



Advocating on behalf of the individuals living with a skin condition.

2023/2024 Annual Report





Kelly Barta
Executive Director

Dear Partners,

As we reflect on the accomplishments of the past year, I am proud to share how, together, we have made significant strides in advocating for the 84+ million Americans living with skin conditions. Your continued support and partnership has been instrumental in advancing our shared mission to raise awareness to the burden and impact of skin diseases, improve access to healthcare and treatments, and promote vital research into dermatologic diseases.'

Throughout this past year, the Coalition of Skin Diseases has remained steadfast in our commitment to ensuring that the voices of individuals affected by skin conditions are heard at all levels of government and within the healthcare system. Through strategic advocacy and educational efforts, we have achieved remarkable milestones.

A standout event in our advocacy efforts this year was the CSD Fly-In Hill Day held in April, where 58 passionate advocates from 21 states came together to meet with legislators on Capitol Hill. This incredible event was an essential part of our efforts to raise awareness and drive policy change. The voices of those living with skin conditions, alongside the expertise of our stakeholders, made a lasting impact in Washington, D.C. as we rallied for change.

Looking ahead, we remain committed to strengthening our work and advocating on behalf of those whose voices often go unheard. Our efforts are only possible because of your support, and we are deeply grateful for your ongoing partnership. Together, we will continue to build on this foundation, ensuring that skin diseases are not only recognized but addressed with the seriousness they deserve. Thank you for your unwavering commitment to our cause. We look forward to another year of progress and continued collaboration.

A handwritten signature in black ink, reading "Kelly Barta".

Kelly Barta
Executive Director



ABOUT THE



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

The mission of the CSD is to improve the lives of all people living with dermatologic diseases by uniting patient advocacy organizations and stakeholders in the common goals of advocacy, education, and awareness.

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

Advocacy

**Education &
Awareness**

Research

Resources





LEADERSHIP

EXECUTIVE STAFF

Kelly Barta
EXECUTIVE DIRECTOR

Directors

Kelly Barta, President

Brindley Brooks,
Vice President
HS Connect

Dr. Alanna Bree
Made a Masterpiece

Brent Hazelett, Treasurer
HS Foundation

Linda Markham
Dermatology Nurses' Association

Michele Guadalupe,
Secretary
National Eczema Association

Kristen Wheeden
United Porphyrias Association

Christopher Boynton
FIRST

Jackie Gardner
Vitiligo Support International



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)
- Center for Innovation and Value Research
- Pediatric Dermatology Research Alliance (PeDRA)
- Skin of Color Society (SOCS)
- Society for Investigative Dermatology (SID)

Activities and Accomplishments

EXHIBITION AND AWARENESS MEETINGS

Good Days Effective Compassion: Chronic Disease Day Symposium

July 2023

NIAMS Coalition Outreach and Education Meeting

September 2023

Pediatric Dermatology Research Alliance (PeDRA)

Annual Conference

October 2023

Skin of Color Society

Meeting the Challenge Summit: Population Descriptors in Dermatology Research Studies

December 2023

International Alliance of Dermatology Patient Organizations (IADPO)

GlobalSkin: Skin Matters Reception

March 2024

Dermatology Nurses' Association

Annual Meeting

March 2024

American Academy of Dermatology

Annual Meeting

March 2024

CSD Development Day

March 2024

CSD Hill Day and Congressional Briefing

Understanding and Addressing the Burden of Skin Disease

April 2024

International Dermatology Outcome Measures (IDEOM)

Annual Meeting

April 2024

Health Equity and Social Determinants of Health (SDoH)

Implementation Congress

May 2024

Society for Investigative Dermatology

Annual Meeting

May 2024



Activities and Accomplishments

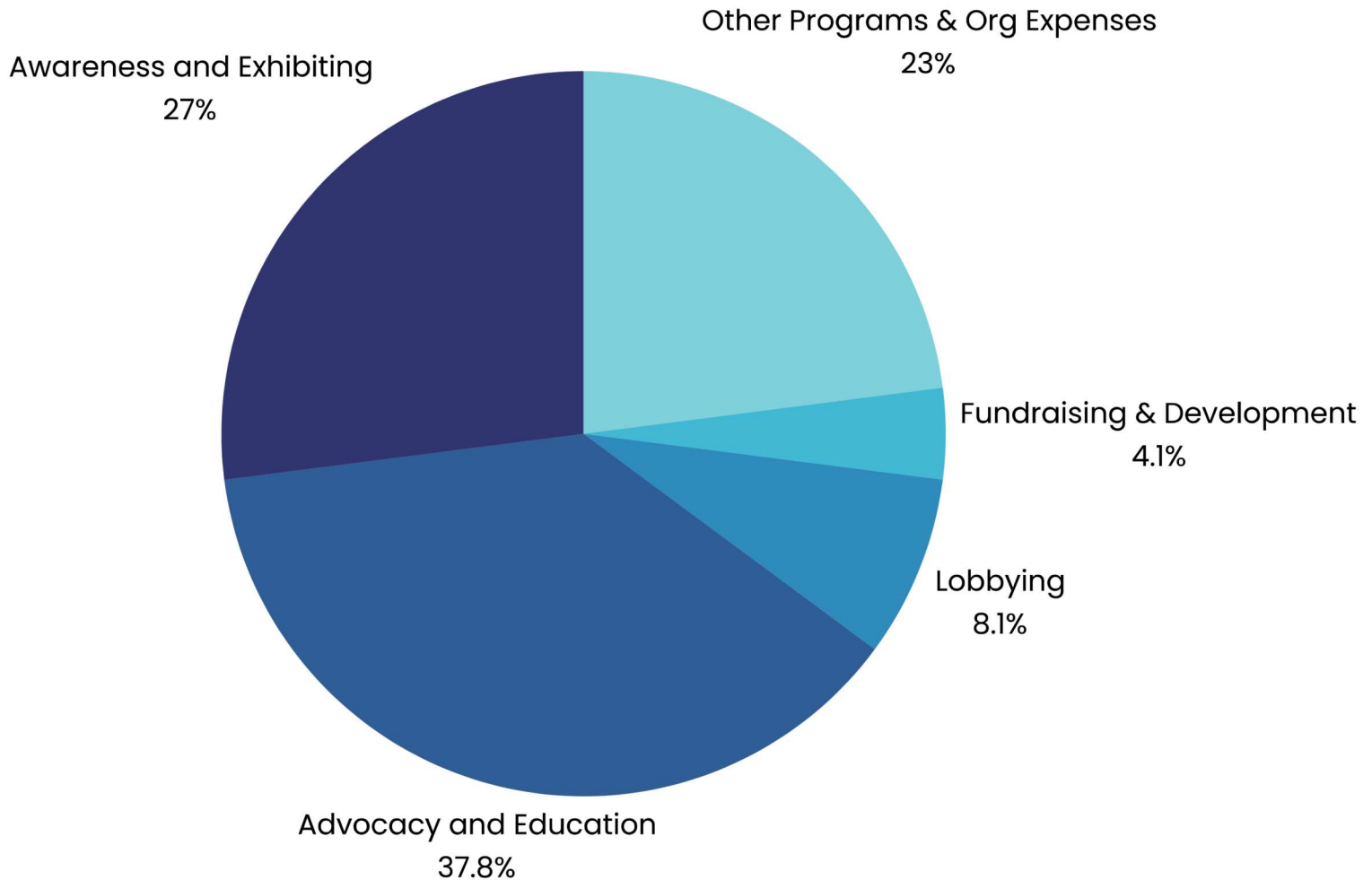
ADVOCACY

In April 2024, 58 passionate Coalition Members – hailing from 21 states – came together to amplify their voices and advocate for crucial policy changes at the CSD's 2024 Hill Day event. CSD advocates conducted meetings with 57 legislative offices. The collective plea to policymakers was clear – a call for enhanced access to quality care and treatment options for individuals battling skin diseases, alongside a strong request for increased funding to advance research and educational initiatives in the field.

Our advocates were met with listening ears and in many cases a positive response from legislators and their staff to support bills on our policy agenda, which included step therapy and pharmacy benefit manager (PBM) reform and banning Copay Accumulator programs. Our “asks” also included robust funding to the National Institutes of Health (NIH), specifically skin disease research at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), along with increased funding toward the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).

The CSD's Congressional Briefing was met with enthusiastic participation from a diverse array of attendees, including representatives from congressional offices, federal agencies, institutions, and industry. The feedback we received was overwhelmingly positive, with many expressing that the content presented was truly eye-opening and impactful. The coalition is proud of all our patient advocates who took time away from work and family to be involved, with a special note of gratitude to our members who bravely shared their stories through video media and in person, truly embodying the spirit of our cause.





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.

PARTNERS

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

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Platinum Sponsor



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Bronze Sponsor



Partner Sponsor



Partner Sponsor



COALITION OF
SKIN DISEASES



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1717 N Street NW, Suite 1
Washington, DC 20036

www.skincoalition.org