COALITION OF SKIN DISEASES

Legislative Priorities
119th Congress, 1st 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 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, sponsorships, and individual contributions.

Medical Research, Education and Awareness Funding

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 have a skin disease.**

Despite the large and increasing number of Americans with skin disease, the largest investor in skin disease studies – the National Institutes of Health (NIH) – has seen minimal funding increases over the past decade. In fact, the NIH and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) received less funding in Fiscal Year 2024 than in Fiscal Year 2023. Ultimately, funding for skin diseases – which impact over a quarter of all Americans – is woefully inadequate.

Therefore, the **CSD requests increased, robust funding for both the NIH and NIAMS in FY2026, as well as 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.

Patient Access Issues

Step Therapy Protocol

The **CSD supports step therapy protocol legislation**, previously introduced as the **Safe Step Act**. This 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

The **CSD supports co-pay accumulator program legislation**, previously introduced as the **Help Ensure Lower Patient (HELP) Copays Act**. This legislation would require private health plans to count the value of co-pay assistance toward a patient’s deductible and/or out-of-pocket maximum (ie. cost-sharing requirements). It would also close 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 legislation 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

The **CSD supports pharmacy benefit manager (PBM) reform legislation**, previously introduced as the **Pharmacy Benefit Manager Transparency Act**. This legislation would 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 legislation would radically increase skin disease patients’ access and affordability to often life-saving prescription drugs.