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International Alliance of  
Dermatology Patient  
Organizations

# RareDERM Community: Three-Year Strategy

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## Introduction

In June 2019, the International Alliance of Dermatology Patient Organizations (IADPO), also known as GlobalSkin, hosted the first RareDERM Forum for leaders of skin patient organizations in Milan, Italy. Thirty-eight leaders representing over 20 rare skin diseases from 13 countries attended the [two-day RareDERM Forum](#). The overall objective of the event was to build a cohesive community of rare dermatology disease patient organizations and support stakeholders around a shared vision which will ensure the lives of these patients are positively impacted in a measurable way. The RareDERM Forum laid the groundwork for the creation of a three-year strategy for the GlobalSkin RareDERM Community.

## Laying the Foundation

Patient organization leaders attending the Forum in Milan agreed that this community must define a three-year strategic plan. The early groundwork for the development of the strategy began on the last day of the Forum as the attendees divided themselves into five working groups. Each group’s discussion focused on one goal, resulting in five focal points for the community at large. One of these working groups is the foundation of the three-year strategy for the community. Following initial discussions at the Forum, an Advisory Committee was formed - with representatives from the five working groups – which would take development of the strategy to the next level.

## Advisory Committee

In October 2019, the RareDERM Advisory Committee was launched and tasked with the following mandate: *Contribute to and shape the development of the GlobalSkin RareDERM Community three-year global strategy.* The Advisory Committee will assist GlobalSkin’s ongoing efforts related to the RareDERM Community by providing strategic counsel on policy issues related to rare dermatology and advising on opportunities to advance patient engagement at relevant international events.

**RareDERM Advisory Committee:** The Committee is comprised of the following representatives from diverse patient associations across the GlobalSkin community:

Name	Member Organization	Location	Disease Area
Laurence Gallu	Assc. Pemphigus Pemphigoid France	France	Pemphigus - Pemphigoid
Mary McGowan	The Mysositis Assc	United States	Myositis
Marjolein van Kessel	Naevus Global	Netherlands	Congenital Melanocytic Naevi
Susan Thornton	Cutaneous Lymphoma Foundation	United States	Cutaneous Lymphoma

Tricha Shivas	The Myositis Assc	United States	Myositis
Rachel Manion	Canadian Skin Patient Alliance	Canada	Multiple Disease
Lex van der Heijden	CMTV-OVM	Netherlands	Van Lahuizen Syndrome
Ellen Swanborn	Stichting Lichen Sclerosus	Netherlands	Lichen Sclerosus
Annemarie Sluijmers	Lupus Europe	Netherlands	Lupus

The Committee met again in November 2019, via videoconference to discuss the Community’s proposed three-year strategic plan. Committee members reviewed the vision and the mission statement as well as, affirmed the key strategic and operational elements. The strategy detailed within this document represents the outcomes of the five working groups at the Forum and the Advisory Committee’s strategic review. The Strategy was officially approved by the larger RareDERM Community through a Member survey on December 15, 2019.

### Framing the Community’s Vision

In order to realize the goals of the RareDERM Community—to *build a cohesive community of rare dermatology disease patient organizations and supporting stakeholders around a shared vision which will ensure the lives of these patients are positively impacted in a measurable way*—the strategic plan is centered on supporting three priorities: Build Community, Activate Community and Mobilize Community. The underlining force of this plan is focus on the community, building it from within. With collaboration and momentum, the Community will drive its messages outward impacting and engaging the larger global health and policy sector. What follows in this document is the outline of the three-year strategic plan which includes the three key priorities that underpin the strategy and reflect a spectrum of activities that are both internally and externally focused.



# GlobalSkin RareDERM Strategic Overview

<b>Vision</b>	<p><b>A world in which people living with rare dermatological conditions and diseases lead healthy and fulfilling lives.</b></p>		
<b>Mission</b>	<p>GlobalSkin RareDERM is an international movement for people living with rare dermatological conditions, led by the International Alliance of Dermatology Patient Organizations, which is:</p> <ul style="list-style-type: none"> <li>• uniting patient voices</li> <li>• empowering patient organizations</li> <li>• stimulating research</li> <li>• influencing decision makers</li> <li>• collaborating with communities of interest</li> </ul>		
<b>Strategic Priorities</b>	<p><b>Build Community</b></p> <ul style="list-style-type: none"> <li>• Establish RareDERM Steering Committee</li> <li>• Grow engaged rare patient organization community</li> <li>• Environmental scan</li> </ul>	<p><b>Activate Community</b></p> <ul style="list-style-type: none"> <li>• Centralized hub</li> <li>• Coalition building (multi-stakeholder)</li> </ul>	<p><b>Mobilize Community</b></p> <ul style="list-style-type: none"> <li>• Global RareDERM Awareness Day</li> <li>• Evidence-based advocacy (global and local)</li> </ul>

## Strategic Priority #1: Build Community

### Tactical Objective 1a: Establish RareDERM Steering Committee

- a. Consider the division of labour for advancing the 3-year strategic plan (IADPO, Patient Organizations)
- b. Identify leaders from the RareDERM Community who will steer the established work of the Community

### Tactical Objective 1b: Grow Engaged Rare Patient Organization Community

- a. Capacity building (online learning, RareDERM 2020 Forum)
- b. Meet annually or bi-annually to collaborate on strategy and further the collective agenda (RareDERM2020 Forum)
- c. Create a patient advocacy board and representative group
- d. Collaborate on patient leader education and capacity building, using best practice examples from existing networks and organizations
- e. Formalize the network under the GlobalSkin umbrella, using GlobalSkin staff/resources to provide infrastructural support to all committees and working/advisory groups

### Tactical Objective 1c: Conduct an Environmental Scan of Rare Dermatology

- a. Assess the current RareDERM patient environment including consideration of industry, patient support and government support (orphan drug policies, etc.).

## Strategic Priority #2: Community Activation

### Tactical Objective 2a: Create a Centralized Hub for Rare Dermatology Resources

- a. Plan the database with these initial key foci:
  - Infrastructure (security (DB)/integration)
  - Design
  - Define purpose (use) data to collect
  - Consent
  - Create guidelines
- b. Create a database that identifies rare dermatological diseases, by country and lists available data on:
  - Incidence
  - Access to treatment and care
  - Economic and social impact
  - Clinical trials



- Publications
  - Registries
  - Patient organizations
  - Social media support groups
- c. Build the database so it is usable by all members of the network to further the collective agenda –improving the lives of those living with RareDERM diseases
- d. Share RareDERM community information via the creation of a resource hub with consistent data standards.

### Tactical Objective 2b: Build a RareDERM Coalition

- a. Create a regular, multi-stakeholder meeting between pharma, payers and patient representatives.
- (i) Establish points of commonality between stakeholders in order to turn challenges into opportunities
  - (ii) Demonstrate that this new network brings value to stakeholders and the patients they all serve
  - (iii) Create action plans for each stakeholder group to further the collective agenda

## Strategic Priority #3: Community Mobilization

### Tactical Objective 3a: Influence Public Awareness and Deliver Global Advocacy

- a. Influence public awareness about RareDERM through a global RareDERM/Skin Awareness Day.
- i) Provide materials and common speaking points for all stakeholder groups
  - ii) Use the occasion to approach decision-makers locally and globally to address policy gaps

### Tactical Objective 3b: Coordinate Evidence-Based Advocacy for the RareDERM Community

- a. Use the Global Research on the Impact of Dermatological Diseases (GRIDD) data and other data sets on human and economic impact of disease
- b. Build a program that adds the validated voice of RareDERM community to the global discussion addressing pressing medical/research and access needs



## RareDERM Community Three-Year Strategy – Major Milestones

	2020				2021				2022			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
<b>BUILD</b>	Advisory Committee Established  Grow Community	Environmental Scan Begins		RareDERM Forum 2020  Environmental Scan Completed	Grow Community	RareDERM Forum 2021			Grow Community			RareDERM Forum 2022
<b>ACTIVATE</b>		Design Strategy for Stakeholder Network	Recruit Stakeholder Advisory Board	Confirm Stakeholder Advisory Board	Design Begins on Centralized Hub			Stakeholder Advisory Board Meets	Launch Centralized Hub to Members			Stakeholder Advisory Board Meets
<b>MOBILIZE</b>					First RareDERM Awareness Day				GRIDD-based Advocacy Begins  RareDERM Awareness Day			