

# HSF news *brief*



**Wow! The HSF celebrated its first birthday on July 26<sup>th</sup>!** We continue to receive support from a variety of resources, and are working diligently to find funding for general operations, HSF-funded research, and future HSF projects. Do you have your own suggestions for a local fundraising event that you would like to be actively involved in? The

HSF will support you to raise local funds in your neighborhood, so together we can achieve our goal to improve the lives of those with HS. Just drop us a note with your ideas to [info@hs-foundation.org](mailto:info@hs-foundation.org). Thank you so much for walking beside us this past year.

~ Michelle Barlow, President & Robert Howes, Vice President

## directions2006 Developing a Global Roadmap for HS Research

The results from the First International HS Research Symposium Survey are now available online [HERE](#).

## Springer to Support the HSF



In the June 2006 Issue of the HSF News Brief, we told you about this new landmark publication. Now, we have more good news! The book's publisher, Springer, is donating 50 cents from each book sold in support of the Hidradenitis Suppurativa Foundation.

The first book to specifically deal with HS, "Hidradenitis Suppurativa" will be available in Europe this September, and in the United States this October. Written by Drs. Gregor BE Jemec, Jean Revuz, and James J. Leyden, these experts present the best current knowledge about the diagnosis, pathogenesis and complications of HS; comprehensive guidelines on diagnosis and therapy; a description of the patients' perspective, as well as patient information. To read more about the book and order your copy today, please visit Springer's Website [HERE](#).

## Health Professional Shares HS Story

In the January 2006 Issue of the HSF News Brief, we told you about "Dermanities," an online dermatology journal providing a human perspective of the dilemmas and joys that skin doctors and their patients face, and encouraged our readers to submit an article about how HS impacts their personal and professional life.

The current issue, dated July 17, 2006 features an outstanding article entitled "Patient Perspectives: The Ordeal of Hidradenitis Suppurativa" written by Janice M. Parrott. Please click [HERE](#) to read a personal account from a 51 year-old woman who has been battling HS for more than half of her life. Thank you, Janice, for publishing your story.

*"I am hoping and praying someone will have the perseverance to do research on this dreaded disorder. There are thousands of people suffering with this malady from which there seems to be no hope of escape."*

HELP US RAISE FUNDS BY SHOPPING AT OUR STORE

## Enter to Win \$50 Each Month at the HSF Online Store!

Now, each time you shop at our online shopping mall, your name will automatically be entered to win a \$50 CASH reward! To enter the Charity Rewards GiveAway, use the DONOR

RECOGNITION option each time you shop and enter your full name and email address. Our partner, Fundraising Solutions, will conduct a drawing every month, on the last day of the month, and will notify the lucky winner by email. Best of all, everyone is eligible to win more than once, so the more you shop, the better your chances to win! For complete details, go to our website and click on the "shop our store" link on either the [Home Page](#) or the [Donate](#) page. This will take you to the HSF marketplace. Good luck, have fun shopping, and thanks for supporting the HSF!!

**P.S.** The HSF has oversized, full-color bookmarks that promote our Online Shopping Mall. If you're interested in helping raise funds for the HSF, please email us at [info@hs-foundation.org](mailto:info@hs-foundation.org) with your name and address, and we'll send you some.

## Patient/Family Support and the HSF

The HSF responds to phone and email requests for information about HS on an ongoing basis. One common problem identified by a majority of inquiries is the difficulty in finding suitable, motivated and empathic treating physicians, as well as local area health care support. In order to address this considerable need, the HSF is currently seeking funding to create an online Medical Provider Directory/Physician Action Network. If you are a healthcare/medical provider treating patients with HS and would like to learn more about the HSF Directory, please send an email to [msab@hs-foundation.org](mailto:msab@hs-foundation.org).

## The HSF Research Database

Ten new documents were added to the HSF Research Database in July. The Database now contains almost 700 articles, abstracts and other research about HS, which can be accessed for FREE by registering online at:

<http://hs-foundation.org/research/database.htm>

Here is a list of the additions, which should act as a reminder to our subscribers to check the database frequently.

2006 Perineal HS Reconstruction Di Saia  
2006 Adalimumab for HS and arthritis Scheinfeld  
2006 1 case PVL Staph Aureus and Hydradenitis Salliot  
1992 HS Surgery Banerjee  
1998 HS Right hip pain Nijhawan  
1997 Abstract Symptomatology Therapy HS Breikopf  
1997 Abstract CO2 laser HS Bacteriologic findings Lapins  
1997 Abstract HS in two brothers Chaidemenos  
1997 Abstract Unusual case Acne Inversa Vohradnikova  
1995 Abstract S lugdensis isolated from HS axillary apocrine glands Till

Today, over 400 people have registered for the database, including patients, their families, physicians, governmental bodies, and universities from around the world. To date, the HSF has spent thousands of hours and over \$1500 to purchase articles and develop our bibliography. Please help us continue to maintain these invaluable global resources by making a financial contribution to the HSF. You can do this by visiting our [DONATE](#) page or by mailing a check to the address below.

## ISSVD Meeting to Discuss HS

The International Society for the Study of Vulvovaginal Disease (ISSVD) is a worldwide organization consisting of practitioners from many specialties who are involved in the care of women with vulvovaginal disease. One of the primary objectives of the society is to provide education to other care-givers who are interested in learning more about vulvovaginal disease. In the United States, a small core of dermatologists and gynecologists offers one to three day meetings in various parts of the country. This fall the ISSVD is sponsoring such a meeting in Baltimore, Maryland from November 4-6, 2006. Attendance is restricted to appropriate health care providers with an interest in Vulvovaginal disease.

Two of the speakers, Lynne Margesson, MD (a member of the HSF Medical & Scientific Advisory Board) and Peter Lynch, MD have special interests in hidradenitis suppurativa. At this meeting, Dr. Lynch will be presenting a review of the disorder followed by audience discussion with Drs. Margesson and Lynch. Dr. Lynch will discuss the possible relationship that exists between HS and Crohn's disease and will cover the role that anatomic follicular abnormalities and non-infectious, inflammatory mediators play in the pathogenesis of the disease. He will also appraise the data regarding the therapeutic efficacy of the recently developed TNF-alpha "biologicals" and review the importance and patient satisfaction of surgical therapy for patients with HS.

For more information, please visit <http://www.issvd.org> or call Debbie Roepe at (704) 814-9493.

You can also find patient information about HS and other vulvovaginal diseases on the ISSVD website [HERE](#).

**If you would like to announce a professional meeting or presentation about HS in the HSF News Brief, please send a short press release, including contact information, to [info@hs-foundation.org](mailto:info@hs-foundation.org).**

## If you live in San Diego County, you can help support the HSF!

From now through August 31, the HSF is holding a neighborhood fundraising campaign. We have \$10 coupon books (with a savings of over \$100), for a restaurant with 44 county-wide locations. It's easy and fun, and the HSF earns a tasty 80% of the sales! Call (858) 901-4747 for details!