Annual General Meeting

September 30, 2020

International Alliance of Dermatology Patient Organizations
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

Gold: Pfizer
Silver: SANOFI GENZYME, REGENERON
Bronze: Pierre Fabre, Novartis, Galderma, Sun Pharma
Contributor: Bristol Myers Squibb, almirall
Supporter: La Roche-Posay, Pfizer

Conference

Gold: Pfizer
Silver: SANOFI GENZYME, REGENERON
Supporter: Beiersdorf
Industry Partners

Atopic Eczema Community

RareDERM

EuropaDERM

COVID-19 Round Table
Board of Directors

Sammie Smith — Board President

David McMahon — Board Vice-President

Marc Wale — Board Treasurer

Cheryl Taliercio — Board Secretary

Jean-Marie Nevejant — Board Director

Julius Muungano — Board Director

Vlasta Zinzaak — Board Director

Michelle Capos — Board Director

Ito Sakaue — Board Director
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
Communities

- EuropaDERM
- Atopic Eczema
- RareDERM
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
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:

Phase 1: Mini virtual conference - June 2021

Phase 2: 2-3 interactive programs - 2021

Phase 3: 2-3 interactive programs - Early-2022

Phase 4: GlobalSkin Conference 2022

GlobalSkin Momentum Series
GlobalSkin 2021 Virtual Mini-Conference

One Day Event – Five hours of programing,

Combination of live/recorded sessions

Highly interactive sessions

Moderated panel and presentations

Live Q & A with presenters following sessions.

Partner Exhibition space interaction with participants

Networking opportunities

SAVE THE DATE:
Saturday June 5, 2021
**PHASE 1**
Initiation: Literature Review

**PHASE 2**
Qualitative: Development

**PHASE 3**
Quantitative: Acquisition Validation

**PHASE 4**
Activation: Data Gathering

**PHASE 5**
Application: Inform Support Advocate

**GRIDD**
Global Research on the Impact of Dermatological Diseases
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

GLOBAL META DATA SURVEY
Sample Size ≈ Million +
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:

1. Analyze responses and internal reporting
2. Conduct a SWOT (strengths, weaknesses, opportunities, threats) analysis
3. Develop Member Value Proposition
4. Establish strategic priorities
5. Build Membership Strategy
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

Vince Zaborrelli — Public Affairs Director

Tammie Shipock — Programs Director

Delaine Laemmle — Research Director

Stephanie Miller — Community Manager

Nicole Sudiasel — Member Services Manager

Alexandra Robinsare — Digital Communications Manager

Wesley Mandev — Senior Advisor, Europe/CRM

Emma Montgomery — Communications Specialist

Lee Garrett — Office Administrator

Pam Hanlan — Finance Director
Thank you!

Questions or comments, please contact:

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