

April 9, 2025

The Honorable Shelley Moore Capito Chair, U.S. Senate

Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies Room S-128, the Capitol Washington, D.C. 20510 The Honorable Tammy Baldwin
Ranking Member, U.S. Senate
Appropriations Subcommittee on Labor, Health
and Human Services, Education, and Related
Agencies
Room S-128, the Capitol
Washington, D.C. 20510

Dear Chair Capito, Ranking Member Baldwin, and Distinguished Members of the Subcommittee:

Thank you for your time and your consideration of the priorities of the skin diseases community as you work to craft the Fiscal Year 2026 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

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 aims to ensure that all Americans 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 and sponsorships and individual contributions.



National Institutes of Health (NIH)

The NIH hosts a modest research portfolio on skin diseases. The CSD works closely with the NIH, and specifically with the National Institute of Arthritis & Musculoskeletal & Skin Diseases (NIAMS), to advance critical activities across all skin diseases. The CSD requests robust funding for the NIH, and specifically, for NIAMS in FY26.

Across all skin diseases, NIAMS supports growing research that has helped us better understand these conditions. In addition to its intra-mural work, NIAMS supports several Resource-Based Centers for skin biology and diseases research across the country. These centers provide critical research infrastructure, shared facilities, services, and resources to groups of investigators conducting research on skin biology and diseases, enabling them to conduct their individual or collaborative research projects more efficiently and effectively.

While these efforts are making much needed progress in the field of dermatology, the sad fact is that although over one quarter of the U.S. population is affected by a skin disease – and estimated costs related to these diseases is over \$86 billion dollars annually – only 17% of the \$110 million allocated to NIAMS is directed toward skin disease research. More must be done to help improve the lives of dermatology patients through scientific research in order to gain a better understanding around the underpinnings of skin disease and prevention, when possible, along with promoting the discovery of viable treatments. We look to this subcommittee for your support in providing robust funding to the NIH and, specifically, to NIAMS.

Centers for Disease Control and Prevention (CDC)

Most skin diseases are chronic in nature and affect individuals throughout their entire lives; as such, it is essential for patients to be provided with adequate education to manage those diseases. The CDC offers grants to patient advocacy groups in the development of these needed resources. The CSD requests robust funding for the CDC and the CDC's Chronic Diseases Education and Awareness Program in FY26.

The CDC's Chronic Diseases Education and Awareness 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. Continued support for this program will benefit the skin diseases community by allowing for more grants to be funded aimed at raising awareness and expanding educational opportunities for CSD organizations. The more funding available, the more opportunities there are to ensure better provider education and general public awareness.

Thank you for giving the CSD the opportunity to make these FY26 funding requests and for your thoughtful consideration. The CSD looks forward to working with you all to advance medical



research and public health activities that will improve patient outcomes for the members of our community suffering from skin diseases.

Sincerely,

Kelly Barta

Executive Director

Coalition of Skin Diseases