

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 past few months were rather busy for the HSF, as you may gather from this less-than-brief News Brief. In addition to all the activities discussed here, we enjoyed meeting with Dr. Lynette Margesson (New Hampshire) and Dr. Hope Haefner (Michigan) on May 6th to learn about their comprehensive medical education programs for HS. They were both in San Diego to present on HS at the American College of Obstetricians and Gynecologists' Annual Meeting. Dr. Margesson is a member of the HSF Medical & Scientific Advisory Board (MSAB) and has been educating doctors about vulvar disease for 25 years. Dr. Haefner, from the University of Michigan, is one of a few doctors who performs surgery for Hurley Stage III HS. We have also been working with another MSAB member, Dr. Richard Gallo of UCSD, and others, to organize the HSF's Second HS Research Symposium planned for October of 2008 in San Diego/La Jolla. We hope to announce more details about the event in the next HSF News Brief. ~ Michelle Barlow, President & Robert Howes, Vice President

The HSF International Physician Action Network Launched

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. At this time the Network lists 13 physicians from 6 countries. Collectively these physicians have over 170 years of experience in treating HS, and see over 430 people with HS per year. To sign up for the Physician Action Network, or to find a doctor, please visit: <http://www.hs-foundation.org/education/education.htm>



This program was made possible by a Grant from the Employees Community Fund of Boeing California. The HSF is grateful for this donation and to those interested in registering for this program.

HSF \$5000 New Investigator Award

The HSF is pleased to announce the establishment of a \$5000 International New Investigator Award. This award recognizes outstanding contributions to the understanding, prevention and treatment of Hidradenitis Suppurativa. Basic and clinical research will be recognized. The first award will be presented at the 2008 HSF Symposium in October of 2008. For more information, please visit: <http://www.hs-foundation.org/grants/grants.htm>

HSF Raffle for Research!

Win a Copy of the Book
"Hidradenitis Suppurativa"

Signed by Editors Gregor B.E. Jemec,
Jean Revuz, & James J. Leyden



All proceeds benefit the HSF

Price: Tickets Only \$10 each or 3 for \$25

Drawing: August 12, 2007 in San Diego, CA

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

About the book: The first book to specifically deal with HS and 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 the patients' perspective, as well as expert answers to patients' FAQs.

To read more about the book, please visit Springer's website at <http://www.springer.com/3-540-33100-X>. (Approximate retail value: \$200 USD)

To purchase tickets, call (858) 901-4747 or email: MichelleBarlow@hs-foundation.org

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

*Actively Raising the Profile &
Understanding of Hidradenitis Suppurativa*

Extensive Updates & Additions Made to the HSF Website

Recently, the HSF revised and updated a significant amount of information on the website, including:

New Content for “About HS” Pages

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

The entire “About HS” section on the HSF website has been updated using the information from the 2006 Hidradenitis Suppurativa book published by Springer in 2006.

Open-Access to HS Publications

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

The following articles were made available for free download, thanks to the generosity and permission of the publishers and authors:

- 2003 Hidradenitis Suppurativa by Gregor BE Jemec
- 2001 Morbidity of Hidradenitis Suppurativa by Jan von der Werth et al.
- 2001 Natural History of Hidradenitis Suppurativa by Jan von der Werth et al.
- 2000 Clinical Genetics of Hidradenitis Suppurativa by Jan von der Werth et al.

2006 Form 990 Now Available

<http://www.hs-foundation.org/aboutus/financial.htm>

The HSF’s IRS Form 990 for the year 2006 is now online.

HSF Cited in Two Medical Journals

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

The HSF has been cited this year in the Journal of the American Academy of Dermatology, and the Chinese International Journal of Dermatology and Venereology.

Thank you to the authors and publications!

Your Feedback & Opinion Matters!

The HSF sent a brief, 5-question survey to those who had requested access to the HSF FTP Research Database. A total of 725 emails were sent out and 121 individuals completed the survey between April 10, 2007 to May 1, 2007, approximately a 17% response rate. The results of the survey indicate that the HSF FTP Research Database is a viable and valuable program of the HSF, for both those affected by HS and by the medical/scientific community.

The vast majority of the respondents have accessed the database, find it useful, and feel that the HSF should continue to offer this as a resource. The majority of the respondents have accessed the database on more than one occasion, and appear to use it as an ongoing resource to find information about HS.

In an immediate response to problems accessing the site, respondents were contacted individually to help them address this issue. In addition, the HSF website was updated to include helpful hints on how to access the site, and we modified our letter sent to those requesting access to include information about typical access problems.

The complete survey results are published online at:

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

Raising the Profile of HS on the World Wide Web

May 2007: Genetic Alliance (US) added the HSF “What is HS” web page as a resource link for a clinical description of the disease. <http://www.geneticalliance.org>

April 2007: The Medical Dermatology Society, (US) added the HSF as a resource. <http://www.meddermsociety.org>

March/April 2007: The HSF became a member of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition. <http://www.niams.nih.gov>

Online Advertising & Raising the Profile of Hidradenitis Suppurativa



The HSF is grateful to Google for providing a Google AdWords Grant which has been running since December 2006. As

of the end of May 2007 this advertising program has resulted in increasing HSF website traffic by over 7,300 clicks. The estimated value of the Google AdWords program to date is over \$2700. *Thank you Google!*

In addition, an in-kind donation from Michelle Barlow and Robert Howes was made to test a Yahoo advertising campaign. Traffic to the HSF website increased by 689 clicks in April and May 2007. The value of this donation for the two months is \$138.

To date, both campaigns have created over 390,000 impressions, which is certainly raising the online profile of this disease.

The information below presents some preliminary results of an analytical review of the HSF FTP Research Database, conducted by Rob Howes. The aim of the review was to help characterize the global landscape of people with Hidradenitis Suppurativa, and to gather data regarding the publication of information on this disease. This non-medical review was performed from May to June of 2007 from the literature contained within the HSF FTP Research Database. A total of 732 HS-specific documents were selected which were published in from 1833 to the present, and a total of 481 documents provide actual descriptions of those with HS.

IF YOU HAVE HS, YOU ARE CERTAINLY NOT ALONE!

- The health and medical stories of nine thousand three hundred and three (9303) people with HS from at least 46 countries are described.
- HS has been described in people from: Australia, Austria, Belgium, Brazil, Bulgaria, Canada, Chile, China, Cuba, Czech Republic, Denmark, Finland, France, Germany, Greece, Iceland, India, Ireland, Israel, Italy, Japan, Korea, Mali, Morocco, Mexico, Netherlands, Oman, Panama, Poland, Portugal, Romania, Russian Federation, Serbia & Montenegro, South Africa, Spain, Sweden, Switzerland, Taiwan, Tunisia, Turkey, United Kingdom, United States and Venezuela.
- 96% of people with HS described in the medical literature are from Sweden, United States, United Kingdom, Germany and Denmark.
- The United States leads in the number of published reports describing people with HS, followed by the United Kingdom, Germany, France, Spain and Denmark. Publications from Sweden, however, describe more people with HS than any other country.

IF YOU TREAT AND RESEARCH THIS DISEASE, THERE IS MORE THAT YOU CAN DO!

- Publications regarding basic research on HS account for only 8% of the FTP database literature.
- Large scale studies for HS (over 100 people described in each study) represent a mere 2% of published research.
- Single case studies represent 50% of HS-specific literature describing people with this disease.
- 37% of the documents are clinical and surgical single case studies or case series.
- Disease reviews account for 14% of the published literature.
- Over half of HS-specific research documents have been published in the last 6.5 years.
- The United States dominates the publication of medical and scientific literature on HS, followed by the United Kingdom, Germany, France and Denmark.

2007 HSF Board of Directors and Medical & Scientific Advisory Board Meeting

The HSF held their Annual joint Board of Directors/Medical & Scientific Advisory Board meeting in San Diego on Friday, April 27, 2007. Michelle Barlow, Robert Howes, Barbara Krueger, Christy Pasela and Mary Veta attended in person; Sylvia Shawcross, Lynn Wedell, Dr. Lynne Margesson, Dr. John Sundberg, Dr. Jan von der Werth and Dr. Bill Danby attended via teleconference. The group engaged in active and passionate discussions about a whole range of issues facing not only the HSF, but for those who have the disease and those who treat and research it as well.

HSF business items included the Treasurer's report and a review of the 2006 Annual Report, the delay in holding a Clinical Guidelines meeting, the challenges involved in establishing the HSF International Physician Action Network, creating HSF memberships, and the difficulties and possible solutions in raising funds for HSF programs and HS research (including overcoming the stigma of the disease). Other topics of discussion included the research grant received by Dr. Christos Zouboulis, Dr. Hjalmer Kurzen's studies on smoking and nicotine, other new research, the problems in finding doctors and surgeons with experience in treating HS, problems with the billing code system in the United States, health care issues in Canada, promising new treatments for HS, HS education and the value of the new book published by Springer.

The HSF Research Database

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

Thirty-seven new documents were added to the HSF FTP Research Database, nine of which were published this year. These documents include descriptions of an additional five hundred and sixty-four (564) people with Hidradenitis Suppurativa. There are more people with this disease who have been described. Help us find them!

The Database can be accessed for FREE by registering online at: <http://hs-foundation.org/research/database.htm>

In addition, 8 scanned documents were replaced with text readable PDFs. As part of an extensive content review in the first week of June, 25 documents were re-assessed as not relevant or were duplicate publications or abstracts later published in full, and have been deleted. 161 documents were moved into three sub-folders in order to make navigating the database easier.

Here is a list of the additions:

Folder 3. HS CASE LAW & MEDIA ITEMS

- 2006 Enbrel coverage for HS denied by Health Care Plan DMC
- 2005 Surgery for axillary lesions coverage denied by Health Care Plan DMC
- 2004 Laser Hair destruction coverage for HS denied by Health Care Plan DMC

Folder 2. HSF-FTP GLOBAL RESEARCH DATABASE

- 2007 2 HS cases surgery Ortiz
- 2007 Abstract HS case excision_engraftment_dermal substitute Crombie
- 2007 Hidradenitis Suppurativa Review (CHINESE) Shi Jihai
- 2007 HS and Zinc_A New Therapeutic Approach Brocard
- 2007 HS & perianal mucinous adenocarcinoma do Val
- 2007 Variable response of Infliximab for HS Usmani
- 2007 Anal fistula in acute anorectal sepsis includes HS cases Toyonaga
- 2007 Consider nonsurgical treatment for mild HS Johnson
- 2007 Pilonidal Disease and HS Nelson
- 2006 Acne incidence in renal transplants and Sirolimus Mahe
- 2006 Abstract HS misdiagnosed as complex anal fistula Madiba
- 2006 Home Study Course_HS Haefner
- 2006 Treatment of Hidradenitis Axillaries Suppurativa (JAPANESE) Iida
- 2006 Obesity and Infection Falagas
- 2006 Poster_herida Cronica por Enfermedad de Verneuil (SPANISH) Jimenez_Sanchez
- 2005 Abstract Hidradenitis_like cysts in pachyonychia congenita Liao
- 2005 Severe HS of Axillae (GREEK) Rallis
- 2004 French National Assembly questions on Maladie de Verneuil (FRENCH) Kert
- 2001 Editorial_Is HS Rare (FRENCH) Siproudhis
- 1996 Fecal diversion in management if severe case HS Ger
- 1996 Recurrence fistula_in_ano following Sx rediagnosed as HS McCourtney
- 1995 Abstract Complications 239 HS patients_Baragwanath
- 1992 Abstract management of 13 Severe HS Cases Basil
- 1991 2 HS cases out of 56 Anterior perineal sinus tract cases Oliver
- 1984 HS and Circumferential Perianal Pilonidal Sinuses Taylor
- 1983 100 Recurrent anorectal abscesses in 97 patients_32 cases HS Chrabot

- 1983 30 cases Chronic HS of the anal canal Culp
- 1978 104 Cases Sx Rx perianal and perineal HS Thornton
- 1976 1 case HS and Anal Condyloma Acuminatum Abcarian
- 1970 Perianal HS Surgical Treatment Barron
- 1967 HS of Perineum Cocke
- 1959 Investigational Rx of Triacetyloleandomycin of 7 HS cases Lefebvre
- 1958 3 cases of Fox_Fordyce disease with HS Spiller
- 1957 HS etiology pathogenesis specific vaccine RX Benedek

Thanks to your financial support, we are able to continually expand and maintain this invaluable resource. To find out how you can support the mission, vision and programs of the HSF, please visit our [DONATE](#) page online at <http://www.hs-foundation.org/support/donate.htm>

Use of Articles on the HSF FTP 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 Hidradenitis Suppurativa. 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.

Upcoming Meetings

October 2007: Interactive Meeting of Minds

21st World Congress of Dermatology (International League of Dermatological Societies), Buenos Aires, Argentina. "Hidradenitis suppurativa - Acne inversa - Follicular occlusive syndrome: what's in a name?" Prof. Jean Revuz (France) - October 4, 2007- 08:30 to 10:00.

July 2007: Vulvovaginal Postgraduate Course

July 26 & 27, 2007, Renaissance Vancouver Harbourside, Vancouver, BC. For more information, please visit <http://www.issvd.org> or call Debbie Roepe at (704) 814-9493.

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.

Save the Date!

DISCOVERY 2008:

The HSF Second International
HS Research Symposium & Conference
October 9-12, 2008
La Jolla, California, USA

(Dates are tentative. Details to follow as they become available.)