COALITION OF SKIN DISEASES

DCAN
DERMA CARE ACCESS NETWORK

CONGRESSIONAL BRIEFING:

Addressing Barriers to Patient Access in Dermatological Care

MAY 2026





Introduction

On May 19, 2026, the Derma Care Access Network and the Coalition of Skin Diseases co-hosted a briefing on Capitol Hill. The event brought together 75 skin disease advocates from 26 states traveling to Capitol Hill to participate in CSD's annual Hill Day event, along with legislative staffers, to examine federal policy challenges affecting access to medically necessary dermatological treatments. In particular, the program focused on the misclassification of conditions such as vitiligo and alopecia, as well as insurance utilization management practices.

Through expert presentations and an interactive discussion, participants explored the impact of these diseases beyond their visible symptoms, examined how outdated insurance coverage policies continue to limit access to FDA-approved therapies and supportive services, and identified opportunities for collective action to advance equitable, patient-centered access to care at both federal and state levels.



Congressional Keynote Speaker

U.S. Congressman John Joyce

U.S. Congressman John Joyce (R-Pennsylvania), chairman of the Energy and Commerce Oversight and Investigations Subcommittee, is a board-certified dermatologist and a co-lead of the bipartisan Congressional Skin Disease Caucus. In his remarks, Rep. Joyce emphasized the critical role of patient advocacy, urging fellow members of Congress to treat constituents with the same care and attention they would if they were their own patients.

For Rep. Joyce, advocating for skin diseases is both professional and personal. After losing his grandfather to skin cancer, he was motivated to prioritize addressing skin cancer and other dermatological conditions.

During his remarks, Rep. Joyce underscored the power of patient voices in advancing awareness and policy change. He noted that personal stories resonate with lawmakers and can be instrumental in driving action.

He concluded by reinforcing his commitment to improving access to care, stating:



"As a member of Congress, my job will only become complete when each and every one of you have access to the medicines you need at affordable prices, and each and every one of you have access to the care that Americans expect and deserve."

U.S. Congressman John Joyce

The National Institute of Arthritis and Musculoskeletal and Skin Diseases Overview

The National Institute of Arthritis and Musculoskeletal and Skin Diseases, or NIAMS, is one of the 27 institutes and centers within the National Institutes of Health. NIAMS is the lead NIH institute for research on arthritis and diseases affecting the muscles, bones, joints and skin.

NIAMS supports research into the causes, treatment and prevention of arthritis and diseases affecting muscles, bones, joints and skin. The institute also trains basic and clinical scientists and shares research progress with patients, providers and the public.

> Many conditions within NIAMS' purview—including eczema, psoriasis, vitiligo, hidradenitis suppurativa and alopecia areata—are **chronic** and can **significantly affect quality of life.**



Anna E. Mazzucco, PhD, deputy director of NIAMS, highlighted several key research and collaboration initiatives within the institute.



The Accelerating Medicines Partnership Autoimmune and Immune-Mediated Diseases Program addresses critical gaps in autoimmune conditions, including psoriasis spectrum disorders. The program also focuses on identifying disease markers, improving clinical trial design and advancing personalized therapies.



Exposome in Autoimmune Disease Collaborating Teams, or EXACT, is a national, interdisciplinary research network developed in partnership with the NIH Office of Autoimmune Disease Research and NIAMS. The network seeks to better understand environmental drivers of autoimmune diseases, including psoriasis and eczema.



Skin biology and research funded by NIAMS has shown that early interventions—such as daily moisturizer use in children younger than 2—can reduce the incidence of eczema, underscoring the importance of prevention-focused strategies. NIAMS also continues to advance skin disease research through collaborations across NIH and sustained investment in rare disease research.



"The total budget for NIAMS for fiscal year 2025 was $688 million. NIAMS strategically uses this funding to address bone, joint and skin disease conditions that affect Americans each year through extramural and intramural programs."

Anna E. Mazzucco, PhD, NIAMS

NIAMS plays a critical role in advancing skin disease research and fostering innovation across autoimmune and immune-mediated conditions. Its investments in collaborative research, early intervention strategies and workforce development are essential to improving outcomes for patients living with chronic and often underserved diseases.



PANEL DISCUSSION

Barriers to Patient Access in Dermatological Care

Leading skin disease experts and advocates discussed persistent barriers to accessing dermatological care. Although skin diseases affect millions of Americans, patients continue to encounter significant challenges in obtaining medically necessary treatment. Conditions such as vitiligo and alopecia areata are clinically recognized autoimmune diseases with well-documented physical and psychological impacts. However, insurance coverage policies—particularly within Medicare Part D and state Medicaid programs—often continue to classify these conditions as cosmetic, limiting access to appropriate care.

Misclassification of Skin Diseases as "Cosmetic" Limits Access

Alisha Archibald, founder of So Rare They Stare, Inc. shared her experience living with vitiligo, emphasizing the physical and emotional toll of the condition and the impact of her condition misclassified as "cosmetic" by providers and insurers. Despite a clear diagnosis, she was not referred to a specialist and self-managed her condition for several years. Panelists noted that when conditions such as vitiligo and alopecia areata are treated as cosmetic, patients face significant barriers to care, including lack of coverage and high out-of-pocket costs. This can lead to delayed treatment, emotional distress, and stigma. Panelists highlighted the need for Congress and CMS to address coverage inconsistencies and standardize access to medically necessary therapies.



"Even though there are FDA approved medications on the market, insurance companies may deny coverage, leading to patients paying out-of-pocket for expensive treatments."

Alisha Archibald
So Rare They Stare, Inc.

Copay Accumulators and Affordability Challenges



Kim Czubaruk, JD, vice president of policy at Cancer*Care*, discussed affordability challenges in commercial insurance, focusing on copay accumulator programs. Also known as accumulator adjustment programs, these policies allow insurers and pharmacy benefit managers to prevent manufacturer copay assistance from counting toward a patient's deductible or out-of-pocket maximum. Approximately 69 percent of patients who rely on copay assistance are low-income, making them especially vulnerable to these practices. The HELP Copays Act (H.R.6423/S.864) would require insurers and pharmacy benefit managers to count third-party payments made on a patient's behalf toward annual deductibles and out-of-pocket limits, helping prevent insurers from benefiting twice from the same assistance. If enacted, the legislation would help patients with skin diseases better afford medically necessary treatments and reduce their out-of-pocket costs.

> **"Copay accumulator programs target people that have chronic, serious or complex conditions, because treatments for those conditions are more costly."**
>
> **Kim Czubaruk, JD**
> Cancer*Care*

Step Therapy Delays Appropriate Treatment

Liz Siembida, PhD, MPH, associate director of health policy and advocacy at the National Psoriasis Foundation and co-chair of the Safe Step Coalition, discussed the challenges associated with step therapy. These policies require patients to try and fail insurer-preferred medications before accessing the treatment prescribed by their health care provider. Utilization management practices such as step therapy can delay appropriate treatment, worsen disease progression, and undermine trust between patients and providers. Panelists identified the Safe Step Act as a bipartisan federal solution that would establish a clear, medically reasonable exceptions process while preserving appropriate use of step therapy.



"Most step therapy protocols set by health insurance plans are more stringent than clinical guidelines. Many patients in the psoriatic disease community must try and fail more medications than clinical guidelines to recommend or remain on them for longer periods. This can lead to disease progression and future diagnoses of conditions that are comorbidities of psoriatic disease."

Liz Siembida, PhD, MPH
National Psoriasis Foundation and co-chair of the Safe Step Coalition



Policy Recommendations

Pass the HELP Copays Act to ensure copay assistance counts towards patient cost-sharing obligations.

Advance the Safe Step Act to limit harmful step therapy practices.

Address the coverage gaps within Medicare and Medicaid, particularly for conditions often misclassified as cosmetic.

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About Derma Care Access Network

The Derma Care Access Network sponsors educational initiatives and advocacy programs designed to encourage informed policymaking about the benefits of access to approved therapies and appropriate clinical care.

dermacareaccess.org

COALITION OF SKIN DISEASES

About the Coalition of Skin Diseases

The Coalition of Skin Diseases is a 501(c)(3) nonprofit organization that advocates on behalf of 84 million Americans living with a skin condition.

Skincoalition.org