

2024 HILL DAY



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



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 34 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.



On **April 21-23, 2024**, the Coalition of Skin Diseases orchestrated a remarkable event with a Capitol Hill Day fly-in and Congressional Briefing dedicated to Understanding and Addressing the Burden of Skin Diseases.

This significant gathering saw **58 passionate patient advocates**, hailing from **21 states**, come together to amplify their voices and advocate for crucial policy changes. CSD advocates conducted meetings with **57 legislative offices**. 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 increased 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 to support bills on our policy agenda and robust funding to National Institutes of Health (NIH), specifically skin disease research at National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), along with increased funding toward the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).

The CSD's Congressional Briefing was met with enthusiastic participation from a diverse array of attendees, including representatives from congressional offices, federal agencies, institutions, and industry. The feedback we received was overwhelmingly positive, with many expressing that the content presented was truly eye-opening and impactful. The coalition is proud of all of our patient advocates who took time away from work and family to be involved, with a special note of gratitude to our members who bravely shared their stories through video media and in person, truly embodying the spirit of our cause.

This event not only showcased the power of unity and advocacy but also laid the foundation for a future where those affected by skin conditions can receive the care and treatments they truly deserve.

We are truly grateful for our sponsors, whose generous support made this incredible Hill Day possible:



CSD on Capitol Hill April 21 - 23, 2024

The Morrow Hotel

222 M Street NE
Washington DC 20002

Tel: (202)280-2288

<https://www.themorrowhotel.com/>

Sunday, Apr 21

4:00 PM Check-In begins at The Morrow Hotel

7:00 - 8:30 PM CSD Reception at The Morrow Hotel

Monday, Apr 22

8:15 AM Breakfast

9:00 AM Welcome and Introductions

9:20 AM Policy Brief and Advocacy Training

10:30 AM *** Break ***

10:50 AM Hill Day Overview and Team Meetings

12:30 PM *** Lunch ***

1:30 PM Various Virtual Meetings - Group Video Footage Sessions

2:15 PM Social Event

6:00 PM CSD Group Dinner

El Presidente

Address: 1255 Union St NE, Washington, DC 20002

Tuesday, Apr 23

7:45 AM Shuttles leave promptly for “Homebase” on the Hill

ADA Townhouse

Address: 137 C Street, SE in Washington, DC

8:20 AM Photograph on Capitol Hill Steps

9:00 AM Meetings with Members of Congress

12:30 PM Congressional Briefing and Lunch in Nancy Pelosi Caucus
Room (Cannon Bldg) Meetings wrap up

1:30 PM Meetings with Senators

5:00 PM Have luggage out of ADA Townhouse

**The Coalition of Skin Disease
was proud to host a**

CONGRESSIONAL BRIEFING

Understanding & Addressing the Burden of Skin Disease

*Nancy Pelosi Caucus Room,
Cannon House Building, Room 390*

 **12:30 PM - 1: 30 PM**

 **Tuesday, April 23rd**

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



**Lindsey A. Criswell,
M.D., D.Sc., M.P.H.**

Director, National Institute of Arthritis and
Musculoskeletal and Skin Diseases (NIAMS)



Dr. Ian Myles

Principal Investigator, Epithelial
Therapeutics Unit and National Institute of
Allergy and Infectious Diseases (NIAID)



Olaniyan Thurmon (Lani)

Actor Avenger Movies and Co-founder,
Glowboyzz



Marc Yale

Advocacy & Research Coordinator,
International Pemphigus and Pemphigoid
Foundation



Jasmine Espy

Founder and CEO, Association of
Hidradenitis Suppurativa and
Inflammatory Diseases (AHSID)



**SCAN TO VIEW
SPEAKERS BIOS**



A Deep Dive into our Legislative Agenda for the **118th Congress, 2nd Session**

Patient Access Issues

Step Therapy Reform, which implements 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.

The Safe Step Act legislation (S.652/H.R.2630)

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. Please work with your colleagues to advance this key legislation.



Banning Copay Accumulator Programs, which requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements. Specifically, plans must apply third-party payments, financial assistance, discounts, product vouchers, and other reductions in out-of-pocket expenses toward the requirements. This legislation 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. Your bill will require all private plans to count all cost sharing for covered services to accrue to a patient’s deductible and out-of-pocket maximum.

The HELP Copays Act (H.R. 830) 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. Your bill will require all private plans to count all cost sharing for covered services to accrue to a patient’s deductible and out-of-pocket maximum.



Pharmacy Benefit Manager Transparency, which would ban deceptive unfair pricing schemes; prohibit arbitrary claw backs of payments made to pharmacies; and require PBMs to report to the FTC how much money they make through spread pricing and pharmacy fees.

The Pharmacy Benefit Manager Transparency Act of 2023 (S.127) bans deceptive unfair pricing schemes; prohibits arbitrary claw backs of payments made to pharmacies; and requires PBMs to report to the FTC how much money they make through spread pricing and pharmacy fees.



PROTECT for Rare Act, which provides coverage under the Medicare prescription drug benefit, Medicaid, and private health insurance of certain drugs that are used to treat rare diseases or conditions.

The Providing Realistic Opportunity To Equal and Comparable Treatment (PROTECT) for Rare Act (H.R. 6094) provides coverage under the Medicare prescription drug benefit, Medicaid, and private health insurance of certain drugs that are used to treat rare diseases or conditions.



Funding for Medical Research

We request an increase of funding to the National Institutes of Health (NIH) of \$51.3 billion for Fiscal Year 2024, which includes a proportional increase to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

Our community would like to thank Congress for providing \$46.76 billion for the NIH in FY 2024 but know that more research activities are needed to continue emerging opportunities to advance our scientific understanding of skin diseases.

Our overarching concerns are that without meaningful financial support the development of treatment options will be delayed, and we may lose the next generation of talented young investigators to foreign competition and other fields.

To fully capitalize on innovative research projects investigating skin diseases and related conditions, please work with your colleagues to provide NIH with at least \$51.3 billion in FY 2025.



Funding for Education & Awareness

We support increased funding of \$6 million for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).

This program seeks to provide collaborative opportunities for chronic disease communities that lack dedicated funding from ongoing CDC activities. 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.

The CDC's Chronic Diseases Education and Awareness Program (CDEA) seeks to provide collaborative opportunities for chronic disease communities that lack dedicated funding from ongoing CDC activities. 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.

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, please provide this new program with \$6 million for FY 2025.



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

