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Dear CSD Members,

February brings major advocacy milestones, new research funding opportunities and important insights into the patient experience. From preparations for CSD Hill Day 2026 to the release of new affordability survey findings and federal policy victories, the skin disease community continues to drive meaningful change. Please contact [Natalie Mamerow](#) if you have additional questions.

Best regards,
Natalie Mamerow

CSD Hill Day 2026



Mark your calendar for the upcoming **CSD Hill Day from Sunday, May 17, to Tuesday, May 19, 2026!** We're excited to head to Washington, D.C., to advocate on behalf of the 84 million Americans with a skin disease.

Throughout the event, attendees will meet with legislators to discuss CSD's key [legislative and policy priorities](#), hear from prominent speakers and participate in hands-on advocacy training.

We're also pleased to announce that [applications for CSD Hill Day 2026 are now open!](#) Stay tuned for an upcoming social media toolkit to help you spread the word.

Patient Experience Project: Patient-Reported Affordability and Unaffordability Survey 2.0 Results

The EACH/PIC Coalition Patient Experience [survey report](#) is now available. The survey sought to better understand the reasons patients consider their drugs unaffordable, as well as determine how to solve patient-identified problems. The survey responses show that insurance rules and whether financial assistance is applied consistently determine if patients can maintain access over time.

Key findings include:

- 95% of patients who stopped taking their medications cited insurance-related challenges, not cost, as the primary cause.
 - 87% who never started taking their medication cited insurance-related challenges, including denial of coverage and high out-of-pocket costs even with insurance.
 - 71% of patients stated financial assistance as the reason why their medication was affordable.
-

FIRST 2026 Research Grant Program

The Foundation for Ichthyosis & Related Skin Types' Research Grant Program is now accepting letters of intent supporting scientific discovery in ichthyosis and related skin disorders for the 2026 cycle.

The program offers both pilot grants (up to \$15,000) and research grants (up to \$50,000 with potential funding in a second year) to investigators pursuing basic science or clinical studies that advance the understanding of these conditions.

Researchers are invited to [submit](#) LOIs by **Monday, March 2, 2026**, with invitations for full proposals will be notified **Monday, August 31, 2026**.

Legislative & Policy Updates

Victories for the FY26 Spending Bill

Thanks to the dedicated efforts of our CSD patient advocates, Congress passed H.R. 7148, the Consolidated Appropriations Act of 2026, which includes a meaningful increase in funding for the National Institutes of Health, or NIH. The bill provides \$47 billion for the NIH in FY26, a \$415 million increase over FY25 funding levels.

In addition, many of the key provisions from H.R. 4317, the Pharmacy Benefit Manager Reform Act of 2025, were enacted as part of the federal spending package passed in February 2026. These reforms are expected to improve access to and affordability of life-saving prescription medications for individuals across the skin disease community.

Please take a moment to [thank your legislators](#) for supporting increased NIH funding and advancing PBM reform! Your voice makes a difference.

CSD Demands Health Insurance Reform from Congress

CSD joined a sign-on letter led by Let My Doctors Decide Action Network to the House Ways and Means and Energy and Commerce committees, ahead of their upcoming hearings on the urgent need for health insurance reform. The letter highlighted how patients and providers nationwide are grappling with an alarming expansion of insurer practices that prioritize corporate financial gain over patient well-being.

[Read Letter](#)

Upcoming Conferences

AAD Annual Meeting and CSD Development Day



The CSD is excited to host our annual Development Day in conjunction with the American Academy of Dermatology's Annual Meeting in Denver, CO.

Our full Membership is invited to this event taking place on Saturday, March 28th, from 8:30 am - 12:45 pm in Room 605 of the Colorado Convention Center. The CSD and the AAD are thrilled to be able to offer two complimentary registrations for each of our Patient Group member organizations. Additionally, we will be voting on a change in the bylaws, which can be viewed [here](#).

This event is designed to give back to our keynote speakers and provide meaningful opportunities to connect with colleagues – both familiar faces and new connections. Development Day will include a catered breakfast and lunch.

Please be on the lookout for an email with the Development Day agenda in the coming weeks, but in the meantime, please reach out to Natalie Mamerow and/or Liz Demorest at the AAD with any questions.

2026 SID Annual Meeting CSD Tabletop Exhibit Invitation



The Society for Investigative Dermatology is excited to invite members of the CSD to join us in Chicago, Illinois, for the [2026 SID Annual Meeting](#), taking place at the Chicago Hilton from **May 13 - 16, 2026!**

As a valued partner, they are pleased to offer each Coalition member organization a complimentary tabletop exhibit space along with two (2) complimentary meeting registrations.

Complimentary Tabletop Exhibit

Each coalition member organization is eligible for:

- One complimentary tabletop exhibit
- Two complimentary SID Annual Meeting registrations

Confirming Your Tabletop Exhibit Space

This year, the request process is a bit different. To reserve your tabletop exhibit space, please complete the online request form [here](#).

Once your tabletop request is received, SID's registration team will follow up directly with a separate link and instructions to register your complimentary attendees.

Tabletop Exhibit Details

- Location: Chicago Hilton (exact location to be confirmed)
- One six-foot skirted table
- Two chairs
- Set-up times and additional logistics will be shared closer to the meeting date

Meeting Registration

- Each coalition organization may register two complimentary attendees
- Registration instructions will be provided by our registration team after your tabletop request is submitted
- All registered attendees will have access to the meeting's networking events and social programming

Learning Opportunities

Public Meeting: FDA Rare Disease Day 2026



The FDA will host [Rare Disease Day](#), a virtual public meeting, on Monday, February 23, 2026, from 9 AM - 4 PM ET in global observance of Rare Disease Week. The theme is: “Moving Forward. Looking Ahead. An Event for Patients.”

The goal of this year’s Rare Disease Day is to explore ways to engage and collaborate with patients and their communities to support and accelerate the development of medical products for rare diseases.

The FDA wants patients to connect with them and stay involved with their outreach and engagement programs to ensure the patient voice informs medical product development and regulation throughout the FDA.

[Register Now](#)

Made A Masterpiece Mini Exhibit Now on Display in Houston

Made a Masterpiece, a powerful mini exhibit created by Alanna F. Bree, MD, and Lindsay O’Sullivan, CCLS, is currently on display in Houston, TX. The mini exhibit is designed to challenge how the world views visible skin differences.

Visitors are encouraged to look beyond the surface and recognize the beauty, strength and individuality of every person. The mini exhibit is on view at The Health Museum through April 2026 and will move to the TMC Helix Hall in the summer.

[Learn More](#)

Made a Masterpiece Working to Change the Conversation Around Skin Disease



Made a Masterpiece is working to create a powerful, collaborative, traveling exhibition that challenges how people with visible skin differences are perceived. At the heart of this project are photographs and stories of children that are being brought to life by the Magic Wall Experience – an immersive, interactive, multimedia installation that combines photography, video, storytelling, art, games and education.

The exhibition will premiere in late fall 2026 at The Health Museum in Houston, TX and will travel for five years to museums, hospitals, educational institutions, and galleries across the U.S.

[Learn More](#)

Skin in the News

- Model Winnie Harlow is working to [demystify vitiligo](#) through a new partnership with Incyte, a biopharmaceutical company.
- Bride goes viral for [breaking the stigma](#) of alopecia.
- Woman shares her [personal journey](#) living with eczema.



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