

# GlobalSkin Year in Review 2023



GLOBALSKIN.ORG

International Alliance of  
Dermatology Patient  
Organizations

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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 Venerology (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



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



Q1

Q2

Q3

Q4



- ✓ 2023 ELEVATE Conference in Brussels
- ✓ Atopic Eczema Forum
- ✓ RareDERM Forum
- ✓ Regional Meetings
- ✓ GRIDD Study launched



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

# 2023 Membership Summary



256 Members



70 Countries



58 Disease Areas



## Regional Representation

	#
Africa	36
Americas	78
Eastern Mediterranean	3
Europe	105
Southeast Asia	11
Western Pacific	23
<b>TOTAL # OF ORGANIZATIONS</b>	<b>256</b>



## January 2023 – December 2023

47 new members  
= 22.5% growth



# 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:**

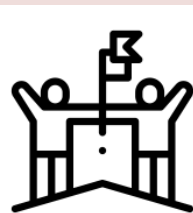
Amplify the voice of the dermatology patient community globally



### 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







# In 2023, we ELEVATED our Members.

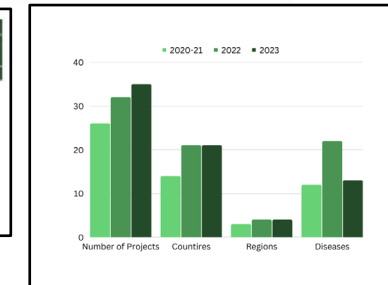
## Capacity Building

- **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](#).



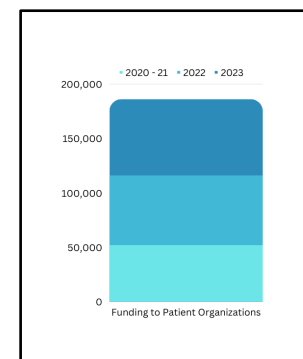
## Member Impact Fund

- 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**



**In-person, June 2-4  
Brussels, Belgium**



**Multi-day dynamic  
and interactive  
program**



**Member engagement  
and networking**

[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!](#)







## 2023 Recap

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



# MY SKIN IS RARE



[Read the full details!](#)



# GlobalSkin-Europe



## 2023 Recap

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

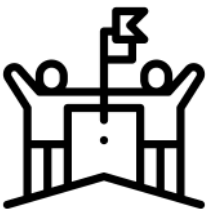
EU Pharmaceutical Legislation Working Group, EPF Working Groups on Universal Health Care



[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](#))

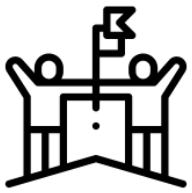


## Global Advocacy ([details](#))

- 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.



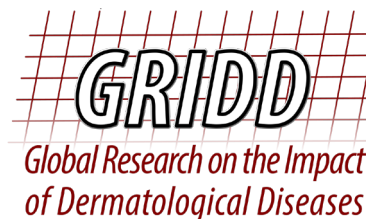
## Strategic Alliances ([more details](#))

- 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



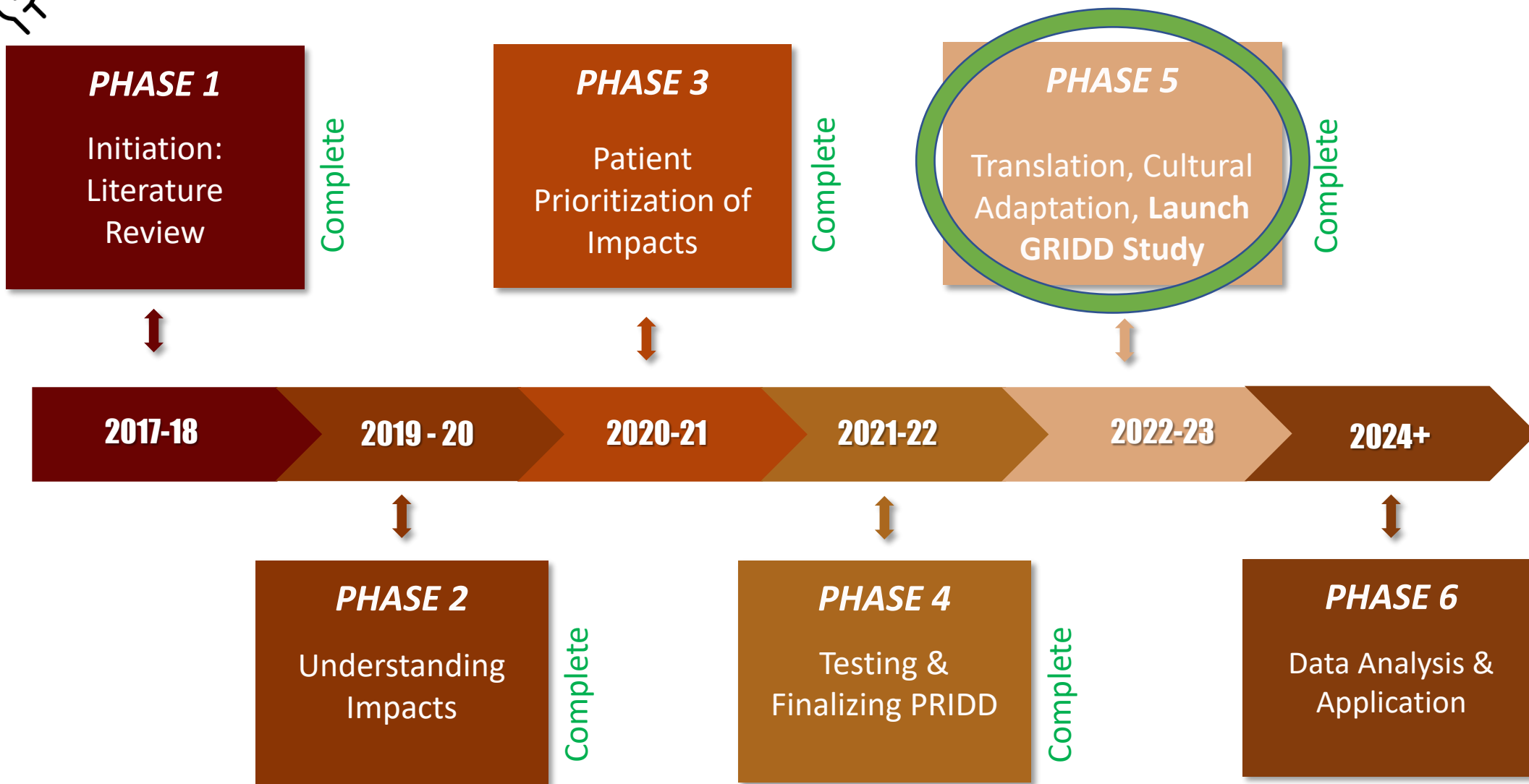
## World Skin Health Coalition ([more details](#))

- Multi-stakeholder group of 27 organizations
- Built Awareness campaign for March 2024





# GRIDD Project







# 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





# GRIDD

*Global Research on the Impact  
of Dermatological Diseases*

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**

Phase  
2

## Delphi Surveys: 2020-2021

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

Phase  
3

## Cognitive Interviews: 2021

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

Phase  
4

## 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**

Phase  
4

## 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)

Phase  
5



University Medical Center  
Hamburg-Eppendorf





## 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



[Learn more here](#) 

## 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.**

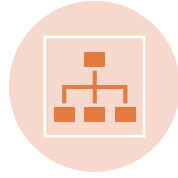




# 2023 Coalition Accomplishments



Executed Strategic Plan, Year One – comprehensive operations plan guided activities



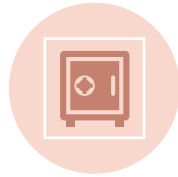
Streamlined and formalized governance structure – saw active participation of the Steering Committee and formed two key working groups (Awareness and Advocacy)



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



# GlobalSkin Board of Directors



## Executive Committee

Marc Yale – President



Ritu Jain – Vice President



David McMahon – Treasurer



Gaylord Inena Wa Inena - Secretary



## Directors

Michelle Capon - Board Director



Guillermo Gutierrez - Board Director



Tina Mesarič - Board Director



Tran Hong Truong - Board Director



Maya Tulpule - Board Director



Murray Turner - Board Director





# 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**

Fundapso 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

### **Isobel Davies**

PEM Friends  
UK

### **Tina Mesaric**

Atopika  
Slovenia

### **Antoine Gliksohn**

Genespoir (Albinism)  
France

### **Spela Novak**

Drustvo Atopijski Dermatitis  
Slovenia

### **Africa Luca de Tena**

Asociación de Afectados por la Dermatitis Atópica (AADA)  
Spain

### **Annemarie Sluijmers**

Lupus Europe  
Netherlands

### **Yalchin Mammadov**

GlobalSkin  
Belgium

### **Gunter Van Dyck**

Allergienet  
Belgium

### **Jaime Melancia**

PSOPortugal  
Portugal

### **Karin Veldman**

Vereniging voor Ichthyosis Netwerken  
Netherlands

# GlobalSkin Advisory Committees

## GRIDD Patient Organization Advisory Committee

**Love Gifty Afezuke**

Vitiligo Support Bahrain  
Bahrain

**Myriam 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

# GlobalSkin Staff



Jennifer Austin  
Chief Executive Officer



Allison FitzGerald  
Director of Operations



Tammi Shipowick  
Programs Director



Visnja Zaborski Breton  
Public Affairs Director



Stephanie Miller  
Communities Manager



Jakub Sadocha  
Strategic Partnerships Manager



Nicole Sudiagal  
Member Services Manager



Lexy Rodionova  
Digital Communications Manager



Fahad Parvez  
Communications Manager



Yalchin Mammadov  
Senior Advisor, Europe



Catriona Grant  
World Skin Health Coalition Coordinator  
Coalition Secretariat – GlobalSkin



Amal Shah  
Grants Coordinator



Marianne Pushavetz  
Executive Assistant



Pam Hanlan  
Finance Advisor



# Industry Partners

## 2023 Core Partners

### Founding Visionary Partners



PLATINUM

sanofi

REGENERON

GOLD



Boehringer  
Ingelheim



SILVER

abbvie



almirall

KYOWA KIRIN

AMGEN

Bristol Myers Squibb™



BRONZE

AstraZeneca



GALDERMA

EST. 1981



CONTRIBUTOR



Lilly

# Industry Partners 2023

## Atopic Eczema Community

abbvie  almirall  AMGEN  Bristol Myers Squibb™

 KYOWA KIRIN



 Pfizer



 sanofi  
REGENERON

## GlobalSkin – Europe Community

 **Boehringer  
Ingelheim**

 Pfizer

## RareDERM Community

 **Boehringer  
Ingelheim**

 sanofi  
REGENERON

## World Skin Health Coalition

GOLD

 Pfizer

 sanofi  
REGENERON

SILVER

 LA ROCHE POSAY  
LABORATOIRE DERMATOLOGIQUE

 Bristol Myers Squibb™

 **Pierre Fabre**  
Taking care, living better

# Industry Partners 2023

## GRIDD Partners

### GOLD



### SILVER



### BRONZE



### CONTRIBUTOR





# Industry Partners

## 2023 Conference Partners

### PLATINUM



### SILVER



### BRONZE



### CONTRIBUTOR



### SUPPORTER



# Looking Ahead to 2024

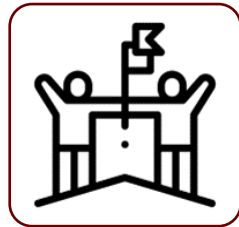


## ELEVATE



- 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](mailto:Nicole.Sudiacal@globalskin.org)

**To explore partnership opportunities, please contact:**  
Jakub Sadocha, Strategic Partnerships Manager  
[Jakub.Sadocha@globalskin.org](mailto:Jakub.Sadocha@globalskin.org)

