GLOBALSKIN.ORG

International Alliance of
Dermatology Patient
Organizations

Atopic Eczema Forum Report

Neil Bertelsen

What did we cover, and what did we advise that GlobalSkin should focus on in the coming years?

What we covered at the forum

Policy in action: A look at examples and case studies of patient organisation policy work and its impact. Deep dive into the skin health resolution as a potential lever for national policy action

Workshop 1: 2030 Policy Goals: Working together to identify your national policy goals by 2030 and the global community actions and activities from GlobalSkin and GAAPP that will be needed to support you

Current resources from the community: Tools, guides, resources, evidence that has been produced by GlobalSkin and GAAPP to facilitate policy-type interactions

Workshop 2: Steps to reach the goal: To reach your goals, what steps will you have to take each year, and what additional activities, resources and tools will you need from GlobalSkin and GAAPP?

Tracking progress: Facilitated discussion on how to track progress and know when to course-correct
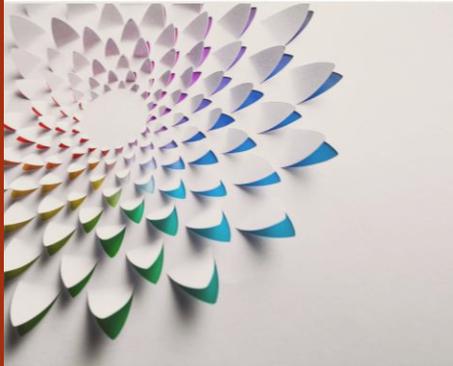**Workshop 3:** Building your measures

Feedback and discussion: Discuss both your organisation's policy goals, and the activities, resources, evidence and tools needed from the global community through GAAPP and GlobalSkin

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

Main inputs to the planning:

Impacts of policy on our health and care

Covering the impact on regulations, access to treatments, health and care services, guidelines and national skin disease strategies and plans

Various levels of policy making we need to consider

Global: to set goals and frameworks
Continental: to set regional goals
National: to impact access and services
Local: on specific issues

Resources already available to help with policy work

Resources from both GlobalSkin and GAAP including work on the **Skin Disease Resolution (Hooray!),** evidence, campaign materials, work with medical societies, ...

A strategic approach to develop plans

Workshops were guided in a step-by-step format to build the strategies and plans for future policy work

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

REMINDER

We covered two levels of policy planning

Policy planning for an individual organisation

- A 2030 policy goal for the organisation
- Resources to use to get there
- Yearly steps needed to get there
- Initial steps to take to start

Policy planning for the global community

- Common issues that we should address collectively
- Advice for GlobalSkin and GAAP on what they could focus on
- Additional resources the community could create to help national policy goals

We covered two levels of policy planning

These plans remain the property of each individual organisation taking part and are not part of this report
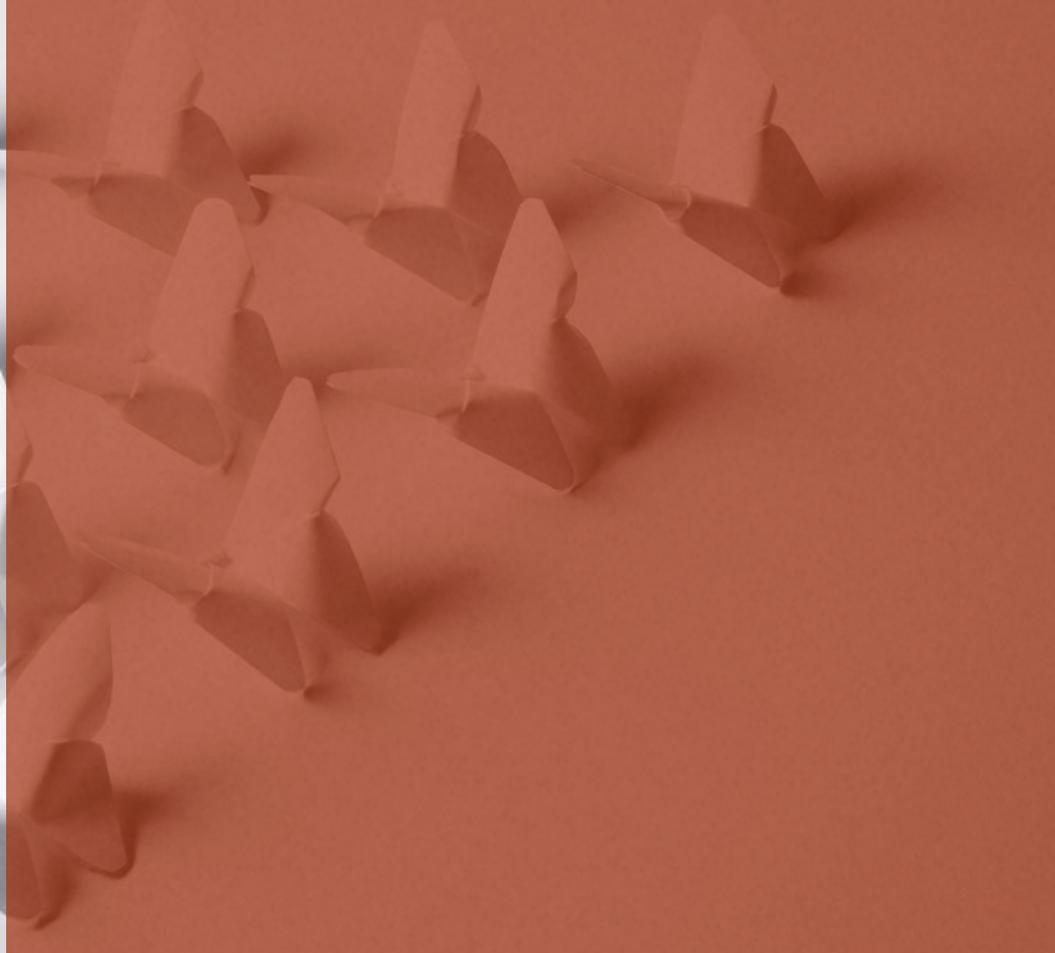
These plans were developed by teams focused on each region, and collected by GlobalSkin and GAAP to inform their strategies and activities and are the basis of this report

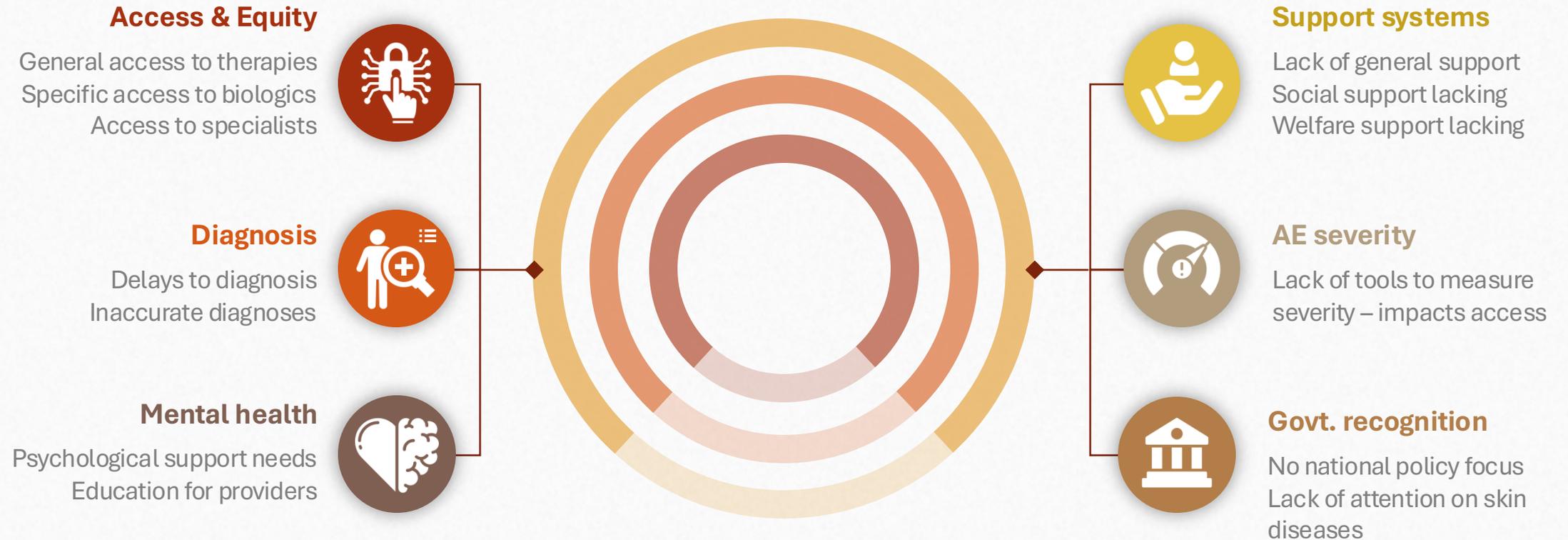# Key findings for community policy action

What could GlobalSkin/GAAP be working on?

Access to prescribed treatments
Activities, tools and resources that empower national advocates to impact access policies

Education for those living with AE
Improve patient education

Continuity of care
Policy initiatives, white papers and evidence that highlight the need for continuity of care

Data and research
Use existing data to inform policy focus and messaging

Identify evidence gaps that need to be filled to argue for better access and policies and work with the communities to fill the gaps

Partnerships with others will be needed to achieve this

COLLABORATION	RELATIONSHIPS
Strengthen ties with medical associations and collaborate across stakeholders	*Develop strong relationships with policy makers and facilitate links to national MoHs*

Public-private partnerships
Industry partnerships
Relationships with media
Relationships with researchers

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

What could GlobalSkin/GAAP be working on?

Access to prescribed treatments
Activities, tools and resources that empower national advocates to impact access policies

Education for those living with AE
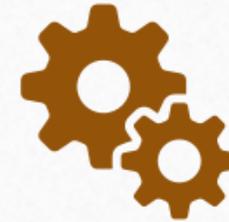Improve patient education

Continuity of care
Policy initiatives, white papers and evidence that highlight the need for continuity of care

Data and research
Use existing data to inform policy focus and messaging

Identify evidence gaps that need to be filled to argue for better access and policies and work with the communities to fill the gaps

What activities of GlobalSkin and GAAP could support these?

RESOURCES & TOOLS

Focused on these issues, designed for use by national advocacy groups

INFORMATION SHARING

To update on the policy landscape and global/national activities

GENERATE EVIDENCE

Conduct surveys, research to support policy aims and publish results

What should GlobalSkin be leveraging and supporting the community to do?

✓ **PRIDD**
Use of PRIDD to gain validated and robust evidence to support global and national policy aims

✓ **Leveraging GRIDD Study data**
Around issues such as access to care and treatments, burden of AE for policymakers etc.

✓ **Artificial Intelligence**
Build capabilities on the use of AI to accelerate resource development and analysis of data

✓ **Share good practices on research methods**
Both conduct surveys at the international level and support national groups in their use of survey instruments and validated tools such as PRIDD

Develop and strengthen expertise on research methods and educate to build capabilities across the community

TOPIC AREAS COULD INCLUDE

- *Statistics*
- *Generating ideas for research*
- *Medical writing*
- *Survey design*
- *Health Economics and Outcomes Research*
- *Use of artificial intelligence in research*

Through best-practice sharing

Member state engagement

Share best practices that enable national groups to better engage with national policy stakeholders

Generation & use of research

Share examples of research projects that are focused on shaping policy and how the results were used and their ultimate impact

Media engagement

Using case studies and member experiences, share best practices on media relationship building and engagement on policy-related topics

Best Practice Sharing

Growth strategies

Facilitate the growth of member organisations using best practices on business and growth strategies

Authorship

Using case studies from PRIDD/GRIDD and member projects, share best practices on publishing evidence and authorship
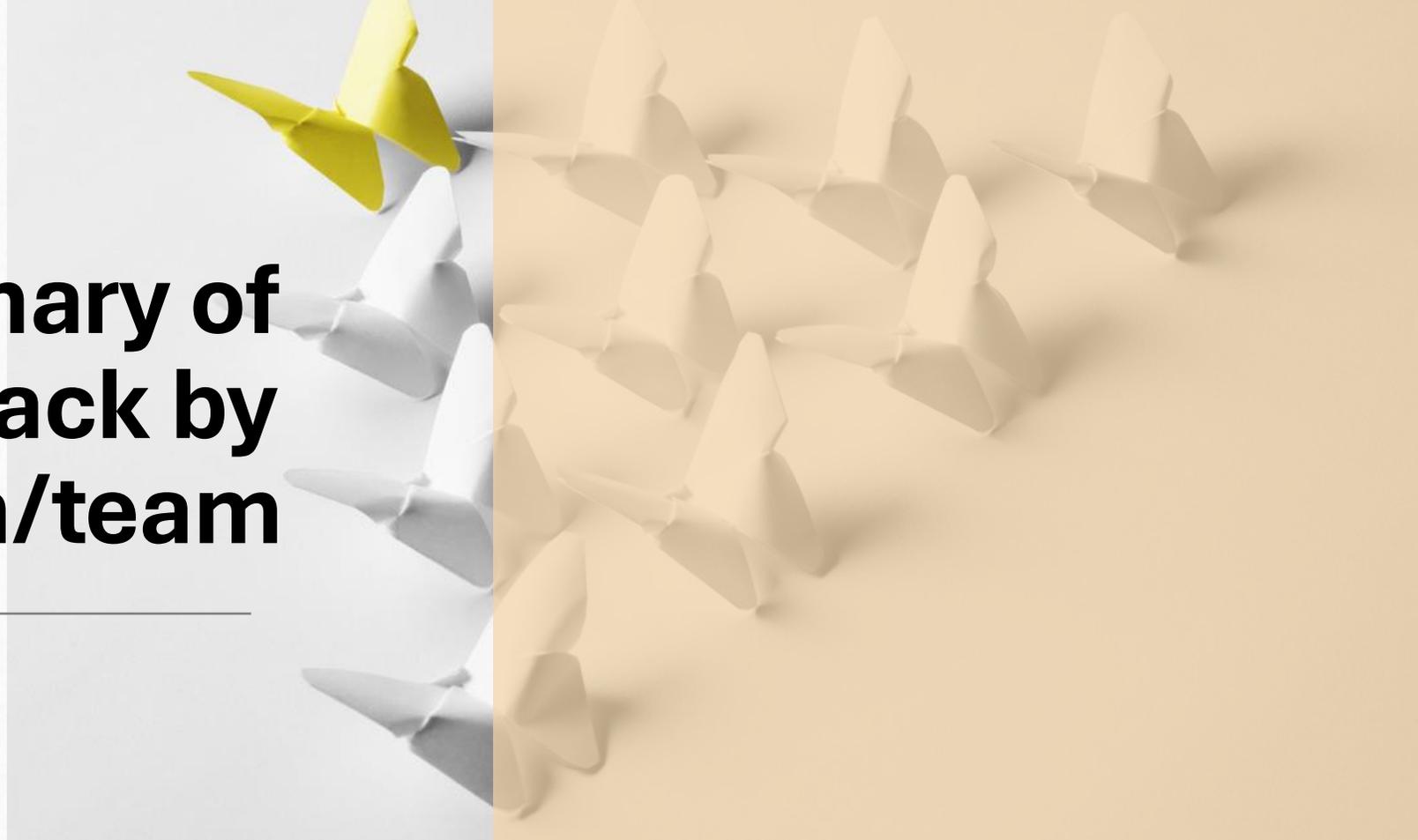
Researchers

Building from the experiences in developing and using PRIDD, share best practices on working with the research community

GLOBALSKIN.ORG

International Alliance of Dermatology Patient Organizations

Summary of feedback by region/team

LAT AM & Caribbean Team

Policy goals for 2030 roadmap

2026	Build a shared, evidence-based dataset in partnership with the medical community
2027	Investigate and define the most pressing unmet patient needs across the region
2028	Develop a proposal centred on the top 5 priority needs, to be presented to Congress or national legislative bodies
2029	Establish alliances with political parties or influential senators from health committees responsible for health reform legislation—ensuring their support
2030	Socialize and implement the approved proposal within the MoH, ensuring alignment with decision-makers, health providers, and agencies for full adoption
2031	Monitoring and evaluation to confirm policy measures are being implemented – ensuring they effectively benefit patients across the region

ISSUES IDENTIFIED

EVIDENCE

- Lack of evidence and data, particularly from low- and middle-income countries

BURDEN OF DISEASE & MYTHS

- Burden of disease and impact on mental health
- Perception of skin diseases as 'cosmetic'
- AE impact on productivity

ACCESS TO CARE & TREATMENTS

- Cost of treatments
- Limited access to specialists (esp. rural/remote)
- Long wait time for appointments & treatment

POLICY MAKING

- Frequent changes in health authorities' policies
- Frequent changes to political stakeholders

RELATIONSHIPS

- Collaboration with medical societies and specialists needs strengthening

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

LAT AM & Caribbean Team

COLLECTIVE ACTION IDEAS

- Launch a pilot data collection project to measure disease burden (physical, social, economic), in collaboration with medical societies

- Use a scorecard model to compare data across countries

- Strengthen and formalize collaboration with medical societies and multi-sector stakeholders (e.g., psychosocial and economic sectors)

- Encourage governments to continue collecting and publishing actionable official data

- Build a growing body of published, comparable data to drive credibility and awareness

COMMUNITY-DRIVEN RESOURCES

- Collect and analyse more localized and disaggregated data

- Improve access to affordable treatment and specialist care, including rural outreach

- Collaborate with medical societies to identify gaps and opportunities

- Secure resources including:

  - Funding

  - A network of doctors ready to partner (to increase reach and legitimacy)

  - Access to WHO tools and disease frameworks

  - Support for social amplification and awareness campaigns

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

SUMMARY

Europe Team

Policy goals for 2030 roadmap

2026	**STEP 1: Identify key stakeholders and data** *(Need local economic data, data from health institutions, landscape analysis and literature searches. We also need to catalogue data that is available to identify gaps)*
2026	**STEP 2: Identify key stakeholders and data** *Develop messaging and education based on data*
2027	**STEP 3: Create formal relationships with professional organizations**
2027	**STEP 4: Step 4 Contact policy-makers while gaining support** *(For example, the ministry of health – involve them in securing the data we actually need!)*

ISSUES IDENTIFIED

CLINICAL PRACTICE
- Lack of time with doctors
- Inflexibility around guidelines
- Patients not treated individually
- Lack of a multi-disciplinary approach
- Need education on continuity of care
- Delayed or inaccurate diagnoses in some countries

BURDEN OF DISEASE & MYTHS
- Burden of disease and impact on mental health
- Lack of attention to emotional issues
- Psychologists need education on issues of AE

ACCESS TO CARE & TREATMENTS
- Emollients not always prescribed therapies (cost)
- Lack of long-term options for patients
- Need better equity to access
- Access to specialists a problem (long waits)
- Access to biologics and long wait for access

TOOLS
- Lack a way to measure severity

RELATIONSHIPS
- Collaboration with medical societies and specialists

Europe Team

CONSIDERATIONS

- You do not need to wait to have perfect data.

- You can conduct research and messaging with existing data simultaneously

- But be sure not to saturate patients and families with requests

COMMUNITY-DRIVEN RESOURCES

- We need data! Decide what we **need** to have and what is **nice** to have

- We need to share information and GAAPP and GlobalSkin can be organizers of that process

- If we decide to do the survey, GAAPP should oversee and own the process. They should engage experts, health economists, epidemiologists etc. for high quality data that is validated.

- Own publication and project management of dissemination of results

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations

SUMMARY

North America

Activities suggested

- Targeting medical students
- Engaging nurse practitioners
- Engaging GPs
- Engaging pharmacists
- Raise awareness of stigma
- Raise awareness to address disparities

ISSUES IDENTIFIED

HEALTHCARE STAKEHOLDERS

- *Nurse Practitioners*
- *Pharmacists*
- *Improved access to dermatologists (especially in rural areas and through the use of telehealth)*

DISPARITIES

- *Need to address disparities for skin of colour*

SUPPORT PATIENT ORGANISATIONS

- *Need to recognise the important role of patient organisations and support their work*

SUGGESTIONS ON HOW TO ADDRESS

Collaborate with AADRN and AAD

Arrange joint meetings to discuss shared issues

SUMMARY

Australia, Asia, Africa

COMMUNITY-DRIVEN RESOURCES

- Help smaller patient organizations to team up and go through resources together

- Help bring the stakeholders to the table (like in the AE Forum)

- Strengthen and map the network

- Connect stakeholders to our communities

ISSUES IDENTIFIED

DATA AND EVIDENCE

- Need local data on the impact of the condition for policy-makers

EDUCATION

- Need to educate both HCPs and patients around condition and its treatment
- Need awareness and education for patients to empower them on their own journey

STIGMA & MENTAL HEALTH

- There exists a lack of recognition of chronic conditions that lead to stigma and mental health problems

CLINICAL PRACTICE

- Should treat children and focus on early diagnosis and early treatment so it doesn't get worse

SUGGESTIONS ON HOW TO ADDRESS

Share resources

Team up with the skin community

For 2026: What could GlobalSkin be working on?

TOPIC AREAS

✓ **Access to prescribed treatments**
Activities, tools and resources that empower national advocates to impact access policies

✓ **Education for those living with AE**
Improve patient education

✓ **Continuity of care**
Policy initiatives, white papers and evidence that highlight the need for continuity of care

✓ **Data and research**
Use existing data to inform policy focus and messaging

Identify evidence gaps that need to be filled to argue for better access and policies and work with the communities to fill the gaps

✓ **PRIDD**
Use of PRIDD to gain validated and robust evidence to support global and national policy aims

✓ **Leveraging GRIDD Study data**
Around issues such as access to care and treatments, burden of AE for policymakers etc.

✓ **Artificial Intelligence**
Build capabilities on the use of AI to accelerate resource development and analysis of data

✓ **Share good practices on research methods**
Both conduct surveys at the international level and support national groups in their use of survey instruments and validated tools such as PRIDD

GLOBALSKIN.ORG
International Alliance of Dermatology Patient Organizations