# My life of struggle with hidradenitis suppurativa

Dave Machell

**Dave Machell has endured decades of suffering with hidradenitis suppurativa, a chronic, recurrent, painful disease that presents with inflammation of the apocrine glands. Here he describes his journey through the first symptoms, diagnosis, treatments, the pain and psychological isolation, and the support he finally found in HS-UK.**

I've had a disease for the past 34 years that has no cure, very little effective treatment and that the medical world knows very little about. It causes agonising pain when flaring, major scarring, embarrassment, depression and anxiety. Mine has affected me in both underarms, at the base of the spine, across both buttocks, on the inside of both thighs, across my lower stomach, on my face, neck and in my hairline. I have friends whose HS affects many other areas of their bodies, including under their breasts and on female genitalia. HS does not discriminate: it affects skinny people, larger people, both sexes, all ethnicities. Anybody can have HS and you may not even know it because it is too embarrassing to talk about, and due to lack of knowledge by the medical profession it can often be misdiagnosed .

I've had HS since the age of 11. It began on my inner thighs and in my groin. I thought it was due to puberty at first, along with sweating and being hot down below. I thought it was all perfectly normal so I never mentioned it. It wasn't until a few months later when the lumps had become quite large and extremely sore that I let my mother look and she took me to see my GP. He told her the best treatment was to have them lanced, so off I went to hospital. I was in hospital for a couple of days taking flucloxacillin and having the wound packed with a long wick covered in Inadine. When I came home the nurse came out every other day to repack them until they healed from the inside out. On another lancing operation, within 6 months of the initial procedure, a doctor doing ward rounds told me it was hidradenitis suppurativa and he said I was going to have a rough time with it in the years to come. How I wish I could meet him now and tell him he was so right.

School wasn't easy. PE was out of the question as stretching and contact sports were agonising to take part in, as was sitting at a desk. Days off became weeks off and so my education suffered. When I was in school, I had to catch up during my breaks

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so friends drifted away — isolation was second nature to me. Over the next few years I persevered with the lumps rather than go into hospital as I had learnt that once they burst the pain eased and I was able to cope better. When they wouldn't pop and I couldn't cope because of the excruciating pain I would go to A&E to have them lanced. I quickly became de-sensitised to hospitals and when nurses gave the welcome speech I was able to mimic them as I knew it so well.

During my late teens and into my early 20s I would get a new abscess at least every 6 weeks. Doctors told me I was getting them because I wasn't washing often enough, or too much, using the wrong soap, wrong soap powder, using deodorant, not eating the right foods or eating too many sweets. They simply didn't have the answer and were clutching at straws. Treatments in the early stages ranged from putting Bactroban up my nose twice a day and covering myself with various creams, to taking New Era (no 7) tissue salts. I became so disheartened about going to dermatology clinics at one hospital that I gave up and visited my GP for pain relief, although at that time it was thought co-codamol, paracetamol or Neurofen were the best things to treat my pain. It took a long time to convince doctors that they were not helping. During my early 30s I was persuaded to try a different dermatologist at a different hospital. As soon as I entered the doors I felt I was being treated like a person and not a number. The staff had time for me, they listened and helped as much as they could. There was no rushing or frowns when I limped slowly, there were no looks of disdain when my weepy lumps and pus smelled; everything was explained in layman's terms so that I could understand what was happening.

I thought I had seen everything this condition could throw at me, but sadly I was wrong. Just into my 40s the flares escalated fast. They would centre on one part of my body at a time and go all out to take over. It was agonising to move, my painkillers were doing nothing so I had to get stronger meds from my GP — I went from low-dose ibruprofen and diclofenac up through the range to tramadol, morphine and OxyContin. I would sleep on my sofa so I didn't have to move too much. I would have bottles of water and simple snacks near me so I only had to move to go to the toilet, and I was

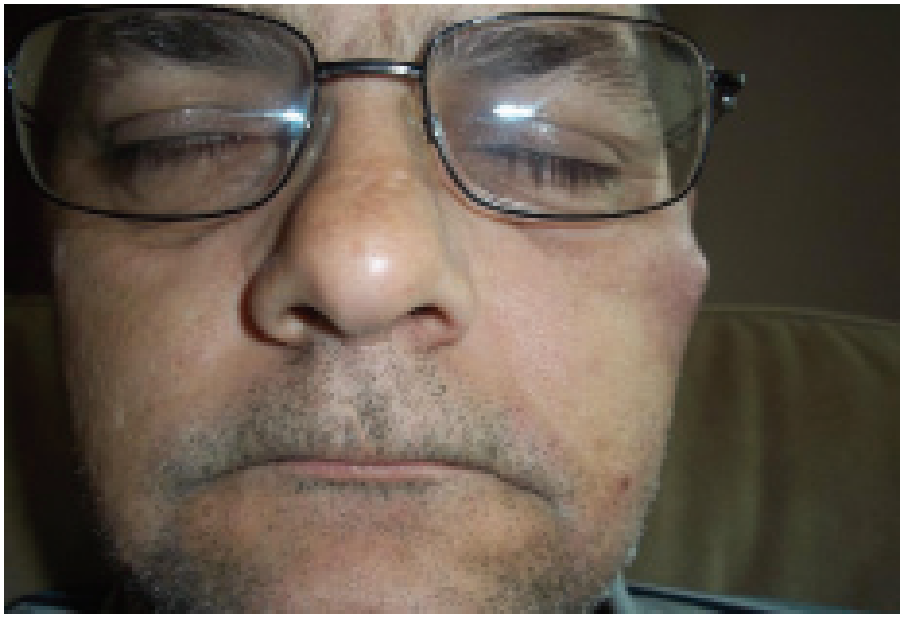

**Figure 1. HS continues to affect the author, above, in numerous sites on the body and on the face.**

in agony even doing that. I became really depressed and didn't open my curtains for weeks on end. I would cry for no reason, sleep for days on end, then go days without sleep. My house was a mess and I didn't care about anything. I had huge, infected, weeping abscesses all over my body, they were peeling and the skin was thin and bright red, yet they wouldn't pop. Wearing clothes was agony, as was changing dressings.

I had a laptop computer I used to surf the internet and one day I googled my condition and came across a support group. My first contact with them was soul-lifting for me. Finally I had found others that understood what I was going through and offered support. This yahoo-based support group, HS-UK, was private so I knew only those that understood would be able to offer advice and be there for much-needed support. They are still a huge lifeline for me and have helped me to get back on track. I have made many lifelong friends through the support network. Now that I can talk more freely about HS I also use other support groups on social networking sites such as Facebook.

I had high-dose antibiotics to fight the infections and I talked about surgery with my dermatologist because all the conventional antibiotics had failed to work. I had been told about a new drug that was working for some on the support group called etanercept. I received funding for it and gave it a go, but sadly even that didn't work for me. My dermatologist seemed to be as devastated as I was and it felt as if the fight was over. I accepted surgery was the only way forward and went in to have a series of removals with skin grafts. After four surgeries I stopped; the side-effects seemed worse than the HS. I now have nerve damage, very thin skin that is too tender to sit on or touch, scars I'm afraid of anyone seeing; I feel ugly and to top it all the HS has started to come back on the edges of the surgery sites.

I'm now 45 and have recently found out that I have passed this on to my beautiful 23-year-old daughter. I'm helping her to gain as much knowledge as I can but I hate the fact I have given her this. She has three small children that need her to play, hold them and do everything a mother should. For her to have to go through that while coping with this is a terrible thing for me to think about, which I do every day. I have just received funding for infliximab, which itself has scary side-effects; however, another condition has come to light that may mean I can't take it. I really wish a cure could be found for this painful, debilitating, life-limiting illness.

## Further information

UK charity The Hidradenitis Suppurativa Trust is dedicated to helping and supporting sufferers and to raising awareness among the general public and medical profession. www.hstrust.org DN

## Response from St John's Institute of Dermatology

Regrettably, this article echoes with such clarity the experiences of so many individuals that pass through our specialist clinic. This debilitating condition has long been under-recognised and continues to be in many medical settings. While research into hidradenitis suppurativa (HS) has continued steadily for some time, it has gathered increasing momentum in recent years, now attracting greater funding and international interest. It is becoming clearer that HS may not relate to one single disorder, but in fact to many sub-types that present with subtly different symptoms. We and others recently reported genes (relating to the enzyme gamma-secretase) that underlie a subset of familial cases of HS. This is a significant breakthrough and one that will help unravel how genetic variations affect the skin to cause HS, while allowing potential development of new specific and targeted treatments for HS. That said, many current standard therapies (including antibiotics and retinoids) can be extremely effective in mild to moderate HS, while novel biologic agents such as the anti-TNF therapies infliximab and adalimumab offer hope for select patients with severe disease. Tailoring management strategies to meet individual requirements requires close dermatology follow-up, often within a multidisciplinary setting. This patient's story emphasises the benefits of a specialist clinic. In line with other chronic inflammatory dermatoses, we should strive to see patients within dedicated services; we are hopeful that such services will deliver novel, individualised therapies for HS in the coming years.

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