



RareDERM Forum Report



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Welcome & Introductions

On April 24, 2025, the RareDERM Community Forum convened in Prague, Czech Republic, marking a milestone in the collective effort to enhance quality of life, mental health awareness, and advocacy for those living with rare dermatological conditions. With nearly 80 participants in attendance the forum embodied the spirit of shared learning, community building, and forward-thinking collaboration.

The event opened with a warm welcome from Jennifer Austin, CEO of GlobalSkin, who acknowledged the growth of the RareDERM community since the previous Forum in 2023 and welcomed both returning and new members. Her remarks set the tone for a day focused on empathy, advocacy, and actionable change. Toni Roberts introduced the forum moderator, Matt Bolz-Johnson, who in turn welcomed Andres Trevino of Chiesi. Andres provided valuable insight into Chiesi's work in the rare disease space, emphasizing their ongoing commitment to patient-centered approaches. With the agenda set, the day began with energy and anticipation.

Icebreaker

To build rapport and ease participants into the day, the Forum was launched with a fun and energising icebreaker. Attendees paired off to share their favorite cultural activities and personal strategies for maintaining mental health and wellbeing. A lively quiz about Prague further encouraged movement, mingling, and the forging of new connections. This introductory exercise energized the room and laid the foundation for the community spirit that would permeate the remainder of the sessions.

Session 1: Explore the Mental Health Unmet Needs of Rare Skin Conditions

Increasing the Importance of Quality of Life and the Impact of Rare on Mental Health, Keynote Intervention

The RareDERM Forum of April 2025 casts a vital spotlight on a long-overlooked dimension of rare skin conditions: their deep psychological and emotional impact. While the physical manifestations of rare dermatological diseases are often the focus of clinical attention, it is the invisible mental health challenges, compounded by diagnostic delays, stigma, and lack of support, that frequently leave individuals and their families struggling in silence.

Rare skin conditions share with other rare diseases a distinct set of stressors, often placing individuals and their families in uncharted and deeply unsettling territory. Unlike more common health conditions, they carry a level of unpredictability and unfamiliarity that disrupts daily life and emotional stability. Prolonged diagnostic journeys, limited access to knowledgeable healthcare providers, and a scarcity of targeted treatments mean that many challenges arise unexpectedly, with little precedent or guidance available. Even medical experts often lack a complete understanding of these conditions, forcing patients to navigate their care independently, while simultaneously educating those around them. In this context, each person living with a rare skin disease must forge their own path, not only toward managing their condition but also toward improving their quality of life through advocacy, learning, and adaptation.

The emotional and psychological landscape is marked by feelings of isolation, uncertainty, and distress. The data presented by EURORDIS' Rare Barometer Survey reveals that over 90% of people living with a rare disease (PLWRD) report significant anxiety, stress, or depression, with nearly one in five experiencing suicidal thoughts. The mental health impact of rare conditions are not isolated to the individuals themselves, they also impact the whole family, affecting parents, partners, and siblings. The family becomes not just a support system, but the frontline of emotional support and resilience. As such, a purely individualistic model of care falls short. A broader, family-centred approach is imperative, one that acknowledges the complex emotional ecosystem, and the unique associated psychosocial risk (and protection factors) surrounding each patient.

The diagnostic process itself is often traumatic. With an average wait of nearly five years and frequent misdiagnoses, this journey can erode trust in the healthcare system and adds and magnify psychological stresses and strains. The moment of diagnosis, when it arrives, can be a point of crisis: many feel overwhelmed, unsupported, and misunderstood. Miscommunication, lack of clear information, and an absence of psychosocial support at this critical time often deepen the distress. In contrast, those with access to timely psychosocial support tend to receive a diagnosis more quickly (more than one year earlier) and show greater capacity to adjust, providing the evidence that early psychosocial intervention is both compassionate and effective.

Beyond diagnosis, people with rare diseases confront a world ill-equipped to support them. The stigma they face, whether experienced or enacted, internalised and anticipated or perceived in nature, exacerbates feelings of shame and social disconnection (Baynam G. et al 2024). Many withdraw from relationships or forgo support altogether, fearing exposure, judgment, or the emotional cost of disclosure. This stigma is compounded when psychological symptoms themselves are dismissed or misunderstood, leaving individuals feeling delegitimized, frustrated and left feeling alone to suffer in silence.

In response, the RareDERM Forum were presented advocacy tools to secure access to psychosocial care that is fully integrated into clinical settings, by sharing EURORDIS outline position paper that details the psychosocial model of care ([link](#)). Not only should psychologists and social workers should be embedded in multidisciplinary care teams, but medical care (and teams) should be enhanced to be psychologically informed. Psychosocial needs should be assessed at every stage from diagnosis to treatment to long-term management. The proposed model emphasizes eight pillars: holistic care, prevention, family-focused support, person-centeredness, resource orientation, supportive therapy, alignment with the rare disease journey, and interdisciplinary cooperation. These principles are designed not only to treat psychological distress but to foster resilience, empowerment, and dignity.

The progress of EURORDIS Mental Health & Wellbeing Network and its activities was presented. The Network spans 27 UN Member States and it's objective is two-fold, at a EU and international level, to make visible rare diseases in mental health policy and at a national level to make visible mental health needs of PLWRD in national rare disease plans and strategies. The Network is developing the evidence base and disseminating findings to influence policy and practice as well as amplifying the voices of those with lived experience by conducting a population survey. The Rare Barometer Survey, is planned to be launched in 25 languages and will provide the opportunity to quantify the population needs in concrete data to drive targeted advocacy and improvements. The RareDERM Forum were invited to take part in the survey as survey results and data would be available for each rare skin condition and also by country. The survey will be live between June & September 2025 and the results available at the end of 2025.

Ultimately, this session underscored to the RareDERM Forum the imperative to increase the recognition and importance of family functioning, quality life and overall mental health and wellbeing not only of the PLWRD but the wider family. Mental health is not a secondary concern for people with rare skin conditions, it is foundational needs and basic human right. Psychological wellbeing must be addressed not just as a complement to physical care, but as a core component of what it means to live well with a rare disease. Care must be compassionate, family-oriented, and built on a deep understanding of the rare disease journey. Only then can we begin to replace isolation with connection, uncertainty with support, and despair with hope.

Group Discussions: Explore the Mental Health Unmet Needs of Rare Skin Conditions & Moderated Feedback

As part of the RareDERM Forum, attendees joined a breakout session to explore the unmet mental health needs of people living with rare dermatological conditions. A central theme was the pervasive discrimination faced by patients and their families, rooted in societal norms that marginalize those who don't conform to typical notions of health. Among the key issues raised was the pervasive sense of discrimination that people living with a rare skin condition and their families often experience. Discrimination shaped by societal norms that marginalize those who don't fit conventional ideas of health and illness. Participants described feelings of dismissal within their own social communities and wider society, where the validity of someone's condition may be questioned if they lack visible or "sufficient" symptoms. This gatekeeping of illness identity can be deeply damaging, particularly when layered onto the already complex journey of living with a rare skin condition.

Uncertainty during long diagnostic journeys also emerged as a major source of stress. People living with a rare skin condition and caregivers frequently bear the emotional and logistical burden of self-advocacy, which is both draining and essential. The lack of therapists with rare disease expertise further compounds these challenges, limiting access to empathetic, tailored care. Despite these hurdles, participants expressed hope through everyday self-care practices, walking in nature, exercising, and connecting with community, highlighting small but meaningful steps toward wellbeing for both individuals and their support networks.

Explore the Mental Health Unmet Needs of Rare Skin Conditions & Moderated Feedback

During the RareDERM Forum, the breakout sessions were designed to delve into the unique mental health challenges faced by individuals living with rare skin conditions. These group discussions offered an intimate space for sharing lived experiences, voicing frustrations, and identifying systemic gaps. As the groups reconvened to present their insights, a recurring theme emerged: the psychological toll of living with a rare skin condition is both profound and multifaceted, often shaped as much by social and institutional barriers as by the conditions themselves. Participants described how societal norms can create an environment in which discrimination is not just likely, but almost unavoidable. People living with rare skin conditions, and their families, often feel excluded or stigmatized, not necessarily due to explicit prejudice, but because of the pervasive assumptions embedded in healthcare systems, workplaces, and communities. This can result in an isolating experience where individuals feel excluded simply for existing with a rare skin condition that falls outside of mainstream understanding.

One particularly disheartening issue raised was about the perception around disease severity. Attendees shared that affected individuals often feel pressured to prove the severity of their illness, whether through a number of diagnoses, visible symptoms, or dramatic health declines, in order to gain validation. This was seen to create an unnecessary ‘toxic’ dynamic where people may feel they haven’t ‘earned’ the right to speak about their suffering or seek support unless their condition visibly meets certain thresholds.

Healthcare interactions were also identified as a key source of frustration. Many shared experiences of healthcare professionals who appeared reluctant to engage in discussions around mental health and wellbeing, often citing time constraints during appointments. The lack of structured psychological support leaves many patients without proper referrals or acknowledgment of their emotional wellbeing. Mental health is too often viewed as a secondary (and lesser) concern, despite its obvious interconnection with physical health, especially in complex, chronic and rare conditions.

The emotional impact of uncertainty was another dominant theme. The lengthy and convoluted journey to diagnosis, often involving years of inconclusive tests and medical ambiguity, leaves both individuals and their families in a prolonged state of anxiety. This chronic uncertainty extends beyond the diagnosis itself; even after confirmation, there is often limited information available about prognosis or treatment, leaving families adrift as they try to make informed decisions in a knowledge vacuum.

Adding to this is the weight of expectation placed on patients and caregivers to become de facto experts and advocates for their condition. Many participants expressed a deep fatigue with the constant need to explain their illness, advocate for resources, and the need to educate healthcare providers. This advocacy burden often falls on those who are already emotionally and physically exhausted, compounding their distress.

Equally troubling is the scarcity of health professionals who are equipped to understand the complex interplay between rare diseases and psychological distress. Standard therapy models often fail to account for the multi-layered trauma, grief, and identity disruption that accompany a diagnosis of a rare skin condition. The lack of tailored psychological care leaves patients feeling misunderstood and unsupported even within therapeutic settings.

Yet amidst these challenges, there were also reflections on hope and resilience. Participants emphasized the value of small, consistent actions, like being connected into a community of people who share their experience, peer support, leisure and sports activities, etc. These are powerful tools for maintaining mental wellbeing. These seemingly simple practices provide a sense

of control, routine, and connection that can be profoundly stabilizing for both patients and their support networks.

Overall, the breakout session revealed a community that is both struggling and striving to navigating systemic gaps while clinging to the small acts of care that make a tangible difference. The insights shared during this discussion underscore the urgency of integrating psychosocial support into all levels of care for rare skin condition and remind us that healing is not just clinical, but also emotional, relational, and deeply human.

Session 2: Explore Community Needs and Landscape Mapping Across the Region

Results of RareDERM Survey, Presentation

At the 2025 RareDERM Forum, Toni Roberts presented the findings from the latest RareDERM survey, which was distributed to the community at the end of 2024/beginning of 2025. Her presentation also marked the official unveiling of a renewed vision and mission for the RareDERM community—one that reflects the evolving needs and growing momentum of patient organizations (POs) supporting individuals with rare skin condition.

This was the second such survey, following an initial environmental scan conducted in 2021. Designed to profile the community, identify unmet needs, and evaluate progress, the latest survey revealed both impressive growth and persistent structural challenges. GlobalSkin's RareDERM Forum has expanded significantly since 2021, not only in membership but also in reach: the number of diseases represented by POs has risen from 29 to 40, and the RareDERM Forum itself now attracts twice as many attendees as in its earlier years. The data also highlighted an encouraging increase in organizational capacity. In 2025, 62% of POs had at least one employee, compared to just 40% in 2021. Additionally, 35% of organizations surveyed had joined in the last year, pointing to fresh engagement and new leadership across the community. Despite this growth, however, funding remains the most pressing barrier. A striking 38% of respondents reported operating with either no guaranteed annual income or less than \$10,000 in funding, unchanged from earlier years, underscoring the community's ongoing financial fragility.

Beyond operational issues, the survey exposed enduring gaps in patient care and treatment satisfaction. Only 15% of organizations said their members were very satisfied with current treatment options, a marked decline from 31% in 2021. Many rare skin conditions are complicated by comorbidities, amplifying both medical and psychosocial impact. While access to healthcare has seen some incremental improvements, dissatisfaction persists, and support systems often fall short of what patients and families need.

In conclusion, the latest RareDERM survey paints a portrait of a dynamic and growing global community, one that is more connected and better organized than before, but still wrestling with financial instability and unmet healthcare needs. Toni Roberts' presentation served as both a progress report and a rallying call: to build on this momentum, reinforce advocacy, and ensure that no patient or organization is left behind in the evolving landscape of rare skin care.

Group Discussions: Explore Community Needs and Landscape Mapping Across the Region & Moderated Feedback

The group discussions brought together participants from diverse global regions, including North America, Africa, India, Malaysia, Europe, and others, to discuss pressing advocacy issues in the rare skin conditions space. Through the roundtable discussions, several key themes and proposals emerged.

Improving Patient Support Tools and Information Pathways

Participants expressed a strong desire to make patient support more accessible, standardized, and impactful at key moments in the care journey. One commonly proposed action was the creation of a 'universal QR code' linking to a trusted support group index. This tool could be displayed in dermatology clinics worldwide, making it easier for newly diagnosed patients to find condition-specific resources. There was also consensus around the need for 'adaptable patient education kits' that included core templates that organizations could customize based on regional or cultural context.

Another unmet need identified was 'guidance for patients attending their second medical appointment', after receiving a diagnosis. Participants proposed a 'follow-up checklist' to empower patients with questions and resources once they've had time to absorb their diagnosis.

Elevating Mental Health and Lived Experience

Mental health was recognized as a significant concern across all discussions. Participants stressed the ongoing emotional burden of rare skin conditions, particularly the sense of isolation, the pressure to self-advocate, and the lack of psychological support. There was also widespread frustration at the tendency among healthcare professionals to avoid mental health discussions due to limited appointment time. The inclusion of lived experience was positioned not as anecdotal but as essential. People living with a rare skin condition and caregivers bring irreplaceable insight into understanding the natural history of rare skin conditions, as well as service design and system navigation. Their voices, participants argued, should be embedded across all levels of healthcare planning and research, not just heard, but acted upon.

Advancing Education, Awareness, and Clinical Engagement

A recurring recommendation was to embed ‘patient stories’ into medical and allied health education. Participants called for structured involvement of patient advocates in university curricula and professional training, particularly to increase clinician awareness of rare diseases early in their careers.

Participants also emphasized the need to improve clinician’s referral of newly diagnosed to patient organization. In many countries, dermatologists do not routinely direct patients to advocacy groups or support networks. Drawing comparisons to cancer care pathways, where organizations like Macmillan are integral, participants called for rare skin conditions to be treated with similar holistic referral practices.

Addressing Structural Gaps in Research and Treatment Access

Access to therapies, particularly multi-indication treatments, emerged as a critical policy gap. Several participants noted that in many countries, there is no dedicated regulatory framework to assess or reimburse treatments for rare diseases, especially when those drugs are already approved for more common indications. This leaves patients navigating unnecessary hurdles or denied access altogether. The groups called for urgent reforms, including rare disease-specific approval pathways and pricing models. They also urged advocacy organizations like GlobalSkin to take a global leadership role in elevating this issue within health policy and regulatory circles.

Strengthening Data Systems and Documentation

Across all discussions, data was viewed as foundational. Without reliable documentation, on patient numbers, disease impact, and service gaps, advocacy loses legitimacy. Participants urged the development of robust data collection systems, ideally integrated into national health records and supported by umbrella organizations.

Surveys, patient-reported outcomes, and case registries were all seen as tools to empower advocacy and shape healthcare planning. Moreover, participants emphasized that data should not only be collected but actively shared returned to patient boards and used to inform research, clinical trials, and local policymaking.

Building Capacity and Organizational Sustainability

Participants repeatedly highlighted the fragility of patient organizations. Many operate on volunteer energy, with minimal funding and unclear succession plans. Concrete actions included developing more structured mentorship programs, legacy-building strategies, and leadership development to ensure continuity and growth.

Funding remained the most frequently cited barrier across all group discussions. Organizations shared the difficulty of securing sustainable financial support, noting that funding sources vary widely by region and political context. Participants asked for tailored funding strategies and greater investment, not only in research or treatment, but in organizational infrastructure, education, and advocacy systems.

Group 7. Fostering Regional and Global Collaboration

While global collaboration was praised in principle, many participants noted that regional coordination could offer more practical value. Different regions share similar healthcare systems, cultural contexts, and policy environments, making regional coalitions a powerful mechanism for advocacy, resource pooling, and knowledge exchange.

Participants encouraged GlobalSkin and other umbrella organizations to help facilitate these networks, providing tools, platforms, and strategic support to bridge local realities with global momentum. As one participant noted, "when small drops come together, they fill the bucket", which underscores the belief that collective action, especially at the regional level, can drive impactful change.

Group 8. Encouraging Research and Mentorship for Future Leaders

Lastly, the group discussions turned to the long-term future of rare dermatology research. Participants spoke of the need to attract early-career researchers and clinicians into the field by highlighting the scientific value and human impact of rare skin conditions. They recommended targeted fellowships, awareness campaigns, and mentorship opportunities to create a thriving next generation of advocates and investigators.

Mentorship was also seen as a means of supporting growth within patient organizations. By pairing established groups with newer or less-resourced ones, the community can build capacity, share lessons learned, and avoid reinventing the wheel.

Session 3: Co-Creating a Global RareDERM Call to Action

Summary of Key Rare Skin Advocacy Needs

In the transition to the afternoon portion of the RareDERM Forum, Jennifer Austin, CEO of GlobalSkin, who provided a timely and important update on the progress surrounding the World Health Assembly (WHA) Resolution on rare diseases. She also spoke about the broader advocacy work being led by Rare Disease International (RDI) in support of this resolution, highlighting its potential to drive systemic change at the global policy level.

Matt opened the final session by outlining the agenda and setting expectations for the discussions ahead and presented the key findings that emerged during Session 2. To further refine the community's direction, participants were asked to vote on which items they believed should take precedence moving forward.

Following a prioritisation process, the following topics were selected as the focus of Session 3 group discussions:

- Group 1 Advocacy for access to holistic care, mental health and wellbeing of the individual and family
- Group 2 Tackling stigma through the power of sharing stories with medical students, doctors, and nurses to understand rare diseases
- Group 3 Development of data collection capacities and infrastructure, incl. lived experience data
- Group 4 Strengthening solidarity amongst the RareDERM community, regionally and globally and increasing opportunities to collaboration, share resources and mentorship
- Group 5 Shared advocacy resources and toolkit to support communities locally to find resources
- Group 6 Recognition of rare skin advocacy groups by policy makers and healthcare professionals (in congresses)
- Group 7 Building sustainability of RareDERM advocacy groups (diversification and generate more funding opportunities, building future leaders)

Group Discussion: Co-Creating a Global RareDERM Call to Action

The RareDERM Forum, through seven working groups articulated a unified advocacy agenda that reflects the lived experiences, clinical complexities, and systemic gaps impacting people living with rare skin conditions. The key advocacy messages and asks are grouped below by key stakeholder group to inform advocacy strategic to deliver meaningful policy change.

Group 1. Advocacy for Access to Holistic Care and Psychosocial Support

The group emphasized the urgent need for health systems to address the full spectrum of needs for people living with rare skin condition, advocating for holistic care models that include psychosocial support to affective individuals, parents/caregivers/partners and wider family, and improved coordination of care. Discussions raised key messages for policymakers that focused on justifying coordination and comprehensive care through economic arguments, stressing that early, integrated support reduces long-term costs by preventing crises and caregiver burnout. The group called for investment in inclusive healthcare systems, equitable reimbursement, and the involvement of patient leaders in policy design.

Key advocacy aims with clinicians and researchers highlighted the fragmentation of care as a major barrier. The group championed interdisciplinary collaboration to improve outcomes and streamline patient experiences. Acknowledging the scale of systemic transformation required, they proposed a phased approach: developing and piloting models for holistic care in selecting (and willing) expert centers, refining them through implementation studies, and gradually scaling successful frameworks. The ultimate goal is to reimagine healthcare where patients and families are treated as whole people, supported by integrated, compassionate systems.

Key Asks to Policy Makers

- Invest in integrated healthcare systems that treat rare skin conditions holistically, including psychosocial care and caregiver support.
- Design equitable reimbursement frameworks that remove barriers to access based on geography or income.

Key Asks to Healthcare Providers

- Prioritize interdisciplinary collaboration among primary and secondary care medical teams, specialists, therapists, and support workers.
- Expand care planning to address the wellbeing of caregivers and family networks.

Key Asks to Researchers

- Partner with patient groups to co-design and evaluate holistic care center models.
- Incorporate mental health and family impact metrics into rare disease outcome research.

Group 2. Tackling Stigma Through Storytelling in Medical Education and Society

The group focused on using storytelling as a tool to dismantle the stigma surrounding rare skin conditions. They emphasized the need to embed patient voices into medical education, arguing that hearing firsthand experiences helps future healthcare providers understand the emotional and social impact of rare skin diseases. The group advocated for structured inclusion of lived experience in training programs for medical students, nurses, and general practitioners.

To reach broader audiences, the group proposed collaborations with “skinfluencers” and patient storytellers to run public awareness campaigns, particularly on social media. These campaigns would aim to humanize rare skin conditions and reduce social stigma, while addressing the concerns that were raising about misinformation online. Participants called for stronger partnerships between advocacy groups and ‘digital storytellers’ to ensure accuracy, ethical messaging, and emotional resonance in public outreach.

Key Asks to Policy Makers

- Fund storytelling campaigns that highlight lived experiences of stigma and drive social change.
- Embed patient perspectives in public health education and rare disease policy narratives.

Key Asks to Healthcare Providers

- Incorporate first-person stories into medical and nursing education to humanize rare skin diseases.
- Recognize the psychosocial needs as an integrated dimension to diagnosis and care.

Key Asks to Researchers

- Study the psychosocial impact of stigma and validate storytelling as an advocacy tool.
- Collaborate with patient communities to co-create materials that dismantle stigma through evidence.

Key Asks to Industry

- Sponsor ethical, co-produced digital storytelling initiatives, ensuring factual accuracy.
- Support influencer education and community standards for responsible messaging.

Group 3. Advancing Data Collection Capacity & Infrastructure, Including Lived Experience Data

The group underscored the critical importance of improving data systems to make rare skin conditions visible within healthcare and policy frameworks. They highlighted that both clinical and patient-reported data are fragmented or undervalued, limiting the ability of advocates to influence policy and funding. The group emphasized the need for standardized coding, such as Orphacodes, to track rare diseases consistently in health records and national databases.

To move policymakers into action, the group recommended leveraging initiatives like PRIDD and advocating for the inclusion of rare disease indicators in national health surveys. They also called for stronger infrastructure at the hospital level to support local data collection that feeds into national systems. Their vision is a multi-level data ecosystem that can inform care delivery, budget planning, and service design, making rare skin conditions visible, measurable, and actionable.

Key Asks to Policy Makers

- Mandate the inclusion of rare dermatological indicators in national health surveys.
- Integrate Orphacodes and standardized coding systems into health information platforms.

Key Asks to Healthcare Providers

- Capture both clinical and patient-reported data at hospital and outpatient levels.
- Train staff to document diagnosis, lived experience, and comorbidity data systematically.

Key Asks to Researchers

- Champion mixed-methods studies that combine clinical metrics with patient-reported outcomes.
- Expand initiatives like PRIDD to include underrepresented regions and populations.

Key Asks to Industry

- Fund anonymized real-world data collection that incorporates quality of life and lived experience.
- Use rare skin condition data to inform development pipelines and market access plans.

Group 4. Strengthening Solidarity & Collaboration Across the Global RareDERM Community

The group explored how to foster meaningful collaboration across the global RareDERM community while respecting cultural diversity. They emphasized the need for solidarity that balances shared goals with regional sensitivity, encouraging mentorship, resource exchange, and peer support among patient organizations. Participants discussed the value of learning from both successes and failures, advocating for a platform where experience could be shared without judgment.

The group proposed a mentorship network and a online collaboration hub to support mutual learning and reduce duplication of effort. They also highlighted ethical considerations in building a global resource library, calling for oversight by a culturally diverse committee to ensure sensitivity and inclusivity. Their ultimate aim is to create an ecosystem where organizations from all regions feel equally empowered to lead, contribute, and innovate in rare skin advocacy.

Key Asks to Policy Makers

- Support regionally tailored rare disease collaboration platforms through funding and policy alignment.

Key Asks to Healthcare Providers

- Engage with regional advocacy networks to better understand cultural and logistical needs, provide clinical expertise to cross-border communities and develop shared protocols.

Key Asks to Researchers

- Co-author global or regional publications with patient leaders that reflect localized insights.
- Mentor early-career investigators through patient-organization-led research collaboration.

Industry

- Support and fund initiatives that foster cross-regional collaborate and supporting infrastructure.

Key Asks to Patient Networks

- Launch a global mentorship program and peer resource-sharing initiative.
- Co-manage a resource library overseen by a diverse ethics board.

Group 5. Developing Shared Advocacy Resources & Toolkits to Support Local RareDERM Communities

The group discussed the creation of a global advocacy platform to support rare disease communities with shared toolkits and resources. Participants envisioned a centralized, user-friendly platform offering templates for grant writing, public education, and campaign development. They emphasized the importance of accessibility, cultural relevance, and clear audience segmentation, ensuring the platform meets the needs of patients, providers, and advocacy groups alike.

Concerns about ownership and data control were addressed through proposals for open-access and member-only content layers, with patient organizations maintaining full control over their contributions. The group also recommended a community-led governance model, managed by RareDERM or a trusted coalition. With the right structure and support, the platform could reduce duplication, improve advocacy outcomes, and strengthen organizational capacity worldwide.

Key Asks to Policy Makers

- Allocate seed funding for publicly accessible, multilingual platforms for patient use.

Key Asks to Healthcare Providers

- Refer patients to approved advocacy toolkits for self-advocacy and service navigation.
- Participate in co-developing materials that strengthen patient-provider trust.

Key Asks to Researchers

- Translate scientific findings into advocacy-ready formats.
- Support toolkit development with evidence-based insights on policy influence.

Key Asks to Industry

- Provide technical support or seed funding for resource platforms under community governance.
- Refrain from content control and instead offer neutral infrastructure support.

Key Asks to Patient Networks

- Develop a tiered-access advocacy resource hub with open and member-only content.
- Maintain content ownership, version control, and community-led moderation protocols.

Group 6. Recognition of Rare Skin Advocacy Groups by Policymakers, Healthcare Professionals, and Industry

The group emphasized the need for formal recognition of patient advocacy groups (PAGs) in healthcare decision-making, policy development, and industry collaboration. With general practitioners often unaware of the impact of rare skin conditions, the group advocated for centralized information portals, like a clinician-focused version of Orphanet, to improve early diagnosis and care coordination.

In policy discussions, participants highlighted the importance of data on disease burden and comorbidities to justify investment. They proposed formal patient advisory boards within government structures to institutionalize patient perspectives. For industry, the group recommended a “seal of legitimacy” or certification program to help identify trustworthy, organized PAGs, encouraging earlier, values-based collaboration across the product development cycle.

Key Asks to Policy Makers

- Formalize the role of PAGs through national advisory councils and working groups.
- Use rare disease data incl. comorbidities to inform strategic priorities/budget allocations.

Key Asks to Healthcare Providers

- Recognize and collaborate with PAGs during conferences, training, and referrals.
- Disseminate PAG-developed materials to improve diagnosis and care continuity.

Key Asks to Researchers

- Involve PAGs in early-stage design and review of studies and clinical guidelines. Including to attribute intellectual and strategic contributions through co-authorship and funding shares.

Key Asks to Industry

- Adopt a certification model for legitimate PAG partnerships to ensure ethical and trusted collaboration.

Group 7. Building Sustainability for RareDERM Advocacy Organizations

The group addressed the sustainability challenges facing volunteer-led patient organizations, particularly the need for stable funding, professional staffing, and leadership succession. Participants stressed that passion alone cannot sustain advocacy, and called for investment in organizational infrastructure, including paid staff roles to manage daily operations, knowledge transfer, and volunteer coordination.

The group also proposed initiatives to support leadership development, such as youth internships and training programs focused on advocacy, communications, and digital engagement. Networking was identified as a critical tool for growth, but one that requires funding and coordination. They recommended that umbrella organizations provide grant-writing support, digital infrastructure, and shared learning opportunities to help advocacy groups grow from fragile volunteer efforts into resilient, professionalized networks.

Key Asks to Policy Makers

- Include PAG sustainability as a pillar in national rare disease frameworks and provide core operational grants to support staffing, leadership development, and continuity.

Key Asks to Healthcare Providers

- Offer in-kind support (e.g. meeting space, clinical access) and co-host patient engagement events.
- Collaborate on co-branded resources that demonstrate shared value in improving patient outcomes.

Key Asks to Researchers

- Include PAGs as formal collaborators or subcontractors in grant applications and capacity-building projects.
- Help deliver training modules for leadership and data use within advocacy groups.

Key Asks to Industry

- Fund capacity-building initiatives, not only outreach campaigns.
- Support professionalization of patient organizations as co-developers of care solutions.

Key Asks to Patient Networks

- Establish a shared infrastructure platform for grant writing, legal templates, onboarding materials, and digital tools.
- Create an internship and youth engagement pathway to ensure leadership succession and innovation.

Closing Remarks

The RareDERM Forum remained highly engaged and enthusiastic throughout each session of the workshop, contributing thoughtful insights and collaborative energy from start to finish.

GlobalSkin committed to turn these key asks into a Call to Action for policymakers, clinicians, researchers, industry leaders, and advocacy networks to prioritize rare skin conditions and structure concrete actions and funding, ensuring that people living with rare skin diseases are seen, supported, and empowered within systems that recognize their humanity, complexity, and contribution.

The Call to Action will align with the existing United Nations resolution on rare diseases and anticipate the forthcoming World Health Organization resolutions expected to be approved in 2025, providing a strategic framework for collective advocacy and action across the RareDERM community.

Total Participants: ~80

Photos from Session

Shared Drive Folder: [Photos from RareDERM Forum](#)