COALITION OF
SKIN DISEASES

Advocating for the 84 million Americans living with a skin condition

2025
HILL DAY

HILL DAY
ONE VOICE
2025

COALITION OF
SKIN DISEASES

“Working together to ensure those living with dermatological diseases and skin traumas receive the care they need to live healthy and productive lives”

Why We Exist

The Coalition of Skin Diseases (CSD) advocates on behalf of the 84 million Americans living with a skin disease. As the largest consortium of skin disease patient advocacy organizations in the United States, the efforts of the CSD aim to ensure that all individuals living with dermatological diseases and skin traumas receive the care they need to live healthy and productive lives.

By working independently, in coalition, and alongside advocacy organizations committed to patients living with dermatological conditions, the CSD endeavors to be at the forefront of progress toward a day where all individuals affected by skin disease have access to life-preserving/changing treatments and high-quality care.

We aim to accomplish this by:

- Fostering education and awareness of skin diseases and disorders,
- Advocating for access to appropriate and quality health care and treatments,
- Contributing to burden and related skin disease research, and
- Strengthening dermatologic patient advocacy organizations through the sharing of resources

The CSD is a 501c3 non-profit organization founded in 2007 by several national dermatological patient organizations, which has since grown to 36 patient advocacy groups. The coalition is passionate about raising the profile of skin disease and supporting those living with a skin disease by providing the patient perspective in medical, research, political and regulatory arenas. The CSD is run by a Board of Directors composed of representatives from member organizations and is sustained by funds provided through membership dues, grants and sponsorships and individual contributions.

THANK YOU TO OUR SPONSORS

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On May 18 – 20, the Coalition of Skin Diseases orchestrated a remarkable event with a Capitol Hill Day fly-in and Congressional Briefing about "Skin Disease: How Science, PBMs, and Access to Care are Impacting 84 Million Americans." For the first time ever, we held a complimentary skin check event on the Hill for Members of Congress and their staff – courtesy of the Dermatology Nurses' Association.

This significant gathering saw **81 passionate patient advocates**, hailing **from 24 states**, come together to amplify their voices and advocate for crucial policy changes. CSD advocates conducted 106 legislative meetings. The collective plea to policymakers was clear – a call for enhanced access to quality care and treatment options for individuals battling skin diseases, alongside a strong request for robust funding to advance research and educational initiatives in the field.

Our advocates were met with listening ears, and in many cases a positive response, from legislators and their staff in our "asks" to cosponsor the bills on our policy agenda: the **Safe Step Act**, the **HELP Copays Act**, and **PBM reform legislation**. We legislative agenda also included requests to **robustly fund to the National Institutes of Health (NIH)**, specifically skin disease research at the **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**, as well as the **Chronic Diseases Education and Awareness Program** at the **Centers for Disease Control and Prevention (CDC)**, in Fiscal Year 2026.

The CSD's Congressional Briefing attracted strong engagement from a wide range of participants, including staff from congressional offices, federal agencies, academic institutions, and private sector organizations. During the briefing, **Congressman John Joyce (R-PA) – Congress's sole dermatologist – delivered extensive remarks that both motivated our advocates and validated the importance of our proposed legislative reforms**. Attendees responded very positively, with many noting that the presentations were genuinely enlightening and compelling. The coalition extends its appreciation to all patient advocates who dedicated their personal time to participate, with particular recognition for those members who courageously told their personal stories, truly representing the heart of our mission.

This year, the CSD introduced a new **Virtual Hill Day component for participants unable to join us in person**, allowing more individuals to raise their voices and advocate for those living with skin disease. We envision a world in which all patient advocates - and their family, friends, and colleagues - feel equipped and empowered to advocate on behalf of the skin disease community regardless of their physical abilities, location, advocacy experience, and/or time constraints. The Congressional Briefing, broadcast live, highlighted how collective advocacy can drive change and set the stage for improved access to care and treatments for individuals living with skin conditions. Both on-site and remote attendees received pre-event social media resources and were given information to our new digital advocacy platform so they could easily reach out to their legislators through automated action alerts. These online action tools **generated 144 emails** delivered to **81 legislators**.

CSD on Capitol Hill May 18-20, 2025

Yours Truly Hotel
1143 New Hampshire Ave NW
Washington DC 20037
Tel: (202)775-0800

For Hotel Information
Scan or visit:
https://bit.ly/42Vw8vi

Sunday, May 18

4:00 PM	Check-In begins at Yours Truly Hotel
7:00 - 8:30 PM	CSD Reception at Yours Truly Hotel - El Chalet
	Located at the back of the entrance behind Mercy Me
	Please pick up your name badge on the CSD table before entering the lounge.

Monday, May 19

8:15 AM	Breakfast
9:00 AM	Welcome and Introductions
9:10 AM	State of Affairs on Capitol Hill - Jason Harris
9:25 AM	Policy Brief and Advocacy Training - NIH Funding: Natalie Mamerow; CoPay Accumulators: Rachel Klein; Step Therapy: Michele Guadalupe; PBM Reform: Dr.Mark Kaufmann
10:30 AM	*** Break ***
10:40 AM	Hill Day Overview and Team Meetings
11:30 AM	Soapbox Overview
12:30 PM	*** Lunch ***
1:30 PM	Breakouts: Team Leaders and Vets, New to the Hill, Youth Track
2:30 PM	***Free Time***
5-8:00 PM	Social Event and Dinner
	Swingers Crazy Golf
	Address: 1330 19th St NW, Washington, DC 20036

Tuesday, May 20

7:00 AM	Shuttles leave promptly for “Homebase” on the Hill (check out & bring luggage)
	ADA Townhouse
	Address: 137 C Street, SE in Washington, DC (map on pg. 3)
7:45 AM	Store Luggage and grab a light breakfast in ADA Townhouse
8:20 AM	Photograph on Capitol Hill Steps
9:00 AM	Meetings with Members of Congress
12-1:00 PM	Congressional Briefing and Lunch in Nancy Pelosi Caucus Room (Cannon Bldg)
	Skin Disease: How Science, PBMs, and Access to Care are Impacting 84 Million Americans
4:00/4:30 PM	Meetings wrap up
5:00 PM	ADA Townhouse doors locked (must have luggage out prior to then)

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Members and Staff are Cordially Invited

Tuesday, May 20th

CONGRESSIONAL BRIEFING

Topic :

Skin Disease: How Science, PBMs, and Access to Care are Impacting 84 Million Americans

Cannon Caucus Room,
Cannon House Building, Room 390

12:00 PM - 1:00 PM

*Refreshments and Lunch will be served

Participate in Complimentary Skin Checks by the Dermatology Nurses' Association

Cannon Room 401

1:00 PM - 4:00 PM

Special Thanks to Representative John Joyce for making this Briefing a Reality

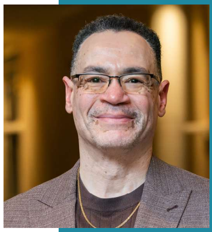
SCAN HERE
TO RSVP TODAY

Brindley Brooks

CSD President and Founder & Executive Director of HS Connect

Turner Young

Teen Patient Advocate With Psoriasis



Stephen Taylor

Patient Advocate With Vitiligo

Joyel Crawford

Patient Advocate With Alopecia & National Alopecia Areata Foundation (NAAF) Legislative Liaison, MBA, CPCC, PHR

Olivia Casey

Senior Director of Programming at the Autoimmune Association

Aimee Payne, MD, PhD

Herbert and Florence Irving Professor and Chair of Dermatology, Columbia University

Mark D. Kaufmann, MD, FAAD

Advanced Dermatology and Cosmetic Surgery; Clinical Professor of Dermatology, Icahn School of Medicine at Mount Sinai

SCAN TO VIEW
SPEAKERS BIOS

COALITION OF SKIN DISEASES 1717 N Street NW Ste 1 Washington, DC 20036 | info@skincoalition.org | www.skincoalition.org

A Deep Dive into our Legislative Agenda for the 119th Congress, 1st Session

Patient Access Issues

Step Therapy Reform – Step therapy, or "fail first," **requires patients to prove** that cheaper or insurer-preferred **medications don't work** before accessing their doctor's prescribed treatment. While this approach can make clinical sense for some conditions and align with medical guidelines, it's often excessive and arbitrary. Insurers may use step therapy primarily as a cost-saving barrier that can harm patient health rather than improve care.

The Safe Step Act legislation would require insurers to implement a clear and transparent process for a patient or healthcare provider to request an exception to a step therapy protocol and requires group health plans to grant exceptions if certain protocol is met. This bill would ensure that employer health plans offer an expedient and medically reasonable step therapy exceptions process and would **ultimately improve timely access to care**. We asked our legislators to please co-sponsor this bill once it's re-introduced in Congress.

Banning Copay Accumulator Programs – Copay accumulator programs are **catching patients off guard** with an unpleasant shock when they pick up prescriptions: The assistance cards they rely on to make their medications affordable no longer apply toward meeting their yearly deductible requirements. With an increasing number of insurance companies and employers implementing these policies, patients encounter **significant challenges**, such as discontinuing necessary treatments, experiencing economic strain, and being forced to switch medications for non-medical reasons. Protecting patient access to essential therapies demands **practical policy remedies**.

The Help Ensure Lower Patient (HELP) Copays Act (H.R. 864) requires that all copays paid by or on behalf of an enrollee, including financial assistance offered by a nonprofit organization or a drug manufacturer, be counted toward the enrollee's annual deductible and cost-sharing obligations. This legislation also closes a loophole that allows many employer health plans to deem certain covered drugs as "nonessential," which means that the insurer will not count any cost-sharing toward the patient's deductible and out-of-pocket maximum. Ultimately, it requires all private plans to **count all cost sharing** for covered services to accrue to a patient's deductible and out-of-pocket maximum. This bill would **create more affordable access to care**.

We asked our Senators to please co-sponsor S. 864, and we asked our Representatives to please co-sponsor the bill once it's re-introduced in the House.

Pharmacy Benefit Manager (PBM) Reform – A pharmacy benefit manager (PBM) is a third-party company that administers prescription drug benefits for health insurers, employers, and government programs. PBMs act as intermediaries between insurance plans, pharmacies, and pharmaceutical manufacturers. Their primary functions include:

- Negotiating drug prices and rebates with pharmaceutical companies
- Creating formularies (lists of covered medications)
- Processing prescription claims
- Managing pharmacy networks
- Implementing utilization management tools like prior authorization and step therapy

In addition to charging insurers for performing these functions, PBMs also derive revenue in other ways: for example, they receive a share of the drug rebates they negotiate with pharmaceutical companies; they collect the difference between what insurers are reimbursed and the amount that pharmacies are paid (the “spread”); and they steer business to their affiliated pharmacies. **These practices impact patients’ access and affordability to medications**.

Any PBM reform legislation must ban deceptive unfair pricing schemes, prohibit arbitrary claw backs of payments made to pharmacies, and require PBMs to report to the Federal Trade Commission (FTC) how much money they make through spread pricing and pharmacy fees. PBM reform will **increase transparency** – resulting in **improved access and affordability** to often life-saving prescription drugs.

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Funding for Medical Research

We request robust funding for the National Institutes of Health (NIH) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) in Fiscal Year 2026.

Global skin diseases are on the rise, with an estimated increase of over 7% from 1990 to 2017. Within the United States, more than 84 million people – or a quarter of all Americans – have a skin disease, yet the nation's funding for medical research for skin disease does not match the need.

Despite the large and increasing number of Americans with skin disease, the largest investor in skin disease studies – the NIH – has seen minimal funding increases over the past decade. Robust and sustained support for biomedical research is essential for the U.S. to sustain its competitive edge and maintain its position as a global leader in scientific research and medical innovation.

Continued congressional support for the NIH drives economic growth, benefiting communities across the nation and secures U.S. leadership in medical research and innovation. Federal investment in medical research saves lives and will help decrease our nation's health care costs and debt.

Funding for Education & Awareness

We request robust funding for the Centers for Disease Control & Prevention (CDC) and the Chronic Diseases Education and Awareness (CDEA) program in Fiscal Year 2026.

The CDEA program seeks to provide educational opportunities for chronic disease communities that lack dedicated funding from ongoing CDC activities, particularly pediatric chronic conditions. Such a mechanism allows public health experts at the CDC to review project proposals on an annual basis and direct resources to high-impact efforts in a flexible fashion.

Chronic diseases account for seven of the top ten causes of death in America and more than 90 percent of our annual health care spending.

Hundreds of thousands of Americans who suffer from unpreventable chronic conditions need access to care.

It is our hope that additional funding will enable CDC to support more proposals in subsequent years. In the interest of growing the program, supporting timely public health efforts, and ensuring the viability and effectiveness of emerging opportunities, we request robust funding for this program in Fiscal Year 2026.

2025 CSD Hill Day Post-Event Survey Results:

Reflections from our advocates.

CSD Hill Day Follow Up

We are pleased to present insights directly from our advocates regarding their experience at the 2025 CSD Hill Day. Their unwavering dedication and passion were instrumental in the event's success, ensuring their voices resonated effectively on Capitol Hill. This report leverages data from our post-event survey to provide a comprehensive overview of their collective experience, highlighting key findings, significant moments, and their perception of the profound impact achieved for our shared mission.

> “This was a great family reunion for not just one type of dermatological disease but for all of us who are linked through the stigmas, frustrations and triumphs.” - 2025 Hill Day Advocate

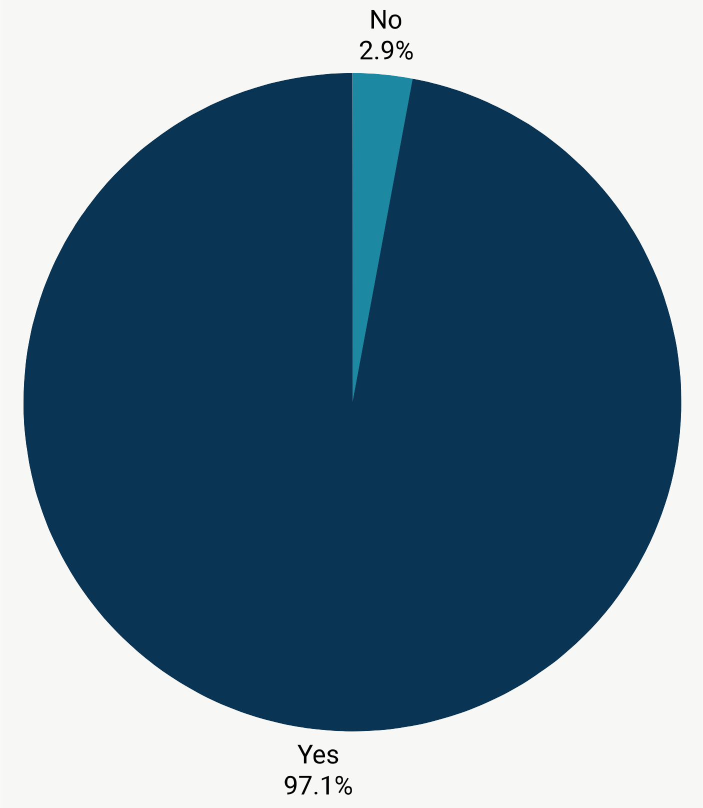
> “...Every staffer and Member of Congress I met with expressed strong support for our policy asks. They were not only receptive but genuinely aligned with the urgency and importance of the issues we presented. Each individual demonstrated a clear commitment to advocating for change and conveyed interest in being part of the solution. There were no signs of opposition on the contrary, there was a shared sense of purpose and a willingness to take action.”
> - 2025 Hill Day Advocate

CSD Hill Day Follow Up

Question	Count	Score
Communication w Event Facilitator	34	4.85
Hotel Accommodations at the Yours Truly Hotel	32	4.72
Training and Education on Advocacy Asks	34	4.85
Social Event at Swingers	33	4.52
Meetings with Legislators	34	4.53
Ease of navigating Capitol Hill - finding buildings, connecting w offices, etc.	34	4.56

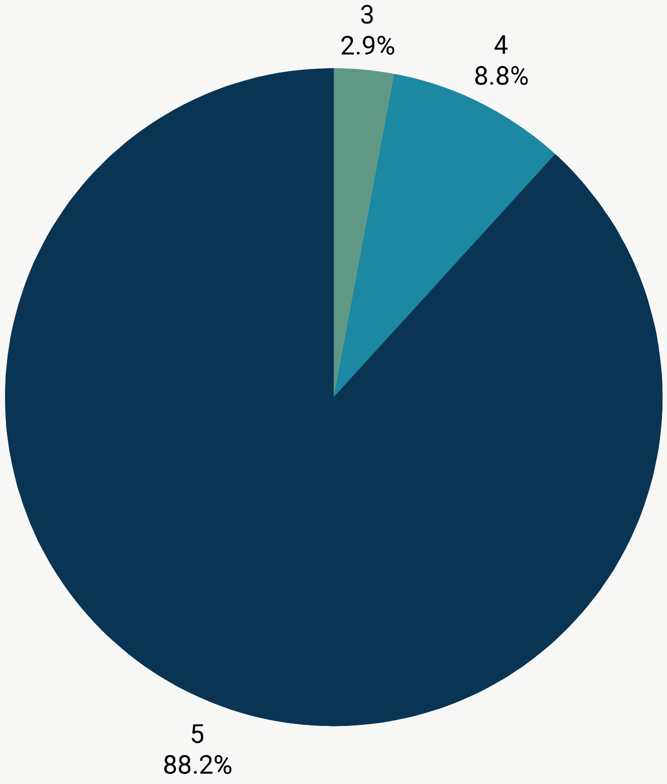
How was your overall CSD Experience?

Question: Did you feel prepared for your meetings in regard to understanding the issues we were asking legislators to support?



> "...The prep materials were spot-on. Everything from the talking points to the background info made it easy to feel prepared and confident going into meetings. Team pairings were really helpful. Having a mix of experienced advocates and newer folks made the conversations flow better and gave everyone a chance to contribute. Sharing personal stories made a difference. It was clear that our lived experiences helped connect the dots for lawmakers and made the issues more real and urgent...."
> - 2025 Hill Day Advocate

Question: On a scale of 1 - 5, with five being excellent, rate the training and education on advocacy asks.



> "...the team seems to go out of their way to make materials easy to understand and present it in a number of ways so that it is easily understood by all. And when questions arise, you are all so quick to answer, and it's never like we're bothering you. The briefing and the stories shared by the selected patients were heartwarming and moving and exactly what the staffers needed to hear...."
> - 2025 Hill Day Advocate

Thank YOU!

Because of the support of our sponsors and the participation and passion of our advocates, we continue to make strides for the dermatology patient community

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