

# HSF news *brief*



With September upon us, it seems like a good time to take a deep breath; to pause and reflect. This month, with the holidays knocking on our back door, we would like to count our many blessings, and give thanks for the many things we have. To our families, our friends, and to those of you who have supported the HSF and our vision, by word or by deed, we extend our heartfelt thanks. And to those who continue to suffer with this disease, the HSF remains dedicated to supporting you. Our collective voice is strong, our commitment is real, and our message is unwaivering. We will find a way. Or make one.

~ Michelle Barlow, President & Robert Howes, Vice President

## directions2006

Developing a Global Roadmap for HS Research

### HSF Symposium Survey Highlight: Impact on Research

Two months after the First International HS Research Symposium held March 31 - April 2, 2006 in Dessau, Germany, the HSF distributed a questionnaire to all attendees. Over 90% of those responding agreed that the symposium will have a positive impact on HS research. Click [HERE](#) to download a PDF of the survey results.

## Springer Donates Books to the HSF



In addition to donating 50 cents from each book sold in support of the HSF, Springer will also be donating several books to the organization. The first book to specifically deal with HS, "Hidradenitis Suppurativa" should be available in Europe this month, and in the United States in October. Published

by Springer and edited by Drs. Gregor B.E. 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, please visit Springer's Website [HERE](#).

## HSF Raffle for Research!

Thanks to the generous donation from Springer, the HSF is holding a **RAFFLE FOR RESEARCH!** We'll be raffling off TWO BOOKS signed by the editors. Patients, families, researchers, physicians, healthcare providers, and anyone else interested in HS can enter to win a signed copy of "Hidradenitis Suppurativa." This landmark publication has a retail value of approximately \$200 USD. Tickets will be on sale through November 30, and all proceeds from the raffle will help support the programs and services of the HSF. For details, see page 3 of this newsletter.

**Call or email us & purchase your tickets today!**

**(858) 901-4747**

**[MichelleBarlow@hs-foundation.org](mailto:MichelleBarlow@hs-foundation.org)**

HELP US RAISE FUNDS BY SHOPPING AT OUR STORE

## Back-to-School Specials at the HSF Online Store!

If you shop online, there's no better time than NOW to shop for back-to-school items and support the HSF. From school supplies and textbooks, to gift certificates and new clothes for the kids, thousands of merchants are ready to donate a percentage of your purchase to the HSF. And remember, each time you shop at our online shopping mall and use the **DONOR RECOGNITION** option, your name will automatically be entered to win a \$50 CASH reward! For 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!!

## New HS Web Resource for Patients

The British Association of Dermatologists has an informative online “leaflet” about HS at their Patient Information Gateway. Per the website, “This information site is for patients, their relatives and friends who want to know more about hidradenitis suppurativa. Healthcare professionals may also find it useful.” The authors include Dr. Amy Stanway MBChB, Specialist Dermatology Registrar, Queens Medical Centre, Nottingham; Dr. Joanne Chalmers BSc PhD, Research Associate, University of Nottingham; and Professor Hywel C. Williams MSc PhD FRCP, Professor of Dermato-Epidemiology, University of Nottingham. Click [HERE](#) to read this comprehensive resource.

## The HSF Research Database

28 new documents were added to the HSF Research Database in August, and the Bibliography has been updated. The Database now contains 718 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 a few additions, which should act as a reminder to our subscribers to check the database frequently.

2006 2 HS case Rx with ALA\_PDT Rivard  
1994 CO2 Laser surgery for HS Lapins  
1992 Crohn's associated HS Burrows  
1986 11 out of 38 hirsute women have HS Barth  
1985 Hormone Study 42 HS patients Mortimer  
1984 HS case initially Dx as Hyper-IgE immunodeficiency Bingham  
1982 Impaired phagocytosis and PG following excision axillary HS Bentley\_philips  
1975 26 cases Axillary HS Anderson  
1955 Possible Familial HS Rx with ethinyl oestradiol Inman  
1894 Hidradenitis Suppurativa Pollitzer

Today, nearly 450 people have registered for the database, including patients, their families, physicians, governmental bodies, and universities from around the world. 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 at the bottom of the page.



## Thanks! Domino's Does Deliver, and So Do You!

The HSF held a neighborhood fundraising campaign in August, thanks to the help of San Diego Domino's Pizza merchants. In a very short period of time, we were able to sell coupon books and raise over \$200 for the HSF. Your individual \$10 donations will help pay for our annual website dues and other operating expenses, plus you got a free pizza and a whole lot more! We consider this a success, and will hopefully do this again next year, for at least two months. *Thank you for your support!*

## Problems with the HSF Website?

In the past month, we received a few emails regarding some difficulties in downloading PDFs from the HSF website. We apologize for this inconvenience, and appreciate the help we received from our readers in trying to rectify the problem. We believe these problems occurred because we are operating on a MAC platform and have limited testing ability without a PC. The HSF is currently seeking funding for and/or a donation of a Windows-based PC (a laptop due to space issues) to eliminate this problem. A PC will also allow us to save countless hours to more efficiently manage current and future database operations. Please email the HSF at [info@hs-foundation.org](mailto:info@hs-foundation.org) if you can help us with this request. And please, email us if you experience any difficulties with our website.

## Also of Note...

If you are interested in becoming a corporate investor or major sponsor of the HSF, we have many opportunities available that will give you wide exposure to our specific, worldwide community. For more information, please contact us at (858) 901-4747 or by email at [info@hs-foundation.org](mailto:info@hs-foundation.org).

If you are a healthcare/medical provider treating patients with HS and would like to learn more about the HSF Online Physician Action Network, please send an email to [msab@hs-foundation.org](mailto:msab@hs-foundation.org).

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).

We have received several inquiries and must clarify the following: **The HSF is not affiliated with HS-USA, Inc. or any online patient support group at this time.**

# Raffle for Research!

Win a Copy of the New Book “Hidradenitis Suppurativa”  
Signed by Editors Gregor B.E. Jemec, Jean Revuz, & James J. Leyden

**Two Lucky  
Winners!**



**Price:** Tickets are \$20 each or 3 for \$50

**Drawing:** Held December 1, 2006 in San Diego, CA

You must be at least 18 yrs. old to enter; you need not be present to win.

All proceeds benefit the  
**Hidradenitis Suppurativa Foundation, Inc. (HSF)**

The HSF is dedicated to improving the quality of life for individuals and families affected by Hidradenitis Suppurativa.

<http://www.hs-foundation.org>

**TWO CHANCES TO WIN!!** Two books will be given away to two individuals. In the event the second name drawn is the winner of the first book, another name will be drawn to select the second winner.

**About the book:** The first book to specifically deal with HS and edited 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, please visit Springer's website at <http://www.springer.com/13-540-3310-X>. (*Hidradenitis Suppurativa*, Jemec, Gregor B.E.; Revuz, Jean; Leyden, James J. (Eds.), 2007; Approx. 280 p., 67 illus., 53 in colour, Hardcover.)

Approximate retail value: \$200 USD

To purchase tickets or for more information, call  
(858) 901-4747 or email [MichelleBarlow@hs-foundation.org](mailto:MichelleBarlow@hs-foundation.org)

Many thanks to the book's publisher, Springer, for their generous donation,  
and to the editors for signing the books.