

2021/2022
**ANNUAL
REPORT**





LETTER FROM THE EXECUTIVE DIRECTOR

It's been another wonderful and exciting year as the Coalition of Skin Diseases continues to grow and strengthen our work together to represent the collective voice of dermatologic patients in public policy and the healthcare system.

The power of collaboration cannot be understated, especially when it is matched with shared passion and determination. Our member organizations take advocacy seriously, with many of our leaders being patients themselves, and are committed to helping create much needed change that will support and improve the lives of individuals living with a skin disease.

Our goal is to find a seat at every table that the dermatologic patient voice is needed and missing, to facilitate a grassroots movement that raises awareness of skin disease and to push forward progress in the field of dermatology through education, research and advocacy.

Together we are stronger!

Kelly Barta, President & Executive Director



WHY WE EXIST

As the largest consortium of skin disease patient advocacy organizations in the United States, the efforts of the Coalition of Skin Diseases (CSD) aim to ensure that all Americans living with dermatological diseases and skin traumas receive the care they need to live healthy and productive lives.

OUR MISSION

To advocate on behalf of the individuals living with a skin disease and increase the pace of discovery or a cure, while improving the quality of life for those affected.

CSD IS GUIDED BY THE PRINCIPLES OF

- Patient-Centricity
- Respect and Inclusion
- Integrity and Transparency
- Spirit of Collaboration and Good Faith
- A Mindset of Growth and Innovation

Leadership

Kelly Barta

President and Executive Director

Becky Abbott

Vice President

National Foundation for Ectodermal Dysplasias

Brent Hazelett

Treasurer

HS Foundation

Lauren Isbell

Secretary

NEVUS Outreach

Gary Sherwood

Board Member

National Alopecia Areata Foundation

Jackie Gardner

Board Member

Vitiligo Support International

Chris Boynton

Board Member

Foundation for Ichthyosis and Related Skin Types



ASSOCIATE MEMBERS

- A Childrens House for the Soul
- Allergy & Asthma Network (AAN)
- Autoimmune Association
- Beautifully Unblemished
- Cutaneous Lymphoma Foundation (CLFoundation)
- Foundation for Ichthyosis & Related Skin Types (FIRST)
- Foundation for Sarcoidosis Research (FSR)
- Global Parents for Eczema Research (GPER)
- Global Vitiligo Foundation (GVF)
- Gorlin Syndrome Alliance (GSA)
- HS Connect
- HS Foundation
- International Hyperhidrosis Society (IHhs)
- International Pemphigus and Pemphigoid Foundation (IPPF)
- International Topical Steroid Awareness Network (ITSAN)
- National Alopecia Areata Foundation (NAAF)
- National Eczema Association (NEA)
- National Foundation for Ectodermal Dysplasias (NFED)
- National Psoriasis Foundation (NPF)
- Nevus Outreach
- Pachyonychia Congenita Project (PC Project)
- Scarring Alopecia Foundation (SAF)
- United Porphyria Association (UPA)
- Vitiligo Support International (VSI)
- Xeroderma Pigmentosum (XP) Family Support Group

AFFILIATE MEMBERS

- American Academy of Dermatology (AAD)
- Canadian Skin Patient Alliance (CPA)
- Derma Care Access Network (DCAN)
- Derm Nurse Association (DNA)
- International Alliance of Dermatology Patient Organizations (IADPO)
- Innovation and Value Initiative (IVI)
- Pediatric Dermatology Research Alliance (PeDRA)
- Skin of Color Society (SOCS)
- Society for Investigative Dermatology (SID)

This past year, the CSD experienced significant growth of over **38%**. Our organization now includes 25 national patient advocacy groups and 9 professional groups, representing a diversity of perspectives.

ACTIVITIES AND ACCOMPLISHMENTS

MEETINGS

American Academy of Dermatology Association

Legislative Conference and Capitol Hill Day
September 2021

Learnskin

Integrative Dermatology Symposium
October 2021

American Academy of Dermatology

Annual Meeting
March 2022

CSD Development Day

Patient Journey Project
March 2022

Skin of Color Society

Diversity in Clinical Trials Summit
June 2022



ACTIVITIES AND ACCOMPLISHMENTS

MEMBERSHIP DEVELOPMENT WEBINAR SERIES

501c3 Compliance and Planned Giving
Jeri Holmes, Nonprofit Solutions, P.C.



Pharma and the Patient Organization
Ilana Tabak, Regeneron
Trisha Devlin, Eli Lilly



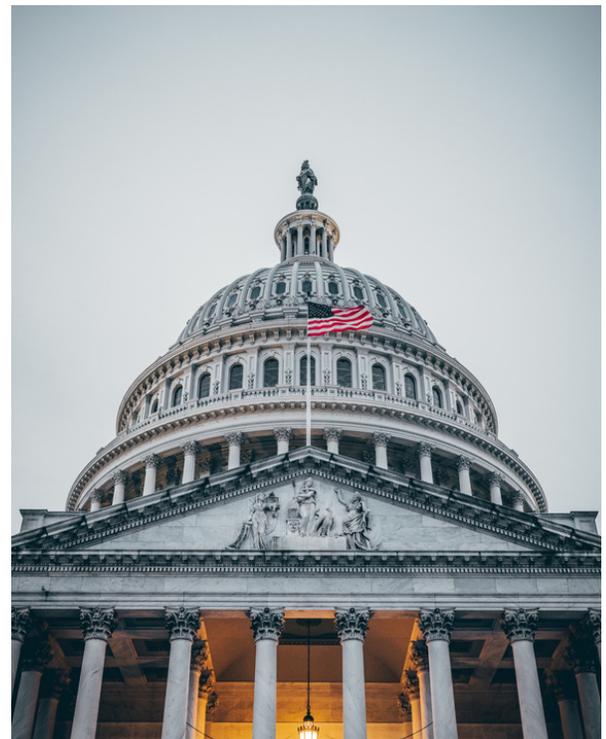
ADVOCACY

Coalition Members participated in 219 Congressional Meetings with dermatologists at the AADA Capitol Hill Day

Member Advocacy Survey to determine Legislative Priorities for 2022 CSD Hill Day

Supported Policy Efforts:

- Safe Step Act - Step Therapy Reform
- HELP COPAYS ACT - Banning Copay accumulator and maximizer programs
- PASTEUR ACT - Mitigate Antimicrobial Resistance
- PBM Transparency
- Stop Medicare Cuts
- Funding for NIH/NIAMS and CDC Chronic Disease Education Program



219

Congressional Meetings
in 2021

84M

Americans Living with
a Skin Disease

26

Dermatological Related
Non-Profit Groups

\$86B

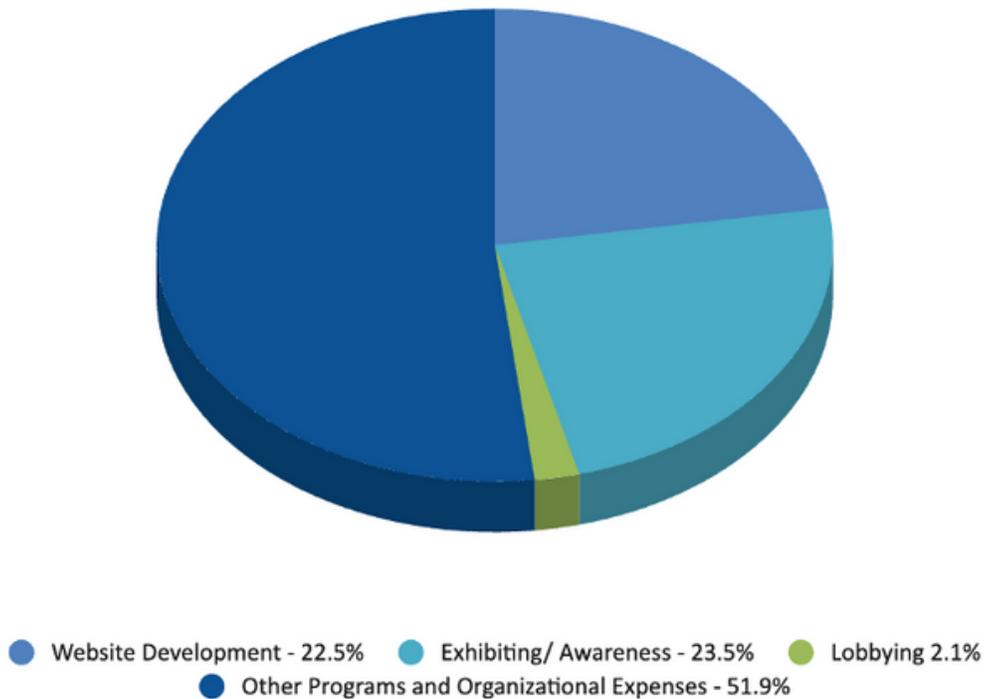
In Direct and Indirect Costs
Related to Skin Disease

FINANCIALS

07/01/21 - 06/30/2022

The CSD appreciates the support received from our members through member dues. These resources are used to underwrite operations, provide education for our patient groups, raise awareness through exhibiting at key meetings for the dermatology community, advocate for skin disease patients, and stakeholder engagement. We also are grateful to our corporate sponsors providing grants that are allocated toward specific, missions related programming.

Expenses by Program



PARTNERS

The Coalition of Skin Diseases gratefully acknowledges the generous support of our Healthcare Industry Partners

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Platinum Sponsor



Gold Sponsor



Silver Sponsor



Silver Sponsor



Silver Sponsor



Partner Sponsor



ABOUT THE CSD

The Coalition of Skin Diseases is a private, tax-exempt, nonprofit organization pursuant to Section 501(c)(3) of the Internal Revenue Code, and all gifts and donations to CSD are tax deductible.

Federal Tax ID number: 20-8948050



1717 N Street NW, Suite 1
Washington, DC 20036

www.skincoalition.org

