



2022/2023 ANNUAL REPORT





LETTER FROM THE EXECUTIVE DIRECTOR

It's been a full year of rewarding milestones for the Coalition, from hosting our first stand-alone Advocacy Day on Capitol Hill to expanding the CSD's footprint in the dermatology space by exhibiting or presenting at a variety of meetings and joining forces with other stakeholders to push forward skin disease research and support patients.

The power of collaboration cannot be understated. And the more we network to develop meaningful relationships with others who share a similar passion and dedication, the closer we come to accomplishing our mission of improving the lives of the 84 million Americans living with a skin condition.

As I look over this past year of working together to advocate on behalf of those we all serve, I am truly proud of the accomplishments we have made. We are moving toward a world that understands the true burden and impact of skin disease, and creating policies which will provide needed access to appropriate care and treatment along with the funding for research to help unlock the puzzles around skin diseases and provide hope for a healthier future.

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

Brent Hazelett

Treasurer
HS Foundation

Lauren Isbell

Secretary
NEVUS Outreach

Chris Boynton

Board Member
Foundation for Ichthyosis and Related Skin Types

Dr. Alanna Bree

Board Member
Made a Masterpiece

Brindley Brooks

Board Member
HS Connect

Jackie Gardner

Board Member
Vitiligo Support International

Linda Markham

Board Member
Dermatology Nurses' Association

Kristen Wheeden

Board Member
United Porphyrias



ASSOCIATE MEMBERS

- Allergy & Asthma Network (AAN)
- Association of Hidradenitis Suppurativa and Inflammatory Diseases (AHSID)
- 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)
- Made a Masterpiece
- Masse World
- 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)
- Dermatology Nurses' 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)



ACTIVITIES AND ACCOMPLISHMENTS

EXHIBITION AND AWARENESS MEETINGS

American Academy of Dermatology Association

Legislative Conference and Capitol Hill Day
September 2022

CSD Hill Day

September 2022

Learnskin

Integrative Dermatology Symposium
October 2022

Innovation and Value Initiative

Annual Meeting
October 2022

Pediatric Dermatology Research Alliance

Annual Conference
November 2023

Dermatology Nurses' Association

Annual Meeting
February 2023

American Academy of Dermatology

Annual Meeting
March 2022

CSD Development Day

March 2022

CSD Hill Day and Congressional Briefing

April 2023

Pediatric Dermatology Research Alliance

Day at NIH
May 2023

World Orphan Drug Congress

May 2023

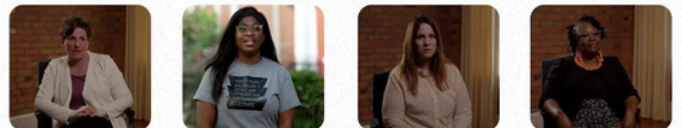
Globalskin Conference

June 2023

SKIN DISEASE AWARENESS VIDEOS

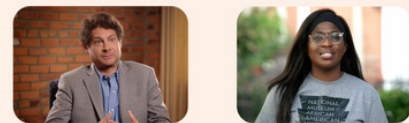
THE IMPACT OF SKIN DISEASE 1

ALOPECIA, PORPHYRIA, EB, CONGENITAL NEVI, PEMPHIGUS, TSW



IMPACT OF SKIN DISEASE 2

HS, VITILIGO, PC, ECZEMA, ICHTHYOSIS



ACTIVITIES AND ACCOMPLISHMENTS

ADVOCACY

In September of 2022, **34 Coalition Members participated in 227 Congressional Meetings** with dermatologists at the **AADA Capitol Hill Day** and **an additional 23 meetings** with key Committee Members in the House and Senate later that week as part of the inaugural **CSD Hill Day**.

In preparation for the first stand alone CSD Hill Day in 2023, the coalition ran a **Member Advocacy Survey** to determine Legislative Priorities and drafted policy positions now hosted on the CSD website.

The CSD held its **Hill Day Event**, April 23-25, 2023, bringing 40 advocates to Washington DC, to further train and equip them to then meet with their Members of Congress. Patient Advocates conducted **80 Congressional Meetings on Capitol Hill** supporting CSD policy positions..

On April 25, the coalition hosted a **Congressional Briefing** on the Burden of Skin Disease, which included a presentation by Dr. Lindsey Criswell, director of NIAMS, along with a panel of CSD members and a video of patients highlighting the impact of skin diseases.

The CSD Supported Policy Efforts Around:

- 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



Skin Biology and Diseases Research at NIAMS

Lindsey Criswell
M.D., M.P.H., D.Sc.
NIAMS Director



NIH National Institute of Arthritis and Musculoskeletal and Skin Diseases

Coalition of Skin Diseases Congressional Briefing



ACTIVITIES AND ACCOMPLISHMENTS

ADVOCACY TRAINING SERIES



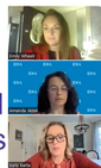
MEMBER DEVELOPMENT WEBINARS



The Urgent Need Action to Address Antimicrobial Resistance (AMR)

*A Discussion with the BIO and the
Infectious Diseases Society of America*

Emily Wheeler – Director, Infectious Disease Policy, BIO
Amanda Jezek – SVP Public Policy and Government
Relations, IDSA
Nov 15, 2022



FDA Engagement: Where Does the Patient Organization Fit In?

October 20, 2022

Moderated by:
Kelly Barta, Executive Director @CSD

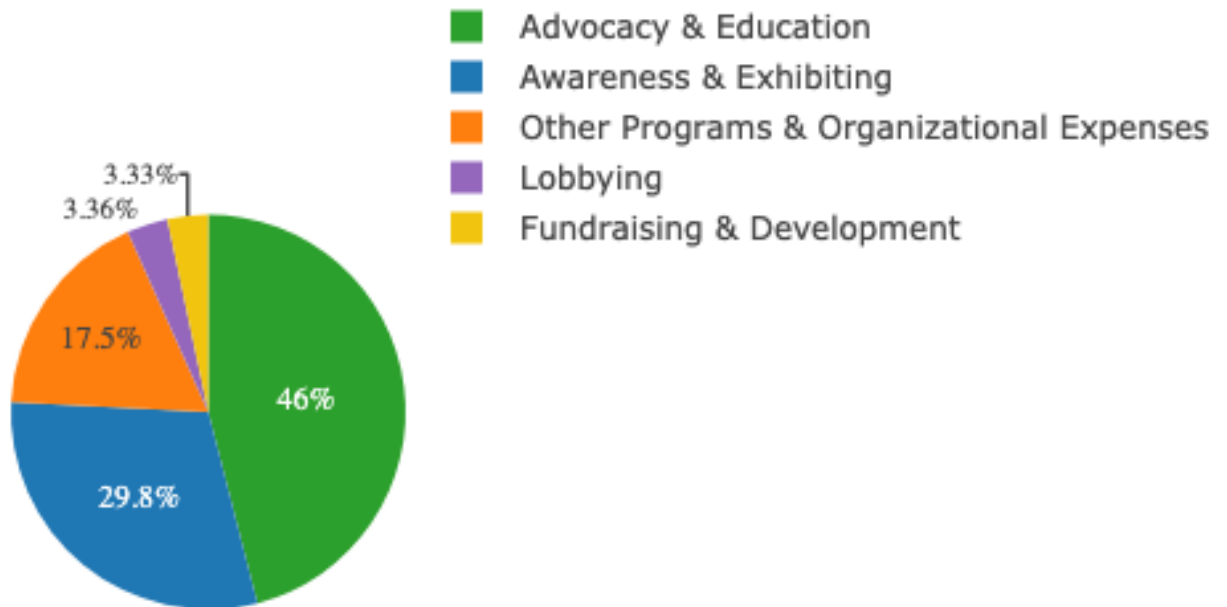
Presented by:
Larry Bauer, Senior Regulatory Drug Expert @Hyman, Phelps, & McNamara
Julie Breneiser, Executive Director @Gorlin Syndrome Alliance

FINANCIALS

07/01/22 - 06/30/2023

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



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



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