



COALITION OF SKIN DISEASES

LEGISLATIVE PRIORITIES



119th Congress, 2nd Session

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 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, 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.

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. CSD is run by a Board of Directors composed of representatives from member organizations and is sustained by funds provided through membership dues, grants, sponsorships, and individual contributions.

Funding for Medical Research

Robust Funding in FY27 – CSD supports funding for the National Institutes of Health (NIH) and National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). 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..

Congressional Skin Disease Caucus

CSD supports the creation of a Congressional Skin Disease Caucus to address the significant and growing health, economic, and social burden of dermatologic conditions. Skin diseases affect nearly one in four Americans, cost the U.S. health care system an estimated \$75 billion annually, and are often associated with serious comorbidities including cardiovascular disease, diabetes, depression, and anxiety. The proposed caucus would serve as an educational and policy-focused forum for Members of Congress and staff, offering briefings, resources, and collaboration opportunities to improve patient access to affordable, high-quality care and advance evidence-based policy solutions. With administrative support provided by the CSD, the caucus would raise awareness, foster bipartisan engagement, and support legislation that improves outcomes for individuals and families affected by skin disease.



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Patient Access Issues

Step Therapy Protocol – CSD supports step therapy protocol legislation, specifically the **Safe Step Act (S. 2903/ H.R. 5509)**. This bipartisan legislation ensures that employer-sponsored health plans offer an expedient and medically reasonable step therapy exceptions process. Step therapy is a utilization management protocol in which patients must try insurer-preferred medications and demonstrate that they do not work before the payer will cover the treatment initially selected by the patient and their provider; this is why step therapy protocol is often referred to as “fail first.” When medically inappropriate, step therapy delays access to needed care, can lead to severe or irreversible health outcomes for patients, and can even increase overall healthcare spending.

Co-Pay Accumulator Programs – CSD supports co-pay accumulator program legislation, specifically the **Help Ensure Lower Patient (HELP) Copays Act (S.864/ H.R. 6423)**. This bipartisan legislation requires private health plans to count the value of co-pay assistance toward a patient’s deductible and/or out-of-pocket maximum (i.e. cost-sharing requirements). It also closes a loophole that currently allows many private health insurance plans to deem certain covered drugs as “non-essential,” which means that the insurer will not count any cost-sharing towards the patient’s cost-sharing requirement. This bill would bring much-needed relief to skin disease patients by ensuring that all payments – whether they come directly out of a patient’s pocket or with the help of co-pay assistance – count towards their out-of-pocket costs.

Pharmacy Benefit Manager Reform – CSD supports pharmacy benefit manager (PBM) reform legislation, specifically the **Pharmacy Benefit Manager (PBM) Reform Act of 2025 (H.R. 4317)**. This bipartisan legislation bans spread pricing in Medicaid, ensures fair reimbursement for pharmacies, and breaks the link between PBM profits and the price of medications in Medicare. It also requires PBMs to disclose key information to patients and employers so they can see exactly where their money is going. This bill would radically increase skin disease patients’ access and affordability to often life-saving prescription drugs.

