

### What is Hidradenitis Suppurativa?

HS (also called Acne Inversa) is an inflammatory skin disease that affects an estimated 1% of the population. The main features of HS include painful, nodular and boil-like lesions, scarring, sinus tracts and recurrent discharge, which have a significant impact on a patient's quality of life.

HS generally appears in the second or third decade of life. It is not contagious, and is not a sexually transmitted disease. The areas most commonly affected are under the arms, the groin and buttocks, and under the breasts. Patients may present with solitary or multiple lesions in one area, with lesions in many areas, or in more severe cases may have large, recurrent, draining lesions that never completely heal.

For many of those with long-standing HS, it is difficult to understand the unpredictable nature of a disease that is marked by a variable resistance to therapy and alternating periods of disease activity and disease remission.

Patients with HS are advised to not delay their treatment. Talk with a doctor about current treatment options. Insist on appropriate pain relief. Discuss feelings of anxiety and depression that are so common to this disease. And finally, consider seeking support from friends, family and co-workers and help them understand the nature and severity of the condition.

### The Challenge of Treating HS

There is an urgent need to identify and resolve the real and perceived barriers that exist, which may prevent those with HS improving the quality of their lives. This is a representative list of such obstacles, challenges and health disparities which may hold back a search for meaning, understanding and improved health for those with HS:

- Once the symptoms of HS appear, delays in diagnosis lasting years may lead to worsening physical and additional psychological disease.
- Poor communication of a diagnosis leaving the patient uninformed.
- Once diagnosed, many patients may be faced with repeated re-diagnosis to another disease and back to HS again over many years.
- Unacceptable and risky delayed diagnosis, and delayed effective treatment.
- Treatments are commenced before a diagnosis is made, multiple prescriptions of drugs and treatments which may be inappropriate or harmful.
- The physical and psychological condition of HS patients and their families may be worsened by a perceived lack of hopeful treatments.
- Multiple medical consultations, lack of accurate disease information, lack of referral to physicians with experience in treating HS leading to significant shortfalls in quality health care and perceived reductions in the quality of their lives.
- Reduced career options, career loss, workplace and societal disability discrimination.
- Extra financial expense of coping with the disease; lost employment income.
- Significant administrative problems applying for and receiving financial assistance, legal aid, private health/medical insurance and social security benefits.
- Social stigma, alienation and isolation from the community.

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- Reductions in real and perceived intimacy with family, friends and life-partners.
- Loss of libido/sexual desire, inability to enjoy sex due to chronic and painful genital HS.
- Feelings of loneliness, anxiety, chronic anxiety and depressive states due to those with HS perceiving no-one understands their repeated daily struggles. These feelings are compounded by untreated pain and discomfort. Those with HS may feel that they have to live in this manner for several years without medical attention.

## Why the HSF Needs Your Support

The Hidradenitis Suppurativa Foundation (HSF) is dedicated to improving the quality of life for individuals and families affected by Hidradenitis Suppurativa (HS), also called Acne Inversa.

Past medical research details a disease in which the time taken to diagnose is measured in years, or is regularly misdiagnosed. These issues compound the high morbidity and disabling nature of a disease that often goes untreated. Therefore there is an urgent need for detailed medical and scientific investigations into the nature of HS.

The HSF fosters and encourages worldwide research by developing and supporting an interdisciplinary “family” of scientists and physicians devoted to studying HS and its molecular and cellular basis. Our aim is to develop and deliver more effective forms of therapy and preventative measures to patients with this common, debilitating, and eminently chronic disease.

Please help those with HS and their families to overcome these obstacles by donating and supporting the Hidradenitis Suppurativa Foundation Inc.

## Living with HS/Acne Inversa

Excerpts taken from “The Natural History of Hidradenitis Suppurativa” by JM von der Werth and HC Williams  
J Eur Acad Dermatol Venereol. 2000; 14(5):389-392.

“Disease flare-ups seem to occur particularly as a result of sweating, heat, stress and tight clothing or friction. The adverse effects from sweating and heat help to explain why nearly one-third of responders reported a deterioration of their condition in the summertime. Although only few women listed menstruation as a disease-aggravating factor in the open section of the questionnaire, direct questioning about this factor showed that almost half of all females reported perimenstrual exacerbations of their HS. Similar figures have been recorded by other authors.”

“Several patients were able to obtain some relief from their condition through certain life-style measures, particularly swimming, bathing and avoidance of tight-fitting clothing. Whereas some of this has been suggested before it is not regularly included among the suggested treatments in most textbooks or patients' information leaflets. Nearly a quarter of our patients had been unable to list any measure that helped their condition, despite an average disease duration of nearly 19 years. This is an indictment that the available treatments for HS are on the whole still unsatisfactory, including surgical approaches, with which almost half of our patients had previously been treated.”

“The textbook recommendation for treatment is systemic antibiotics, despite the fact that a poor response to standard antibiotics has been so well documented that Mortimer made it a defining criterion for the definition of HS. The belief in the efficacy of antibiotics originates from the assumption that HS is an infection of the apocrine glands. It is now thought that HS is an acneiform disease in which pathogens are likely to be only secondary invaders of an as yet incompletely understood primary disease process.”

“Still, approximately 10% of our patients reported some benefit from the use of systemic antibiotics. An explanation for this may come from our findings on the average duration of boils in HS. The observed figure of 6.9 days almost equals the average length of a course of antibiotics. It may thus not be the antibiotics but simply the natural history of the disease that has led to the registered improvement. No placebo-controlled study of the use of systemic antibiotics in HS has ever been published. Such a study seems urgently required to clarify this issue.”

The HSF was founded for the sole purpose of funding efforts to dissect the molecular and cellular causes of Hidradenitis Suppurativa (HS), also known as Acne Inversa (AI), to aid in the development and delivery of more effective therapy to patients with this common, debilitating, and eminently chronic disease that affects an estimated 1% of the population.

This will be accomplished by fostering and encouraging worldwide research through the following activities:

- Create an international and truly interdisciplinary “family” of scientists and physicians devoted to studying HS and its biological basis and to developing more effective forms of therapy and prevention.
- Develop and maintain an informative, educational website for researchers, doctors, patients, and the friends, partners and family of affected patients.
- Develop and continuously update a professionally organized virtual HS library, a scientific database on all issues relevant to HS.
- Host an annual or biannual International HS Symposium as a public debate forum for exchanging new concepts and research findings on HS pathogenesis and management, and as a forum where new, productive international cooperative research efforts on HS are forged.
- Offer annual travel fellowships to qualified scientists worldwide to attend this meeting.
- Offer start-up research grants to qualified scientists and physicians, with the explicit purpose to broaden the circle of researchers and doctors interested in HS and to encourage “the best and the brightest” to devote their energies and creativity to HS research and management.
- Encourage and assist in the worldwide establishment of Clinical Centers of Excellence for HS Management.
- Create and provide an Annual International HS Research Award for the most outstanding paper published on Hidradenitis Suppurativa and/or its biological basis.
- Seek corporate and private donations as well as government funding to support the pursuit of these goals via the HSF organization.
- Promote the HSF and the interests of affected patients through global media, by educational campaigns, and through interacting both with national and international government agencies and with industry.

These challenging and ambitious tasks will be addressed gradually, as funding becomes available, and the HSF will take additional active steps to realize its goals, as decided by its Board of Directors, depending on funding.

**T**hank you for your interest in supporting the Hidradenitis Suppurativa Foundation.

In order to develop and deliver more effective therapies to those with Hidradenitis Suppurativa, the HSF requires financial support from not only research and development grants but also through financial support from individuals and corporate sponsorships. Together, with your help, we can make a difference in the lives of those who suffer from HS. Your gifts to the HSF help support and promote our programs, and are essential to our continued success. There are many ways you can help:

**HSF LEADER'S CIRCLE** Individuals can join the Leader's Circle by providing a donation to the HSF using our secure online form at [www.hs-foundation.org](http://www.hs-foundation.org) or by mailing the form below with a check payable to Hidradenitis Suppurativa Foundation to the address below. Gifts to the Leader's Circle will be recognized in our online Annual Report with the Donor's name and level of contribution. If you wish your gift to remain anonymous, please let us know.

**HSF PRESIDENT'S CIRCLE** Corporations and businesses become part of the President's Circle with a general donation or by participating as a sponsor for one of our specific programs. Corporate donations and sponsorships will be recognized in HSF publications, on our website, and in our online Annual Report with the Company name and level of contribution. You may make your gift by completing the form below or by using our convenient and secure online form at [www.hs-foundation.org](http://www.hs-foundation.org). Contact us for more information about becoming a corporate sponsor for our new Physician Action Network, conferences and symposiums, or Research Awards.

**HSF LEGACY CIRCLE** Make a planned gift through the Legacy Circle. To learn more about giving options such as Wills, Gift Annuities, and Life Insurance Policies, please contact us.

**MEMORIAL & CELEBRATION GIFTS** You can create a living memorial in the name of a family member or friend, or a gift of celebration such as a birthday or wedding, through the HSF's Memorial & Celebration program. Your gift will show your loved ones how much you care while helping the HSF fund research to find a cure for HS. We'll send a personalized card to the person you designate to notify them of your donation (the amount of the gift will not be indicated). A suggested donation is \$50 or more for each remembrance. You can make your donation by phone or by mail.

**GIFTS-IN-KIND** The HSF also accepts non-monetary items of tangible personal property or other physical assets that represent value to the HSF. Examples of such items include real estate, equipment, meals, and travel/transportation/lodging certificates. If you believe you have a potential gift-in-kind, please contact us.

**SHOP OUR ONLINE STORE** Your thoughtful support will help us continue to run and develop important programs as well as serve the HS community. Shopping online is easy, and in doing so, a percentage of your purchases will be returned to the HSF. Truly, you understand our mission and our need for people just like you. Visit [www.hs-foundation.org](http://www.hs-foundation.org) for details.

### *Thank You for Your Support!*

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Please contact me regarding:

- Including the HSF in my Will or Living Trust  
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Other \_\_\_\_\_

The Hidradenitis Suppurativa Foundation, Inc. is a 501(c)(3) nonprofit public charity incorporated in the state of California, USA on July 26, 2005. Your donations are tax deductible as allowed by law. All donors will receive an acknowledgement letter via email and/or mail.