understanding Impacts

**PHASE 3**
Patient Prioritization of Impacts

**PHASE 4**
Testing & Finalizing PRIDD

**PHASE 5**
Translation, Cultural Adaptation, Launch GRIDD Study

**PHASE 6**
Data Analysis & Application

- 2017-18
- 2019-20
- 2020-21
- 2021-22
- 2022-23
- 2024+

Complete Complete Complete Complete Complete
2023 GRIDD Project Recap

✓ GlobalSkin is first user of the **new PRIDD measure**

✓ We are collecting **patient impact data** through the **GRIDD Study** (June to December 2023). The Study was launched in 17 languages at the GlobalSkin Elevate Conference and has seen participation from over 3300 patients. [Read more here](#).

✓ We have engaged the global dermatology community in 94 countries across 95 skin diseases around a **common goal**

✓ GRIDD Project was published in two journals in 2023 - [Read more here](#)

✓ The project was presented in poster and abstract form at several conferences in 2023: ISOQOL, EADV, WHO Skin NTD meeting, PeDRA

✓ Through the study we will be able to develop **new compelling proof-points** for public and policy-maker education
Patient Inclusion in GRIDD: 5600+ patients

**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 (Completed December 2021)
- Survey #2: Test - 504 patients completed July 2022; re-test – 272 patients (Completed Sept. 2022)
- Outcome: 16 items

**GRIDD Study: 2023** used the 16 question PRIDD measure for the first time
- Survey #1: 3380+ patients (To close Dec 31, 2023)
- Survey #2: Re-test 1230+ patients (To close Dec 31, 2023)
What are we?
A patient-led, multi-stakeholder group of 27 like-minded organizations focused on putting medical dermatology on the global health agenda.

Who are we?
Registered organizations with members and/or operations in more than one country with a commitment to dermatology patient care

What do we do?
Harness our collective power to raise awareness about the global impact of dermatological diseases/conditions and increase their health policy prioritization.

How do we do this?
Provide a forum where stakeholders can pool resources to Raise Awareness, Mobilize and Advocate.

Learn more here
2023 Coalition Accomplishments

- Executed Strategic Plan, Year One – comprehensive operations plan guided activities
- Streamlined and formalized governance structure – saw active participation of the Steering Committee and formed two key working groups (Awareness and Advocacy)
- Increased Coalition Partners by 28% – from 21 (January) to 27 (September)
- Welcomed new partners in the HCP/Medical Societies and Patient Organizations groups
- Secured more partners and extended geographic representation – outreach to more partners continues
- Received unanimous approval of the Global Awareness Campaign strategy; extensive research and testing has been done to ensure that the campaign’s message resonates correctly and powerfully with all Coalition partners
- Agreed to the campaign’s core creative concept which involved all Coalition partners and definition of campaign assets and materials
- Began developing awareness campaign for launch in March 2024
- Learn more about the multi-year activities.
GlobalSkin’s Community of Support
Recognition of Outgoing Board Director & Former Vice-President

Cheryl Talent
Eczema Association of Australasia

Director 2016-2023
GlobalSkin Board Committees

Finance & Risk Committee
Marc Yale, Chair
International Pemphigus & Pemphigoid Foundation
USA

Tina Mesarič
Institut Atopika
Slovenia

Rachel Ogola
Eczema Society of Kenya
Kenya

Susan Thornton
Cutaneous Lymphoma Foundation
USA

Murray Turner
Psoriasis Australia
Australia

Nominating Committee
David McMahon, Chair
Irish Skin Foundation
Ireland

Murray Turner
Psoriasis Australia
Australia

Ogo Maduewesi
Vitiligo Support and Awareness Foundation
Nigeria

Conference Committee
Guillermo Gutierrez, Chair
Fundapaco Colombia
Colombia

*Additions will be listed in 2024

Membership Committee
Tran Hong Truong, Chair
PSORVIET
Vietnam

Michelle Capon
Canadian Association for Porphyria
Canada

Gaylord Inena Wa Inena
CORBETTA/RDC
Democratic Republic of the Congo

Maya Tulpule
Shweta Association
India

Špela Novak
Društvo Atopijski Dermatitis
Slovenia

Jorge Perez
Vitiligo Support and Research Group
Cuba

Vlasta Zmazek
DEBRA Croatia
Croatia

Past Board Committee Members (2023)

Gary Lai, Hong Kong
Patients Association

Ritu Jain, DEBRA
Singapore

Cheryl Talent, Eczema
Association of Australasia

Julie Block, National
Eczema Association

Susanna Palkonen, European Federation of
Allergy and Airways Diseases Patients Association (EFA)
GlobalSkin Advisory Committees

**Atopic Eczema Advisory Committee**

- **Vanessa Jenkins**  
  Eczema Association of New Zealand Inc.  
  New Zealand

- **Cheryl Talent**  
  Eczema Association of Australasia Inc.  
  Australia

- **Sabrina Ribau**  
  Canadian Skin Patient Alliance  
  Canada

- **Korey Capozza**  
  Parents for Eczema Research  
  USA

- **Spela Novak**  
  Drustvo Atopijski Dermatitis  
  Slovenia

- **Kelly Barta**  
  Coalition for Skin Diseases  
  USA

- **Rachel Ogola**  
  Eczema Society of Kenya  
  Kenya

- **Tina Mesarič**  
  Atopika  
  Slovenia

- **Michele Guadalupe**  
  National Eczema Association  
  USA

- **Melanie Funk**  
  Eczema Support Australia  
  Australia

**RareDERM Advisory Committee**

- **Susan Thornton**  
  Cutaneous Lymphoma Foundation  
  USA

- **Tricha Shivas**  
  Foundation for Sarcoidosis Research  
  USA

- **Rachael Manion**  
  Canadian Skin Patient Alliance  
  Canada

- **Laurence Gallu**  
  PEM Friends  
  France

- **Marjolein van Kessel**  
  Naevus Global  
  Netherlands

- **Annemarie Sluijmers**  
  Lupus Europe  
  Netherlands

- **Lex van der Heijden**  
  CMTC  
  Netherlands
GlobalSkin Advisory Committees

**GlobalSkin-Europe Patient Leader Advisory Committee**

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<tr>
<th>Name</th>
<th>Organization</th>
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<tr>
<td>Isobel Davies</td>
<td>PEM Friends</td>
<td>UK</td>
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<tr>
<td>Antoine Gliksohn</td>
<td>Genespoir (Albinism)</td>
<td>France</td>
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<td>Africa Luca de Tena</td>
<td>Asociación de Afectados por la Dermatitis Atópica (AADA)</td>
<td>Spain</td>
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<td>Yalchin Mammadov</td>
<td>GlobalSkin</td>
<td>Belgium</td>
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<td>Jaime Melancia</td>
<td>PSOPortugal</td>
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<td>Tina Mesaric</td>
<td>Atopika</td>
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<td>Drustvo Atopijski Dermatitis</td>
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<td>Annemarie Sluijmers</td>
<td>Lupus Europe</td>
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<td>Gunter Van Dyck</td>
<td>Allergienet</td>
<td>Belgium</td>
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<tr>
<td>Karin Veldman</td>
<td>Vereniging voor Ichthyosis Netwerken</td>
<td>Netherlands</td>
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GlobalSkin Advisory Committees

**GRIDD Patient Organization Advisory Committee**

- **Love Gifty Afezuke**  
  Vitiligo Support Bahrain  
  Bahrain

- **Myrlam Ben Lamine Jarrar**  
  Association Tunisienne du Vitiligo  
  Tunisia

- **Laurence Gallu**  
  PEM Friends  
  France

- **Gary Hing-kwan Lai**  
  Hong Kong Psoriasis Patients Association  
  Hong Kong

- **Ritu Jain**  
  DEBRA Singapore  
  Singapore

- **Ogo Maduewesi**  
  Vitiligo Support and Awareness Foundation  
  Nigeria

- **Rachael Manion**  
  Canadian Skin Patient Alliance  
  Canada

- **Bill McCue**  
  PRP Alliance  
  USA

- **Toni Roberts**  
  DEBRA South Africa  
  South Africa

- **Christine Roxburgh**  
  Eczema Outreach Support  
  UK

- **Truong Tran**  
  PSORVIET  
  Vietnam

- **Marc Yale**  
  International Pemphigus and Pemphigoid Foundation  
  USA
Industry Partners 2023 Core Partners

Founding Visionary Partners

- Celgene
- LEO

PLATINUM
- sanofi
- REGENERON

GOLD
- Boehringer Ingelheim
- Pfizer

SILVER
- abbvie
- almirall
- KYOWA KIRIN

BRONZE
- AstraZeneca
- GALDERMA
- Incyte

CONTRIBUTOR
- wcb
- Lilly
GRIDD Partners

**GOLD**

- Sanofi
- Regeneron

**SILVER**

- LEO
- Novartis
- La Roche-Posay

**BRONZE**

- AstraZeneca
- Bristol Myers Squibb
- Galderma
- Pfizer

**CONTRIBUTOR**

- AbbVie
- AMGEN
- Beiersdorf
- Boehringer Ingelheim

**SUPPORTER**

- Janssen
- Immunology
- Pierre Fabre
- SUN Pharma
- UCB
- Almirall
Industry Partners

2023 Conference Partners

PLATINUM

Pfizer

SILVER

abbvie  argenx  Bristol Myers Squibb  NOVARTIS  sanofi  REGENERON

BRONZE

AMGEN

CONTRIBUTOR  SUPPORTER

UTC  almirall  Beiersdorf  Pierre Fabre  New ways to care
Looking Ahead to 2024

ELEVATE
- Member Impact Fund - supporting 40 new projects
- Webinars and training for patient leaders
- Planning GlobalSkin Conference 2025
- Supporting new EUPATI cohort
- Implementation of Atopic Eczema, RareDERM and European Community Plans

CHAMPION
- Expanding support of Rare Disease Day activities
- Continuing to support World Atopic Eczema Day activities
- Growing Global Advocacy efforts – developing WHO All Skin Resolution
- Continuing to represent the patient voice at dermatology conferences
- Developing Regional Networks

UNITE
- World Skin Health Coalition Awareness Campaign
- Co-hosting event with ILDS during World Health Assembly
- Launch PRIDD Measure
- Data analysis and Publication of GRIDD Study
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 Sudiacal, Members Services Manager
Nicole.Sudiacal@globalskin.org

To explore partnership opportunities, please contact:
Jakub Sadocha, Strategic Partnerships Manager
Jakub.Sadocha@globalskin.org