Dear Primary Care Provider (PCP)

This letter is provided by the Hidradenitis Suppurativa Foundation to introduce patients who have been to our website, [www.hs-foundation.org](http://www.hs-foundation.org) and have self-identified as likely to have the disorder known as Hidradenitis Suppurativa or Acne Inversa (HS/AI).

This disorder can be thought of as a kind of acne that erupts mainly in armpits, groins, under breasts and in areas of clothing pressure. This acne ‘goes deep’ (acne inversa). It causes painful swellings, nodules, cysts and sinuses that discharge material which can become very smelly when it becomes infected. The plugging of the pores is deep, so you may not see blackheads until late in the disease.

This plugging is caused by androgens (male hormones) just like regular acne. The hormones and growth factors in all cow-and goat-based dairy products appear to be a major factor. Any food that raises insulin levels (and milk is one of these) also makes matters worse. This is the reason for the need for dietary management. The other major factor is nicotine, which may work both by plugging pores and by slowing healing.

We expect that the self-examination done by the patient will identify the disorder and may even classify it according to areas of involvement and types of lesions. That part of the website is still in the design phase.

To save you time the patient has already filled out a form that details their full physical examination (LINK still under development). He or she will bring a copy of it to their first appointment. Please confirm the patient’s notes with a check mark and mark any errors with an X. It will be up to the patient to enter the corrected information on his or her online HSF Registry page. If you wish to have your staff complete this Registry information with the patient for accuracy that can be done with a paper copy and transferred to the electronic record by the patient later.

Next, we need your help in guiding your patient towards help from various sources.

A - Education – HS/Al is often poorly covered (or not even mentioned) in Medical or Nursing School, and the availability of updated information has been limited until now. The HSF website has an overview with links to various sources, including specific physicians, specialized clinics, interested groups, blogs, websites, and eventually Facebook page links. HSF plans to keep these updated as new services become available. This will include not only traditional medical and surgical services but also non-traditional treatment plans.

B - Dietary advice. Many nutritionists are unaware of the impact of the hormones and growth factors in all cow and goat milk products. While not everyone has the genes that lead to acne of various types, those who do have the gene tend to develop plugs in their pores when exposed to androgens (male type hormones) and growth factors that cause this disorder. See [The Diet](http://www.hs-foundation.org). We are addressing this new knowledge through nutritionists’ national organizations but it will
take time to get everyone up to speed. HSF will meanwhile provide downloadable handouts and diet worksheets in the short term.

C - Non-smoking support. The plugs in the pores are caused by two major factors, the hormones from various sources and nicotine. The science on this is new and convincing - see (LINK) **Why No Nicotine?** and print out the handout on that. ALL sources of nicotine must stop immediately and **permanently**. This is a big hurdle for many nicotine-addicted patients and your understanding and support is critical to stopping new lesions. Please do everything possible to stop the nicotine of whatever source. Using nicotine gum or patches, electronic cigarettes, chewing tobacco or snuff is likewise totally forbidden.

D - Hormonal management. The plugs in the pores that lead to the explosions under the skin are started by over-production of the lining cells down in the pores. The hormones come from ovaries, testes, adrenal (stress) glands, and from inside the folliculopilosebaceous unit (FPSU) itself – they all feed into this plugging process and all need to be minimized or blocked. For men, the only effective hormone blocking medication is dutasteride or finasteride. For women, non-androgenic hormonal birth control is advised. (LINK Gynecologists) This may be supplemented with spironolactone, a blocking agent that blocks the male hormone receptor. It also has anti-inflammatory activity and can be used alone or in combination with contraceptives of all types (even IUDs) to improve results.

E - Dermatological care. If you have a dermatologist who cares for your complex skin patients, arrange a referral as soon as possible. It may take a while to get an appointment, but the HSF strongly encourages you to remain the primary provider. Most of what we dermatologists do for this disease is well within the skill set of primary providers. The lifestyle modifications especially need your ongoing support and coordination. Please encourage the patient to get started with those. (LINK The Diet) All dairy should stop immediately. All high sugar drinks and high glycemic food, too. Get your patient started with maximum encouragement and a healthy dose of hope. You can start the birth control, the spironolactone and possibly the anti-inflammatory antibiotics, but there are some special skills required that dermatologists can assist with, such as injections, unroofing, and specialized drugs. Start the referral process early - most of these patients have waited years for a diagnosis and they really deserve to be treated without further delay.

F - Emergency Room care. The ER is for emergencies and is a highly expensive option. We encourage your patients to use those services only when necessary. A hot ‘boil’ that needs opening, any area that is very painful, the presence of a fever, feeling really unwell - all deserve that assessment. We encourage patients to check with their Primary care or dermatologist **first**, when possible. We recognize that the experts are scarce in many locations and in other areas some are not comfortable treating the disease. The HSF mission is to upgrade the knowledge base and keep all ‘providers’ as up to date as possible. The subscription online educational website UpToDate is available in many ERs and larger clinics and hospitals to assist their staff. If your patient has had the experience of having a painful ‘boil’ / HS/AI lesion incised and drained
(I&D’d), only to have it recur, they need to know that we encourage ER staff and dermatologists to “Un-roof or De-roof” these lesions and clean out the material that keeps the problem going. (LINKS Unroofing Poster, Emergency Room Physicians) This leaves a larger wound and is a bigger procedure but the healing is usually complete and the recurrence rate is exceptionally low. Recurrences after I&D are close to 100%, a great waste of time and pain.

G - Weight management. Does Obesity Cause HS? ABSOLUTELY NOT!

Indeed there are hundreds of millions of overweight people who are quite healthy and have never had a hint of this disorder. BUT HS patients who lose significant amounts of weight will often improve their HS/AI to the point that no more pain and drainage occur. This may occur with volunteered weight loss through dieting or following bariatric surgery.

But there is a very worrisome public relations problem that crops up when dealing with this subject. Most overweight patients are sick and tired of being told that obesity is the cause of the problem. And they are (mostly) right.

There are actually three sides to the story.

First, to have HS you need to have the fragile follicle problem, whether it is genetic or ‘just happens’.

Second, the dairy products and the sugary and high glycemic load foods that actually cause the plugs in the pores - and that lead to the explosions – in other words all the foods that cause the disease - are the exact same foods that lead to difficulty in losing and controlling weight. By eliminating these foods (LINK The Diet) the whole insulin-driven, and growth hormone-driven, and most of the androgen hormone-driven part of the disease is changed. Weight loss becomes possible, indeed easier. This is rewarding in so many ways, as the weight loss becomes a bonus.

Third, the obesity is responsible for the friction of belts and bra straps and tight panty openings on involved skin – all this makes matters worse. No doubt about that.

Much of the best advice in this area comes from “HSFolks” (we try not to call them patients or sufferers or victims) who gave up on their doctors and the antibiotics and the surgeons. Many turned their lives around by themselves - taking control of their disease through dietary management. There are books and blogs and support groups and web sites out there that can provide you, as the primary carer (as the British call them), and your patient with all sorts of helpful hints, advice, and most of all, their experience. We at HSF plan to provide links to as many of these sources as possible, even though some are based on shaky (or no) science. But we never argue with success – instead we try to learn from it. As always, our suggestion that patients access this information does not imply that the HSF endorses the opinions of others.

H - Psychological support. HSFolks have something to hide, and that secret is not only painful and sometimes smelly but also causes stress beyond what most of us can imagine. That stress by itself is one of the causes of the disease and stress certainly can cause flares and keeps HS/AI going. The disease and the stress are very hard on all who encounter this disorder, including physicians and surgeons, our staff members and HSFolks’ family members.
Anxiety is a constant when you are hiding something even in your most intimate moments. And years of hiding and failing to find successful treatment causes even more anxiety and sometimes a second effect, depression. It may not be life-destroying but it certainly takes the fun out of life. Some HSFolks have a built-in happy personality, others are very tolerant of their situation, some are resigned, and some are fighters. Others are just plain angry at the disease, and their doctors, and the cost of their medications, and the pain, and the smell, and the expense, and the embarrassment - and they take it out on anyone in their path. Who can really blame them? Each patient’s need for help varies, from person to person and from time to time, and allowing ‘venting’ is sometimes part of the help we need to offer.

Inner strength is great, but additional support is sometimes needed. Consider the stress of this question – ‘What if I reveal my secret and that ends a valued relationship?’ Family support is needed, or a sympathetic counselor, or a primary care physician willing to dig in and help, but professional psychological or psychiatric support may sometimes be needed to bring a serious depression around to the point that the ‘patient’ has enough energy to get to work with the problem. Often a support group does a better job than the professionals - one reason may be that dermatologists with HS/AI are few, so we really don’t ‘own’ the problem the way HSFolks do. A support group can make lemonade with these lemons.

If there were a solid perfect predictable way to get rid of this disease, we would be happy to add a ‘stamp of approval’, but even the most potent drugs we have are not perfect, and the only cures we have seen are in patients who totally avoid nicotine, are highly compliant with the diet, take their medications as ordered, and get the material that causes the trouble removed from under the skin. This material must be eliminated surgically, the earlier the better.

The present active therapy side of the management algorithm is best summarized as follows
- treat existing true cellulitis with aggressive antibiotics
- cool the inflammatory component if small with intralesional triamcinolone, and if large or extensive with a biologic
- use a choice of surgical techniques to
  - eliminate residual purulent material (pus and other drainage)
  - dissect out any sinus tracts and associated scarring
  - aggressively expose and accurately curette away or otherwise remove the subcutaneous gelatinous mass found in the base of these lesions, using
    - a large biopsy punch (mini-unroofing)
    - scissors and gauze grattage
    - CO2 laser or
    - electrosurgery
- allow the wound to heal by secondary intention.

We at HSF cannot treat everybody, indeed we can not treat anybody. The law of the land requires ‘face-to-face’ contact to document an ‘encounter’. We can provide information, encouragement, coordination and cooperation, but we need local physicians and surgeons to
join us and you the PCP to complete the circle of care. We need your help to build this network. Please take an active role in getting this disorder out of the shadows and into proper treatment.