

HSF news *brief*



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).

The first two months of the new year have been very busy for the HSF. While I may frequently comment about how exciting I think these times are – for both HS research and for the HSF – I just can't help myself! From the upcoming article that will be published in "Experimental Dermatology" and the benefit concert Ruth is planning, to the possibility of having June designated as HS Awareness Month, I believe we'll continue to see many more of these historical "firsts." One step at a time, we are all building a new path for the future, and on a global scale. I hope you all share a small part of my enthusiasm, and once again I would like to let you know how grateful the HSF is for your support. ~ Michelle Barlow, President

HSF Joins the CSD

One of the many positive outcomes from participating in the NIAMS Coalition Day in December of last year was the opportunity to network with other skin and bone disease organizations. Because of the contacts made, the HSF was able to apply for and receive approval to become a member of the Coalition of Skin Diseases (CSD), a voluntary coalition of patient advocacy groups addressing the needs and concerns of millions of people whose lives are affected by skin disease. We are looking forward to becoming an active member of this organization. For more information about the CSD, visit: <http://www.coalitionofskindiseases.org>



Back on the Hill!

The HSF is pleased to announce they will be attending the 5th Annual Skin Disease Research Day this April where patients, researchers and physicians meet to share their expertise in raising awareness on Capitol Hill about the physical, mental and economic costs of

skin disease, as well as meet with members of Congress and their staff about the importance of an increased investment in skin disease research. The HSF will also attend a day-long training program where CSD members will explore the themes of "Innovation Through Partnership." This event is sponsored by the American Academy of Dermatology Association (AADA), the Society for Investigative Dermatology (SID) and the Coalition of Skin Diseases (CSD).

New Date & Venue for HS Research Symposium: March 5, 2009

The HSF will be holding a 1-Day HS Research Symposium on Thursday, March 5, 2009 in San Francisco, California. This will be the day before the American Academy of Dermatology (AAD) begins their annual meeting. The previously scheduled symposium for October of 2008 has been cancelled, and we apologize for any inconvenience this may have caused.



Coming this May!

"Experimental Dermatology," the home journal of the HSF, will be publishing a group of articles about HS in their "Controversies in Experimental Dermatology" section. Entitled "What causes hidradenitis suppurativa?" experts discuss the possible patho-

biology of HS in the hopes of heralding in a new tradition: getting to the heart of HS pathogenesis within a framework of solid basic HS research. This is a historic first for HS research; truly exciting stuff!!

HS Conference & Benefit Concert

HSF Board Member Ruth Breitrack is organizing an HSF Conference and Benefit Concert, to be held June 20 and 21 in Shawano, Wisconsin. The June dates are in accordance with our hopes to make June "HS Awareness Month" and proceeds will benefit the HSF. You can read all about it on Page 4! >>>

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 B.E. 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>

HS Awareness Month: Help Make it Happen!

If you are registered to vote in the United States, please contact your Congressional Representative and ask them to support the resolution to create June as "HS Awareness Month." Although it may sound a bit intimidating, it is actually quite simple. Just use the links below. And then ask your rep via phone or email to please support H. RES. #1037 introduced by Rep. Steve Kagen, MD (D).

It's so easy... register to vote if you haven't already, and then send an email or make the call today! You really can make a difference and our voices will be heard.

To read the Resolution:

<http://thomas.loc.gov/cgi-bin/query/z?c110:H.RES.1037>:

To register to vote:

<https://ssl.capwiz.com/congressorg/e4/nvra/>

To email your congressional representative:

<http://www.congress.org/>

To call your congressional representative:

<http://www.congress.org/congressorg/issues/basics>

The HSF Research Database

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

On February 28, the HSF added another 8 documents to the research database:

- 2007 HS Infiximab.Moschella.pdf
- 2008 Early Electrosurgery.Aksakal.pdf
- 2008 Gentamicin in surgery.Buimer.pdf
- 2008 SCC mesothelioma.Barresi.pdf
- 2008 Acne inversa(german).Huber.pdf
- 2008 MRSA Antibiotics.Pallin.pdf
- 2008 MRSA Editorial.Pallin.pdf
- 2008 TLR2 C-type Lectin.Hunger.pdf

The following are also recent publications about HS, which are not yet on the database. If you have the full article and would like to help us maintain this valuable resource, please email a PDF document to us. We would appreciate it! MichelleBarlow@hs-foundation.org

B Goo et al. Intramuscular immunoglobulin for recalcitrant suppurative diseases of the skin: a retrospective review of 63 cases. *Br J Dermatol.* 2007 Sep;157(3):563-8. Epub 2007 Jul 11. PMID: 17627790

L. Rees et al. The anterolateral thigh (ALT) flap in reconstruction following radical excision of groin and vulval hidradenitis suppurativa. *J Plast Reconstr Aesthet Surg.* 2007;60(12):1363-5. Epub 2007 Oct 10. PMID: 17928283

P. Arriola-Villalobos et al. Bilateral Candida chorioretinitis following etanercept treatment for hidradenitis suppurativa. *Eye.* 2008 Feb 1; [Epub ahead of print] PMID: 18239677

D. Meixner et al. Acne inversa. *J Dtsch Dermatol Ges.* 2007 Dec 17; PMID: 18093218

J. Kraft and G.E. Searles. Hidradenitis suppurativa in 64 female patients: retrospective study comparing oral antibiotics and antiandrogen therapy. *J Cutan Med Surg.* 2007 Jul-Aug;11(4):125-31. PMID: 17601419

J. Revuz. Medical treatments of hidradenitis suppurativa: a new paradigm. *Dermatology.* 2007;215(2):95-6. PMID: 17684369

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.

German Research Project in Need of European Volunteers

The Departments of Dermatology, Venereology, Allergology and Immunology, Dessau Medical Center, Dessau; and the Laboratory of Biogerontology, Dermato-Pharmacology and Dermato-Endocrinology, Institute of Clinical Pharmacology and Toxicology, Campus Benjamin Franklin, Charité – Universitätsmedizin Berlin, Germany, are conducting a research project entitled “Molecular biology of hidradenitis suppurativa (acne inversa) and the role of age and androgens in regulating apocrine gland activity using microarray analysis.” The project is supported by the German Ministry of Education and Research (BMBF) and is being conducted by Doctors Christos C. Zouboulis, Sabine Fimmel, and Kim Vogel.

Using mRNA microarray analysis they are studying the differences in mRNA expression of axillary apocrine secretory cells *in vivo*, between HS patients and non-HS sufferers. They will also study and compare gene expression in axillary apocrine secretory cells of old vs. young men and pre- and post-menopausal women to identify those genes whose expression is linked to circulating androgen levels and highlight any gender/age differences in apocrine gland function.

By applying modern bioinformatics approaches it would be possible to identify the function of a number of those expressed genes providing valuable insights into the basic physiology of these secretory cells i.e., what biosynthetic, cellular trafficking and secretory pathways are active in these cells and implicate androgens in their regulation. This data would also identify genes and biochemical pathways that could act as new targets of classical drugs but also of siRNA molecules in the treatment of HS. Such a study would be expected to provide huge amounts of data on the biochemical and regulatory processes involved in apocrine gland secretion in HS and non-HS patients and the effect of siRNA technology in their modulation.

Skin biopsies are obtained under local anesthesia of:

- the axillary region of healthy volunteers of both sexes (20-30 years old as well as over 60 years) and
- the diseased and healthy skin of the axillary region of patients with Hidradenitis Suppurativa

The study has been approved by the ethics committee of the Charité Universitätsmedizin Berlin, and volunteers must give informed consent.

If you are interested in participating in this important study, please have your physician email Kim Vogel for additional information. kim.vogel@charite.de

Canadian Skin Patient Alliance

Canadians suffering from HS and other skin disorders may be interested in learning about a not for profit organization called the Canadian Skin Patient Alliance (CSPA). Please visit their interim website for more information: <http://www.skinpatientalliance.ca>

2007 HSF Financial Documents/ Reports Now Online

Recent IRS law allows 501(c)(3) non profit organizations with gross receipts of \$25,000 or less to file a new electronic form called a 990-N. By electing to file this form, the HSF realizes a substantial savings of both time and money. This form is now available on our website in the "Financial Reports" section for your review. This PDF document will also serve as our annual report for 2007 and includes our unaudited financial statements and a list of our generous donors for the year. Thank you for your support!!

2008 HSF Board of Directors

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Christos Zouboulis (Germany)

Past BOD/MSAB Members: Robert Howes, Sam Moschella, Rodney Sinclair, John Sundberg. Thank you for your involvement in the HSF mission.

HS Conference & Benefit Concert

June 20 & 21, 2008 • Shawano, Wisconsin

Friday June 20, 2008

HS Educational Conference
Thedacare Physicians - Shawano Clinic
100 County Rd. B, Shawano, WI

Saturday June 21, 2008

HS Benefit Concert
Wolf's Roadhouse (4 Miles West of Shawano)
W8916 Oak Ave., Thornton, WI

We believe this is a great opportunity to get together and help raise awareness about the disease.

Hope to see you there!!

Additional information will be posted on the HSF website in the [NEWS](#) section as soon as it becomes available.

ABOUT THE EVENTS: The Conference is FREE and open to anyone interested: doctors, patients, family members and friends are encouraged to attend. The benefit concert will have a minimal cover charge, and proceeds of the event will benefit the HSF. The Concert will feature the popular group "Burnt Toast and Jam," and other musicians. If you are a musician and are interested in playing at the benefit, or would like to discuss sponsorship opportunities, please email Ruth as soon as possible. ruthb@frontiernet.net

RESERVATIONS: Reservations are not necessary, but would be appreciated. If you would like to attend, please email MichelleBarlow@hs-foundation.org as soon as possible to let us know if you will be attending one or both of the events.

We have also provided the following information and web links to help you in your planning. Just copy and paste the links into your web browser.

For more information about Shawano

www.explorewisconsin.com/northwest_counties/shawano.asp
www.shawanocommerce.com/
www.wisconsinsplayground.com/

For more information about Burnt Toast and Jam

www.burnttoastandjam.com/
www.myspace.com/burnttoastandjam

Air and Ground Transportation

Green Bay Airport (GRB) is the closest to Shawano.
Milwaukee (MKE) is the largest. (~ 3 hour drive).

If you are flying in, a rental car is recommended. If you plan on staying at a cottage around the lake, a campground, or any place not in the *city* of Shawano, then you will definitely want a vehicle.

Taxi service is limited in Shawano.

City Cab - (715) 526-6445
Kap Taxi - (715) 524-4040

Accommodations

The HSF does not endorse any of these establishments or guarantee availability. Please contact the hotel or campground directly to make your reservations.

Hotels

Country Inn & Suites www.radisson.com/hotels/wishawan
Comfort Inn & Suites www.comfortinn.com
AmericInn www.americinn.com/
Super 8 www.super8.com

Houses, Cottages & Camping

www.co.shawano.wi.us/departments/?department=1ed3a547c799
www.shawanocommerce.com/accom.html
www.wi-camping-review.com:80/?n=shawano&id=4289&t=city

Also see:

www.bambooshores.com/
www.driftincottages.com/
www.shawanolakeresort.com/cottages.htm
www.carlandcharlsshawanohideaway.com/
www.shawanolakecottagegartzke.com/

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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