

If I won the lotto tomorrow, I would purchase and give the new book about HS (below) to every person with HS, to all my family and friends, to every Emergency Room in the world, and to every doctor who has treated or will treat HS. A *must-have* for anyone wanting current and comprehensive information about HS, it paints an accurate picture of our disease from the hearts and minds of both doctors and patients. It offers the strong and hopeful message that the best and brightest are ready and willing to put an end to this intolerable condition. And Chapter 27, "An Uncommon Valor" by long-time HS patient advocate Sylvia Shawcross, finally puts into print real stories that illustrate how devastating HS can be – something that has not been described in any textbook, and something I have not yet been able to adequately explain, even to those who are closest to me. Thank you for this book. ~ Michelle Barlow, President



HSF Raffle for Research!

Win a Copy of the New Book
"Hidradenitis Suppurativa"

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

All proceeds benefit the HSF

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

Drawing: Held Dec. 1, 2006 in San Diego, CA

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

TWO LUCKY WINNERS!! 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, 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.

HS Research Partnerships: A Personal Journey

by Robert Howes, Vice President

After living with HS for about a decade, I realized that as a medical/nursing para-professional I had spent my life with HS in near-complete complacency and ignorance regarding every aspect of the disease. For much of the time that I suffered, I had done my best to ignore the pain and my increasing feelings of social isolation, unable to find anyone who understood what I was going through. I was mostly concerned with pragmatic ideas about escalating dry-cleaning costs due to bleeding and suppuration from my skin lesions, and the growing certainty that this condition would prevent me from performing my duties in operational environments. My last years in the military are a blur of worsening disease, many administrative and medical misunderstandings, culminating in major depression. Recovery from my depression occurred after separating from my dream job in the Royal Australian Navy.

My journey towards finding out more about this disease began in earnest when I connected to an online HS patient support group. I felt that I owed it to myself to finally seek answers to the questions I had consistently failed to ask of both myself and of the military medical profession since 1993. As I chose to drift away from clinical nursing, I held onto the most satisfying aspect of the work I loved, which is helping others.

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HS Research Partnerships

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Michelle Barlow and I began working together online in late 2003 to try and make sense of our disease by first finding, and then reading the medical and scientific literature. We proceeded to dive head-long into online patient support groups, and attempted to piece together the puzzling history of global HS patient associations and organizations. Michelle spent a brief period of time on the board of trustees of a US patient support organization.

Our investigations then led us to make direct contact with doctors, researchers and scientists who could quench our thirst for more knowledge, perhaps answer seemingly impossible questions, and maybe even help hasten much-needed research into our disease. In early 2005, we wrote to Prof. W.H. Irwin McLean, who briefly described to us exciting news about an unpublished genetics study from English families with HS. (*The results of these studies and further investigation and analysis are now published.*¹) Around the same time, Michelle and I also contacted Dr. Uppala Radhakrishna with an interest in learning more about his 2003 presentation at the 53rd Annual Meeting of The American Society of Human Genetics, which detailed a large Indian family of 68 people, including 20 with HS.

Geneticists McLean and Radhakrishna were among many expert physicians and researchers who attended the HSF's first symposium, *Directions 2006* this year. Two weeks prior to the symposium, I distributed to attendees the recently published article about a Chinese family with HS/Acne Inversa (*Gao et al, J Invest Derm*) which suggested that a cause of their disease may reside within Chromosome 1. At the symposium, a unique discussion regarding HS in these English, Indian and Chinese families



Drs. Irwin McLean and Uppala Radhakrishna discuss the genetics of HS in Dessau.

ensued. Prof. McLean reported at least two possible HS locations on Chromosomes 6 and 19, and Dr. Radhakrishna explained that his HS families showed no linkage to the location presented in the Chinese study. As a result of these presentations, symposium attendees developed a working hypothesis regarding the genetics of HS.

SUPPORT GLOBAL HS RESEARCH

A worldwide registry of affected people with HS and further research may highlight a potential cause of HS, and in turn lead to new and more effective therapies to relieve the pain and suffering of HS. These global efforts will improve the quality of life of those with HS.

The HSF extends its heartfelt thanks to families, researchers, physicians and organizations around the globe who actively participate in HS research: past, present and future.

To find out how you can help support HS research and a worldwide HS Patient Registry, please contact:

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I would like to share my sure feeling with others who have HS that open communication and collaboration amongst all people concerned with this disease may lead to improvements in the quality of our lives. Around the globe, doctor and patient interest in the research, diagnosis and treatment of HS is steadily increasing. Worldwide patient/physician partnerships, clinical and scientific research participation, consolidation and collaboration are the methods by which the HSF seeks to hasten, expedite and coordinate the search for the molecular and cellular causes of HS. This collaboration and communication between all people interested in this disease, between those with HS and those that study HS, forms the basis for the HSF's rational belief that this collective synergy will enlighten and empower all people who are concerned with HS.

REFERENCE:

1 Jan von der Werth, Pam Wood, Alan D. Irvine and W.H. Irwin Mclean. "Chapter 10: Genetics of Hidradenitis Suppurativa," *Hidradenitis Suppurativa* (1st edition), 2006; Jemec GBE, Revuz J, Leyden J (eds): 70-85.

The HSF Research Database: *Supporting those with HS and those who study & treat HS*

By increasing the availability of past and current medical research, the HSF seeks to improve the quality of life of those that have HS, enhance the quality of medical care they receive, and raise the profile and understanding of this disease on a global basis.

Hidradenitis Suppurativa research and case studies have been written by doctors which describe the medical, scientific and social histories of patients with HS. The information details people with this disease, their contact with the health profession, the course of disease and treatments used. The HSF Research Database empowers and facilitates varying degrees of direct patient support by providing information to government, legal, health and social services organizations, as well as patient advocacy/self-help and support groups around the world. As a patient led, non-profit public benefit corporation that partners with physicians, the HSF finds access to medical research an invaluable and essential tool in its primary mission to improve the quality of life for individuals and families affected by this disease.

A considerable amount of HS research has been conducted over the years, yet most of these documents have not been easily accessible to either medical professionals or patients. The database was started in April 2005 by two patients with this disease in order to satisfy what they saw as the very basic and previously unmet need of people with HS (and their doctors). It 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.

To date, there are over 740 papers, abstracts, presentations and posters at the FTP site, and information is added frequently. The "HSF MSAB Peer-Reviewed Database," located within this FTP site, was recently added, designed specifically for physicians and skin researchers. Doctors who treat HS can use this resource to aid their treatment of those with HS. To the best of our knowledge, there is no other singular, free-access resource that comes close to containing as much published disease information.

Since its inception, 480 people have registered for the database, including patients, their families, physicians, governmental bodies, and universities from around the world. Providing such a comprehensive, valuable and accurate resource takes a considerable amount of time, effort, and expense. 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](#) page online, or make a gift to the HSF by mailing a check to the address at the bottom of this page.

Last month, 24 new documents were added to the HSF Research Database. (Due to time constraints, the Bibliography is now being updated quarterly.) Twelve previously "scanned as image" documents were also converted to text searchable PDFs, and the text-only version of "von der Werth JM. Investigation: Hidradenitis suppurativa. *Dermatology in Practice*. 2001; 9(3):22-27" was replaced with a full-color PDF and is also available online.

You can access the database by registering online at: <http://www.hs-foundation.org/research/database.htm>

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

2006 Sx Rx HS case series and review Ather
2006 Longterm infliximab for HS Thielen
2006 HS Rx Adalimumab Moul
2006 HS Rx with Dapsone Kaur
2006 Abstract HS in Indian families not linked to chromosome 1 Radhakrishna
2006 Progress in Acne Inversa (IN CHINESE) SU Bin
2006 Clinical Trial Efficacy Laser Device Rx of HS Eisen
2006 2 cases HS and penoscrotal elephantiasis caused by obstructive lymphedema following Sx Stokes
2006 I HS case Fibrin sealant as tissue glue Morris
2004 Enlarged hair follicles in patients with EDS Gniadecka
2003 Acne inversa Acne keloidalis nuchae (IN GERMAN) Plewig
2003 Cryotherapy for HS Bong
2002 Cutis verticis gyrata Acne inversa (IN GERMAN) Feldmann
2002 Acne and HS Rx with Acitretin Scheman
2000 Mutilating Facial Acne Conglobata and AC of Inverse areas Patterson
1996 Histology of HS Jemec
1991 Acne Inversa Pathogenesis_genetics (IN GERMAN) Kuster
1994 Acne Tetrad in a Family Zisova
1987 Letter HS Jemec
1986 Axillary HS & Actinomyces meyeri Grant
1986 Mediation of HS Androgens Comment Harrison
1986 Mediation of HS Androgens Points Mortimer
1984 Axillary lesions & Antiperspirants Williams
1983 HS Acne and Acromegaly Chalmers