Hidradenitis™ Suppurativa Foundation, Inc.

2024 ANNUAL REPORT

www.hs-foundation.org/annual-reports

LETTER FROM THE PRESIDENT

Friends, colleagues, patients, HSF family,

This year has been a dramatic year for our community. For example, we witnessed the third drug receive approval for treatment of HS, the largest NIH funding for direct HS research, and the largest number of publications on HS documented in PubMed. These are some of the meaningful changes for people with HS and their families that **renew hope in our ability to make a difference.**

For its part, the HS Foundation has not slouched! **We have significantly increased our research funding, held the largest HS focused meeting to date, and led the largest resident training program in HS to date.** Meanwhile, we continued to produce a wide range of educational resources for patients and providers alike. For example, the HS Foundation partnered with the American Academy of Dermatology to produce a special HS supplemental volume in the Blue Journal, available for six months with open access to the public. We also added more clinics to our clinic finder than any year previously, which helps improve access to care and much more.

Looking to 2025, the HS Foundation is poised to continue being the gravitational point for “everything HS”. We will continue to be the **leading organization focusing on funding HS research**. We will make HS clinical research more accessible by launching a patient mentorship program. We will continue to partner with our generous sponsors and stakeholders to secure support for our rapid growth.

While reflecting on our accomplishments to date, we are all acutely aware this is only the beginning of the journey. Together with your support we will improve the lives of people with HS. But it will take all of us coming together. Step by step, we will get there.

> **Each grant submitted, each article written, each support group organized, each dollar donated, each listening ear and crying shoulder offered, each lecture given, and every single other effort by you brings us closer to this goal.**

This annual report is provided to you as a statement of **our commitment to continued growth**. I hope you will draw inspiration from this document and consider lending a hand. Join a committee, dream up a program, or simply make a donation, and together we will create a world where no one suffers from HS.

President
Hadar Lev-Tov, MD
HSF President 2024-2026

RESEARCH FUNDING

In 2024, the HS Foundation provided **$305,000** in research funding.

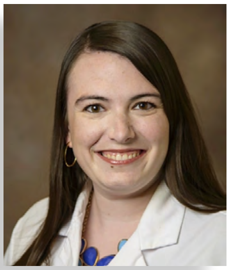
2024 Danby Research Grant Awards

$20,000 in funding was provided to each project below.

Anna Eisenstein, MD, PhD
Yale School of Medicine
Understanding Tissue remodeling in Hidradenitis Suppurativa

Tammy Gonzalez, MD, PhD
University of Miami
Mechanisms of Porphyromonas-mediated Inflammation in HS Tunnels

JaBreia James, MD and Nnenna Ezeh, MD
Harvard Dermatology Residency
Real World Efficacy and Financial Feasibility of Laser Hair Removal in Patients with Stage I-III Hidradenitis Suppurativa



Colleen Cotton, MD
George Washington School of Medicine
Characterizing Systemic Cytokine: Profiles in Children with Hidradenitis Suppurativa

Leandra Barnes, MD
Stanford University School of Medicine
Leveraging Epic Cosmos for Nationwide Analysis of Sex, Racial, Ethnic, and Social Determinants in Hidradenitis Suppurativa Health Care Utilization and Treatment Disparities

By the numbers: 2024 research funding was **more the double** what HS Foundation was able to provide two years ago.

RESEARCH FUNDING

2024 Translational Grant Awards

$75,000 in funding was provided to each project below.

Ernest Lee, MD, PhD
University of California
San Francisco
Computational Discovery of Novel Therapeutic Candidates for Hidradenitis Suppurativa

Andrew Sawaya, PhD
University of Miami Miller
School of Medicine
Targeting Epigenetic Inflammatory Memory in Hidradenitis Suppurativa

Dermatology Foundation Career Development Award

$55,000 in funding was provided to the project below in partnership with the Dermatology Foundation.

Michal Kidacki, MD, PhD
Yale University
TIGIT Signaling in HS

CORPORATE PARTNERS

HS Foundation extends their heartfelt gratitude to the following companies for their unwavering support and partnership.

◆ *Purple Heart Partner* ◆

NOVARTIS

◆ *Platinum Partner* ◆

abbvie

ucb Inspired by **patients.**
Driven by **science.**

◆ *Diamond Partner* ◆

Incyte

MoonLake

◆ *Gold Partner* ◆

Boehringer
Ingelheim

insmed®

Their contributions empower the HS Foundation to advance its mission and make a meaningful difference in the lives of those impacted by Hidradenitis Suppurativa.

Mission

People living with Hidradenitis Suppurativa are at the heart of our mission, which is to improve the lives of people affected by HS through advocacy, education, and research.

Vision

A world where no one suffers from HS.

Income & Mission-Driven Investment

TOTAL REVENUE OF $1,775,343

TOTAL EXPENSE OF $1,317,985

KEY ACHIEVEMENTS

19

new providers *joined the HS Foundation Provider Database.*

110

HS experts in the U.S. are ***now featured in the database.***

25

Prior Authorization Templates *were transformed.*

66

research summaries are available *on the HS Foundation website.*

128

dermatology residents attended *the 4th Annual HS Academy*

NOTEWORTHY

- The Treatment & Research Committee developed a database of **HS mentors** to support junior faculty.
- Dr. Christopher Sayed led a group of **Foundation leaders** to NIH to meet with the leadership team from The National Institutes of Arthritis and Musculoskeletal and Skin Diseases **(NIAMS)** and two other institutes.
- The Foundation collaborated with a marketing strategy consulting group to **expand reach and awareness** of HS.

SUPPLEMENT TO

December 2024
Volume 91, Number 6S
www.jaad.org

AAD

JAAD

Journal of the American Academy of Dermatology

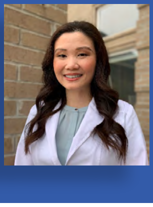
- Partnered with the AAD to publish "Hidradenitis Suppurativa: Embracing Progress" in the Journal of the American Academy of Dermatology (JAAD) with six months of free access.

BOARD OF DIRECTORS

Executive Committee

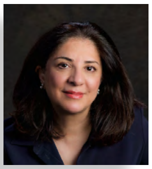
President
Hadar Lev-Tov, MD
Miami, FL

Vice-President
Haley Naik, MD
San Francisco, CA



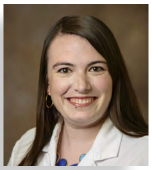
Treasurer
Vivian Shi, MD
Seattle, WA

Secretary
Christopher Sayed, MD
Chapel Hill, NC



Afsaneh Alavi, MD
Rochester, MN

Donna Atherton, EdD
Boston, MA



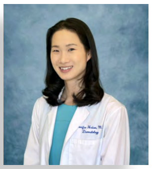
Colleen Cotton, MD
Washington, DC

Steven Daveluy, MD
Dearborn, MI

Amit Garg, MD
New Hyde Park, NY

Athena Gierbolini
Harrisburg, PA

Stephanie Goldberg, MD
Richmond, VA



Jennifer Hsiao, MD
Santa Monica, CA

Michelle Lowes, MBBS, PhD
Miami, FL

Ginette Okoye, MD
Washington, DC

Lauren Orenstein, MD
Atlanta, GA

Barry Resnik, MD
Aventura, FL

HS | ACADEMY

HS Academy is the leading symposium tailored for residents with an interest in hidradenitis suppurativa. It provides content centered on the highest-quality evidence, aiming to empower residents as they navigate the intricacies of HS

Resident Testimonials

> *"HS academy is the* ***best conference*** *for dermatology residents to get a comprehensive overview of HS and the* ***confidence to treat HS patients*** *with cutting-edge therapies so that patients can have gold standard care."*
>
> **—Devea De**

> *"HS Academy is a wonderful conference packed with* ***high-yield, clinically relevant educational material and lectures****. Hearing some of the leading experts...talk about this field with such passion was invigorating and* ***spurred my desire to get involved*** *with enhancing care for HS patients."*
>
> **—Charles Lange**

128

residents funded to attend HS Academy

SHSA 2024

November 1-3, 2024

Marriott Austin
Downtown
Austin, Texas

The Symposium on Hidradenitis Suppurativa Advances (SHSA) is the premier and most significant assembly of researchers dedicated to HS in North America. Co-hosted each year by the Hidradenitis Suppurativa Foundation (HSF) and the Canadian Hidradenitis Suppurativa Foundation (CHSF), this symposium serves as a platform to connect the community with the latest research findings and knowledge related to Hidradenitis Suppurativa.

459 attendees

18 countries

105 research posters displayed

6 plenary sessions

34 oral abstract presentations

Attendee Testimonials

> *"The SHSA is the most complete, renewing, and re-energizing meeting I have ever attended and equips attendees with expertise, practical knowledge, and support in our fight to help our patients find relief from the deleterious effect of HS on their quality of life. I left the meeting with more enthusiasm and encouragement to advocate tirelessly for my patients!"*
>
> *—Dr. Michelle Tarbox*

> *"The SHSA meeting provides an invaluable opportunity to learn about the latest advances in our field while highlighting the dedication and commitment of attendees who care for patients with HS despite endless challenges. It is inspiring to be in the aura of so many like-minded colleagues."*
>
> *—Dr. Steven Cohen*

2024 SHSA Award

The 2024 SHSA Award was presented to Athena Gierbolini.

Patient advocate Athena Gierbolini was honored with the 2024 SHSA Award during the 9th Annual Symposium on Hidradenitis Suppurativa Advances. Athena has been a tireless advocate for HS patients like herself, always championing their needs with empathy, compassion, and dedication that inspires us all.

SPOTLIGHT HS

This **complimentary online event series** supports individuals impacted by HS. The HS Foundation hosts Spotlight HS to reach those affected by HS on their own terms. In its third year, it featured weekly sessions during April and covered a variety of **important topics**.

Expert faculty joined people impacted by HS to present topical sessions to a **global audience**. Presenters carefully developed content that emphasized high-quality evidence, and also empowered and validated folks on their HS journey.

Topics

- Clinical Trials 101
- Cannabis and HS
- Emotional Impact of HS
- Myth Busting
- Wound Care

Highlights

1,438

attendees from

39

different countries

Patient Testimonial

> *"Spotlight HS encouraged me to* ***stop living in the shadows*** *with this disease. I'm not alone. With ongoing research and medical advances, all HS warriors will someday see* ***better treatment and a possible cure****."*
>
> **—Carol H.**

WEBSITE & SOCIAL MEDIA

We strive to reach captive and new audiences via social media. Below please find notable statistics from our primary platforms.

Instagram

FOLLOWERS	PROFILE VISITS	CONTENT VIEWS	CONTENT REACH
2,759	**4,704**	**93,530**	**41,316**
NEW FOLLOWERS	INCREASED		INCREASED
1,139	**22.4%**		**29.2%**

Facebook

FOLLOWERS	PAGE VISITS	CONTENT VIEWS	CONTENT REACH
5,859	**9,557**	**43,806**	**45,260**
NEW FOLLOWERS	INCREASED		
671	**16.6%**		

LinkedIn

FOLLOWERS	IMPRESSIONS	PAGE VIEWS	UNIQUE VISITORS
1,340	**65,457**	**1,819**	**776**
NEW FOLLOWERS			
618			

Website

ACTIVE USERS	1ST TIME USERS	VISITORS FROM	WEBSITE VIEWS
107,000	**105,000**	**188**	**230,000**
		COUNTRIES	

PARTNERS

The following patient advocacy organization are invaluable partners in our efforts to fulfill our mission and vision.

Hope for HS, founded in 2013 by Angie Parks-Miller and Dr. Melissa Williams, was the first face-to-face support group in the United States for those with HS, their caregivers, and loved ones. Support group meetings first started at Henry Ford Hospital in Detroit, Michigan, with chapters now present in several other cities and states, with a list that continues to grow.

HS Connect is a patient-centered organization providing resources, support and solutions to the Hidradenitis Suppurativa community. Passionate about helping others navigate HS, they personally know the toll this disease takes physically, mentally, emotionally, and financially. Their goal is to change the narrative, eradicate the stigmas surrounding HS, and help educate as many people as possible, including non-HS specialty dermatologists, surgeons, caretakers, spouses, kids, partners, parents, family, and friends. HS Connect was created to empower those who have HS to share their stories, allow their voices to be heard, and ensure they're not living alone or in silence.

The International Association of Hidradenitis Suppurativa Network provides help you need while promoting research to find a cure.

An estimated 1% of Americans have hidradenitis suppurativa. Many will develop other comorbidities and/or symptoms of mental illness. For over 10 years, we've provided advocacy, education, support, and community to millions of individuals impacted by this chronic disease. We won't stop until there is a cure.