

The holiday season is a time for us to count our blessings, and the HSF has truly been blessed by the support and participation of sooo many people around the globe. There is so much to be thankful for, and we are quite eager to tell you all about it in our Annual Report for 2006. As such, we will be skipping the January 2007 issue of the HSF News Brief to focus on publishing the Annual Report, early in the first quarter of 2007. From all of us, to all of you, we wish you a joyous and safe holiday season, and a very happy and healthy new year! ~ Michelle Barlow, President & Rob Howes, Vice President



And the Winners Are...

On Friday, December 1, 2006 the HSF held the drawing for our “Raffle for Research,” where two lucky winners were selected to receive a copy of the book “Hidradenitis Suppurativa,” signed by editors Gregor B.E. Jemec, Jean Revuz, and James J. Leyden.

Congratulations! The first winner, Ms. Maureen Casey of Delaware, says she is thrilled to be a winner. The second name drawn was a member of the HSF Board of Directors, Mr. Lynn Wedell. Mr. Wedell instructed us to donate the book to someone else if his name was selected, so we drew another name, Ms. Caithe Cameron of Queensland, Australia. Ms. Cameron plans on donating her book to a hospital.

A total of \$600 was raised in the raffle, which will help support the HSF. We would like to thank all of the people who entered to win a copy of this landmark publication. For more information about the book, visit: <http://www.springer.com/3-540-33100-X>.

Many thanks to the book's publisher, Springer, for their generous donation of 5 books, and to the editors for signing 3 copies!



Last Minute Shoppers & Holiday Travelers!

There's still time to get your 2007 Entertainment Books this holiday season! Help support the HSF & save up to 50% from local and regional merchants. A fantastic gift for nearly anyone in the US or Canada, you can purchase one online by clicking [HERE](#) or by using the link below. But Hurry! Offer expires December 31, 2006.

<http://www.fundraising.entertainment.com/esale2.cfm?CI=889394&SI=602829&LI=1>

The HSF Welcomes New MSAB Member

Drs. Ralf Paus and Christos Zouboulis take great pleasure in announcing that **Dr. James J. Leyden** has graciously accepted an invitation to serve on the HSF Medical & Scientific Advisory Board. Dr. Leyden is an Emeritus Professor of Dermatology at the University of Pennsylvania and an investigative dermatologist for the Skin Study Center, Ivy Laboratories. He has been involved with clinical research and patient care for over thirty years, and has served as a Director of the American Academy of Dermatology, and Chairman of the Board of the Dermatology Foundation. Dr. Leyden is a co-editor and co-author of the new book “Hidradenitis Suppurativa.”

The HSF Welcomes New Board Member

The HSF is excited to announce that **Ms. Sylvia Shawcross** has accepted an honorary position on the HSF Board of Directors. Ms. Shawcross has over 6 years of intensive personal and professional experience in actively raising the profile and understanding of HS, and is a co-author in the new book “Hidradenitis Suppurativa.” In 1997, she helped co-found the Canadian-based and internationally focused “Hidradenitis Suppurativa Information and Development Exchange” (H.I.D.E.), a self-help and supportive group of patients who worked together to find more effective treatments for HS. H.I.D.E. was cited as a health-related and patient support resource in a variety of peer-reviewed journals of the time, including the British Medical Journal, Journal of the European Academy of Dermatology & Venereology, and the British Journal of Dermatology.

The HSF is honored to have Dr. Leyden and Ms. Shawcross join our organization!

HSF Receives Grant for Physician Action Network

The HSF receives dozens of phone calls and emails each week, and hands down, the most frequently asked question is: "Can you recommend a doctor that treats HS near where I live?"



Thanks to Michelle Bruning, an employee at Boeing California, the HSF will soon be able to provide some answers. The HSF was awarded a \$2000 grant from the Employees Community Fund of Boeing California (ECF) in late October of this year to help fund an online physician database to identify physicians and other health care professionals around the globe who are interested and experienced in treating HS.

Ms. Bruning submitted the name of our organization to the ECF because her husband, Mike, has been suffering with severe HS for most of his adult life. Rob Howes and Michelle Barlow of the HSF enjoyed meeting Michelle and Mike to thank them for their support over a leisurely Saturday lunch in mid November, and found their warm, positive outlook on both HS and life uplifting and inspiring. Thank you Michelle and Mike, and thank you, Boeing California!

The HSF is committed to improving the quality of life and quality of care for individuals and families affected by HS. We look forward to additional support that will allow us to sustain such a valuable global resource. Healthcare and/or medical providers interested in assisting those with HS are strongly encouraged to contact us at msab@hs-foundation.org for more information on how to become a part of the HSF Physician Action Network. Additional sponsorship opportunities are also available. Please contact info@hs-foundation.org to find out how your organization can benefit from supporting this or other HSF programs.



EMPLOYER MATCHING GIFT PROGRAMS

If you are considering making a donation to the HSF, you may want to ask if your employer has a Matching Gift Program, which can often double your contribution to the HSF. In most cases, all your employer will need is an IRS Determination Letter, which proves the HSF is a 501(c)(3) tax-exempt public charity. You can download the HSF IRS Determination Letter from our website at:

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

The HSF would like to thank our supporters and their employers for choosing the HSF as part of their Matching Gift Program.

Health Professional Shares HS Story

Dermanities, an online dermatology journal providing a human perspective of the dilemmas and joys that skin doctors and their patients face, recently featured an outstanding article by Kirsten McNaught entitled, "[Hidradenitis Suppurativa: A Nurse's Story.](#)" Ms. McNaught has been a Staff Nurse with the National Health Service Trust in Scotland since 1993.

The author's health and medical perspectives about living with HS are positive and valuable: "I survive with this and I cope with it, but I feel that more provision should be given in the way of support and research."

The HSF would like to thank both Ms. McNaught and the editors of *Dermanities* for raising the profile and understanding of Hidradenitis Suppurativa.

To read the complete story, please visit:
<http://www.dermanities.com/detail.asp?article=242>

If you're doing online holiday shopping, help support the HSF by shopping at the [HSF ONLINE STORE](#). There are hundreds of stores to choose from, and there's no cost to you!

The HSF Research Database

Supporting those with HS and those who study & treat HS

To access this database please register online:
<http://www.hs-foundation.org/research/database.htm>

By increasing the availability of past and current medical research, the HSF seeks to improve the quality of life for people with HS, enhance the quality of medical care they receive, and raise the profile and understanding of this disease on a global basis. The HSF Research Database empowers and facilitates varying degrees of direct patient support by providing information to government, legal, health and social service organizations, as well as patient advocacy/self-help and support groups around the world. The HSF also hopes to encourage and hasten research by providing this comprehensive, valuable and accurate resource. This Database is a tribute to all of the people who have suffered from HS, and an acknowledgment and thanks to those who have volunteered to be studied. It is also an honor roll of the caring doctors and researchers who have helped illuminate the mysteries of HS.

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

You can also help the HSF by sending comments or additional reference source materials to info@hs-foundation.org

NEW TO THE DATABASE IN NOVEMBER

The Bibliography and FTP content lists were updated, adding 116 citations to the bibliography and 111 full text documents to the FTP since September 1, 2006.

The English abstract of the following was replaced with full article in Korean: Hwang D, Park W, Lee J, et al. Clinical Aspects and Surgical Methods in Perianal Hidradenitis Suppurativa. JKSCP 2001 Issue17 pp. 20-25.

A text version of the following was replaced with a full reprint of the article: Kircuval D, Tuzun B, Korkut C. A case of follicular occlusion triad. *Turkiye Klinikleri J Med Sci.* 2004; 24(3):291-294.

There were nine additions to the HSF FTP Global Research Database in November:

2006 Quality of Life Impairment in 61 HS cases Wolkenstein
2006 Clinical Trial PDT for HS KUMC_Hurwitz
2006 HS A Nurses Story McNaught
2006 Disorders of Neutrophil # and Function (1 case HS) Newburger
2005 Case study lack of success Infliximab for HS (IN DUTCH) Suis
2002 7 out of 12 SAPHO cases have HS Steinhoff
2000 Radiotherapy for HS (IN GERMAN) Frohlich
1997 Hidradenitis Suppurativa (IN DUTCH) Rasker
1989 HS_Acute hepatitis_exfoliative dermatitis_minocycline Davies

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.

Research In Brief: Quality of life impairment in hidradenitis suppurativa

Whilst quality of life (QOL) studies assist the clinical consultation, evaluation and clinical decision making process, the results of these studies also present positive implications to patients and their families and to society in general. The recent QOL publications and presentations of Prof. P. Wolkenstein et al. studied French patients with HS/Maladie de Verneuil to scientifically validate the severity and whole life effects of this disease. [1, 2]

From the results of these studies, the scores for HS “showed much more impairment than those found in several other dermatologic conditions including chronic urticaria, psoriasis, atopic dermatitis and neurofibromatosis, all conditions traditionally regarded as causing significant disability. **Compared with these diseases, one can conclude that HS is a distressing condition for many patients and is one of the worst that has been systematically studied in dermatology.**”

[1, emphasis added] Analysis of these studies also produced positive and promising findings; those who have late, adult-onset disease tend to have a better overall outcome, with increased chance of spontaneous recovery.

QOL studies such as these can be the means and method to raise the profile and understanding of this disease, and to lobby industry and government to provide a much-needed increase in social and medical services to those who suffer with HS.

REFERENCES:

1. Wolkenstein P, Loundou A, Barrau K, Auquier P, Revuz J. Quality of life impairment in hidradenitis suppurativa: A study of 61 cases. corrected proof. *J Am Acad Dermatol.* 2006 Oct; Epub ahead of print. <http://www.eblue.org/article/PIIS0190962206023590/abstract>
2. Wolkenstein P. Quality of life in Hidradenitis Suppurativa. In: Jemec G, Revuz J, Leyden J (eds). *Hidradenitis Suppurativa.* 1st ed. Heidelberg, Germany.: Springer, 2006 Sep:116-119.

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: \$ _____

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

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Please contact me regarding:

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

Other _____

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