

JDPA

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SDPA NEWS AND CURRENT AFFAIRS

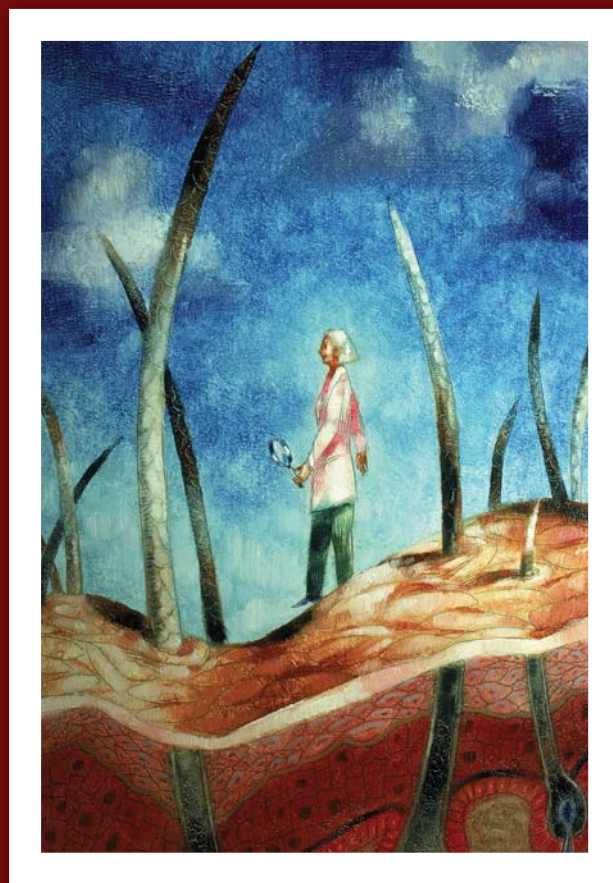
DERMATOLOGY PA NEWS AND NOTES

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COSMETIC DERMATOLOGY

PROFESSIONAL DEVELOPMENT



SUPPLEMENT
for the
Hidradenitis Suppurativa
Foundation



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FROM THE PATIENT'S PERSPECTIVE

It's Not That Bad... My Journey With Hidradenitis Suppurativa

By Suzanne Roupas

The setting: Dr. B's dermatology office, Spring 1985. I had never met him, but he had a good reputation in the community. So there I was, thirty years-old and for the first time in my life confronting the disease that had changed my life when it began ten years before. He asked me to stand, take off the gown and show him what I was worried about. He donned a pair of white cotton gloves (this was before the days of universal precautions for anything but blood contact) and examined my naked, lesion-covered self. Dr. B. took off his gloves announcing, "I have seen a lot worse, it's not that bad. Learn to live with it." And here I thought I had been trying that for quite a while. He told me the name of this disease, Hidradenitis Suppurativa (HS), and sent me on my way with a script for some antibiotic or another. I believed it was "not that bad."

I remember growing up with a mother who took to her bed on a regular basis saying, "I have a boil." She would lie in bed with an arm over her head and a little gauze bandage soaked with "Boil-Ease" taped on the lesion. When I had my first lesion at twenty or so, I showed her. She told me that I deserved it because I had been so bad as a teenager. I believed her as well.

In the ten years between my first lesion and my first foray into the world of treatment for HS, I learned several things. These remain some of my most ingrained habits and actions to this day. I cannot wear white or light colored pants or shirts (being a nurse, that is always a challenge). I cannot wear sleeveless shirts. I have to buy new underwear every few months to replace the ones ruined from the drainage. I am sensitive to most adhesive tape. I am extremely aware of how I smell every single day. When I go to the beach I keep my arms down

and a towel around my waist until the last possible moment. I cannot take my time getting used to the water but have to plunge right in to prevent others from seeing my lesions. I need to have "the talk" with lovers before we become intimate. I am always in pain in at least one place. I am covered with scars on my axillae, under my breasts, my belly, inner thighs and labia. I have a great early warning system that my period is on its way – who needs PMS? There are lots more.

I have seen many dermatologists and primary care providers. They were not only uninformed, they had no clue how this affected my life every single day. I have tried every quack treatment out there; collidal silver, tea tree oil and what have

you. I have been on a million antibiotics, both systemic and topical. I have killed zillions of flora with antibacterial washes. I have been on isotretinoin, twice. It helped a lot the first time and not a bit the

second. I have soaked, washed, scrubbed, sanitized, bandaged and babied every lesion that I have ever had. I am covered with scars. It is somehow ingrained in me that my mother was right... I deserve this.

I have learned about HS on my own and educated my providers. I have seen the revulsion on their faces when I have needed an I&D of a bad lesion. I have gagged at my own drainage. I have been told that I have this condition because: I am too fat, I have olive skin, it is sunny/humid, I drink orange juice, I shave my underarms, I use the wrong detergent and mostly I just hear in my mind... I deserve this.

Fast forward to 2004. In my research, I learned of a serendipitous finding in a Florida study done to test a new medicine for Crohn's Disease. Several of the patients in the study had both HS and

*"It is somehow ingrained in me
that my mother was right...
I deserve this."*

Crohn's. The drug, a tumor necrosis factor (TNF) blocker had helped the patients with their Crohn's AND their HS. I was stunned. I joined a web site that would notify me if there were any studies (with the parameters I had selected) involving this drug. There was nothing for quite a while and then I received an e-mail that had me riveted to my chair. The University of Pennsylvania Hospital was doing an HS study using a TNF blocker called Enbrel. I called. I traveled to Philadelphia (a five hour drive each way) to see if I might qualify. I waited. I qualified! Maybe my HS was "that bad".

I started the study in October of 2005. I drove those ten hours every two weeks for a long time. I injected myself every week. The researchers measured my quality of life, pain and counted lesions. Not much changed in my eyes, then near the end there were some changes. There were fewer lesions, but the real change was in the decrease of pain and drainage. I was ecstatic. Over the course of the study I was forced to "come out" to my friends about my HS. I needed my friends to dog and cat sit for those long days when I would leave home at 5 am for a one-hour appointment. The study ended in early 2006.

I was better. I found a new provider. For the first time in my life I had a local provider that not only understood my distress, he treated me as a partner in my care, not as a patient who is too pushy. After a lot of work on my part and advocacy from my PA, we convinced my insurance company to cover the Enbrel at a higher dose than I had received in the study. I had become convinced that the effects of the medication were weight related and that I would do better with a higher dose. I did great for several months. I had no pain, occasional

odor that was easily treated with systemic antibiotics, and had fewer lesions. Then there were roadblocks. My insurance company would no longer cover the higher dose of medication because they used the psoriasis protocols as guidelines and those guidelines do not support the higher dose after a certain length of time. The lower dose was not effective. My lesions came back, the drainage was horrid and the pain returned. My PA and I began to strategize ways to approach the insurance company when I came down with an intestinal virus that continues to plague me eight weeks later. No more Enbrel right now. I do not dare take antibiotics to control the smell and I cannot tolerate the spironolactone that helps to diminish the severity of the lesions.

So here I am, full circle. My HS is running rampant. My insurance company is dictating what kind of care I can receive. I am worried about my immune system. I smell. Maybe it is "that bad." 📞

TAKE HOME POINTS for DERM PAs:

By Steven K. Shama, M.D., MPH

- 1) Make a promise to yourself that no patient will ever remember you saying, "I have seen a lot worse, it's not that bad. Learn to live with it."
- 2) When you are treating a chronic debilitating disorder of the skin for which there is no clear cure at the time... always give hope. Say words like... "I am always here to help"... and mean it!
- 3) The Hidradenitis Suppurativa Foundation, Inc. (HSF) is a nonprofit public benefit corporation dedicated to improving the quality of life and quality of care for individuals and families affected by Hidradenitis Suppurativa.

Find them online at: www.hs-foundation.org

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- Interested in writing?
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