

Well, the dust has barely settled from “Directions 2006” Symposium, and with summer here, the heat is on to develop and deliver the many goals the HSF has identified for the remainder of 2006 and 2007. Now more than ever, the HSF needs your financial support to help us continue operations, maintain our website and research database, implement programs and services that will assist individuals and families with HS, and fund research programs vital to finding the cause and more effective treatments for HS. Together, we can make this happen! ~ Michelle Barlow, President & Robert Howes, Vice President

directions2006

Developing a Global Roadmap for HS Research

HS Genetics Research Update

At the First International HS Research Symposium, held March 30-April 2, 2006 in Dessau, Germany, the world learned that three HS genetic loci [gene locations] have been identified on Chromosomes 1, 6 and 19. Further research is required to identify the genes within these loci. Geneticists from the symposium hypothesize that HS is most likely a polygenic disease with sporadic cases having defects in a number of critical genes involved in the pathogenesis of HS, and familial cases with a probable highly penetrant defect(s) in one of these genes. [LINK](#)

What does this mean for those with HS? Geneticists have an unprecedented opportunity to make rapid progress in unravelling the mysteries of this disease. As we all know, this cannot happen without funding. You can play an active role in helping meet the HSF’s main mission: to find the molecular and cellular cause(s) of HS.

The HSF is actively seeking individual, institutional, and corporate donations to raise funds for genetics research, as well as for other research, services and programs in support of our goals to improve the quality of life and quality of care for those with HS. We have identified several funding opportunities to help us fulfill our mission, however, many of these grants are contingent upon matching funds from the HSF, as well as the total number of actual contributors to the HSF.

Now more than ever, a gift from you, no matter what size, will help the HSF raise money help find a cure for this distressing and often disabling disease. To learn how you can help, please visit www.hs-foundation.org.

Symposium Survey Says...

A two-month Symposium followup survey was given to all “Directions 2006” attendees. Here are a few results that exemplify the value of this, and future HSF symposiums:

- Over 90% of respondents agreed that the symposium will have a positive impact on HS research, and 71% agreed they learned something specific that will save time, money or accelerate reaching a research goal.
- 14 of 17 respondents who treat patients with HS agreed they learned something specific at the symposium that will benefit the patients they treat.

The HSF will publish complete survey results online sometime next month. Once again, we would like to thank everyone who contributed to the success of this event. We are still seeking contributions to help recover the majority of costs incurred from the symposium, and with your continued support, can continue plans for future HSF symposiums for researchers, clinicians and patients/families with HS.

Raising Awareness: HSF in the News

The HSF would like to thank HSF MSAB member Dr. Lynne Margesson and the International Society for the Study of Vulvovaginal Disease (ISSVD) for publishing an article about the HSF Symposium in their April, 2006 newsletter, the other symposium attendees who published information on their organizations’ websites, and the Dessau media for newspaper and television coverage. In addition, together with FundraisingSolutions.org, the HSF distributed a June news release to about 10,800 newspapers, magazines and internet news sites. [LINK](#)

HSF 2005 Annual Report Online

The HSF 2005 Annual Report, as well as the tax returns for the year, are now available online [HERE](#).

The HSF Research Database

Seventeen new documents were added to the HSF Research Database in June. The Database now contains almost 700 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 the additions, which should act as a reminder to our subscribers to check the database frequently.

2006 Clinical Trial_ Etanercept in HS registration completed trial GB.pdf
2006 Fatal Epidermoid Carcinoma HS Rx with Infliximab Maalouf.pdf
2006 Legal discussion HS masking Breast Ca CRICO_RMF.pdf
2006 ALA-PDT expanded use medical evidence Gold.pdf
2003 Acne Inversa Surgery Shekarriz.pdf
1997 Pathogenesis Clinical Features Management HS Parks.pdf
1996 Scrotal Elephantiasis HS Konety
1991 3 cases extensive HS rx with SSG & fibrin glue Saltz.pdf
1989 Rx HS Ovarian Adrenal suppression Camisa.pdf
1977 HS of Scrotum Ray.pdf
1975 Surgical Rx Axillary HS Tasche.pdf
1975 HS of scrotum and perineum Surgical Rx Vickers.pdf
1970 HS Systemic Amyloidosis Brownstein.pdf
1969 Surgical Rx HS Masson.pdf
1965 Clinical review HS Ching.pdf
1963 Pathologic Study Use of Skin Flaps Paletta.pdf
1960 Riboflavin for HS_GlucoseTT Mackenna.pdf

Why is this database so important? Prior to its creation, there was no single online HS research resource available. (While medical and scientific abstracts about HS are available online, we found the list to be incomplete, and the information often misleading.) Today, nearly 400 people have registered for the database, which include patients, their families, physicians, governmental bodies, and universities from around the world. We can only guess at the amount of time and money and frustration this valuable resource may save based on our own experience: over two and a half years - thousands and thousands of hours of research, plus the costs to purchase articles, reference software, and FTP site space.

Please help us continue to update and maintain this comprehensive global resource 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 below.

What's Your Opinion?

A recent online poll revealed that a large majority of Americans agree that the results of federally funded research on health issues and other topics should be readily available (for free, and online) to doctors and the general public. 81% of adults strongly (49%) or somewhat (32%) agree that having this type of research data on the Internet - and at no charge - will help those who cope with chronic illnesses or disabilities to get the latest information that can assist them. **Furthermore, 6 in 10 agree it will help speed up finding potential cures for diseases.**

Source: The Harris Poll® #44, May 31, 2006

http://www.harrisinteractive.com/harris_poll/index.asp?PID=671

ALL NEW at the HSF Online Store Now it's easier than ever to support the HSF!

At the HSF, we know that many people with HS do not have any money left over at the end of the month to financially

HELP US RAISE
FUNDS BY SHOPPING
AT OUR STORE

support the mission and goals of the HSF, but would still like to contribute in some way. Well, if you or someone you know shops online, shopping at the HSF's online store can help raise money for the HSF at no cost to you!

And now, thanks to a new technology, PC users* can shop online and support the HSF **directly from their desktop!** Instead of going to our website each time you want to shop, you can download a desktop shortcut, and have access to thousands of merchants, including Wal-Mart, Best Buy, GNC, Target, Office Max, Barnes & Noble; and many more! To install the HSF shopping button on your desktop, 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. Then, click on the "Download Desktop Shortcut" link (on the left side) and follow the simple instructions. Once set up, each time you shop through the icon on your desktop, a percentage of your purchases will be automatically sent to the HSF. **So have fun shopping** and help the HSF by downloading this icon to your desktop today!

*A version for Mac users is being tested and should be available soon.

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