



Hidradenitis Suppurativa

Foundation, Inc.

A Year of Unprecedented Progress:
2022 Annual Report



The HSF unveiled our logo three years ago: blue and purple blending to represent the colors of both patients and healthcare providers coming together. Coming together to change HS—the misdiagnosis and misunderstanding, the conversations about treatment, and partnerships in research. The sun in our logo is both rising and setting: sunsetting the symptoms and struggles and rising on a new day with fewer flares, more control, and a world where no one suffers from HS.

This year we are delighted to unveil our sleek new HSF annual report that makes it easier to explore and engage with the HS Foundation! As a non-profit that has been around for 18 years, in 2022 the HS Foundation delivered on the Board's desire to "Go Pro" by hosting over 1,000 attendees to our four meetings, welcomed nearly 100,000 visitors to our website, and awarded the most money in HS research grants than ever before.

This report is both a celebration of the HSF's achievements and an annual challenge for us to do more. We continually aim to advance the care of people affected by HS through education and research in ways that will help us achieve our vision, that no one suffers from HS.

We'll continue to inspire with easy-to-read summaries of HS research, cutting-edge HS research funding, and one of the best HS-focused research conferences around the world—the Symposium for HS Advances (SHSA). We're proud of our brand of education that puts patient experience and evidence at the center of everything we do. And finally, a huge shout-out to our dedicated volunteer leadership that work tirelessly on behalf of the HSF in concert with our event planning, marketing, and administrative staff who bring the energy of the sun to all of our work!

Let us know what you think, and join us in making 2023 the best year yet!

Joslyn Kirby, MD

HSF President, 2022-2024

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.

Total Research Funding of more than \$135,000 Provided in 2022

2022 Translational Grant Award

\$75,000 in funding provided to the University of California San Francisco

**“Hidradenitis Suppurativa PROspective Observational REgistry
and bioSpecimen repoSitory (HS PROGRESS)”**

**An additional \$10,000 each to the University of North Carolina
and Penn State University for new site onboarding**

\$255,000 in HSF funding provided to HS PROGRESS between 2020-2022

2022 Danby Awards

\$10,000 in funding for each of the four projects below:

Sarah Whitley, MD, PhD, Assistant Professor of Dermatology,
University of Pittsburgh Medical Center

**“Targeting cutaneous nociceptors to reduce
type 17 inflammation in hidradenitis suppurativa.”**

Jaehwan Kim, MD, PhD, Assistant Professor,
School of Medicine, University of California Davis

**“Cutaneous single-cell transcriptomic study of type 17 T
cells in hidradenitis suppurativa compared to psoriasis.”**

Irena Pastar, PhD, Associate Professor, Miller School of Medicine,
University of Miami AND Natasa Strbo, MD, PhD, Assistant Professor,
Miller School of Medicine, University of Miami

**“The role of antimicrobial protein Perforin-2 in
hidradenitis suppurativa.”**

Victoria Fang, MD, PhD, PGY3 Dermatology Resident,
University of Pennsylvania

**“Highly multiplexed imaging and characterization of tertiary lymphoid
structures in patients with hidradenitis suppurativa.”**

2022 HSF Mentored Experience Grant Program

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

MENTEE	MENTOR
Natalie Villa, MD	Iltefat Hamzavi, MD
Richard Flowers, MD	Christopher Sayed, MD
Gretchen Roth, MD	Joslyn Kirby, MD
Julia Mhlaba, MD	Ginette Okoye, MD
Stella X. Chen, MD	Haley Naik, MD
Laura Dellalana, MD	Alexa Kimball, MD and Martina Porter, MD
Swetha Atluri	Vivian Shi, MD

Income and Mission-Driven Expenses

TOTAL REVENUE OF \$1,148,339



Contributions
\$34,450.17

Partnerships
\$539,719.33

Events
\$574,169.50

TOTAL EXPENSE OF \$1,139,181



**Research and
Grants** \$159,485.34

Infrastructure
\$296,187.06

Education
\$683,508.60

A Few Things We've Done Over the Past Year

7 research articles were translated by Foundation leaders into plain language summaries

50 summaries available on the HSF website

Developed enduring CME content for providers: HS in Emergency and Urgent Care, How to Diagnose HS, Management of HS.



14 prior authorization templates were created to make it easier for providers to get patients the treatments they need.



Provided financial support to give open access to the latest research articles in HS published by HS Experts

- HS: Diagnosis and Management in the Emergency Department—*Journal of Emergency Medicine*, August 2022
- Diagnosing and Managing HS in *Pediatrics*—*Pediatric Annals*, March 2022
- Guidance on COVID-19 Vaccination in HS Patients—*Skin Appendage Disorders*, January 2022
- Biologic Therapy is not Associated with Increased COVID-19 Severity in Patients with HS—*Journal of the American Academy of Dermatology*, January 2022

10 locations were added to the HSF Clinic Finder resource

50+ HS experts around the country are now on the list

Educated over **2,000** clinicians, researchers, and patients about HS

The HSF contributed more money to research in 2022 than ever before and is more than doubling that number again in 2023.



The HSF welcomed its first full-time Executive Director, Brent Hazelett



Dr. Iltefat Hamzavi, who served as president of the Foundation for nearly six years, handed over the reins to Dr. Joslyn Kirby in March 2022



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 7-9, 2022
InterContinental Miami
100 Chopin Plaza , Miami, Florida

SYMPOSIUM ON HIDRADENITIS
SUPPURATIVA ADVANCES



The Symposium on Hidradenitis Suppurativa Advances is the largest, most important gathering of HS researchers in the United States. The 2022 SHSA was the first in-person meeting of these researchers since 2019 due to the COVID-19 pandemic.

313 attendees **13** countries **9** plenary sessions **35** oral abstract presentations

120 research posters displayed **33+** hours of On-Demand content viewed

Attendee Testimonials

"The SHSA is an opportunity like no other. It's amazing to hear the groundbreaking research that is happening for this disease. It's also wonderful to have time to connect with colleagues in the field and share practices and ideas."

"This meeting really helped me remember why I treat HS patients. It was so great to connect with colleagues and patient support groups and hear what everybody else is doing and brainstorm how we can work together to make the lives of HS patients better. It was very encouraging to hear about the new pharmacologic treatments that are coming down the pipeline - the future of HS is bright!"

2022 SHSA Award

The 2022 SHSA Award recipient Dr. Iltefat Hamzavi, HS Foundation's Immediate Past President.

*"We got three things right that you have to get right in a non-profit. **PURPOSE. PROCESS. And the PEOPLE.**"*

"I believe we love each other as we loved our HS patients. They are us. They are a part of our community. And how can we bear witness to their suffering? 84% have pain every day. At the very least we say that's not ok."





HS SUMMIT

The HS Summit was the first ever patient-focused meeting designed to meet people affected by HS where they are. Content was developed and delivered with a focus on best-level evidence for people affected by HS to empower and validate them in their treatment journey.

Topics Covered:

- Current Treatments
- Pain Management
- Psychosocial Challenges
- Wound Care
- Complimentary Treatments
- Exercise with HS

1,360 registrants from— **56** countries **5,775** + hours of content viewed

Patient Testimonials

"I can't say enough good things about this HS summit! I learned so much about HS as a whole, but I also learned how to better deal with it on a daily basis, in regard to treatment options, wound care, and pain management, but also how to better cope with the negative mental impacts that HS can cause."

"The HS Summit has been instrumental in helping myself and other HS patients not feel alone, learn correct information about the disease and finding the proper help from physicians who truly understand HS. It is a life saver for many!"

—from Athena (a HSF Board Member and person with HS)

"As a patient living with disease, I can say that it is an absolute joy to not only watch the work of this foundation happen, but also to participate in it. HS Patients have so many complex needs and live in a world that is now catching on to them, thanks in huge part to the countless volunteer hours that our board and committee members put in. From the outreach to the various medical specialties to the in depth training for dermatologists, the work that this foundation has done will serve the HS patient community for generations to come. I am so proud to know this board and serve where and when I can. 2022 was a stellar year for HS education, advocacy, and research. The future looks bright for our community and I am confident that 2023 will be just as amazing!"



HS | ACADEMY

The HS Academy is the premier symposium for residents interested in hidradenitis suppurativa that delivers content with a focus on best-level evidence to empower residents as they learn the ins and outs of HS.

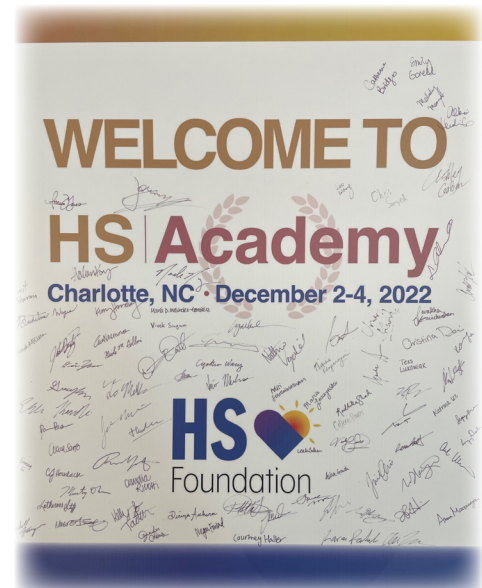
Attendance nearly doubled from 2021—**115** residents attended

Resident Testimonials

"I had such a wonderful time at the HS Academy. This event was packed with up-to-date information. It was incredible to learn from experts about various therapies and updates on research in HS. If you want to feel more comfortable taking care of HS patients, this academy is a must!"

"The HS Academy provided an amazing opportunity for me to advance my knowledge in HS, meet fellow residents also interested in HS, and also network with key faculty members from the HS Foundation."

"The HS conference was fantastic! It was a game-changer in terms of practical tips, counseling techniques, and fundamental understanding of HS for the future dermatologist."



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



Instagram Statistics:

Instagram Followers

1,086

New Instagram Followers

516

Instagram Reach

6,999

↑ 172.3%

Instagram Profile Visits

2,632

↑ 85.5%



Facebook Statistics:

Facebook Followers

4,504

Facebook Page Reach

41,411

↑ 126.1%

Facebook Page Visits

2,861

↑ 10.9%



Website Analytics:

New Followers in 2022

91,000

Visitors From

75 Countries

Increase in Web Traffic

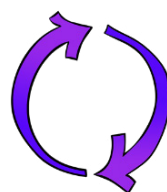
300%

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.

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

Special thanks to these companies for their ongoing support!

Purple Heart Partner

abbvie

Diamond Partner

 NOVARTIS

Gold Partner

 **Boehringer
Ingelheim**



Stay tuned—2023 is going to be even more amazing!