

THE HIDRADENITIS SUPPURATIVA FOUNDATION, INC. (HSF) IS DEDICATED TO IMPROVING THE QUALITY OF LIFE AND QUALITY OF CARE FOR INDIVIDUALS AND FAMILIES AFFECTED BY HIDRADENITIS SUPPURATIVA (HS).

Happy New Year! I can say 2007 was a remarkable year, ending with our attendance at the Dermatology Congress in Argentina this October, the NIAMS Outreach Day and the recent developments with the HS Awareness Resolution (see below). Financially, while the number of donors to the HSF was down a bit from last year, contributions were still very good and with a lot of frugal spending, we were able to pay off a \$15,000 loan and are in the black – with absolutely no debts (other than debts of gratitude for all of your support!). Also, thanks to The Jackson Laboratories, there is now a grant application submitted to NIAMS for our 2008 Symposium (cross your fingers, eyes and toes, folks!), and most of our energies in the ensuing months will be spent focusing on making our second scientific meeting even more successful than our first. I would like to thank everyone here for participating in this often maddening march to raise the profile and understanding of this disease, and for helping make each day a bit better for those of us who suffer with HS. ~ Michelle Barlow, President



The HSF's Day on the Hill & NIAMS Coalition Outreach Day

DAY ONE: On Monday, December 10, longtime HS patient advocate Ruth Breitrick and HSF President Michelle Barlow visited "The Hill" to meet with representatives at the offices of Wisconsin's Senator Russell Feingold and Rep. Steve Kagen, MD. Ruth resides in Wisconsin and has been instrumental in spearheading the movement to create an "HS Awareness Month" Resolution (see article on page 2). The HSF had invited Ruth to attend the NIAMS Coalition Outreach Day, and she took the initiative to set up these meetings and take advantage of the Washington, D.C. visit.

Dr. Kagen's office phoned shortly after their visit to say they agreed to sponsor the HS Awareness Resolution and would submit it in the upcoming January session.

"We are grateful for this commitment," Ruth said. "We hope to garner more government support next year, and I encourage the HS Community to support this issue by registering to vote and contacting their elected officials."

The HSF would like to thank Ruth for her ongoing efforts in raising awareness about HS on this and many other levels, and would also like to thank Rep. Kagen, Legislative Assistant Joy McGlaun, Sen. Feingold and Legislative Director Rob Mosher for their time and interest in helping the HS community.

DAY TWO: Bright and early on December 11, the NIAMS Coalition Outreach Day began with introductions and a presentation by Dr. Stephen Katz, Director of NIAMS. The event was extremely well organized, well attended and quite informative. Networking with members of other non-profit organizations was equally rewarding. The HSF is proud to be a member of this organization, looks forward to the next annual meeting, and will continue to pursue all applicable avenues of opportunity available through the NIAMS and the NIH.

"I am grateful to have been invited to this event and happy that Ruth was able to share this experience with me," Michelle said. "The information provided by NIAMS will prove invaluable. The people attending the event were just wonderful. There are so many out there doing so much good; it's inspiring."

More Good News!

Ruth Breitrick has agreed to join the HSF Board of Directors, where she will continue to garner support for the HS Awareness Month Resolution, and help develop and organize activities to help raise funds for the HSF and HS Research.

"I want to encourage the HS community to unite and work collectively to achieve results," Ruth explained. "We need each other; future generations need us to pave the way."

Please join us in welcoming Ruth to the HSF!

Join the HSF International Physician Action Network

The most frequently asked question of the HSF is, "Where can I find a doctor to treat this condition?" The HSF International Physician Action Network was created to help answer this question and to meet one of the primary goals of the HSF: to improve the quality of life and quality of care for those with HS. To sign up for the Physician Action Network, or for more information, please visit:
<http://www.hs-foundation.org/education/information.htm>

"Hidradenitis Suppurativa"



Edited by Drs. Gregor BE Jemec, Jean Revuz, and James J. Leyden, 36 experts present the best current knowledge about the diagnosis, pathogenesis and complications of HS; comprehensive guidelines on diagnosis and therapy; a description of patients' perspectives, as well as expert answers to patients' FAQs. The publisher is donating a

portion of the proceeds to the HSF.

<http://www.springer.com/3-540-33100-X>

Support HS Awareness:

Ask Your Elected Officials to Support the HS Awareness Month Resolution

A resolution to designate June as the official **National HS Awareness Month** has been written, and we need your help! If you are a registered voter in the U.S., you can write to your elected officials and ask them to sponsor this important resolution. Simply visit:

<http://www.frontiernet.net/~ruthb/HSAwareness.html>

At the website above, you will find a link to the government website where you can locate the elected officials in your district. A suggested letter, along with the exact wording of the resolution is also provided, so you can quickly copy and paste it into your personal correspondence to your representatives. Please ask your friends and family members to do the same so our voices will be heard and this resolution can be submitted as a Bill to Congress. (See Page 3 for the Resolution.)

The HSF would like to thank everyone who helped put together this resolution. We would also like to encourage others with personal websites, blogs and HS support groups to promote this resolution on their sites by including a link to Ruth's Awareness page listed above.

OCTOBER 3-5, 2008 Second International HS Research Symposium: "Discovery 2008"

The Second International HS Research Symposium will be held **October 3-5, 2008 at The Jackson Laboratory's Highseas Conference Center in Bar Harbor, Maine.** The HSF is grateful to The Jackson Laboratory for hosting this important event. We will be publishing more information about the symposium as soon as it becomes available. For more information on sponsorship opportunities and benefits, please email:

MichelleBarlow@hs-foundation.org

The HSF Research Database

Actively supporting those with HS and those who study & treat HS

The HSF added another 17 publications to the FTP since the last issue of our HSF News Brief. The topics are diverse: from treatment of HS with biologics, cancer and HS, to perhaps the most widely publicized article on HS in many years – Sam Shuster's discussion on Karl Marx's skin disease as HS and the considerable psychological effect that it had on the man and his works.

The HSF also had an article published in the Autumn Issue (no. 24) of the EADV News, which you will find on our our database. We would like to give special thanks to Mary O'Nyon for volunteering to write her own personal perspective for the paper. *Thank you, Mary!*

To access this FREE resource, register online at:
<http://hs-foundation.org/research/database.htm>

Use of the HSF Research Database Copyright laws may restrict the use of some of the articles on the FTP site. These articles are provided by the HSF for the exclusive use in teaching, scholarship or research regarding HS. To the best of our knowledge, in supplying this material to you we have followed the guidelines of Title 17, Chapter 1, Section 107 regarding fair use of copyright materials.

New! Online!

From the Patient's Perspective:
"It's not that bad...My journey with Hidradenitis Suppurativa"

<http://jdpa.org/advocacy.html>

The Hidradenitis Suppurativa Foundation, Inc. (HSF) respectfully requests that you consider the following resolution to help increase awareness about a debilitating disease called Hidradenitis Suppurativa (HS). It is a painful, often disabling inflammatory skin condition primarily occurring in inverse areas of the skin, e.g. axillae and groin. It presents with painful and chronically recurring, deep-seated follicular nodules, papules, pustules and abscesses, leading to suppuration, fibrosis, and scarring of the skin. Those who suffer with this condition experience a severely reduced quality of life, and both patients and physicians alike have a difficult time in both diagnosing and treating this mysterious disease.

There is a critical need to increase awareness about HS in the general population which may aid in earlier diagnosis of the condition; in the medical community, who remains generally in the dark about disease definition, diagnosis and treatment options; and patients, who are in need of physical, emotional and financial support and who need comfort in knowing that they are not alone in suffering with the condition.

Therefore we respectfully submit the following resolution:

- Expressing the need for enhanced public awareness of Hidradenitis Suppurativa, and for the designation of a National Hidradenitis Suppurativa Awareness Month.
- Whereas Hidradenitis Suppurativa is a common skin disease affecting at least 1% of the general population and data suggests that the number of individuals afflicted may be under reported;
- Whereas Hidradenitis Suppurativa affects both males and females of every race and nationality, usually beginning in the second or third decade of life and often persisting into old age;
- Whereas Hidradenitis Suppurativa is considered as one of the most difficult and chronic diseases of dermatology, causing significant pain, disfigurement, anxiety, depression, temporary or permanent disability, and a severe reduction in quality of life, even for those with mild forms of the disease;
- Whereas the time from disease onset to diagnosis is often measured in years or decades, greatly increasing the morbidity and complications of long-standing Hidradenitis Suppurativa;
- Whereas there is currently no medical consensus on the definition of Hidradenitis Suppurativa, no standard method of diagnosis, nor any consistently effective treatment;
- Whereas there is an urgent need to conduct systematic, large scale research studies to discover the cause(s) of Hidradenitis Suppurativa and develop rational, evidence-based treatments;
- Whereas those afflicted with Hidradenitis Suppurativa see many different medical specialists, there is a critical need to educate all medical professionals in all fields about this disease;
- Whereas receiving early and appropriate medical intervention may decrease the morbidity of Hidradenitis Suppurativa, there is an essential need to increase awareness of Hidradenitis Suppurativa among the general public;
- Whereas Mayor John Street of Philadelphia proclaimed June 2007 as Hidradenitis Suppurativa Awareness Month;
- Whereas June would be an appropriate month to establish as National Hidradenitis Suppurativa Awareness Month.

Thank you for your consideration.



Michelle Barlow, President

Thank you for your interest in supporting the Hidradenitis Suppurativa Foundation.

In order to develop and deliver more effective therapies to those with Hidradenitis Suppurativa, the HSF requires financial support from not only research and development grants but also through financial support from individuals and corporate sponsorships. Together, with your help, we can make a difference in the lives of those who suffer from HS. Your gifts to the HSF help support and promote our programs, and are essential to our continued success. There are many ways you can help:

HSF LEADER'S CIRCLE Individuals can join the Leader's Circle by providing a donation to the HSF using our secure online form at www.hs-foundation.org or by mailing the form below with a check payable to Hidradenitis Suppurativa Foundation to the address below. Gifts to the Leader's Circle will be recognized in our online Annual Report with the Donor's name and level of contribution. If you wish your gift to remain anonymous, please let us know.

HSF PRESIDENT'S CIRCLE Corporations and businesses become part of the President's Circle with a general donation or by participating as a sponsor for one of our specific programs. Corporate donations and sponsorships will be recognized in HSF publications, on our website, and in our online Annual Report with the Company name and level of contribution. You may make your gift by completing the form below or by using our convenient and secure online form at www.hs-foundation.org. Contact us for more information about becoming a corporate sponsor for our new Physician Action Network, conferences and symposiums, or Research Awards.

HSF LEGACY CIRCLE Make a planned gift through the Legacy Circle. To learn more about giving options such as Wills, Gift Annuities, and Life Insurance Policies, please contact us.

MEMORIAL & CELEBRATION GIFTS You can create a living memorial in the name of a family member or friend, or a gift of celebration such as a birthday or wedding, through the HSF's Memorial & Celebration program. Your gift will show your loved ones how much you care while helping the HSF fund research to find a cure for HS. We'll send a personalized card to the person you designate to notify them of your donation (the amount of the gift will not be indicated). A suggested donation is \$50 or more for each remembrance. You can make your donation by phone or by mail.

GIFTS-IN-KIND The HSF also accepts non-monetary items of tangible personal property or other physical assets that represent value to the HSF. Examples of such items include real estate, equipment, meals, and travel/transportation/lodging certificates. If you believe you have a potential gift-in-kind, please contact us.

SHOP OUR ONLINE STORE Your thoughtful support will help us continue to run and develop important programs as well as serve the HS community. Shopping online is easy, and in doing so, a percentage of your purchases will be returned to the HSF. Truly, you understand our mission and our need for people just like you. Visit www.hs-foundation.org for details.

Thank You for Your Support!

PLEASE DETACH HERE AND MAIL WITH YOUR DONATION TO THE ADDRESS BELOW

Please accept my gift of: \$ _____

- I have enclosed a check payable to Hidradenitis Suppurativa Foundation.
 Please add my name to the database to receive news from the HSF.

Name _____

Company _____

Address _____

City/State/Zip _____

Phone (B) _____ (H) _____

Email _____

To make a gift online, please visit: www.hs-foundation.org

I would like to make a PLEDGE of \$ _____ to be paid:

- Monthly Quarterly Semi-Annually Annually
 with payments to begin on (mo/day/year) _____ / _____ / _____
 My first check is enclosed. Please Send Me Pledge Reminders.

Please contact me regarding:

- Including the HSF in my Will or Living Trust
 Corporate Sponsorships
 Volunteer Opportunities at the HSF

Other _____

The Hidradenitis Suppurativa Foundation, Inc. is a 501(c)(3) nonprofit public charity incorporated in the state of California, USA on July 26, 2005. Your donations are tax deductible as allowed by law. All donors will receive an acknowledgement letter via email and/or mail.

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