



Legislative Agenda  
118<sup>th</sup> Congress, 2<sup>nd</sup> 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 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.

### **FY2024 Funding Recommendations**

#### Medical Research

- **Please provide the National Institutes of Health (NIH) with \$51.3 billion for Fiscal Year 2024.** Please also provide a proportional increase to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

#### Education and Awareness

- **Please provide \$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.



## **Patient Access Issues**

- **Please cosponsor and work to advance the Safe Step Act (S.652/H.R.2630)** 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.
- **Please cosponsor and work to advance the HELP Copays Act (H.R. 830)** 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.
- **Please cosponsor S.127 - Pharmacy Benefit Manager Transparency Act of 2023** 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.
- **Please cosponsor H.R. 6094 – Providing Realistic Opportunity To Equal and Comparable Treatment (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.