

# **Hidradenitis Suppurativa**

Foundation, Inc.

---

***2023 Annual Report***

# This Can Change

How it started...worry, stigma, pain.

How it started...frustration, fighting for treatments, few answers.

Change is an inevitable force that shapes our lives, driving progress and innovation. As George Bernard Shaw famously said, "Progress is impossible without change, and those who cannot change their minds cannot change anything." This quote describes the challenges to be overcome and, in contrast, the adaptability and openness that pervade the HS Foundation's Board, Committees, and work.

Many people with HS experience diagnostic delays of 3-12 years, are told hurtful and outdated notions about HS, and don't receive disease-modifying therapies early enough, or at all. This underscores the importance of the HS Foundation's education of [healthcare providers](#), [people affected by HS](#), and the [general public](#) about HS. More change is needed, so over the next three years the HSF's educational work is growing with goals to:

- double our number of educational events for providers, including a focus on specialties outside of dermatology.
- increase each year the proportion of primary care and emergency care providers that are familiar with HS, and
- equip people affected by HS with information that helps them achieve their goals.

The HS Foundation believes that proper education can change perspectives, knowledge, and actions.

What do you call people who see change as an opportunity to explore? **Researchers.** In research, investigators initiate change and are regarded as trailblazers, capable of innovative solutions. The HSF has been investing for years in innovative [HS research](#). In the next three years, the HSF aims to increase our research budget by 33% and drive greater dissemination of findings from HS research. The HSF is also aiming to push innovation into action by doubling the number of dedicated HS providers on our [website](#), and having a listing for each state.

Now I enjoy creative writing, but I didn't think I'd be doing it as part of completing prior authorizations and advocating for people to get medicines they deserve. The HSF wants clinicians to do more of what they're good at and wants to decrease the paperwork with its [downloadable prior authorization templates](#). In the next three years, the HS Foundation will be doing more to advocate for treatment access and decreased prior authorization burden, especially for FDA-approved medications for HS.

By embracing change, we cultivate resilience, creativity, and empathy, which lay the groundwork for progress. Shaw's quote reminds us, to change one's mind is a transformation both individually and collectively.

How it's going...join us in this work. Through your dedication and financial support, we can change it.



**Joslyn Kirby, MD**  
*HSF President, 2022-2024*

**Donate  
Today!**



# Total Research Funding of \$280,000 Provided in 2023

---



## 2023 Translational Grant Awards

\$75,000 in funding provided to both awards below:

**Noah Goldfarb, MD, FAAD, FACP**

University of Minnesota and Minneapolis VA Health Care System  
***Capsule Fecal Microbiota Transplant for Hidradenitis Suppurativa***

**Daniel Harper, PhD and Lauren Orenstein, MD, MSc**

Emory University School of Medicine

**Sarah Whitley, MD, PhD**

University of Massachusetts Chan Medical School  
***Pain Mechanisms in Hidradenitis Suppurativa***



## 2023 Danby Research Grant Awards

\$20,000 in funding for each of the projects below:

**Alexandra Charrow, MD, MBE**

Brigham and Women's Hospital, Department of Dermatology  
Harvard Medical School

***Decreasing Emergency Room Utilization in Patients with Hidradenitis Suppurativa***

**Joshy Jacob, PhD**

Emory University

***Elucidating the Specificity of Plasma Cells in Hidradenitis Suppurativa Lesions***

**Michal Kidacki, MD, PhD**

Yale School of Medicine

***Investigation of Immune Checkpoint Dysregulation in Hidradenitis Suppurativa***

**Natalie Fragoso, MD and Matthew Hayden, MD, PhD**

Dartmouth Health and Geisel School of Medicine at Dartmouth College

***Generation of Hidradenitis Suppurativa Models through Gene Editing of  $\gamma$ -Secretase Complex Genes***

**Marita Yaghi, MD and David Mandel, PT, PhD**

University of Miami Miller School of Medicine

***Physical Activity and Hidradenitis Suppurativa: A Novel Controlled Trial Investigating Functional Performance and Activity Limitations and Assessing the Benefits of an Outcome Measures Driven Exercise Program***

## 2023 Mentored Experience Grant Program

\$2,000 in funding for each mentee below:

**Sarah Whitley, MD, PhD**

Mentor:

Iltefat Hamzavi, MD

**Harry Liu, MD**

Mentor:

Christopher Sayed, MD

**Mikael Horissian, MD**

Mentor:

Barry Resnik, MD

**Stephanie Cohen, MD**

Mentor:

Christopher Sayed, MD

---

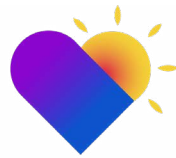
## Mission

*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 and Mission-Driven Investments

### TOTAL REVENUE OF 1,095,670



**Contributions**  
\$37,150

**Partnerships**  
\$600,000

**Events & Sponsorships**  
\$458,520

### TOTAL EXPENSE OF \$1,245,427



**Research and Grants**  
\$300,500

**Infrastructure**  
\$362,888

**Education**  
\$582,039

# HS Foundation's Exciting Activities

**10** new providers were added to the HSF Clinic Finder Page



**70** HS experts around the US are now on the list

**10** research articles were translated into plain language summaries



**60+** research summaries are now available on the HSF website

**135+** dermatology residents participated in a weekend of education about HS at the 3<sup>rd</sup> Annual HS Academy

HS Foundation is partnering with the American Academy of Dermatology to jointly write new HS Treatment Guidelines in the US



HS Foundation is partnering with the Dermatology Foundation to fund an HS-Specific Career Development Award each year

Updated the existing prior authorization templates and added new ones; the HS Foundation website now has over **25 templates available** to healthcare providers



# HSF Board of Directors

---

## Executive Committee:

### President

Joslyn Kirby, MD  
Hershey, PA

### Vice-President

Hadar Lev-Tov, MD  
Miami, FL

### Secretary

Martin M Okun, MD, PhD  
Fort Atkinson, WI

### Immediate Past President

Iltefat Hamzavi, MD  
Detroit, MI

### Treasurer

Vivian Shi, MD  
Little Rock, AR

---

## Board of Directors:

### Afsaneh Alavi, MD

Rochester, MN

### Athena Gierbolini

Harrisburg, PA

### Haley Naik, MD

San Francisco, CA

### Donna Atherton, EdD

Boston, MA

### Stephanie Goldberg, MD

Richmond, VA

### Ginette Okoye, MD

Washington, DC

### Steven Daveluy, MD

Dearborn, MI

### Jennifer Hsiao, MD

Santa Monica, CA

### Barry Resnik, MD

Aventura, FL

### Amit Garg, MD

New Hyde Park, NY

### Michelle Lowes, MBBS, PhD

Miami, FL

### Chris Sayed, MD

Chapel Hill, NC



**Hidradenitis  
Suppurativa**

Foundation, Inc.



**October 13-15, 2023**

**Renaissance Phoenix  
Downtown Hotel  
Phoenix, Arizona**



**SYMPOSIUM ON HIDRADENITIS SUPPURATIVA ADVANCES**


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.

  
**273**  
attendees

  
**105**  
research posters  
displayed

  
**10**  
countries

**3** plenary  
sessions  
**2** panel  
discussions

**42**   
oral  
abstract  
presentations

## Attendee Testimonials

*"This meeting is inspiring and recharging. HS is a tough condition to have and to care for, but being around such amazing clinicians and patients and learning the latest information in our rapidly evolving understanding of this disease reminded me why I do this and energized me to get back to work!"*

*"The SHSA is one of the most well-rounded scientific meetings in the Dermatology space. Its appeals include scientific rigor, emotional intelligence, patient-centricity, and collegiality. I am thoroughly satisfied and will continue to attend all of its future meetings."*

## 2023 SHSA Award

**The 2023 SHSA Award was presented to Dr. Michelle Lowes.**

Dr. Lowes' unwavering commitment to advancing medical knowledge and providing exceptional patient care has set a remarkable standard in the field. Dr. Lowes' compassion and dedication to HS research funding has made a lasting impact on countless lives, earning her the admiration and respect of colleagues and patients alike. This award was a testament to Dr. Lowes' exceptional contributions to the medical community and her enduring legacy of excellence in healthcare.





# SPOTLIGHT HS

Spotlight HS is a complimentary online event dedicated to individuals impacted by Hidradenitis Suppurativa, hosted by the HS Foundation. This virtual experience is crafted to reach people affected by HS on their own terms. In its second year, Spotlight HS featured a collection of sessions, including brief talks, discussions, and interactive chat rooms. Expert faculty and individuals affected by HS collaborated to present these sessions at times convenient for a global audience. The content was thoughtfully developed and delivered, emphasizing the highest quality evidence, with the goal of empowering and validating those on their treatment journey with HS.

## Topics Covered:

- Current Treatments
- Pain Management
- Myth Busting
- Wound Care
- Connecting with HS Patients
- Nutrition & HS
- Ask the Specialist
- Wellness & Yoga



**1,878** registrants from—



**60**  
countries



**475<sup>+</sup>** hours of content viewed

## Patient Testimonials

*“With the information provided from Spotlight HS I feel much more confident when advocating for myself as an HS patient!!”*

*“**Spotlight HS makes me HOPEFUL!** It is an important event to me because it updates me (and everyone) on all the latest news, treatments and forecasts of new biologics. Spotlight HS truly helps shape my mind to be HOPEFUL on my/our journey.”*

*“The Spotlight HS event was full of knowledge with old and new information available for those who are new to the condition and those of us who have struggled with it for a while. The question and answer portion is very helpful as you can get answers on the spot from people who know about HS and also from attendees who might share your same struggles. I recommend this event to everyone; patients and caregivers.”*







# HS | ACADEMY

The 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 Hidradenitis Suppurativa.

**117 residents were funded by the HS Foundation to attend HS Academy in 2023**

## Resident Testimonials

*"The HS Academy was an excellent HS boot camp run by all the leading experts in the field. Over the course of the 2 days we learned about the latest evidence based treatments. We also received detailed instruction on the surgical management of this challenging condition. I would highly recommend this unique educational opportunity to any dermatology resident interested in providing the highest level of care for their patients with HS."*



*"This was the most informative, high yield resident conference I have ever been to. The speakers presented practical information that we could easily take home and use in daily practice. The personal stories from the patient speaker were meaningful and provided additional necessary context to the weekend. The environment also encouraged a lot of fun networking. I would highly recommend this conference to any resident interested in HS."*

*"Because there are so few people specializing in HS in general, it is very difficult to learn about and provide the highest-quality, most up-to-date care for our patients. This conference allowed us to learn directly from the field's experts on the condition, ask questions, and develop a confidence to treat HS with the best possible medical and procedural options known today. I feel energized to employ my new knowledge and skills in the clinic and to help alleviate the burden and distress of this disease in general. I am so grateful and thankful to have been provided this amazing opportunity."*



# Website and Social Media Traffic—All Facebook and Instagram stats are over the previous year



## Instagram Statistics:

Instagram Followers

1,675

New Instagram Followers

589

Instagram Reach

32,244

↑365.4%

Instagram Profile Visits

3,889

↑62.7%



## Facebook Statistics:

Facebook Followers

5,173

New Facebook Followers

669

Facebook Page Reach

73,511

↑82.8%

Facebook Page Visits

8,300

↑227.7%



## Website Analytics:

New Followers in 2022

98,000

Visitors From

99 Countries

Website Views

227,000

# The following patient advocacy organizations play such an important role as partners as we try to achieve our mission and vision:

---

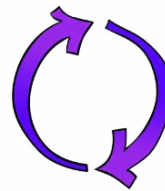


**Hope for HS**, founded in 2013 by Angie Parks-Miller and Dr. Melissa Williams, was the first face-to-face support group in the United States for those with HS, their caregivers, and loved ones. Support group meetings first started at Henry Ford Hospital in Detroit, Michigan, with chapters now present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

---



**HSconnect.org**

Connecting the Hidradenitis Suppurativa  
Community with Resources,  
Support & Solutions



**International Association of  
Hidradenitis Suppurativa Network, Inc.**

**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 9 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.

# *Special thanks to these companies for their ongoing support!*

## *Purple Heart Partner*



## *Platinum Partner*



Inspired by patients.  
Driven by science.

## *Diamond Partner*



MoonLake

## *Gold Partner*



Boehringer  
Ingelheim



**Without the support of our Corporate Partners, the work of the HS Foundation would not be possible.**