



GlobalSkin Initiatives 2021 Progress Report

October 2021



International Alliance of
Dermatology Patient
Organizations

GLOBALSKIN.ORG



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International Alliance of
Dermatology Patient
Organizations



Our Goal: Change the way the world sees Dermatology.

Strategic Priorities



Member Engagement

- *Building a supported, engaged and inclusive Member Community*

Awareness

- *Raising society's awareness and understanding of the full impact of dermatological conditions*

Sustainability

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

Supporting Our Members in 2021

GlobalSkin Member Impact Fund

Financially assisted 24 Members in implementing initiatives in marketing, events, advocacy and organizational development

Accepting applications for 2022 in October

Member Engagement

Meet the Member Series

Monthly Member Bulletins

GlobalSkin Workplace discussion groups

Webinars

E-Learning Fundraising Series

Online training on building fundraising strategies

Badges awarded for completion of each lesson

All sessions available to members online at their convenience

Continuous Learning Series

Helping patient advocates strengthen their role in medicine and research development through partnership with EUPATI

GlobalSkin financially supports member enrollment in EUPATI online courses and Fellow Programme

GlobalSkin Member Impact Fund

Launched in 2020, the GlobalSkin Member Impact Fund was created to financially assist Member organizations in the planning and implementation of patient-led initiatives and projects.

These are just some of the 2021 recipients.



Member Communities

Atopic Eczema

RareDERM

GlobalSkin - Europe



GlobalSkin is actively working to establish a broad global alliance of patient organizations representing as many diseases and countries as possible. At the same time, we have also identified the need to establish several patient organization communities representing specific diseases and regions. As a result, the following three communities have emerged with a focus to build the capacity and advance collective advocacy efforts. We believe by building communities we strengthen the voices of all Members.

2021 Activities

Atopic Eczema
Community



Altogether
Eczema

Coffee Chat Series – quarterly gatherings

Health Care Provider Engagement
Resources

Patient Care Guide and Policy
Document Templates

Multi-stakeholder Round Table

Advocacy Alignment Program



Visit - [Atopic Eczema Community](https://globalskin.org)
(globalskin.org)



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World Atopic Eczema Day

- **Campaign:**
 - Successful social media campaign with more than **2,140,000** impressions/reach on Facebook, **851,000** impressions on Twitter, **77,000** on Instagram and **51,000** impressions on LinkedIn.
 - **2021 Campaign Toolkit** developed in partnership with the European Federation of Allergy and Airways Diseases Patients Associations and shared with over 60 member organizations
- **World Atopic Eczema Day Fund** providing financial support to Members:
 - **22** Patient Organizations projects
 - Located in **16** different countries – UK, Portugal, Belgium, Sri Lanka, USA, Serbia, Slovenia, Australia, Kenya, Israel, Greece, Poland, Sweden, France, Colombia, Bosnia/Herzegovina
 - Each project will receive funding of up to **\$2400 CAD**





2021 Activities

Build and Grow Community

- Quarterly RareDERM Patient Leader Advisory Committee meetings
- Exploring opportunities from results of Environmental Scan 2.0
- RareDERM Community involvement in Rare Disease Day 2021 and preparing campaign for 2022



Activate and Mobilize Community

- Leveraging the power of the GlobalSkin RareDERM multi-stakeholder network
- Supporting RDI UN Resolution for Rare Diseases



RareDERM <-> Rare diseases connections

- IRDiRC TASK Force - Chrysalis project (identifying criteria for making rare disease research more attractive to industry for research and development)
- Member of Panel of Experts for RDI to inform the WHO Collaborative Global Network for Rare Diseases

[Visit RareDERM Community
\(globalskin.org\)](https://globalskin.org)

2021 Activities

Identify and Engage

- Strategically connected with patient organizations through **one-on-one interviews** and write **Landscape Analysis** (2020)
- Setting priorities as a community – **Patient Leader Engagement Event**
- Creating and engaging the **GlobalSkin-Europe Advisory Committee**

Empower

- Building **3-year strategic plan** to build symbiotic relationships with patient organizations, policy-makers, industry and researchers and achieve community's priorities
- Expanding **capacity** through training – especially in communications, outreach, and advocacy

Mobilize

- Presence in **Brussels** since Fall 2020
- **Multi-stakeholder roundtable** co-hosted with EADV took place April 2021
- One-day patient organization **GlobalSkin-Europe Mobilization Forum** in November 2021

GlobalSkin Virtual Conference Thrive 2021

June 3, 2021



Four Dynamic Sessions:

- Jitske Kramer – Keynote; Multi-stakeholder Panel & Member Dialogue; EUPATI; GRIDD Researchers

Interactive:

- One-on-one meet-ups; Networking Sessions

Engagement:

- Exhibitor booths – Patient Organizations and Partners; Thrive Conference Game

[Visit GlobalSkin Conference
\(globalskin.org\)](https://globalskin.org)

Thrive Conference Results

- **91** Dermatology patient group leaders and dermatology stakeholders
- **23** Exhibit Booths from Patient Organization and Partners

*"I liked that the content focused on **leadership, community, and research** - these are areas that are very important to us. It was a great opportunity to take a breath from operations and **think about big picture** issues!"*

*"I like how knowledgeable GlobalSkin is. It's good to **feel part of the bigger picture**. I also enjoyed seeing how you delivered a virtual conference and the platform you used."*

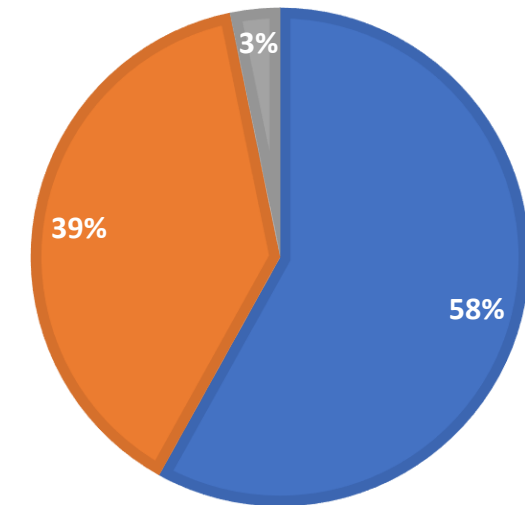
*"Thank you for what you are doing! Your work, support and help to us is **priceless**. Thank you so much."*

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

Overall Event
Rating 4.55 / 5

HOW WOULD YOU RATE GLOBALSKIN CONFERENCE THRIVE 2021?

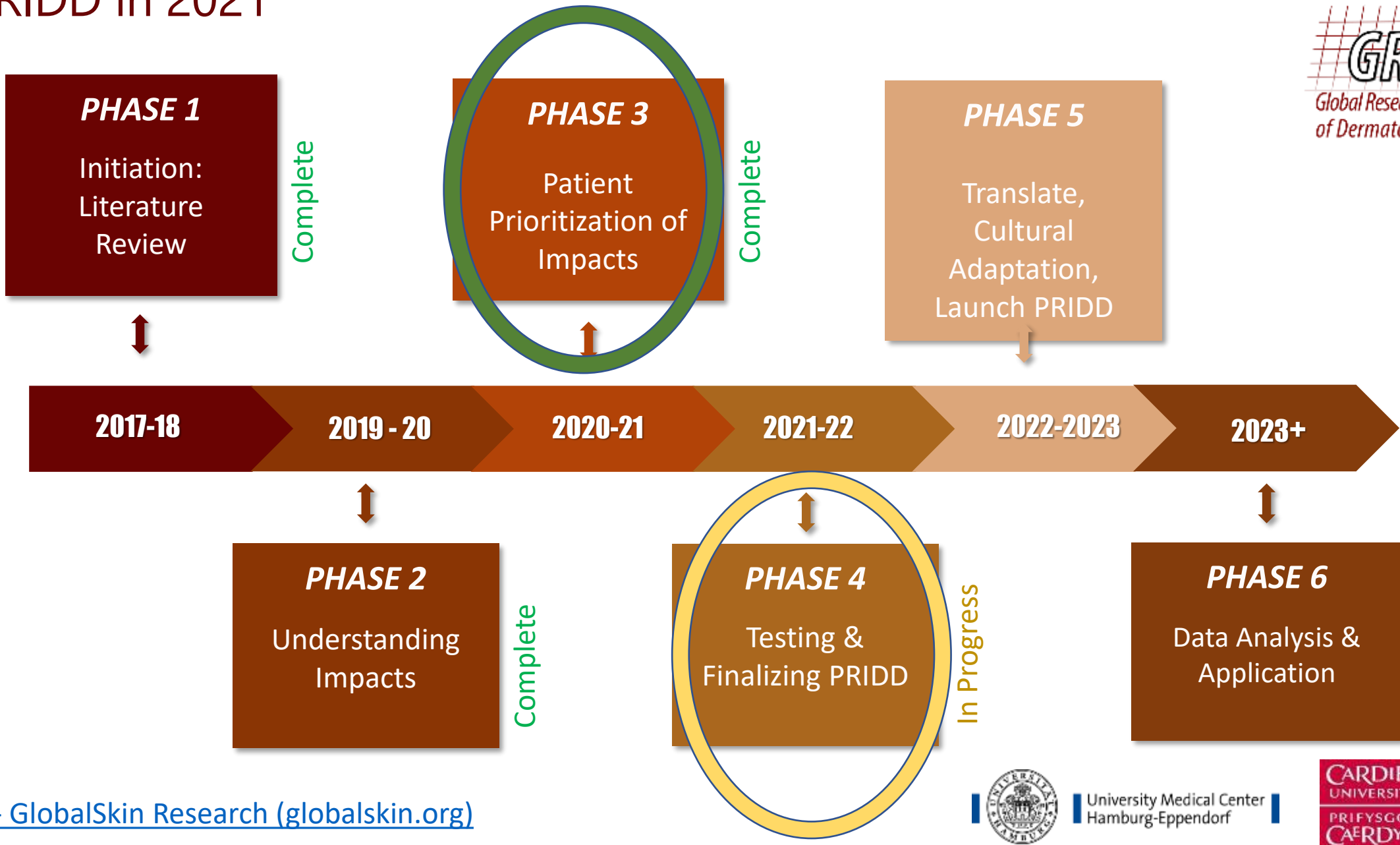
■ Excellent ■ Good ■ Average ■ Fair ■ Poor



97% Good-Excellent



GRIDD in 2021



Visit - [GlobalSkin Research \(globalskin.org\)](http://GlobalSkin Research (globalskin.org))

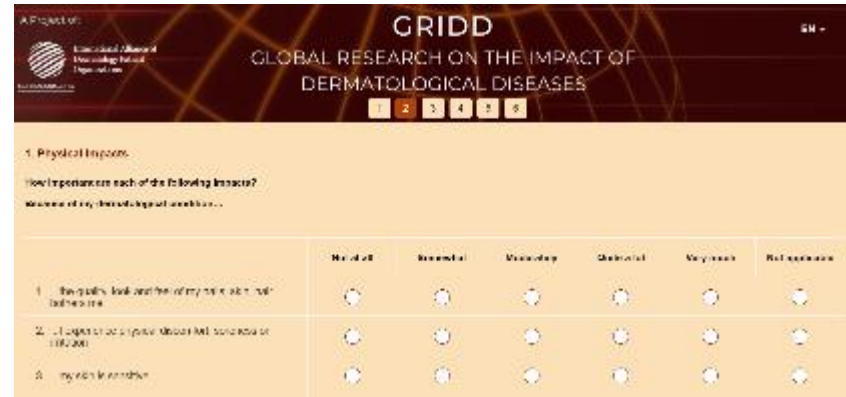
Phase 3

Patient Prioritization of Impacts (Complete)

263 (Delphi 1) → 76 (Delphi 2) → ~33 (Pilot PRIDD)



- **Patient Data Verification Delphi #1 – complete**
 - Purpose: to validate the Phase 2 findings (i.e. patient reported items, accuracy of statements, item gaps etc.)
 - **Six** languages (English, French, Spanish, German, Arabic, Mandarin-simplified Chinese)
 - **1154** patients in **61** countries and **90** diseases included in round 1
- **Patient Data Verification Delphi #2 – complete**
 - **263** questions reduced to **76** questions
 - Same patients asked to participate (493 responses)



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Testing & Finalizing PRIDD



Cognitive Testing

- Purpose: Pilot-test PRIDD with patients to assess whether it works as we intended it to and make refinements accordingly.
- In-depth interviews with 12 patients representing 6 dermatological conditions and 4 countries.
- Each aspect of PRIDD was evaluated – the instructions, recall period, questions and response options.
- Interviews concluded in August





Phase 1

Phase 2

GRIDD Publishing

Manuscript

- Publication in *Acta Dermato-Venerologica*
- Submitted to *Patient Related Outcome Measures* (awaiting editor's decision)



Patient-Reported Outcome Measures in Dermatology: A Systematic Review

TERESITA FELICIANO¹, MARILYN MORALES-RODRIGUEZ², JENNIFER M. JONES³, HELEN M. JOHNSON⁴, LAURENCE M. LAWRENCE⁵, MARCO ORTIZ⁶, TERESITA FELICIANO¹, NICK COOPER⁷, JEROME AKOBI⁸, CHRISTIAN JONES⁹, MATHIAS AUGUSTIN¹⁰ and CHRIS BIRBY¹¹

¹School of Dermatology and Venereology, Cardiff University, Cardiff, UK; ²Department of Health Services Research, Universidad del Rosario (UR) - Universidad Médica del Caribe (UMC) - Universidad del Norte (UN), Barranquilla, Colombia; ³Big Health Ltd, Cardiff, UK; ⁴Department of Dermatology, University of Oxford, Oxford, UK; ⁵Department of Clinical Dermatology, University of Oxford, Oxford, UK; ⁶Department of Dermatology, University of Manchester, Manchester, UK; ⁷Cardiff University, Cardiff, UK; ⁸Cardiff University School of Medicine, Cardiff, UK; ⁹Department of Dermatology, University of Hamburg, Hamburg, Germany; ¹⁰Department of Dermatology, University of Hamburg, Hamburg, Germany; ¹¹Department of Dermatology, University of Hamburg, Hamburg, Germany

Posters/presentations

- EADV; European Society Dermatology and Psychiatry (ESDAP); Health & Care Research Wales 2019
- UK Society of Behavioural Medicine (UKSBM) 2020
- ESDaP; EHPS; IFPA; EADV; PeDRA 2021
- Submitted: ISPOR 2021



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GRIDD Next Steps...



1. Nov. 2021: Selected patient organizations across diseases and regions will be asked to invite 500 patients to participate in PRIDD Psychometric Testing survey
2. Fall 2021: Delphi data analysis and sharing
3. Early-2022: Patient organizations will be again asked to encourage their patients to participate in Psychometric Testing surveys – *test/re-test*
4. Translation will take place after the completion and validation of the PRIDD measure (back translation and validation).



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Global Dermatology Collaboration

COVID-19 Roundtables

- **December 2020 and February 2021**
 - Reflected on the opportunities that COVID-19 has created to promote better understanding and prioritising of skin conditions

Advocating for Medical Dermatology on the EU Policy Agenda

- **April 20, 2021**
 - Explored why medical dermatology is not a priority on the European policy agenda

GlobalSkin Conference – Patient Break-out Sessions

- **June 3, 2021**
 - Patient organization leaders then participated in break-out sessions to discuss the question, “What multi-stakeholder actions are needed to secure more attention for medical dermatology globally?”

Common Themes: Dermatological diseases are not well understood, and their impacts are underestimated.

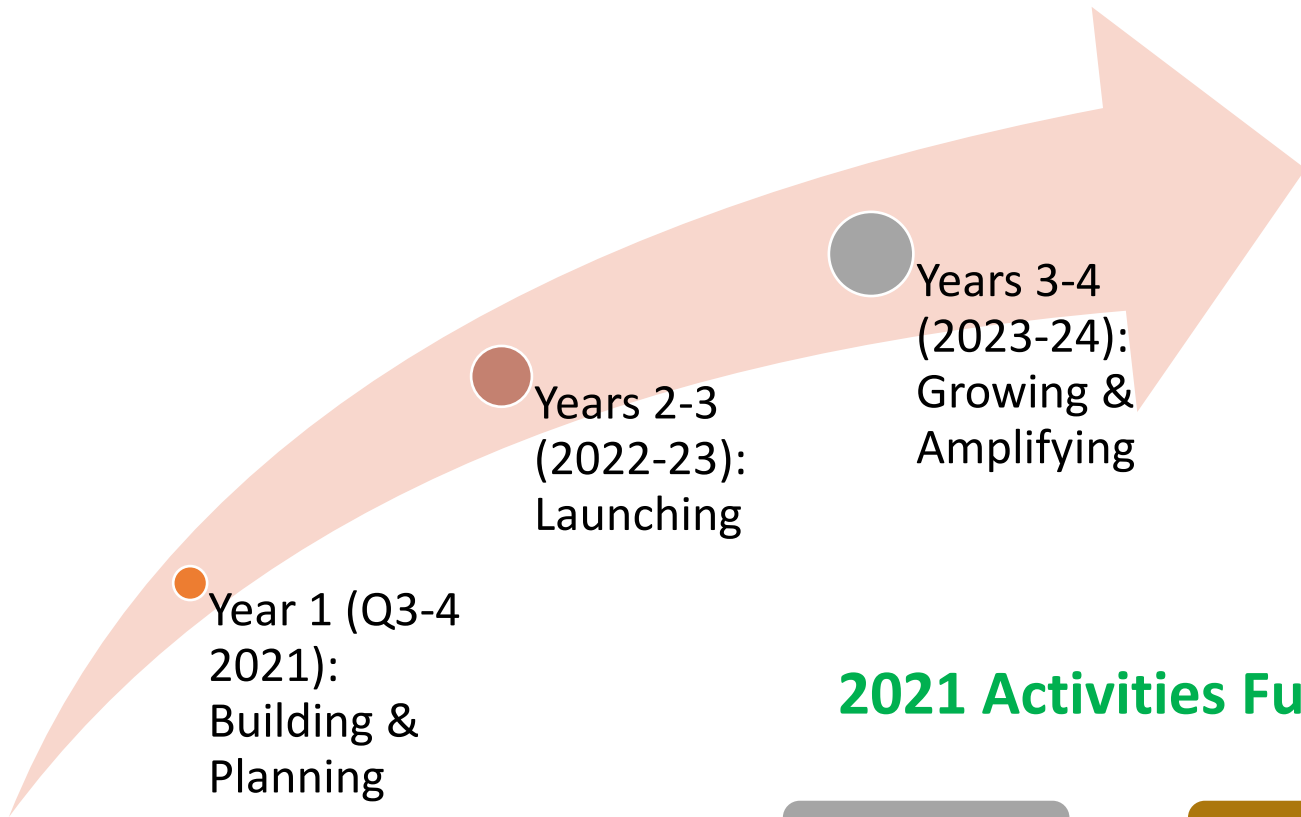
Recommended Calls to Action:

- Destigmatize dermatological conditions
- Show the true burden of dermatological conditions by collating existing data and gathering new data
- Raise the bar for patients’ timely access to high-quality, integrated, person-centred care and treatment.

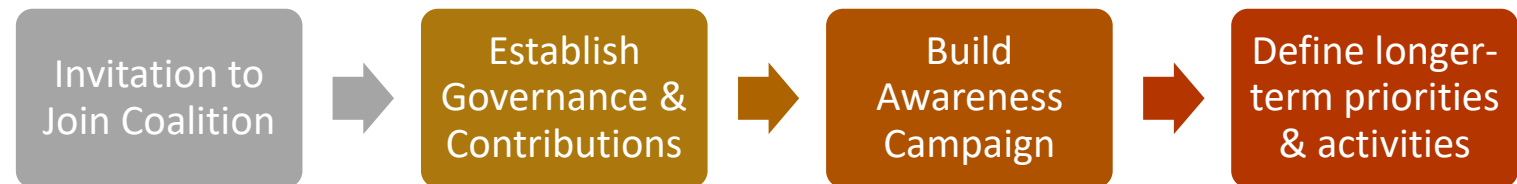
Building a Global Dermatology Coalition - Together

1. **Informal multi-stakeholder partnership** initiative composed of independent organizations, societies, groups, networks, institutions and companies.
2. **Patient-led** with GlobalSkin as coordinator (i.e. secretariat).
3. **Democratically run** with **equal representation** and simple majority rule at all levels of decision making.
4. **Transparency** in operations and decision making.
5. **Feasible, incremental, efficient, tangible, impactful** actions.
6. **Collaborative** approach with each member committing to contributing through **co-creation** (conceptualizing, planning, implementing), people hours, and/or financial resources.
7. **High ethical standards** whereby members are equal and do not unduly influence decisions and outcomes. Adherence to the [Consensus Framework for Ethical Collaboration](#).

Global Dermatology Coalition - Approach



2021 Activities Funded by Pfizer and La Roche-Posay:



Strategic Relationships

GlobalSkin builds key relationships and collaborations to help further the cause of supporting our patient organizations and their dermatology patients around the world.

- 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/PSoProtectME
- Rare Diseases International
- World Congress of Dermatology
- World Patients Alliance



GlobalSkin Board of Directors 2021-2022

Executive Committee

Simmie Smith – Board President



Term concluded
October 2021

David McMahon – Board Vice-President



Michelle Capon – Board Director



Ito Daisuke – Board Director



Vlasta Zmazek – Board Director



Jean-Marie Meurant – Board Director



Directors

Marc Yale – Board Treasurer



Cheryl Talent – Board Secretary



Julius Muungano – Board Director



Term concluded
October 2021

Incoming Board Directors 2021-2022

October 2021



Guillermo Gutierrez



Gaylord Inena wa inena



Ritu Jain

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

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

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

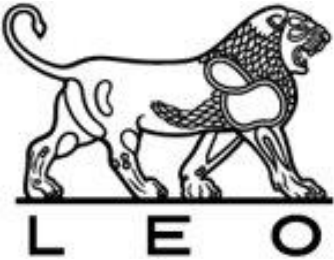
Conference Committee

- **Michelle Capon, Chair**
Canadian Association for Porphyria
Canada
- **Vlasta Zmazek**
DEBRA International
Croatia
- **Oliver Warui**
Vitiligo Group Kenya
Kenya
- **Thea Chassin**
Bald Girls Do Lunch
USA



Industry Partners

Founding Visionary Partners



2021 Core Partners



Silver

abbvie

AMGEN

ARENA
PHARMACEUTICALS



Lilly

GALDERMA
EST. 1981

Pfizer

SANOFI GENZYME

REGENERON

Bristol Myers Squibb

Bronze

Contributor

Industry Partners

Atopic Eczema Community



COVID-19 Round Table



GlobalSkin – Europe



RareDERM Community



Global Dermatology Coalition



Industry Partners

GRIDD Partners



GOLD

Silver

Bronze

Contributor

Supporter

2021 Conference Partners



GOLD

SILVER

BRONZE

SUPPORTER



Thank you!

Questions or comments, please contact:

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