

GlobalSkin RareDERM Community

at the World Congress on Rare
Skin Diseases (WCRSD) 2026

Event Report



International Alliance of
Dermatology Patient
Organizations

GLOBALSKIN.ORG



3rd World Congress

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WCRSD 2026

Summary

The 3rd World Congress on Rare Skin Diseases (WCRSD 2026) brought together clinicians, researchers, patient organizations, industry partners, policymakers, and people with lived experience from around the world in Versailles, France, from 1–3 July 2026. The Congress provided a unique platform to advance research, strengthen international collaboration, and improve the care and quality of life of people living with rare skin diseases.

For the GlobalSkin RareDERM Community, WCRSD 2026 was an invaluable opportunity to elevate the patient voice, showcase the impact of patient organizations, strengthen global partnerships, and ensure lived experience remained at the heart of discussions surrounding research, education, advocacy, and care.



Objectives



Foster global collaboration -

Bring together clinicians, researchers, patient organizations, industry, and policymakers to advance rare skin disease care worldwide.



Advance research & innovation -

Share the latest scientific discoveries, clinical research, and therapeutic developments across rare skin diseases.



Elevate the patient voice -

Highlight patient engagement, empowerment, education, and the critical role of patient organizations in improving outcomes.



Strengthen multidisciplinary care -

Promote collaborative approaches that improve diagnosis, treatment, and long-term management of rare skin diseases.



Build the future together -

Support emerging leaders while encouraging international partnerships that accelerate progress for rare disease communities.



GlobalSkin

Delegation and Membership

A delegation of **19 RareDERM Community Members** actively participated throughout WCRSD 2026, contributing through presentations, panel discussions, community meetings, networking events, and informal knowledge exchange. We were proud to have **strong global representation**, with members joining us from across Africa, Europe, North America, Latin America, Asia-Pacific, and the Middle East. Their diverse perspectives, lived experiences, and expertise **enriched discussions throughout the Congress** and **helped elevate the voice of the global rare skin disease community**.

Advisory Committee

Annemarie Sluijmers, Netherlands, Lupus Europe
Lex van der Heijden, Netherlands, CMTC-OVM
Tim Legenzoff, United States, Foundation for Sarcoidosis Research

Marie-Claude Boiteux, France, Cutiz Laxa International
Holly Priebe, USA, Cutaneous Lymphoma Foundation
Dana Gies, Canada, Canadian Skin Patient Alliance

Members

Marc Yale, United States, IPPF
Andrew Auruku, Uganda, Rare Diseases Uganda
Ai Zheng, China, Chinese Association of Scleroderma
Fikre Hailekiros, Ethiopia, NAPAN
Jolien van der Geugten, Netherlands, Huid Nederland
Rowena Lou Ortiz, Phillipines, SAP
Karin Veldman, Netherlands, Huid Nederland

Benjamin Löffler, Netherlands, Nevus Network Nederland
Vlasta Zmazek, Croatia, DEBRA Croatia
Mateja Krzner, Croatia, DEBRA Croatia
Galena Jennings, Russia, IRIS
Paul Mendoza, Phillipines, Psoriasis Asia Pacific
Elizabeth Beales, Australia, Albinism Fellowship of Australia
Mary-Jean Howard, Australia, DEBRA Australia



When selecting and supporting members to attend international conferences, we aim to create a diverse and representative delegation, balancing different disease areas, geographic regions, backgrounds, and lived experiences.

RareDERM Community Involvement at the WCRSD 2026

Wednesday, 1 July 2026

GlobalSkin Co-Hosted Welcome Cocktail Reception

A wonderful opportunity where RareDERM members connected with stakeholders from around the world. GlobalSkin Board President, Marc Yale, welcomed the WCRSD delegation and set the stage for several days of collaboration, learning, and connection.



Thursday, 2 July 2026

Main Stage Plenary

This session showcased important research and evidence-informed initiatives, with seven RareDERM Community members presenting their validated work. Their presentations highlighted the mental health impact of living with a skin disease and demonstrated the vital role patient organizations play in advancing mental health support and advocacy.



Friday, 3 July 2026

RareDERM Members Event

Facilitated by Veronica Lopez Gousset, this interactive session brought together 19 RareDERM Community members to finalize the Community's shared priorities, identify next steps, and discuss how to translate their roadmap into meaningful action. Together, they focused on turning ideas into tangible outcomes and strengthening their collective impact.



Throughout the Congress

GlobalSkin Exhibition Space

A dedicated space where delegates connected with RareDERM Community members, learned about patient organizations and their priorities, and explored GlobalSkin's PRIDD initiative to promote meaningful patient involvement and its adoption within the research community. Members also shared printed resources highlighting the work of their local organizations.



Power of Partnerships

At WCRSD 2026, we sought to highlight the power of partnerships in advancing outcomes for people living with rare skin diseases. To support this objective, we developed a flyer showcasing successful collaborations between patient organizations and a range of stakeholders, demonstrating **the impact that can be achieved when communities work together** toward shared goals.

To further encourage engagement and connection, we introduced custom lapel stickers for members of the RareDERM Community. The stickers included a space to identify the wearer as part of the RareDERM Community, as well as a second space where delegates could indicate a topic they were particularly interested in discussing.

This simple initiative helped spark conversations between RareDERM members and other stakeholders throughout the Congress, **creating opportunities to share information about the RareDERM Community, exchange knowledge, and explore potential areas for collaboration.**



Thank You To Our Sponsors

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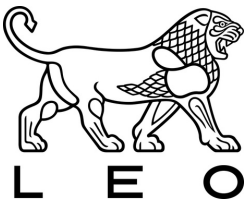
This conference left a deep impression on me. It is rare to see a conference organized with the support of advocacy organizations. Throughout all the aspects, I could see the close cooperation between the advocacy organizations and all parties, which greatly inspired me. The themes and arrangements of the conference were also very rich and thoughtful, not only enhancing my understanding of professional knowledge, but also enabling me to learn from the experiences of other organizations.

– RareDERM Community Member and Travel Bursary Recipient

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GlobalSkin's support was instrumental in helping me participate in the WCRSD for the first time. Living in Australia, the distance and cost associated with attending international conferences can be significant barriers. Being able to attend provided a unique opportunity to deepen existing relationships, establish new connections, and foster opportunities for future collaboration. I am incredibly grateful for this experience and the lasting impact it will have on my work and engagement within the global skin community.

– RareDERM Community Member and Travel Bursary Recipient



We have received overwhelmingly positive feedback from our RareDERM Community patient leaders who attended the WCRSD 2026. As reflected in the testimonial above, this experience has had a meaningful and lasting impact — strengthening advocacy capacity, deepening collaboration, and reinforcing the value of patient voices in research and care!

We extend our sincere gratitude for your support in making this opportunity possible and for your continued commitment to patient-centered progress.