



International Alliance of  
Dermatology Patient  
Organizations

[GLOBALSKIN.ORG](http://GLOBALSKIN.ORG)



# Rare Disease Day 2026 Campaign Report

[#MySkinIsRare](#) [#RareDiseaseDay](#) [#RareDERM](#)

**FEBRUARY 28, 2026**

# Rare Disease Day FEBRUARY 28, 2026

#RareDiseaseDay #RareDERM #MySkinIsRare

Rare Disease Day (February 28) is a global awareness initiative dedicated to the over 300 million people living with rare diseases. This includes more than 800 rare skin diseases that affect 6.8 Million patients worldwide.

Established in 2008 by EURORDIS–Rare Diseases Europe, it highlights the challenges faced by patients, with a focus on engaging policymakers, healthcare professionals, researchers, and the public.

GlobalSkin and our RareDERM Community represent 153 patient organizations supporting people living with rare skin conditions across all WHO regions. This day provides a key platform to raise awareness and advocate for improved recognition, research, and resources for rare skin diseases.

## 2026 Campaign Collaterals



GlobalSkin provided social cards designed to raise awareness and encourage dialogue around rare dermatological diseases across major social media platforms.

The “My Skin Is Rare” campaign supports a global movement to amplify the voices and lived experiences of individuals with rare skin conditions, promoting resilience, community, and improved care and understanding.

To facilitate participation, GlobalSkin offered three options:

- Ready-to-use templates: Pre-designed cards for immediate sharing
- Blank templates: Fully customizable
- Canva templates: Editable in Canva



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## GlobalSkin Campaign

GlobalSkin ran a paid Meta campaign to capture & connect with new global audiences in support of Rare Disease Day. **Here are the results of our reach:**

   
**7,441,452 Views**  
**5,244,675 Reach**



**53K**  
**Engagements**  
(That's Link  
Clicks and likes)




**9.5K** Web  
**Page Visits**



## Top 10 Country Reach

1. India
2. Singapore
3. China
4. Bangladesh
5. United States
6. Nepal
7. Syria
8. Algeria
9. United Kingdom
10. Canada

  
**66% increase**  
**in views, and a 65%**  
**increase in reach**  
**across all social**  
**platforms**

2025 vs 2026

## Patient Stories

GlobalSkin collected stories from our Members to feature lived experience throughout our campaign. These stories were shared on our social media channels & website.

**This year, we received**  
**10 additional stories.**  
**Read them here.** 

**Thank you to**  
**everyone who**  
**shared with us!**

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## New Collaboration

This year, GlobalSkin was invited to collaborate with Rare Revolution Magazine on their “Tuesday Takeover” initiative for Rare Disease Day. GlobalSkin was one of 22 organizations that participated over a 24-hour period.

As part of this partnership, GlobalSkin submitted a series of 5 social media posts, which were published across Rare Revolution Magazine’s Facebook, Instagram, and X channels within a dedicated one-hour “takeover” period.

**RARE REVOLUTION™**  
MAGAZINE



+  
+ 7,000 impressions  
over 200 engagements

## GlobalSkin Rare Disease Day Fund

With the sponsorship of our funding partners, GlobalSkin was once again able to offer grants to our Members to support their Rare Disease Day 2026 campaigns.

This year we are proud to have supported 22 projects across 12 countries and 12 disease areas through this year’s Fund.



# Rare Disease Day

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## GlobalSkin Rare Disease Day Fund Recipients Highlights

BEAUTIFULLY UNBLEMISHED



The GlobalSkin Rare Disease Day Fund enabled **Beautifully Unblemished** to raise awareness, foster inclusion, and build a supportive community for individuals living with vitiligo and other rare diseases. Funding allowed them to create meaningful programs, such as educational events with schools and community spaces, where patients and families could share their experiences, dismantle stigma, and feel empowered and connected. The program created a space where people could share their journeys through spoken word, poetry, music, and storytelling. **“The most meaningful part for us, was seeing families feel supported and less alone, knowing they were part of a community that understands and uplifts one another.” - Tonja Johnson**



The Rare Disease Day Fund allowed **Patients and Civilians Involvement in Health** to bring together over 60 patients living with rare skin conditions, including Neurofibromatosis and Lamellar Ichthyosis. Many participants had never met others with the same condition before. The event provided health check-ups, while creating a safe space for patients to connect and share experiences. One of the attendants was a mother to a Lamellar Ichthyosis patient, who attended for the first time. **“For a long time, we felt like we were fighting this alone. Today we finally see that others share the same struggles, and that gives us hope.” - Warren Simangolwa**



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## GlobalSkin Rare Disease Day Fund Recipients Highlights



The GlobalSkin Rare Disease Day Fund enabled **Corbetta RDC** to host a community event where many participants received their first skin cancer screening, allowing early identification of precancerous lesions and timely medical advice. The distribution of sunscreen provided essential protection against harmful sun exposure. Equally important, the campaign helped educate the wider community about albinism, reducing myths and stigma.



During the Rare Disease Day in Mbuji-Mayi, one memorable moment came from a young woman with albinism who had traveled several hours to attend the free screening. After receiving a skin examination and sunscreen, she expressed deep gratitude, saying it was the first time she had received medical attention specifically for her condition. She shared that people in her community often misunderstand albinism, which makes daily life difficult. **“Her words reminded us why awareness and medical support are so important. Moments like this reinforced our commitment to improving protection, healthcare access, and dignity for people living with albinism.”** - Inena wa inena

[\*\*Click Here For More Stories\*\*](#)



# Rare Disease Day

FEBRUARY 28, 2026

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## Thank You To Everyone Who Participated!

February 28  
IS  
RARE  
DISEASE  
DAY

February 28, 2026  
#RareDiseaseDay  
#RareDERM



FSR  
Foundation for  
SkinDisease Research

28. veljače  
2026.  
DAN  
RIJETKIH  
BOLESTI

#RareDiseaseDay  
#RareDERM  
#MySkinIsRare



MY SKIN IS  
RARE

February 28, 2026  
#RareDiseaseDay  
#RareDERM



ISG  
Ichthyosis  
Support  
Group

February 28  
IS  
RARE  
DISEASE  
DAY

February 28, 2026  
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eaa  
eczema association australia  
support education management

MY SKIN IS  
RARE

5% OF THE WORLD POPULATION IS AFFECTED  
BY A RARE DISEASE.

#RareDiseaseDay  
#RareDERM



SJS  
Stevens-Johnson  
Syndrome Canada  
education support

February 28  
IS  
RARE  
DISEASE  
DAY

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MY SKIN IS  
RARE

February 29, 2024  
RareDiseaseDay  
#RareDERM



# Rare Disease Day

FEBRUARY 28, 2026

#RareDiseaseDay #RareDERM #MySkinIsRare

## THANK YOU!

The Rare Disease Day 2026 initiatives were made possible through the generous support of our partners:

2025 Partners

abbvie

AMGEN



Boehringer  
Ingelheim

KYOWA KIRIN

2026 Partners



sanofi  
REGENERON