

May 5, 2007

### Purpose and Format of Survey

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 also hopes to encourage and hasten research by providing this comprehensive database. This survey was conducted to assess the value of the FTP database and to ensure that our financial resources, consisting mainly of donations from the public, continue to be used to support our mission and vision. In addition, we wanted to identify and issues or problems that could be changed to make the database more user-friendly.

The HSF conducted a brief, 5-question survey from April 10, 2007 to May 1, 2007 with those who had requested access to the HSF FTP Research Database. A total of 725 emails were sent out requesting participation in the online survey; 2 came back as undeliverable, and six declined participation. A total of 121 individuals completed the survey, approximately a 17% total 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.

### Survey Results

QUESTIONS 1-3	YES	NO
Have you accessed and used the HSF FTP Research Database?	105 (86.8%)	16 (13%)
Have you found the HSF FTP Research Database useful?	104 (86%)	17 (14%)
Do you feel the HSF should continue to offer this database as an educational resource to those concerned with this disease?	120 (99.2%)	1 (0.8%)

*Conclusions: The vast majority of those signing up to use the database have accessed the information, find it useful, and feel that the HSF should continue to offer this as a resource.*

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QUESTION 4	NEVER	ONE TIME	< 5 TIMES	> 5 TIMES
How often have you accessed/used the FTP database?	10 (8.3%)	12 (9.9%)	57 (47.1%)	42 (34.7%)

*Conclusions: 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.*

## QUESTION 5 (open-ended): 50 responses received, see Appendix for responses

OPTIONAL FEEDBACK: Do you have any other comments/feedback you would like to make? For example: describe any problems you have had accessing the database or individual documents/describe any improvements you would like to see/describe reasons why you have not accessed the database, etc.

### GENERAL COMMENTS:

Nineteen respondents expressed positive comments regarding the value of the HSF FTP Research Database, using phrases such as “great service,” “invaluable,” “keep of the good work,” and “don’t take this away.” An additional eight respondents made additional unquantifiable general responses.

### ACCESS ISSUES:

Seven respondents expressed difficulty or inability to access the database or contents, and one respondent wanted to know why a password is necessary to access the site.

### CONTENT IMPROVEMENT:

Six respondents would like to see the information on the database presented in a different fashion: ability to find recent additions, simplifying the site, ability to sort by title, difficulty in finding success stories, ability to find country-specific information, and having non-English articles translated.

Four respondents suggested to include more information about treatments and other information to help those who live with HS.

Two respondents would like research articles summarized in laypersons’ terms.

One respondent would like to see a place for patient perspectives that communicate hope and encouragement.

### SURVEY PROBLEMS:

Two respondents pointed out the survey should have provided for a “not applicable” response. The input is appreciated and the HSF will rectify the problem in future surveys.

### Conclusions:

- *The overall response to this open-ended question was positive.*
- *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 FTP site, and we have modified our letter sent to those requesting access to include information about typical access problems. For those who are curious, a password is required to access the site as a requirement of the company who hosts the site.*

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- *With regard to content improvement, the HSF will continue to strive to meet the needs of those who access the database. We would like to note that with appropriate FTP Client Software (available for free), many issues like sorting documents by date to find recent additions, and finding documents that are subject-specific, can be easily overcome.*
- *In the future, with additional funding, the HSF hopes to translate all of the non-English articles on the FTP Research Database.*
- *Unfortunately, there are currently no plans to summarize the research articles on our database into layperson terms. Additionally, the HSF cannot provide specific medical or treatment advice and we encourage you to seek prompt attention from a knowledgeable and competent medical professional.*

## Appendix: Open-Ended Responses to Question #5

Question #5: OPTIONAL FEEDBACK: Do you have any other comments/feedback you would like to make? For example: describe any problems you have had accessing the database or individual documents / describe any improvements you would like to see / describe reasons why you have not accessed the database etc.

### General Comments: Positive

Historical data which was lacking is now essential to answer the question what is HS!

PLEASE DO NOT TAKE THIS DATABASE AWAY. It has helped me so much to better understand my disease.

I don't often access the database, but find it very useful once in a while. Please don't take it away from me. I keep up with it occasionally and I often check for updates on your website, also for clinical research related information.

My search on this subject has just begun in the last two weeks and thus I am sure that my use of it will increase as our involvement with this disease increases. Thanks for what you are doing for all of us.

Anything regarding this disease should be shared patients and family members going through this. I really appreciate what your organization is doing. A cure would be welcomed very much!

Invaluable resource for clinicians/ scientists researching Hidradenitis.

Great service you provide. As a dermatologist I am in constant need of new research for HS a resistant disease.

I used the database to access information prior to surgery for HS.

I think this is invaluable and well organised resource which I frequently use for personal research.

It has been useful.

I have accessed less than five times because I've all downloaded in my computer. Then I went twice to download the new files. Almost read it all.

I enjoy being able to do research in this area and not have to jump all over the internet to look for new articles. Great Job!

Keep up the good work.

This is the most comprehensive list of HS literature anywhere-keep it up!

It has been useful.

I would be glad if there were resources as useful as this one for other genetic diseases I do research into. Please do keep this service going.

Keep up with the great work and update us as frequent

Hi There I have no criticism at all regarding the site it's Brilliant! and I would like to congratulate both Rob and Michelle on a job well done! and to thank you both for all the work your doing to get this Disease out there and find the long awaited cure. Kindest regards

A great insight into this terrible condition.

### General Comments: Misc.

I have H-S.

Someone find a cure!!!!!!!!!! Please....

Accessed when symptoms were present. Cheers

I have accessed the database to learn about more about Hidradenitis Suppurativa because I am suffering from this and would like to know as much as possible so that I can get some help.

My daughter was diagnosed with HS and I am having a difficult time getting her disability started, and I wonder if there are others who might have some advice about this.

Waiting for feedback from my Doctors about the site and its information.

I would like to see more awareness to the condition as so many people have never heard of this disease or if they have they do not know anything about it.

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## Access Issues

I completed the information form and received a username and password, but I couldn't figure out how to actually access the database; therefore, I haven't been able to use it.

I need to access the database, but cannot seem to get in using the password supplied. Any help would be appreciated. It definitely needs to continue.

I never received the instructions and password to access the database, as I requested. Thank you.

Was unable to access the the database. The link I was sent did not take me to a screen where I was able to enter.

Just recently (Feb. & Mar. issues) I have been unable to access the database and am unsure why. I anxiously await any information I can receive on this disease as I have suffered for approx. 18 yrs. and have it in a severe form. I think any information is very helpful and encouraging and I will be glad when my access problem has been resolved.

Hard to access.

Sometime, I fail to load the full text article.

Just a curious question, why is a password required to access the database?

## Content Improvement

I would like to see the database organized in a way that I know what the most recent additions are. Thank you.

Please try to simplify this site. As a mediocre pc user I find it sometimes difficult to navigate your site. Thank You.

Perhaps sorting them under titles. That maybe a large task. However it is easy to look at the titles, but I am unable to determine if I should read on. It is impressive so I am grateful just being allowed access to these articles. From that point I can make more of an educated decision as to which road I would like to take about HS. It is also great to see how others, especially those in the medical profession, perceive this illness.

The info on the site is not very helpful because it takes so long and so much digging to find success stories - i.e., what's worked for others in treating their HS.

If possible, information at a more 'local' level would be helpful i.e. information for people from specific countries or continents.

I wish there was a way to translate the resources that are in foreign languages. I also wish there was a message board where we could discuss the research we read about on there.

A fact sheet with some simple ways to alleviate the symptoms would be useful e.g. don't wear tight fitting clothing as rubbing often causes outbreaks to occur, don't use deodorant/perfume sprays etc. in the usual affected areas etc. etc.

MORE UP TO DATE HELPFUL HINTS TO PREVENT OUTBREAKS OR NATURAL REMEDIES FOR HD..GIVEN BY PROFESSIONALS OR PATIENTS..AS AUTOMATIC EMAILS TO SUBSCRIBERS EVEN IF THERES A FEE FOR THIS SERVICE.

I would like to see treatments on this web site.

Is there any antibacterial cream or anything similar for my condition? I have had numerous operations which causes extreme discomfort and I am due to have at least 2 or 3 more. Surely there must be something in this day and age which can help with the symptoms. kind regards

Clarify Medical terminology with layman(?)terms. I feel confused and stupid, when I read most of these.

Rather than the actual article I would like the articles summarised in laymans terms in your newsletter. I find the newsletter pretty annoying as there never seems to be anything useful in it, just advertising itself. I want to hear the latest research and treatments.

Even though I haven't personally used the database much, it should continue to be made available to those who need it. I've lived with my disease for over 35 yrs., and there wasn't anything available to me when I needed it... not from doctors or specialists, much less the internet. I used it once to see what it was all about, but I've learned, after all these years, how to deal with my disease. There are others out there who are new to the disease and need the info the database holds, and I'm sure it will be a great benefit for them to have it available. Not being that familiar with the information included in it, my only suggestion would be a place for long-term patients to issue statements about their overall experience with the disease, and give others encouragement and hope.

## Survey Problems

I am sure it is useful, but I have not accessed it, so I had to answer question 2 as no. You should add a not applicable answer.

Question 2 doesn't make sense if the answer to question 1 is No, but I didn't want to say that the database isn't useful without having used it.