



Annual General Meeting

September 30, 2020



International Alliance of
Dermatology Patient
Organizations

GLOBALSKIN.ORG



Meeting recording will be posted in our Members-only section of www.GlobalSkin.org

Agenda – Part 1

Members and Invited Guests

- Acknowledgment of the Team:
 - Our Membership
 - Strategic Relationships
 - Industry Partners
 - GlobalSkin Board of Directors
- President's Report Sept. 2019 – Sept. 2020



A rising tide lifts all boats.



President's Report

IADPO 2019-2020 Accomplishments:

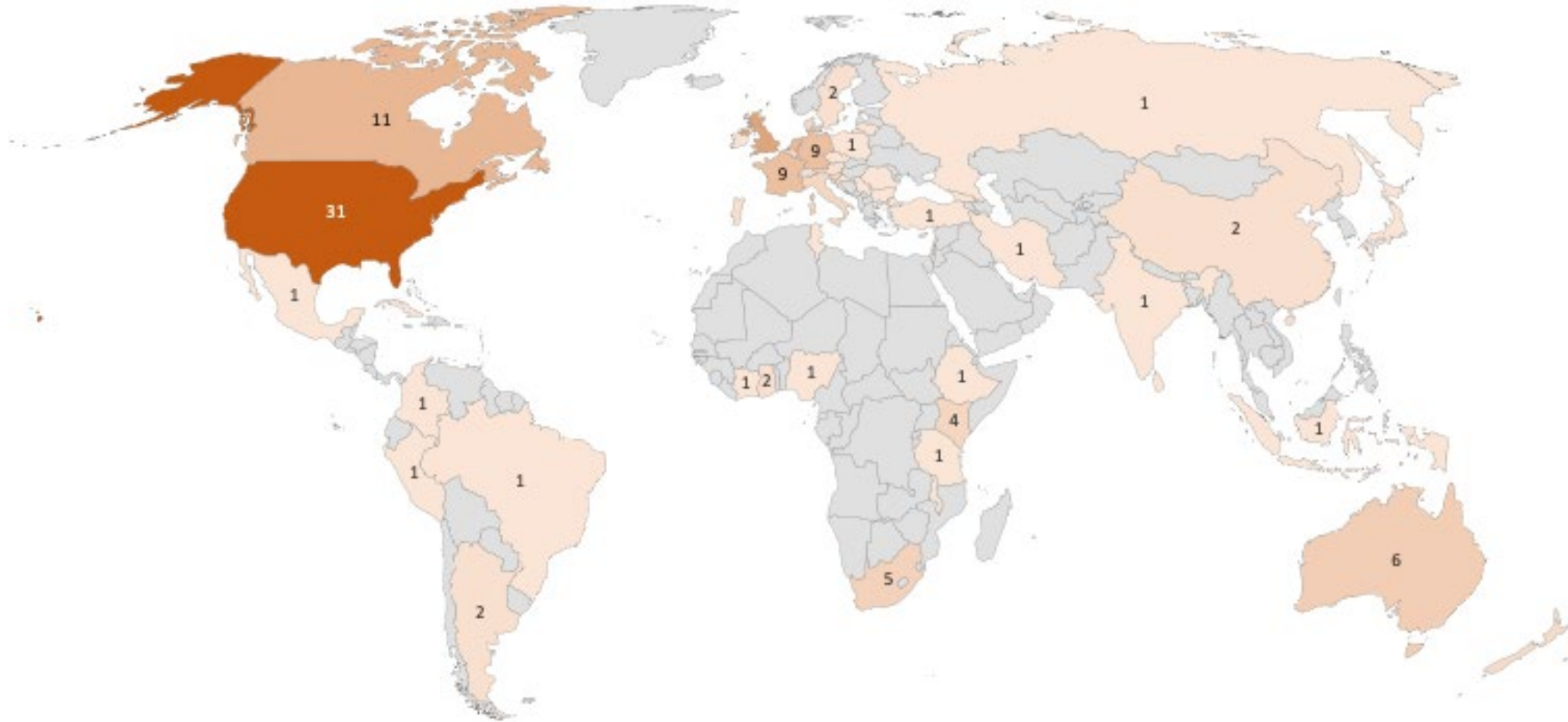
- Building the Movement
- Strategic Plan
- Membership Growth
- CEO Update
 - Member Engagement /Programming
 - Communities
 - *GlobalSkin 2021/2022* Conference Planning
 - GRIDD Phase 3
 - Stakeholder Engagement
- Looking forward to 2021
- Board Election 2020



We ARE our Members



Global Membership



Strategic Relationships

- ILDS
- EADV
- PeDRA
- IDEOM
- PSO Protect/PSoProtectME
- IFPA
- Global Psoriasis Coalition
- IRDiRC - Chrysalis
- RDI
- Global Genes
- EFPIA
- IAPO
- WHO
- GLODERM



Industry Partners

Founding Visionary Partners



2020 Core Partners



Bronze

Contributor

Industry Partners

GRIDD



Silver



Bronze



Contributor



Supporter

Conference



Gold



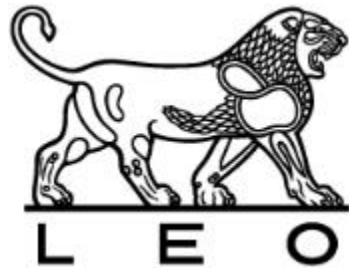
Silver



Supporter

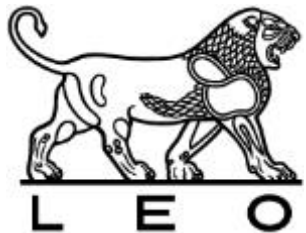
Industry Partners

Atopic Eczema Community

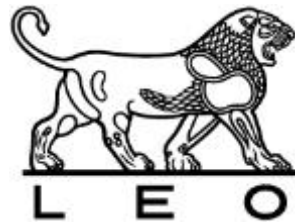


abbvie

RareDERM



EuropaDERM



COVID-19 Round Table



Board of Directors

Simmie Smith — Board President



David McMahon — Board Vice-President



Marc Yale — Board Treasurer



Cheryl Talent — Board Secretary



Jean-Marie Maurant — Board Director



Julius Muungano — Board Director



Vlasta Zmazek — Board Director



Michelle Capon — Board Director



Ito Daisuke - Board Director





GLOBALSKIN.ORG

International Alliance of
Dermatology Patient
Organizations



Our Goal: Change the way the world sees Dermatology.

Membership Support 2019-2020

GlobalSkin Member Impact Fund

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

Accepting applications September 18-Oct 7

Member Engagement

Meet the Member Series

New monthly members bulletins

GlobalSkin Workplace discussion groups

Webinars

E-Learning Fundraising Series

Online training support to learn how to build a fundraising strategy

5 live training sessions (May-Sept)

79 registered patient leaders

All sessions available to members online

COVID-19 Programming

166 patient leaders registered

7 live Online Townhalls

Bringing together experts to respond to skin patients' needs and concerns

COVID- 19 Round Table

Membership Growth

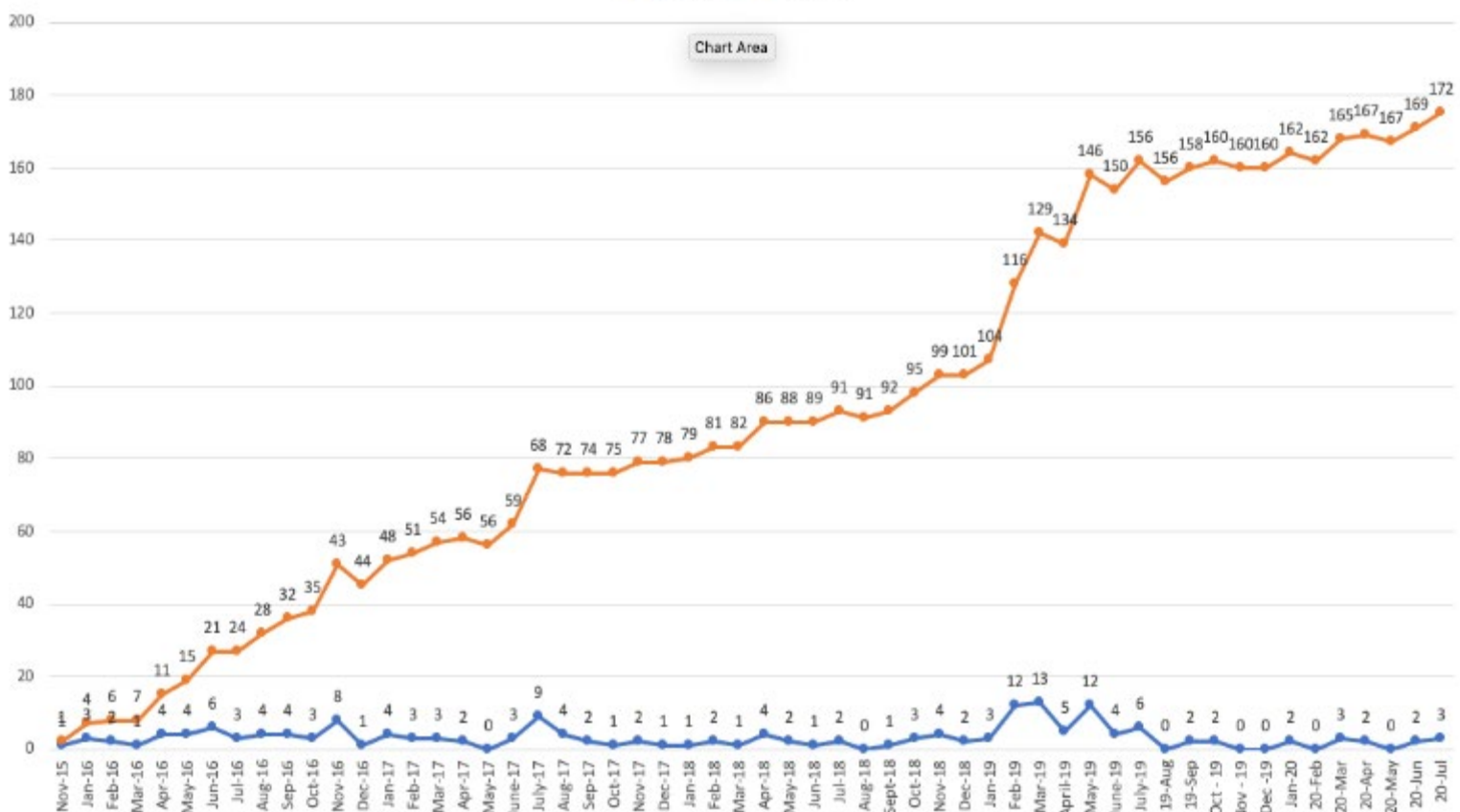
172 Patient Organizations and growing...

60+ Disease areas

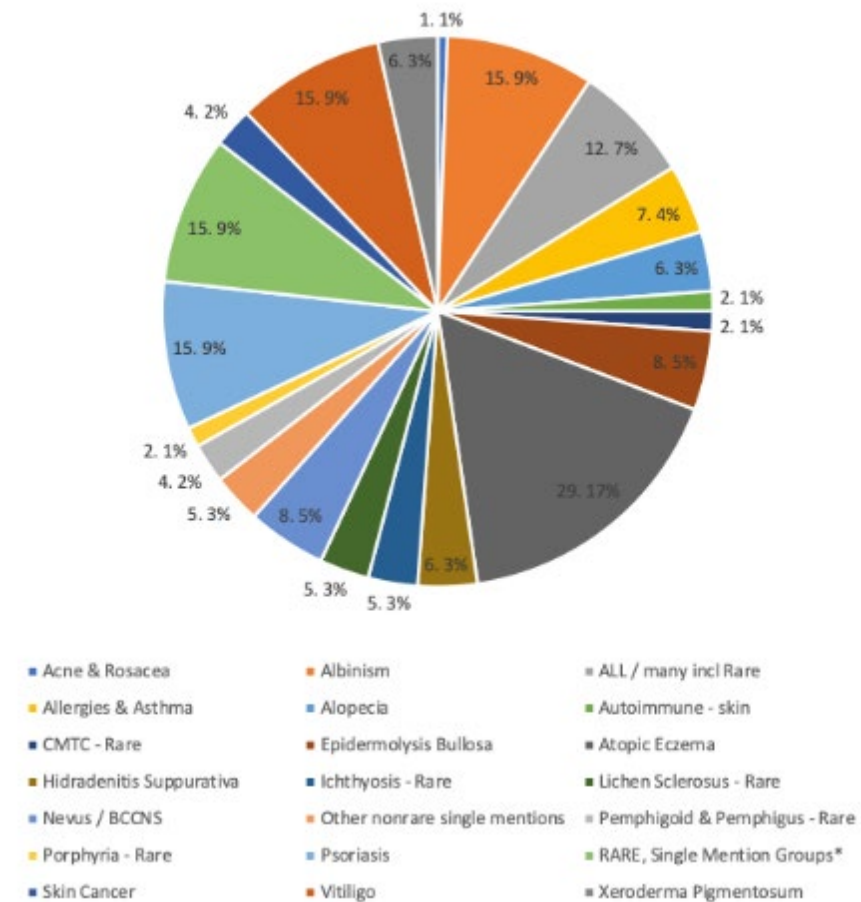
IADPO Growth Chart

Monthly Cumulative

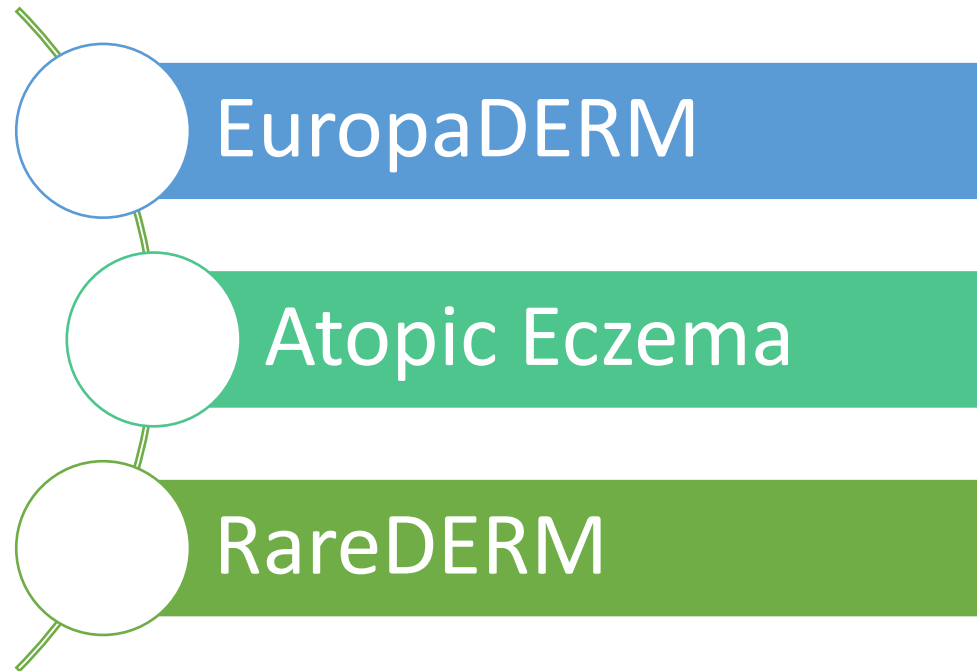
Chart Area



Disease Areas



Communities



EuropaDERM 2020

- Advocacy to EU Parliamentarians around unmet needs of dermatology patients
- Online European Patient Leader Forum - December 2020
- GlobalSkin Senior Advisor located in Brussels – September 2020

**50% of
GlobalSkin
Members are
located in
Europe!**



2020 Atopic Eczema Community Activities

Coffee Chat Series

Landscape Analysis and Stakeholder Mapping

Narrative Development

Care Priorities Survey

Advocacy and Community Mobilization Workshops



World Atopic Eczema Day 2020 – Sept. 14

- New 2020 **Campaign Toolkit** developed and shared with over 60 member organizations in 12 languages
- Very successful social media campaign with over **1.5M and 1.2M impressions** on Facebook and Twitter
- **Grant Fund** providing financial support to Members:
 - 16 Patient Organizations projects
 - Located in 11 different countries – UK, Portugal, China, Belgium, Sri Lanka, USA, Serbia, Slovenia, Australia, Kenya, Israel
 - Each project will receive funding up to 2000 CAD



2020 RareDERM Community Activities

Community Engagement

Environmental Scan

Stimulus Series and Symposium Planning

RareDERM <-> Rare diseases connections



GlobalSkin 2021/22 Conferences:



GlobalSkin Momentum Series

GlobalSkin 2021 Virtual Mini-Conference

One Day Event – Five hours of programming,

Combination of live/recorded sessions

Highly interactive sessions

**SAVE THE DATE:
Saturday
June 5, 2021**

Moderated panel and presentations

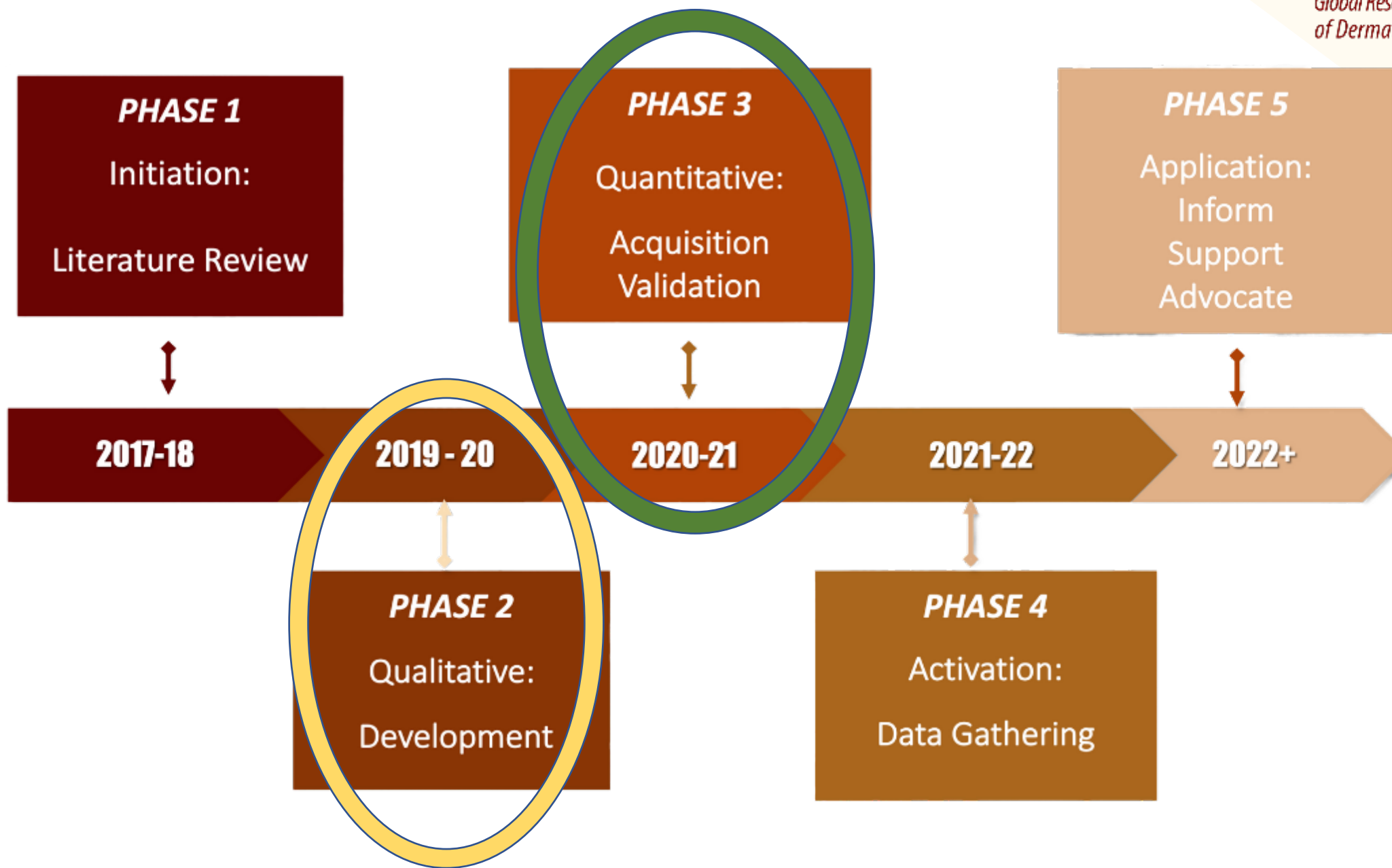
Live Q & A with presenters following sessions.

Partner Exhibition space interaction with participants

Networking opportunities



GRIDD



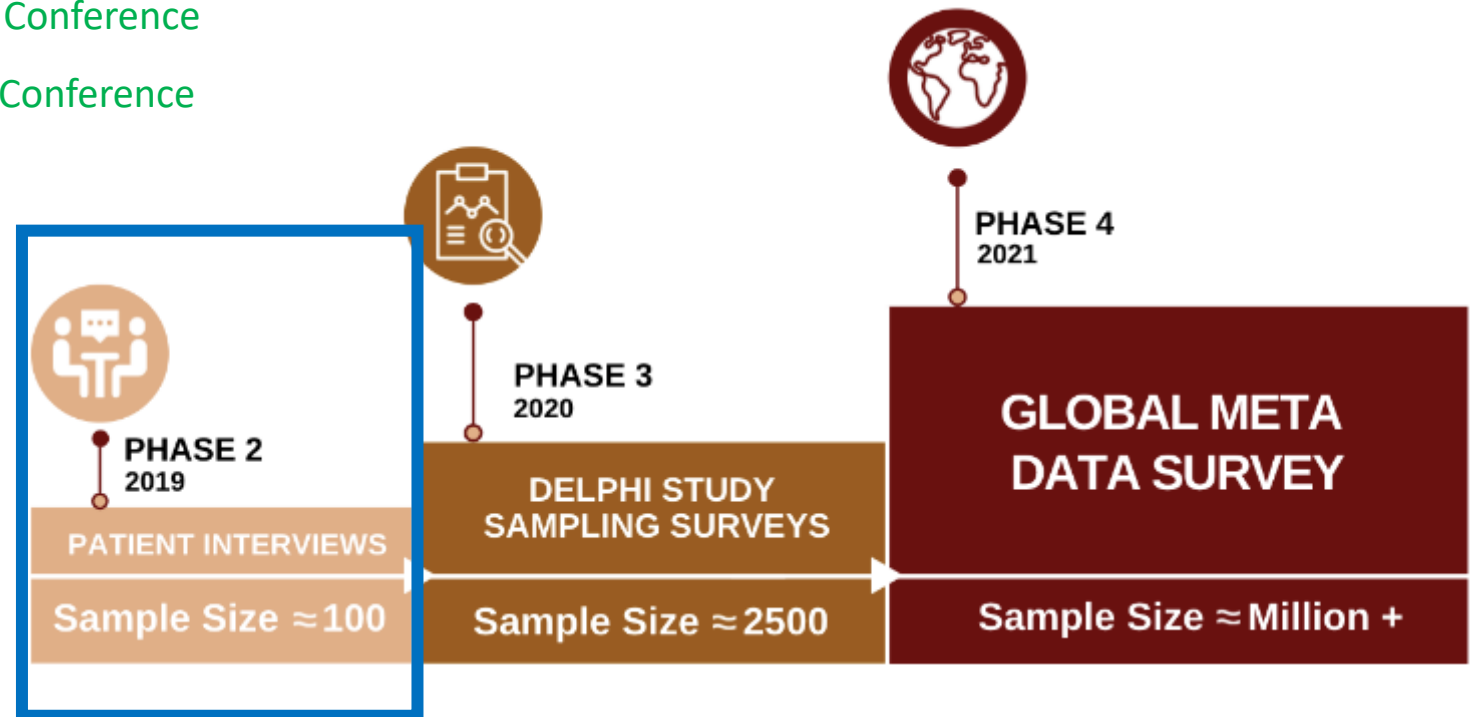
2020

Phase 2

Patient Impact Data Collection - 2020

PHASE 2 – Patient Interviews (June 2019 – June 2020)

- ✓ Identify patient items (impacts)
- ✓ Data Analyzed – Item bank expanded
- ✓ Design of methodology for Phase 3
- ✓ Abstracts submitted to conferences:
 - ✓ EADV 2020 Congress
 - ✓ IDEOM Conference
 - ✓ PeDRA Conference



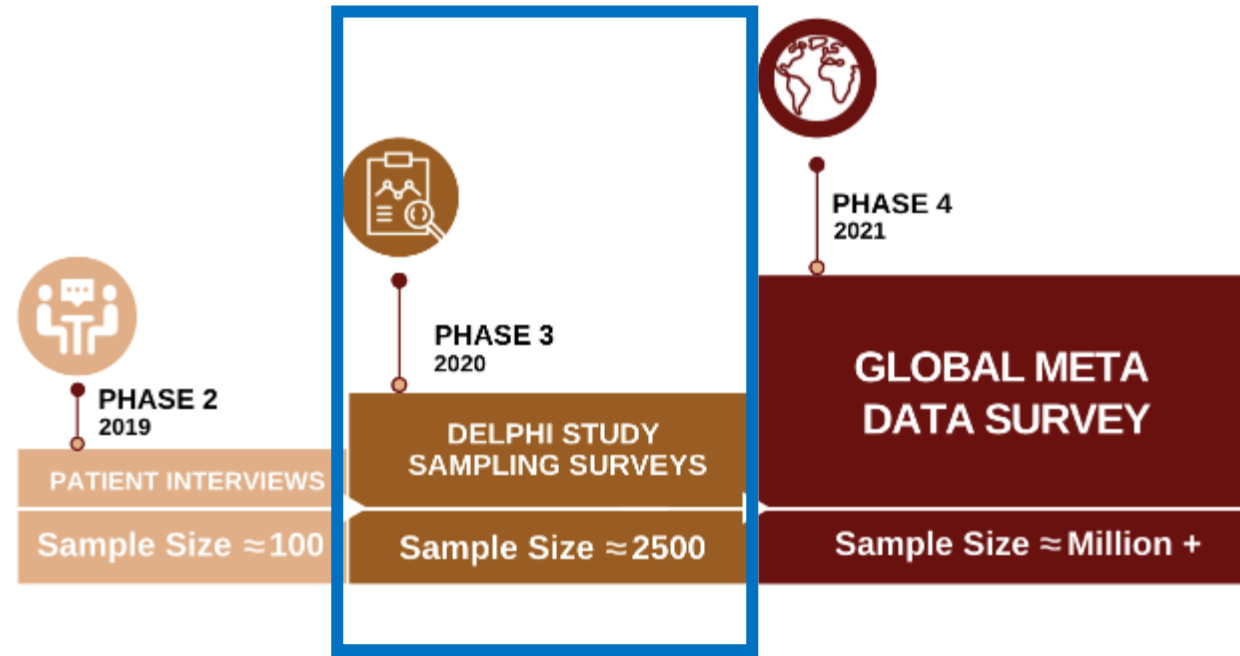
2020

Phase 3

Patient Impact Data Collection - 2020

PHASE 3 – Patient Data Verification Delphi (July 2020 – December 2020)

- ❑ ‘Patient Data Verification Delphi’ of information collected in Phase 2.
- ❑ 2 surveys will be sent in October and December to patients.
- ❑ Goal: 50 participants per disease and from ALL regions and continents.
- ❑ All members organizations will get a communications and outreach **toolkit**.



GRIDD will help you and your patients!

*Ensure your patients'
country and
disease(s) are fully
represented in the
data!*



**Watch for your Toolkit in October and invite
your patients to participate.**

We Hear You!

Member Needs Assessment *68 Members Responded (41%)*

Key Highlights

57% of GlobalSkin Members have no paid employees and are run entirely by volunteers.

Connecting, collaboration, community and networking were the words frequently used to describe the most important benefit that GlobalSkin brings to Members.

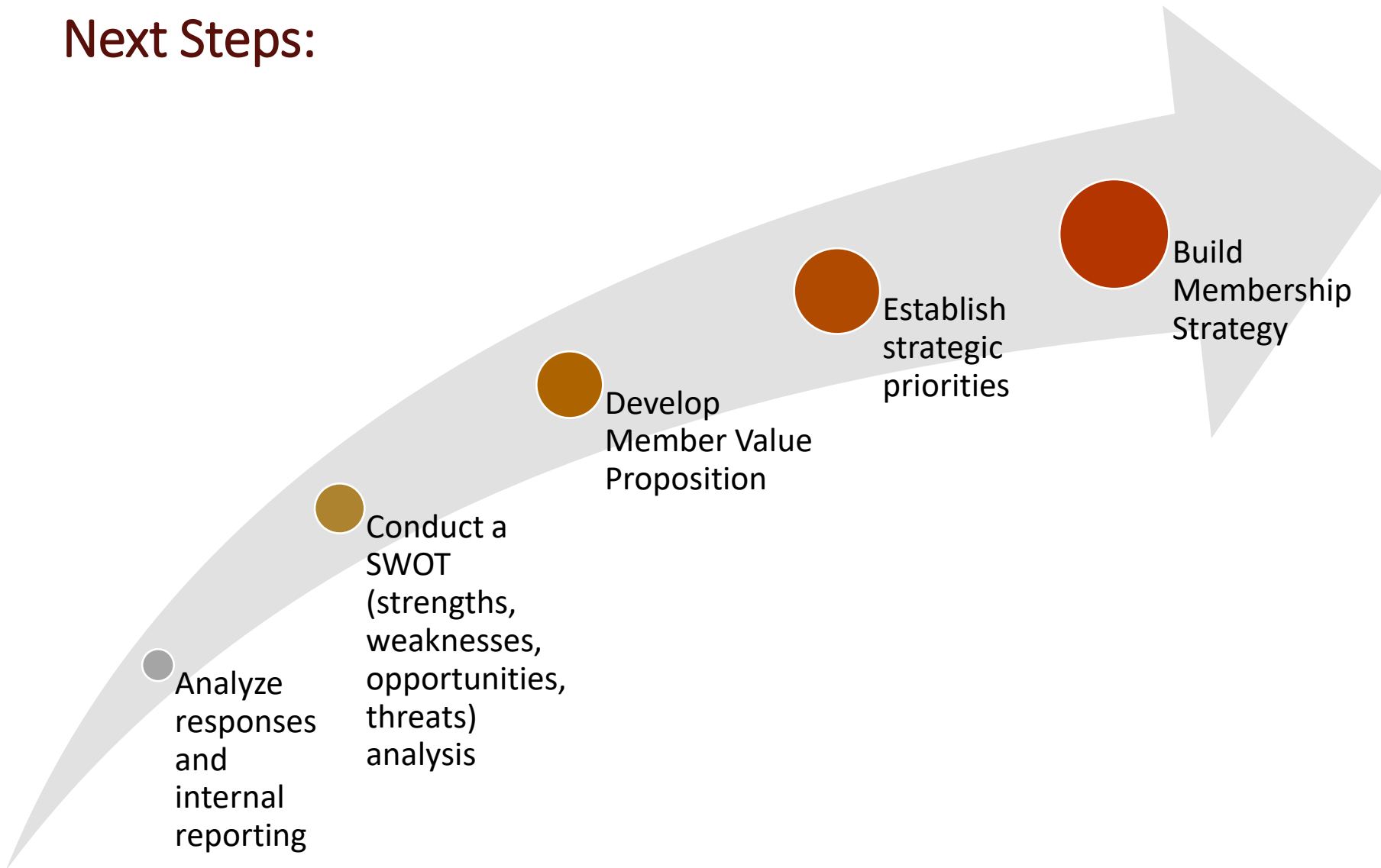
91% of Members rate global advocacy efforts as an extremely/very important benefit of GlobalSkin membership.

77% of Members are engaged in some form of advocacy.

98.66% of Members would recommend GlobalSkin

Member Needs Assessment: Shaping our programs

Next Steps:



2020 Strategic Collaborations

- Presentations at events
 - EADV Congress 2020:
 - Plenary session by our CEO
 - Co-organized EADV-GlobalSkin session – for the **fourth year** in the row
 - Global Albinism Alliance Exploratory Meeting
 - Patients as Partners Europe
 - NEXT Pharma Summit
 - 4th Annual Dermatology Drug Development Summit
- COVID-19 and the Movement
 - Virtual Townhalls - brought in experts to respond to the most common needs and concerns of patients
 - Multi-stakeholder Round table event - being planned for December
- Membership on key committees
 - IRDiRC Chrysalis Committee (Rare Diseases)
 - ILDS Patient Organization Working Group
 - EADV Patient Association Working Group
 - PeDRA Patient Advisory Committee
 - EFPIA Patient Think Tank
 - PSO Protect/Me Steering Committee& Communications Committee
 - Various partner committees (e.g. LEO KPI Committee, etc.)
- Collaborations with other organizations (*some examples*)
 - COVID-19 Virtual Townhalls: ILDS, EADV, PeDRA, Cardiff & Ottawa Universities
 - Working towards MOU with ILDS
 - E-learning with PeDRA



2021 and Beyond

Building our global movement – together:

- ✓ More member involvement /committees
- ✓ More programs and support for members
- ✓ GRIDD Phase 4
- ✓ Advocacy stage setting/relationship building
 - ✓ UN / WHO
- ✓ Global campaigns



Changing the way the world sees dermatology...together.

Get involved!

- Help improve the lives of people living with a dermatological condition locally, regionally and globally.
- Help us shine a spotlight on the impact of these conditions on people and their families.
- Help grow this rising tide grow into a wave! Tell others.



GlobalSkin Staff

Christine Janus — CEO



Jennifer Austin, Executive Director



Vianja Zaborski Breton—Public Affairs Director



Tammi Shipowick - Programs Director



Dairdra Laframboise - Research Director



Stephanie Miller - Communities Manager



Nicole Sudical - Member Services Manager



Alexandra Rodionova - Digital Communications Manager



Valchin Mammadov - Senior Advisor, EuropaDERM



Emma Montgomery - Communications Specialist



Liz Garrett—Office Administrator



Pam Hanlan — Finance Director





Thank you!

Questions or comments, please contact:

Simmie Smith president@globalskin.org

Christine Janus Christine.Janus@globalskin.org

Jennifer Austin Jennifer.Austin@globalskin.org