



International Alliance of
Dermatology Patient
Organizations

GLOBALSKIN.ORG

RareDERM Community



**Value
Proposition**

Common Challenges and Potential Gains of Rare Dermatology Patients

Key Challenges

- Invisible or highly visible conditions with high physical, emotional and social burdens
- Significant stigmatisation of people with rare dermatological conditions in many cultures/countries
- Rare dermatological conditions are not taken seriously by different stakeholders (viewed as cosmetic)
- Inequities in access to rare dermatological treatments and care in comparison to more common conditions
- Lack of dermatologists specialised in rare conditions
- Lack of investment in rare dermatology research

Key Potential Gains

- Leverage collective power to address key problems faced by rare dermatology patient communities
- Greater awareness and understanding about rare dermatological conditions
- More humanised, integrated care for rare dermatological conditions
- Clinicians and researchers interested in rare dermatological conditions
- Investment by pharma companies in the research and development of therapies for rare dermatological conditions

Common Challenges and Potential Gains of Rare Dermatology Patient Organizations

Key Challenges

- Lack of financial and human resources
- Many are volunteer-run organisations with limited capacity and capability

Key Potential Gains

- Secure funds to ensure organisational sustainability
- Connect with/reach people with rare dermatology conditions
- Have sufficient epidemiological data and patient evidence to support advocacy efforts
- Have sufficient advocacy know-how (e.g. engaging with pharma companies)





RareDERM's Original Vision and Mission

VISION

A world in which people with rare dermatological conditions and diseases lead healthy and fulfilling lives

MISSION

RareDERM is an international movement for people living with rare dermatological conditions, lead by the International Alliance of Dermatology Patient Organizations, which is:

- Uniting patient voices
 - Empowering patient organizations
 - Stimulating research
 - Influencing decision makers
 - Collaborating with communities of interest
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RareDERM's Updated Vision and Mission

VISION

A world full of empowered and influential RareDERM patient organisations that are capable of delivering significant value for their community

MISSION

The RareDERM Community is a GlobalSkin initiative that enables the global RareDERM patient organization community to

- connect with colleagues and strategic stakeholders
- share know-how and resources
- take collective action to address common problems



Connect

Potential Tactics

- gather RareDERM members at ongoing forum and conference opportunities
- convene RareDERM members with interested stakeholders including dermatologists, pharmaceutical companies, researchers

Share

Potential Tactics

- create communities of practice to share experience and know-how
- co-develop templates and toolkits

Act

Potential Tactics

- build a team of RareDERM Ambassadors
- co-develop and publish policy papers
- co-create common messaging for Rare Disease Day campaigns