The aim of this brief report is to encourage further interest in researching the genetics of Hidradenitis Suppurativa.

Medical research has clearly demonstrated that a form of familial HS exists. [1] Recent additional research conducted from several online documents supports this fact, and is discussed below.

In December of 2003, an analysis of responses from an online petition for HS [2] was conducted, examining both gender and familial relationships for patients with HS. [3] 592 of 1900 respondents said they had HS. Of this HS group, 13% reported having family members with HS, and more than half of those reported a parent-child link. It was noted that familial HS was probably under-reported because either the respondent did not disclose the information (a direct genetics question was not asked) or because they did not know their family history.

In October of 2004, using the raw data files from HS-USA’s online survey, an in-depth analysis from 1642 respondents was conducted. The statistics indicated 27% reporting they had family members with HS, 35% reporting that they did not know, and 35% reporting no family members with HS. [4]

On May 28, 2005 responses to the open ended question of this survey where respondents described their family members with HS were reviewed. [5] Interestingly, of the 2250 surveys, the percentages of those reporting familial HS (27%) was identical to the October report, even with the addition of 700 respondents. To better understand the prevalence of a familial form of HS, and to assess potential candidate resources for genetic testing, the open-ended responses were quantified and we report the following:

METHOD: 600 respondents reported familial HS with 3 or more family members. Those with fewer family members were excluded with the intent to identify possible families that may be candidates for further genetic research. Additional exclusion criteria included all vague or questionable responses, and any deceased family members with HS. A total of 421 responses were eliminated using these exclusion criteria, and a total of 179 responses were reviewed.

RESULTS:
Total number reporting 3 or more family members: 179
Number reporting 4+ generations: 3
Number reporting 3 generations: 54
Number reporting 2 generations: 110
Number reporting 1 generation (3+ family members): 9
Sets of twins with HS: 3

LIMITATIONS: Self-reported information may not provide clinical evidence of familial HS, and the respondents may not have been properly diagnosed with HS. Therefore, every attempt was made to exclude self-reporting that even vaguely suggested that either the patient or their family members had something other than HS.

CONCLUSION: While there are inherent limitations to this analysis, the information provided here positively illustrates a form of genetic inheritance of HS. We conclude that an International Registry of HS patients be developed as soon as possible; that this Registry would require medical support; that the initial setup of a Registry would not require immediate funding; that funding would be necessary to implement the Registry and should be able to be obtained; and that the data gathered from such a Registry would be an invaluable resource for researchers in studying not only genetics, but many other aspects of this disease as well.

REFERENCES:
[2] petitiononline.com