

HSF news *brief*



It is rather ironic that this HSF News Brief is NOT so brief at 5 pages! It's been a busy month, and a very productive one. The HSF received their first grant, the new HS book is now in print, we added a new Media/Case Law Section to the HSF FTP Database, and added our first Japanese HS article to the global database (along with 75 other research articles)! Rob and I also enjoyed meeting with Dr. Ralf Paus while he was visiting San Diego to discuss the short and long terms goals of the HSF. We are very excited about the rapid progress of the HSF, which would not be possible without the support of our Board of Directors, our Medical & Scientific Advisory Board, and of course, the emotional and financial support from all the generous friends of the HSF. Thank you!! ~ Michelle Barlow, President



LAST CHANCE! 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; 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.

The easiest way to purchase tickets is through our website at the **DONATE** button on the home page, which takes you to PayPal, a secure site. You may use a credit card or your PayPal account if you have one. Just put RAFFLE in the comments section and be sure to include your address so we can mail you your tickets. You may also purchase tickets by sending a request and payment to the address below. BUT HURRY! The drawing will be held December 1. For more information, please call (858) 901-4747 or email: MichelleBarlow@hs-foundation.org

About the book: For more information, read the review on page 3 of this issue of the HSF News Brief, or visit <http://www.springer.com/3-540-33100-X>.

(Approximate retail value: \$200 USD)

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

Japanese Review on HS Published

Dr. Ichiro Kurokawa, a member of the HSF Medical & Scientific Advisory Board, recently published a review article on Hidradenitis Suppurativa. Based at the Mie University Graduate School of Medicine Tsu, Mie, Japan, Dr.

Kurokawa has graciously provided the HSF with a number of full color reproductions of this article, in Japanese. His previous work includes research detailing the molecular nature of HS, pilonidal sinus, and the associated sinus tracts of these diseases. We would like to thank Dr. Kurokawa for his continued interest in actively raising the profile and understanding of HS. If you are interested in a copy of this article, please contact us.

Reference: Kurokawa I. *Hidradenitis suppurativa* (review). *Rinsho Derma* (Tokyo). 2006 Aug; 48(8):977-985.



Dr. Ichiro Kurokawa (R) with Dr. Christos C. Zouboulis, at the 2006 HSF Symposium, Dessau, Germany.



NEW! 2007 Entertainment Books

Help support the HSF by purchasing one of these popular savings books which contain hundreds of exclusive offers on dining, shopping and travel - where you can save up to 50% from local and regional merchants that you may already use! Good for entire year, it quickly pays for itself by using it only a few times. They make fantastic gifts, and can be easily purchased for nearly every area in the United States and Canada. Purchase one for you, your family, and friends online by clicking **HERE** or by using the following link.

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

HSF Receives Initial Grant for HSF Physician Registry & Database

In the August HSF News Brief, we spoke about a common problem for those with HS: finding a knowledgeable local physician that treats HS. This month, thanks to an employee at Boeing California, the HSF received a grant from the Employees Community Fund of Boeing California. The HSF will now be able to begin this project, and is seeking additional public/corporate support. Healthcare and/or medical providers who treat patients with HS are strongly encouraged to contact us at msab@hs-foundation.org for more information.

It's That Time of Year Again!

Every year, with your permission, your contribution to the HSF is recognized in our Annual Report. Each of our donors, regardless of the size of the gift, receive a Thank You/Acknowledgement Letter from the HSF, either via email or regular mail. If you have given a gift to the HSF in 2006 and have NOT received a letter from us explaining how you will be recognized in our Annual Report, please contact us immediately at info@hs-foundation.org so we can correct our records.

Thank you for your continued support!

NEW for October! 25 HS Case Law and Media Items Added to the HSF FTP Database

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

Media and legal perspectives of this disease have the potential to provide hope, inspiration and social justice. In spite of health care, social service and other disease-related obstacles, those with HS may live a courageous and full life, yet sometimes struggle to find understanding in their home, their workplace and out in the world. Media reports, legal opinion, and expert medical testimony in the past have been based upon medical texts which are "rudimentary, incomplete, misleading, even fallacious and contradictory." [1] This historical lack of medical and scientific knowledge about HS may have reduced the ability of those with HS to seek justice via social security and legal avenues.

There is an urgent need to highlight and protect the inherent dignity and rights of those with Hidradenitis Suppurativa detailed in the United Nations Universal Declaration of Human Rights:

<http://www.unhchr.ch/udhr/index.htm>

Such human rights include the right to work, protection against unemployment, the right to social security, and the right to a standard of living adequate for the health and well-being of self and family. It is essential that our society protect these basic human rights of those with HS against any discrimination based on their disease.

Today, with the gathering of a sufficient college of medical experts who have produced the first comprehensive text on Hidradenitis Suppurativa, and with the creation of the HSF Medical & Scientific Advisory Board, there is a

hopeful potential for HS to gain a long-awaited and well-deserved increase in public and scientific interest and understanding.

Reference: Kligman, AM. Introduction In: Jemec G, Revuz J, Leyden J (eds). Hidradenitis Suppurativa. 1st ed. Heidelberg, Germany: Springer, 2006 Sep. p1-3.

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

2006 Mum Left To Live On 12 pounds A Week
2006 HS Patient Care Canada_Barankin
2006 Feb3 News item Express and Star
2004 Rare features of KID syndrome relate to connexin 26
Montgomery
2004 Lewis_Leavy V SSA US Crt Appeals 8th circuit
2004 Jones vs Social Security Respondent US District Crt Alabama
2004 Infliximab etanercept for HS Duquero
2004 Heather Garcia community hero CCA org
2003 Student overcomes effects of HS Post Standard Syracuse NY
2002 Clarke v Helene Curtis Inc Appellate Div Sup Crt NY
2001 Architects Builders Open Doors for Disabled Arellano
1999 Top model meets young HS girl Denver Post
1998 Jay Siwek MD column response The Washington Post
1998 Dr Alan Douma column response Syracuse Herald Jnl NY
1996 Vineyard vs Social Security Respondent Illinois US District Crt
1995 Anti_Fat Crusader dies Conrad
1994 Butcher v. Secretary of Health and Human Services US
Crt Appeals 6th C
1993 Hayes v Secretary of Health and Human Services 10th ct US
Crt Appeals Okl
1992 OLeary v. Callender Supreme Crt Montana
1990 Bealer v Hoffman_La Roche Inc US District Crt La
1989 Tricky Skin Problem Lehmann
1983 Opelousas General Hosp v Guillory Medical Malpractice
3rd ct Crt Appeal LA
1981 Guillory v. Buller Medical Malpractice 3rd circuit Crt of
Appeal La
1971 Holley v Industrial Commission Crt Appeals Az
1966 Dr Brandstedt column response Daily Times Maryland

REVIEW: “Hidradenitis Suppurativa”

Edited by GBE Jemec, J Revuz & JJ Leyden

By Robert Howes

Empowering, insightful and hopeful, the recent Springer publication of the book “Hidradenitis Suppurativa” is the fulcrum which moves our globe towards a greater awareness and understanding of this common yet mysterious, painful and chronic, inverse skin condition which often results in significant reductions in the quality and enjoyment of life.

Medical, scientific and health professionals seeking to educate themselves about Hidradenitis Suppurativa (HS) will find chapters which are appropriate and well-rounded, accurate and evidence-based. Open exploration of what is known and what is not known demonstrates an essential need to encourage greater interest and financial support in the research of HS.

Based on our experience, those with HS have a critical and overwhelming need for experienced medical providers to help ensure accurate and timely diagnosis, and require a great deal of assistance in navigating through the treatment options to decide how best to relieve their pain, reduce their lesions and prevent recurrence. Armed with this book, these people, their families and their care givers may now be greatly supported in their journey by virtue of the authors’ collective expertise and empathic understanding of the wide spectrum of medical, psychological and social issues which touch their lives.

The Hidradenitis Suppurativa Foundation, Inc. would like to thank and acknowledge all of the contributors.

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What is the HSF Research Database? *Supporting those with HS and those who study & treat HS*

A considerable amount of Hidradenitis Suppurativa research has been conducted over the years, yet many of these documents are not easily accessible to either medical professionals or patients. 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 also hopes to encourage and hasten research by providing this comprehensive, valuable and accurate resource. Thanks to your help, we are able to expand and maintain this priceless resource. To find out how you can support 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>

WHAT IS CONTAINED WITHIN THE HSF FTP RESEARCH DATABASE?

The database is separated into three equally important areas:

[HSF MSAB PEER-REVIEWED DATABASE W/ ANNOTATIONS](http://hs-foundation.org/research/landmark.htm)
<http://hs-foundation.org/research/landmark.htm>

Completed in May 2006, this section of the database contains historical medical research which has been selected, reviewed, categorized and annotated by the HSF Medical & Scientific Advisory Board. It specifically targets both treating physicians and skin researchers. Doctors can use this resource to aid their treatment of those with HS. They need to know what they can tell the patient; which clinical and laboratory examinations are required; which treatments must be discussed; and what the preferred options are. All documents are in English and have been published in peer-reviewed medical and scientific journals. A content list in PDF format by file name, file section and year of publication is also available.

[HSF FTP GLOBAL RESEARCH DATABASE](http://www.hs-foundation.org/research/database.htm)
<http://www.hs-foundation.org/research/database.htm>

This section of the database contains historical medical research from 1833 to present. All documents have been selected by Michelle Barlow and Rob Howes, co-founders of the HSF. Included in this section is a sub-folder entitled "Basic Skin Research_Psychiatry" which contains selected peer-reviewed publications which may also be of general interest to physicians, researchers, and those concerned with HS. The majority of items have been published in peer-reviewed medical and scientific journals, but also include internet resources edited and/or authored by physicians. Documents are

predominately written in English; other documents can be found in the following languages: French, German, Spanish, Portuguese, Italian, Dutch, Japanese and Chinese. Two content lists in PDF format are available: one by author (Academic Medicine format) and one by year of publication (non-Academic medicine format).

[New this Month! HS CASE LAW & MEDIA ITEMS](http://www.hs-foundation.org/research/database.htm)
<http://www.hs-foundation.org/research/database.htm>

This database contains historical perspectives of Hidradenitis Suppurativa from media and US case law from 1966 to the present day in year order, also selected by Michelle Barlow and Rob Howes. Media and legal perspectives of this disease have the potential to provide hope, inspiration and social justice. A content list is provided in by year of publication, file name and source. These items have been published in newspapers, magazines and on the internet. All documents are in English.

ALSO AVAILABLE: THE HSF BIBLIOGRAPHY

A search for "Hidradenitis Suppurativa" on PubMed, a service of the US National Library of Medicine, reveals less than 500 citations from MEDLINE and other science journals dating back to the 1950s. The HSF Bibliography provides a list of over 1300 citations, which demonstrates that PubMed, the most common resource for seeking HS information, contains less than 50% of published materials about HS.

The majority of these citations, from 1833 to the current day, have been selected by Michelle Barlow and Rob Howes. Most of the citations refer to documents published in peer-reviewed medical and scientific journals or to internet resources, books and book chapters edited and/or authored by physicians.

Two styles of the HSF Bibliography are provided in PDF format; the first is by author (Academic Medicine format) and the second is by year of publication (non-Academic medicine format). Additionally a version of the HSF bibliography is provided online in HTML format.

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

Remember! If you're doing online holiday shopping, shop at the [HSF ONLINE STORE](#). There are hundreds of brand name stores to choose from, and a portion of your purchase goes to the HSF when you shop directly through our website. You can even purchase gift certificates from many of the online merchants. Just click the button located on the home page or donate page of the HSF website.

76 Additions to the HSF FTP Global Research Database

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

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

In addition to these new documents, the text-only version of: *Jemec GB, Thomsen BM, Hansen U. The homogeneity of hidradenitis suppurativa lesions. A histological study of intra-individual variation. APMIS. 1997 May;105(5):378-83* was replaced with the full article reprint including color graphics, tables and figures.

2006 Hidradenitis Suppurativa Review Kurokawa (IN JAPANESE)
2006 Altered immune response in Patients with HS
 Giamerellos_Bourboulis
2006 Poster 17YO Male perineal HS Hait
2006 Hidradenitis Suppurativa (IN SPANISH) Charua-Guindic
2006 Inactivity of HS after renal transplantation Arnadottir
2006 News Item Antiandrogen Tx Helps HS Boschert
2006 Abstract 2 out of 302 Indians HIVpos have HS Verma
2005 MV et carcinome epidermoide (IN FRENCH) Lavogiez
2005 Acne inversee revelant un syndrome de Turcot (IN FRENCH)
 Seneschal
2005 Poster Infliximab for HS (IN FRENCH) Bouthors
2005 Maladie de Verneuil et cancer (IN FRENCH) Montagliani
2005 Poster Rifampicin_Cлиндamycin for HS (IN FRENCH) Faye
2005 Abstract fasciocutaneous flap for axillary HS Gacevic
2005 Abstract reconstruction of sacral defects Findikcioglu
2005 Maladie de Verneuil et zinc (INJ FRENCH) Brocard
2003 Les formes severes de l acne (IN FRENCH) Humbert
2003 Acne in infancy and acne genetics Herane
2003 MR imaging of ano-perineal suppurations (IN FRENCH) Cuenod
2002 Urethral fistula caused by acne inversa Gronau
2001 HS_AC_spondyloarthropathy Leybiskis
1999 9 HS ambulatory surgical cases in 2 years (SPANISH-CUBA)
 Mederos Curbelo
1997 Lithium therapy associated with HS Marinella
1997 HS_DDD and perianal SCC Li
1997 1 case HS described in first description of PAPA syndrome Lindor
1996 Peristomal HS Fleischer
1996 SCC_follicular occlusion triad Dufresne
1996 Dowling-Degos disease Bedlow
1995 SCC complicating perianal HS Perez_Diaz
1995 SCC complicating HS Shukla
1995 Gender differences_fistula-in-ano_circulating sex hormones
 Lunniss
1995 Crohns Disease initial diagnosis as HS Labia Minora McKinney
1994 Unusual presentation of HS Chaikin
1993 HS_parathyroid hormone_related protein_hypercalcemia Welsh
1993 HS presenting feature of premature adrenarache Lewis
1992 Surgical intervention Cutting
1992 Spondyloarthropathy with HS Hellmann
1992 Pyoderma vegetans_follicular occlusion triad Boyd
1992 Musculoskeletal features of acne_HS_dissecting cellulitis Olafsson

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.

1992 Hysterectomy for HS Bogers
1992 3 cases Downs syndrome_HS Borbujo_Martinez
1991 Acne Inversa diagnosis and therapy (IN GERMAN)
 Rodder_Wehrmann
1991 1 case HS in British troops during the Gulf War Hepburn
1991 Reactive arthritis due to HS mimicking osteomyelitisTallo
1991 Dowling_Degos disease_HS_multiple keratoacanthomas Fenske
1990 Dowling Degos disease_HS SCC Weber
1990 HS and Squamous Cell Carcinoma and Death Anstey
1989 Urethral fistula and sinus formation in Buckley
1989 Familial grouped comedones Mallett
1988 Surgical Rx severe mammary HS Moosa
1988 Successful treatment of HS with acitretin Hogan
1988 HLA-B27 negative ankylosing spondylitis Grassi
1988 Effect of isotretinoin on eccrine gland Rees
1988 1 case HS retinoid immune system effects McKerrow
1987 Beneficial Effects of Staphage Lysate RX of HS Angel
1987 SCC occurring in HS Zachary
1987 Follicular occlusion triad Chicarilli
1987 HS associated spondylarthropathy Radiographic features Ellis
1987 Fatal SCC associated with AC in a father and daughter Whipp
1985 Arthritis occurring with HS Cohen
1984 Abstract HS Bacteriology and Antibiotic Treatment Hight
1983 Spondyloarthropathy and HS Bennett
1982 SCC complicating HS Black
1981 1 HS case X-linked CGD Brandrup
1980 Strep milleri in perineal HS Hight
1978 HS_a closer look Gordon
1978 HS of the breast areolae Glass
1977 Hidradenitis and Lupus Feuerman
1977 SCC and HS Gordon
1975 Ensemble of Acne Conlobata_Acne Tetrad Plewig_Kligman
1974 Sx Rx hyperhidrosis and HS Letterman
1973 HS acne and paroxysmal nocturnal haemoglobinuria Holt
1964 SCC as a complication of HS Donsky
1951 Plastic Surgery Rx Chronic HS Greeley
1945 Schamberg's disease and HS Kindler
1939 HS and Eczema Mammaram Symmetricum Leszczynski
1938 Manic Depression and possible HS Bruce_Low