



VOLUME 4

MILLIONS HIDING HS

A COLLECTION OF
TRUE STORIES,
POEMS AND ARTWORK

BY PEOPLE WITH HS

HS ACTION TOGETHER

**This book is dedicated to
the millions of adults and children living with HS worldwide
by the People with HS from the International HS Community.**

All the stories, poems, and artwork in this book have been crowdsourced from the International HS community, their individual content is and remains their intellectual property. They have granted permission for it to be used to be shared for educational and awareness purposes in regard to HS and all the other names it is known by internationally.

We are standing together internationally in solidarity for the **#HSMillionsHiding** globally by sharing our stories, poems, and artwork to help raise awareness and educate what HS is and the physical, emotional and mental impacts it has upon the person with HS and those around them. We want to draw attention to the worldwide health and social inequality that we face due to lack of medical professionals and public education of HS and the impact and devastating consequences due to years of misdiagnoses and delay in diagnosis due to lack of global Governmental policies and procedures. We are trying to highlight the desperate need for more investment in research and precision treatments as currently there is no cure or effective treatment that works due to there being different types and subsets of HS.

We commonly refer to it as HS, but it is also known as Hidradenitis Suppurativa, Hydradentis Suppurativa, Acne Inversa, Maladie de Verneuil, Verneuil's disease, Hidrosadénite Suppurée, Idrosadenite Suppurativa depending on the country and numerous spelling variations.

Support us to **#BringHStoLight** because there are **#MillionsHidingHS** around the world suffering in silence due to shame, stigma, fear and many do not know they even have HS. Help us spread awareness and reach them as we, the International HS Community, are here waiting to help and support them. All you need to do is share and tell others about it. Amazing things happen when we work together.

Thank you,

This is our Call to Action from the International HS community.

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Hidradenitis Suppurativa

by Bridie Breen, Ireland.



Scars do NOT define me.
I am stronger than you know
HS, a condition with angry flares that show.
Pain may wear me down.
Ignorance of medics
is far from bliss,
but HS is my survivor's badge worn with pride.
My message to all is this:
Don't underestimate the situation HS people endure,
so draining and exhausting.

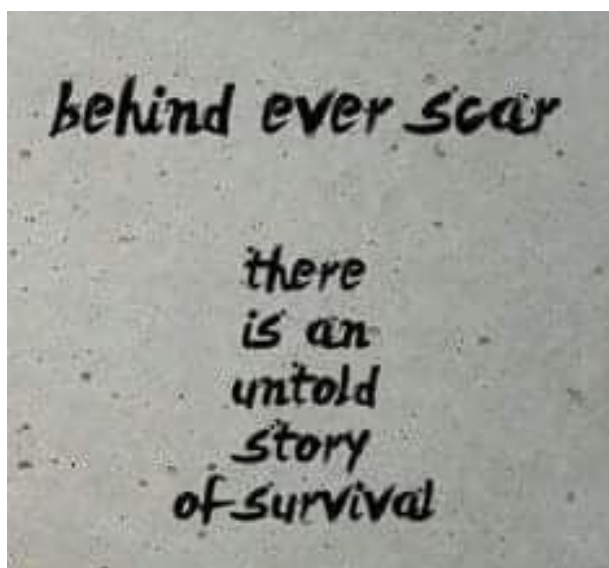
Don't act like you know more.
A mirror for most people
brings a smile to lips
and eyes.
For me, I try, but I fake it.
I fake it. I try but I fake it.
Smile on the outside
big enough and
for long enough,
to mask my fear-filled
inner child,
to hide its impact
on all of me.
Marks that snake uneasily
across my body and intimate parts,
expose me to judgement
of those without a heart.
HS has changed
how I want to be.
Good research will
find a cure.
Soon HS will be no more.
Remember, HS scars
do NOT define you or me.

1.10.18

A poem inspired due to a friend with HS.

Behind Every Scar There Is An Untold Story

by Ally Friday, USA



I'm a paramedic for the last 13 years. I taught inner city children school before that for about 5 years. I have two college degrees. The first is a B.S. in Exercise Science and Sports Studies, and with minors in Medical Modalities and Biology. I also learned how to scuba dive and play steel drum while at University! The second is an A.S. that I got when I realized I didn't want to do anything with my four-year degree, it's in Paramedicine.

I love my job more than anything. I was born to be a paramedic. I love to fix people and make them better. If I can make one person's day better then it was then when the day started I've done something amazing with my time. But dealing with HS in an ambulance over bumps doing 60mph can get painful pretty fast. Unfortunately I was born into a body that causes me nothing but pain and instability, that makes me hide away who I really am. So when everyone else is laughing and smiling, I want to go out and scream into the night. I want to cry into my pillow because my body feels like it's on fire.

It's only been in the last 2 years I've told my co-workers and friends what it's like to be me. I've started to take them on my journeys on my daily routines and how I have to change my bandages, check for smells, constantly cleans the areas, check for infections, clean up puss and blood, smile when you want to punch anything something someone doesn't matter, I've let them in on the 2 to the hospital when sepsis occurred, the shots I take, the extreme fatigue

I used to hide, the tears from the flares. My public safety family went from seeing the strongest women in the rank go from top dog....to the back of the pack. Mentally that took a toll on me.

I started to fight a terrible depression when the Humira stopped working. I started healing phone sessions with people from To Write Love On Her Arms. They kept telling me I'm more than my disease which I've always known and peached to everyone. But even the strongest need help remembering who are when we are sad.

I started fighting for a new cure. I fought my insurance, I did research with my Doctor's. I'm now starting Stelara. So far so good but it's not covered by my insurance and I'm being treated with samples through the office. But they believe in it and they believe in me. I've come to realize Dr. Naura Shah is my best friend and biggest support and I'm lucky. Not everyone has a doctor like her. Kind caring and compassionate are just some of the things I can say about her. When every treatment has failed me she didn't stop and kept finding a way to save and improve my life.

I've been fighting this since I was 11. I've been told you're fat, you have terrible hygiene, this one with CURE you. Silly rabbit there is no cure... But in the early 90s who knew?? I'm just glad at the age of 13 I didn't let that doctor defroff me! I'm 38 now and still don't think I could handle that procedure and continue to work and take care of my family and work full time. My goal is to mashed this disease and still, love my love and be the best me that I can be. So far I'm doing pretty well with room for improvement. I have a supportive husband and very supportive mother and father. Even my daughter who is 6 is learning all they the time.

When we stand together we stand strong. When we stand strong we stand s chance of finding a way to find a cure!!

The Robber

by Penny White, Georgia, USA



Like a thief in the night, Hidradenitis Suppurativa catches a person unaware. One day things are fine. The next day, these mysterious lumps with nasty, smelly drainage rob you of the person you are.

Just like a robber, these lumps take everything you have until you feel you have nothing left. And just when you think HS has taken everything, it robs you of even more.

HS robbed me of the ability to make a living.

Data entry operators are required to sit for up to eight hours per day. Prolonged sitting is one of my HS triggers. My latest, worst flare-up, flared up quickly. Just as quickly, the pain prohibited me from working.

And not just a sit-down type of job. Oh, no, not this pain. This pain also interfered with walking and standing. The affected area is currently, overall, the size of a tennis ball. It feels like about five golf balls all jammed in there together. And that's just the thigh. The outside of the labia contains two more golf balls. When I walk and stand, they all work together to make it as painful as possible.

There are days I stay in bed, my leg propped up on a milk crate and dread those moments when I absolutely must go to the bathroom.

HS robbed me of social interaction.

I belonged to a writer's group. I used to get together with a friend of mine for lunch. I used to love to walk around the lake where I lived and I would have conversations with interesting people. I rode MARTA to the library to pick up books. I looked forward to the coming of spring when I could increase my exercise regimen to include walking again.

I had to stop going to the writer's group. I turned down invitations for lunch. No more visiting the library. And no walking around the lake.

I stayed inside so no one would see the pained expression on my face, or the telltale drainage on my clothing.

It got lonely.

HS robbed me of my self-esteem.

Mind you, my self-esteem never has been very high. I'm not the picture-perfect model; never have been. But I at least had enough confidence in myself to look people in the eye and know I was just as good as anyone else.

With HS, I am aware of the looks I receive when I "hobble" around in public. I'm constantly afraid the drainage will show on my clothing; I always wear black pants now. I'm also afraid of soiling furniture when I lay upon a sofa at a friend's house.

And I am acutely aware of the facial expressions people have when I explain to them what HS is. I imagine the look is akin to looks once given to lepers.

Suddenly, I don't feel as good as anyone else.

HS robbed me of my strength and energy.

Constant pain aside, HS drained me of the desire to even cook a meal. I subsisted on cheese and crackers, salads, sandwiches – anything that was quick and easy to fix and even quicker and easier to clean up after.

Ironically, a side benefit was the loss of twenty pounds. And that was without even trying. But I wouldn't recommend a dose of HS to lose weight. I would much rather have worked at weight loss with exercise.

At least that would have felt better and been healthier, too.

HS robbed me of my health.

And not just my health, but also the opportunity to get quality health care with which to combat this illness. Without health insurance or a load of money, I cannot see those doctors who are knowledgeable about HS and treat their patients with compassion and dignity. Doctors who know I would be better equipped to deal with other situations once my distress and pain are alleviated.

Instead, I get to deal with doctors at “clinics” who hold my health hostage by demanding I conform to the patient they want me to be. Using the very words, “We won’t do surgery until . . .” I jump through whatever hoops they have in place. Not to mention that not once was my depression addressed or treated.

This was not the case when I had health insurance for two previous surgeries. Heck, those two surgeons could hardly wait to get in there and take those lumps away.

What I would give to win the lottery. (Have to buy a ticket first, though, gosh darn it).

HS robbed me of my independence.

I don’t drive long distances now – don’t drive at all if I don’t have to – because I have to prop my derriere off the seat, otherwise it is too painful to drive. I don’t feel comfortable or safe driving this way, but when the cat needs food or I need toilet paper, I have little choice.

If I need something, such as Goody’s headache powders to provide some relief for the pain, I often ask a friend to get some for me. In addition to the pain in my derriere, this also hurts my pride. I’m usually the one people ask for help; I’m not the one who should need it.

But the absolute worst, most vile, thing HS has robbed me of is the one thing that was the most difficult for me to earn:

HS robbed me of my freedom.

The freedom to be who I want to be, to come and go as I please, to do what I like to do.

I’ll spare you the boring details and explain it this way: I spent the majority of my life trying desperately to live up to the expectations others placed upon me. I was trained to do this from the age of three.

I never succeeded.

For the last twelve, blissful years, I didn't have to do that. I was free and I would never have to live up to others' expectations again. I no longer had to explain myself or check with someone when I wanted to go somewhere. I didn't have to cave in to guilt or pressures thrust upon me by anyone else. I could make my own decisions without running them by someone else or fearing disapproval.

I swore I would never go back.

HS heard me. And said, "Think again."

Because after robbing me of my ability to support myself, my ability to interact socially and my independence, there was one last thing HS wanted: my freedom.

I fought tooth and nail. I clung to the tiniest shred of hope. I prayed, hoped and begged for a miracle. I foolishly believed a miracle was forthcoming.

But some things HS will NOT rob me of are my dignity, my will to live and my desire to beat this, this stuff.

As far as I am concerned, HS is an unforgivable illness.

It may rob me, but it won't defeat me. There will come a time when I will be able to rise up and reclaim all that is rightfully mine, all that I have been robbed of. And I can spit in the face of HS.

That is the day for which I live.

The Robber was first published in HS Warrior by Pen. Used here with permission.

HS and Me

by Fiona Macpherson, Scotland



HS.....very few people I speak to know what it is.....I was one of those people, until I saw Embarrassing Bodies on TV and saw people with similar lumps and bumps and symptoms as mine.

In 2009, at age twenty-three, I was nine months or so past having my first baby when I noticed a sore bit down below. Thought nothing of it; it just nipped now and then, nothing major. But then another one, and another one, more, more, more. I had no idea, and my husband had no idea, either. But they were causing me pain, so he came with me to the GP, who told me she ‘thought’ it was Hidradenitis Suppurativa, but arranged for me to go to the local GUM clinic (sexual health clinics), to check and see if it was maybe herpes. I was sooo embarrassed, I never told a soul. Only my husband knew.

A couple of years later, I moved house and GP, and after baby number two, had a nasty blue blister on the inside of my left leg, rubbing on the panty line. I hadn’t yet registered with a GP, but went to the health centre and asked for an emergency appointment. I had photographed the area, as I was too embarrassed to show anyone else, especially as the GP was a man.

However, he looked at the photos, told me definitely HS, and the lump would need drained, could I come back tomorrow to see the nurse. I didn't need to. The blood and yuck was running down the inside of my trouser leg right there. I felt it go, and the mess on the chair when I stood up told him I wasn't needing it drained. Red-faced, with a prescription for antibiotics, I left in a hurry.

The lumps and bumps continued throughout pregnancy number three, but nothing major really to report, so we thought maybe it was just hormones causing the HS. I was wrong.

From 2013 onwards, I was referred to dermatology, where I was told my weight wouldn't help, stop smoking, get exercise etc. Okay, I am a big girl, but I keep clean, I don't smoke, and don't drink much, and get as much exercise as my body can take. I have three kids, I don't get to be lazy, but felt this was implied by the derm. She tried me on a variety of antibiotics over the next few years. Clindamycin, rifampicin, erythromycin, doxycycline, lymecycline. All worked for a short period of time, doxy being the better. But every six months or so I had to have them changed.

I never had a major issue with my HS affecting my day-to-day life, except maybe walking like a cowboy until things burst, etc. But everything changed on 17 October 2015.

Walking around Blackpool with my kids, last day of the October holidays before travelling home, I had my period. And a heavy one at that, so super absorbent pads. And they rubbed and chafed something rotten. My skin was sore.

Into the car, with dad beside me and kids in the back, I drove up to the services at Southwaite near Carlisle, last stop before the A7 (busy road) home. Since two of the kids were asleep, dad and I decided to take turns in going into the services for the toilet, etc. Dad went first, leaving me and Samantha, who was still awake. As I got up, I screamed. It was like my nether regions had been stabbed with a knife. I was knocked for six, and had to catch my breath, and made my way to the toilets to see what I had done. But I couldn't see. And my phone battery had died, so I couldn't use it either.

I limped my way back to the car, got in gingerly, and drove home, trying hard not to cry. The longest journey ever. Arrived late on, had my husband bring the kids into the house and into bed. My limping continued, and my husband was worried.

I stripped my lower half and lay on the bed, and asked him to hold a mirror up to see what I had done. He was hesitant . . . and shocked. There was a 50p-piece-abscessed hole on the inner left butt cheek, below the vijayjay, and it was oozing blood and fluid. My skin had actually went papery and split in two. I couldn't go to the toilet without it stinging, and the pain was unbearable. There was green stuff, blood, yuck, the lot.

I suffered for twenty-four hours, sitting at different angles, crying every time I moved. Eventually I messaged a nurse friend of mine who knew I had the condition, and sent her a pic. She told me to call the out-of-hours GP, and explain. I was hesitant, but I phoned, and explained it all to the NHS 24 nurse, who referred me to the hospital out-of-hours service, where I went within the hour. The doctor and nurse were understanding, but didn't really know the condition, and put a plaster (dressing) on it and handed me amoxicillin, and told me to see my own GP if it didn't clear up. Needless to say, I had another sleepless night.

I had to call in sick to work, and advised I would be in touch asap. I was a receptionist for the local cash and carry, which involved standing all day, greeting customers, answering the telephone, serving on a checkout, handling heavy items, stock checks and general supervising. I was always on the go, and had just been off for a weeks holiday, so being off ill wasn't good.

My GP (who has known me since a little girl) inspected my nether regions, and advised daily appointments with the district nurse to have the wound cleaned and dressed. He said to persist with the antibiotics and come back in a week. Tramadol was also prescribed for the pain. He told me I wasn't to go to work until the antibiotics were finished, and only after I had seen him.

I went to the nurse, who had no idea about the condition, so I had to educate her on it, and where to locate info via the nhs website. But she was fantastic, and put me at ease. I had to visit daily for six weeks, saw five different nurses, three students and explained my condition to all who came to see me. My dignity evaporated, and I became a teaching case for the borders nurses and med students. Needless to say, I was signed off work for the duration, as all the nurses and drs visits took up a chunk of the day.

I went in to work one morning after being at the nurse to hand in my sick line, and my husband was having to drive me everywhere, so he came too. My bosses were less than understanding, as the other receptionist had left, and other members of staff were having to juggle their jobs to accommodate for my not being there. Workmates ignored me, and I felt really alone and isolated. I was normally the one everyone spoke to, or asked for help. Now, because I was 'off sick,' but still able to go shopping, or out to an event with the kids, I was apparently faking it all for attention. A big slap in the face from the workplace I had been so loyal to for eleven years. But, as my doctor said, my official sick line from him was a 'NOT FIT TO WORK' line, meaning I couldn't work, but didn't mean I couldn't live. My bosses didn't like this either. But, give him his due, the deputy manager did research HS, and try and understand what was going on.

I battled on, seeing the nurse, plasters changed daily, but the bruising from the plasters coming off was as painful as the wound itself. I ended up with the same size wound on the opposite inner groin, so dressings doubled, pain doubled, and the walking got worse.

Visiting my Gran one day, my plaster came loose, and came off when I went to the toilet. I was in agony, and I sat on her bathroom floor in tears, blood flowing from both wounds, with nothing to cover them. My then six-year-old daughter told my Auntie my sore bits were bad, and my Gran gave her a couple of her plasters which she had for her legs. My daughter then held the wee mirror over me so I could see where I had to cover, and I plastered myself with Gran's plasters. From that day on, I vowed only to use the brand of plasters Gran had given me. Silicon based, they were designed for skin that was papery and sensitive, so didn't bruise when taking off the skin. Aleyven gentle borders....best invention ever.

My GP referred me to a surgeon at the hospital to look at the wounds, and to see if he could help the healing process. God I wish he hadn't. Four days before Christmas, this doctor put me on a table, spread my legs, and injected me with five vials of anaesthetic, and started cutting the abscesses from my groin. I felt every single cut, pull and stitch. My poor husband sat and held my hand as this man cut away and then stitched my skin back together. I was told the stitches were dissolvable, but overheard the nurse tell him they weren't. I was also told there was no need to return to the nurse, either, and just to go on with life as normal. I have never felt so butchered in all my days, but relieved to get out of there.

I went to the nurse the following day, as I wanted everything checked. All was fine, so I carried on at home. My Granny was visiting that day for tea, so I was quite happy and upbeat. Unfortunately, she fell coming down the steps into my garden, and I ran to help her, and got her into the house. Running on adrenaline I suppose, but it was later I realised I had hurt myself, as I was covered in blood. I had burst a couple of stitches.

At the nurse the following day, she had a GP examine me, and he said I shouldn't have had the stitches put in in the first place. And he told her to take them out. I was distraught. I was still in agony from the procedure of the cutting and stitching, only to have to endure Pauline sit and take the threads back out again. I was screaming so much she stopped, and said she would finish tomorrow, and there would be two of them to do it, so I would be more at ease.

I was petrified, but took some Tramadol before I went so the pain afterwards would be limited. Hubby drove me, and as I lay with her taking the stitches out, the other nurse, Kerry, kept me calm. I barely felt anything thanks to a numbing spray.

Christmas that year was awkward and sad, as I had arguments with my uncle, who thought I was attention-seeking. I was in agony, and I wasn't able to sit at the table for Christmas dinner with everyone else as I needed to sit on a soft chair.

Into the new year, I was gently phased back to work, with alterations to my job so that I could sit at the desk rather than stand all day, and limiting the heavy lifting. But workmates felt I was getting special treatment, and still treated me with contempt.

Slowly, my wounds healed, and I worked my way into full time again. I was my normal self by March 2016.

However, October that year, the bad abscesses returned, in a similar area. Not as severe, but debilitating. My mental state at work with members of the team weren't good either, and one day, I had had enough. I had the pain, and was struggling one Friday morning. I asked my supervisor if I could be kept off the checkout that day, as I was struggling. He told me to ask the assistant manager, which I did. Neither of them would say yes or no....so I never obliged. Another member of staff however took it upon herself to be the bitch, and demand I work tills. I said I had spoken to the two supervisors, and she went all high and mighty and said she had been told my the boss to get me on the till, so I must do it. There were plenty of folks available to do the job; it's not like we were short-staffed. But she wouldn't hear it, so I walked out, No job was worth risking my health anymore, so I left.

GP told me to self certificate for the week, then go from there. I was to be pulled for gross misconduct of walking out of the job, but I had the union on my side for support, and my GP. It was determined that my job was making me ill, that the stress and strain I was being put under both mentally and physically were part of the cause of my increased HS symptoms. After toing and froing over the next three months, it was determined that after twelve years working for the company that I would leave under medical grounds. Soul destroying to have to leave a job I loved, all because of a skin condition, that nobody had heard of.

Now, I am a thirty-two-year-old, twenty-one stone, unemployed married mother of three kids, who is now suffering from HS, hypothyroidism, IBS, depression and idiopathic intracranial hypertension. I take clindamycin, thyroxin, fluoxetine and painkillers. I am also suffering from HS in my right armpit, which began in June this year, an inch-deep hole the size of a 20p piece. It's slowly healing thanks to my lovely nurses who put up with me on a weekly basis now. I have six open lesions in my groin and overhang areas, which are manageable with weekly checks.

I also have my first golf ball-sized lump in my left armpit, which is causing stress and pain, but hasn't come to a head yet. I am not classed as disabled, and get no extra help from the government for the health implications that come with HS.

Some days I can walk miles; others ten feet. Some days I can drive, others I can't. Some days I can lift my kids for cuddles, other days they need to sit beside me and lean on me for comfort, or I lean on them in tears of pain and frustration.

My husband has stood by me every step of the way, as my friend, my lover, and my carer, the latter of which he can't have help because I am not classed as disabled, so can't be a registered carer for me.

My friends are understanding of the condition, which I point them to the HS Trust website for info, so they can read in private the issues surrounding the condition. My children know that some days mummy can do everything, and others they need to help me, but they understand, and I love them more for it. But it is humiliating having to ask your nine-year-old to help get dressed or hand a plaster when sitting on the loo, or even help place one when my hubby is not there.

HS has shaped the person I am today, but it will not beat me. I am me, and I control me, and my body, and my life, not HS.

Hidradenitis Suppurativa (HS)

by Michaela Parnell, BSc (Hons) Biology

What is Hidradenitis Suppurativa

Hidradenitis Suppurativa (HS) is a chronic, relapsing, systemic inflammatory condition that causes sterile, deep-seated, painful nodules that look like boils and abscesses, that can be as small as marbles or bigger than clenched fists, in areas such as breasts, armpits, groin, and buttocks. In the mild stages, HS presents as reoccurring double-headed blackheads, boils, and abscesses. Severe HS results in tunneling between lesions, disfigurement due to scarring and deterioration of the skin resulting in significant pain and disability. There is no cure and difficult to treat as there are different types and subsets of HS. It causes significant morbidity, pain, disfigurement and has profound impacts upon the suffers psychologically, physiologically and emotionally (Jayarajan and Bulinska, 2017). It causes social isolation and affects the person's ability to function in their day to day life, ability to work and also impacts the lives of those around them. HS is also known as Acne Inversa, Maladie de Verneuil, Verneuil's disease, Hidrosadénite Suppurée, Idrosadenite Suppurativa depending on the country.

How many people are affected by HS

HS is estimated to affect 0.5-4.5% of the global population (Jayarajan and Bulinska, 2017). With the current world population estimated to be 7.6 million people and 0.5-4.5% of the global population living with HS. Based on these statistics there is approximately 38 - 342 million people globally suffering with HS. Estimates range from 0.1% of the population in the United States of America (Revuz, 2009) to 4% of European populations (Jemec, Heidenheim, & Nielsen, 1996). It is prevalent but is hardly known about in medical communities, the public, and even with those with the condition. The lack of awareness and education of HS results in health and social inequality, discrimination due to lack of knowledge and misinformation, resulting in years of stigma, misdiagnosis, and unrecognised

pain. People with HS are turning to social media and have formed their own HS communities on an international scale that are working together to help each other, raise awareness and share scientific and personal information to try to figure HS out for themselves. Karl Marx (1818 - 1883) was retro diagnosed with HS in 2007 (Shuster, 2007). He spent his life complaining of being plagued by boils, furuncles and carbuncles - he actually suffered from severe stage three HS. People with HS are still being misdiagnosed in 2018 as having cellulitis, ingrown hairs, staph infections, sexually transmitted diseases, and folliculitis, then being repeatedly prescribed short courses of antibiotics that have no effect, as HS is not caused by an infection and are contributing to antibiotic resistance (Jayarajan, & Bulinska, 2017; Smith, Nicholson, Parks-Miller, & Hamzavi, 2017). People that have been diagnosed with HS are prescribed two to three months courses of oral antibiotics and intravenous antibiotics by dermatologists, not due to infection, but due to their anti-inflammatory properties, but this is also contributing to antibiotic resistance. Currently, HS is difficult to treat and cannot be cured. There are other off-label treatments and surgical procedures that are used in an attempt to treat HS but nothing works for everyone and the HS always returns. The only FDA approved treatment for moderate to severe HS is a biologic medication called Adalimumab (Humira), that works by reducing the inflammatory response by binding to TNF-a (Smith, Nicholson, Parks-Miller, & Hamzavi, 2017).

What causes HS

It is not fully understood what causes HS, genetics, a unique anatomy of the hair follicles, skin microbiome, hormones, malfunctioning immune system, and environmental triggers are all considered to play a role in HS and is further complicated as there are different types and subsets of HS. It is not caused due to poor hygiene and is NOT CONTAGIOUS but is often misdiagnosed as folliculitis, cellulitis, ingrown hairs, or an sexually transmitted disease (STD). Methicillin-resistant *Staphylococcus aureus* (MRSA) infections, sepsis, and squamous cell carcinoma are potentially life-threatening complications that can occur (Jayarajan, & Bulinska, 2017). Two-thirds of cases affect the person with HS (spontaneous HS) but one-third of cases of HS can be passed down genetically to children (Familial HS), therefore there could be 12, 666,666 - 146 million children globally suffering a life of hell. I am aware

from being a member of the digital HS community that there are children as young as 18 months old presenting with what looks like HS and they have a parent with HS. Not all of these children have family members with HS and others have a parent with HS but they are all struggling to get a diagnosis or help - some as young as nine years old.

The delays in diagnosis, an average of 7-9 years for those lucky enough to obtain one, and years of misdiagnosis affect the reliability of the statistics of HS. Currently, studies have been conducted to check registries for people diagnosed with HS and suggest that 1% of the global population may have HS, which is approximately 70 million people worldwide.

Diagnosis is still a major issue here in the UK and worldwide, due to these issues many people diagnosed and undiagnosed with HS do not seek medical help due to issues with lack of medical professionals awareness of HS. For example in America, HS was previously thought to be a rare condition due to only the more severe stages of HS being diagnosed, but recent studies including milder stages of HS diagnosis have shown that the condition affects at least 1 in 100 people (NIH U.S National Library of Medicine, 2017). The number could be as high as 1 in 20 people that have HS due to years of misdiagnosis and years taken to be diagnosed due to lack of knowledge, education with medical professionals, and people with HS not seeking help. As people with HS (diagnosed and undiagnosed) face the constant challenge of finding a doctor that knows what HS is and this results in many people just not seeking medical attention.

Then there is also the stigma attached to HS due to the intimate areas that it affects and it being mistaken for boils, skin infections, sexually transmitted diseases and even cases where people have been accused of being a drug user that makes people feel embarrassed to seek medical help. People with HS feel let down by the medical professionals that they turn to for help and often feel stigmatised and blamed for their condition which for those that are fortunate to find a dermatologist that treats HS, face long waiting times and long gaps between appointments. As HS is unpredictable emergency appointments need to be made available so they can access urgent help.

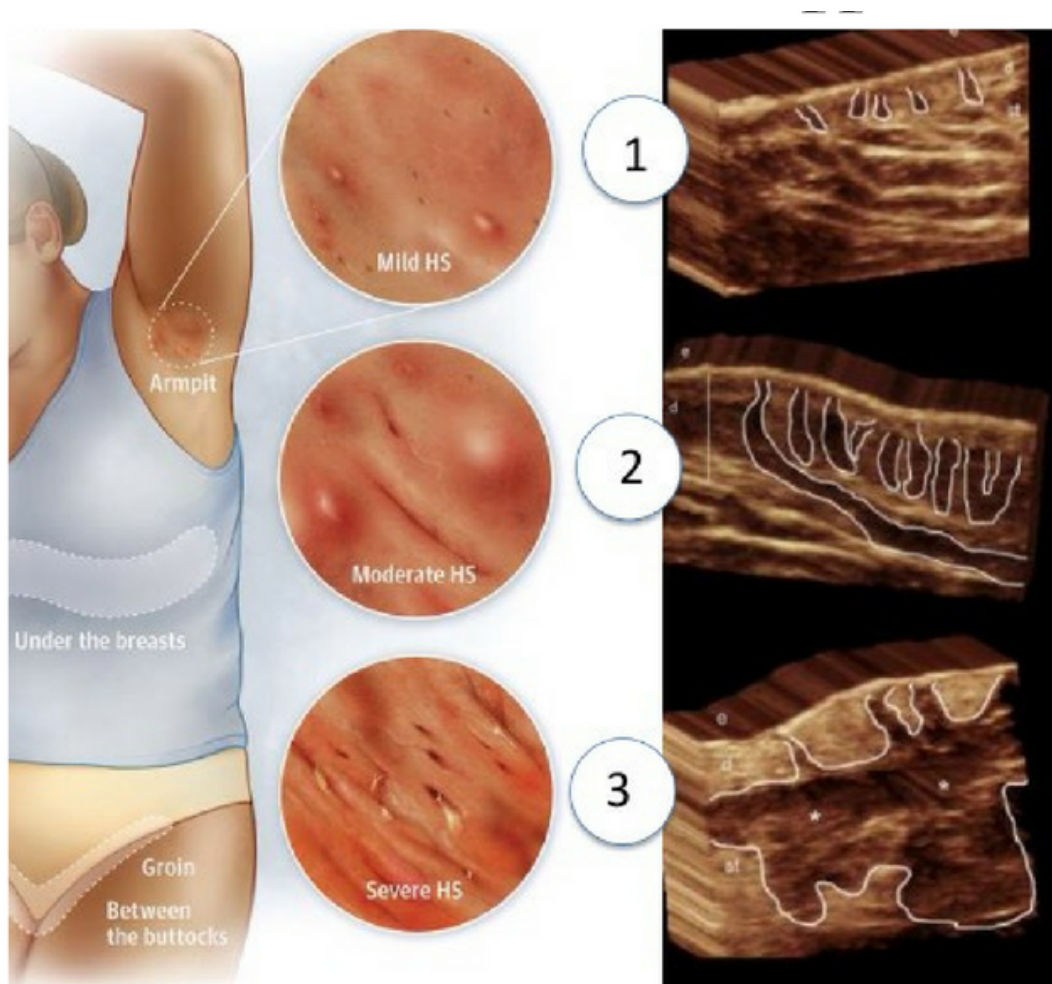
Fluctuations between HS flares varies and it can affect the person continuously as one or multiple flares, flares subsides, and another or multiple flares erupt. There can be different stages of HS on various parts of the body. Due to the various types and subsets of HS it is

difficult to determine each individual's disease progression. Some will remain in the milder stages, some may present with the severest stages, some may continue to progress from mild, moderate to severe HS. Some may have long periods of remission, but others live in a constant cycle of HS flares.

There is no diagnostic test for HS, it is diagnosed instead based on recurrence, location, symmetry, and HS associated medical conditions/health issues (comorbidities) need to be considered too. HS presents as persistent and recurring boil/abscess type lesions in HS site-specific areas such as the armpits, anus, groin, lower abdomen, and inner thighs, but it can occur elsewhere on the body. It causes scarring and destructive lesions that tunnel under the skin. Imagine the tunnels of an ant farm as this is how the insidious nature of HS spreads, continuing to tunnel under the skin even when there is no inflammation in that area.

Stages of HS

HS is classified into three stages to allow medical professionals to determine the severity of HS. Hurley staging is most commonly used by medical professionals to classify HS into three stages to determine the severity of HS and treatment options, but it is limited as it doesn't take into account the disease activity, impact on quality of life or measure pain. HS is painful. HS specialists are working to design a better tool to classify HS.



The three Hurley stages of HS appearance on the skin (Alikhan, 2016), and corresponding Hurley stages shown by colour Doppler ultrasound (Ximena and Gregor, 2013).

Hurley Staging.

- Stage 1, also known as mild HS: single boil or abscess like lesion without scarring and tunneling (sinus tracts).
- Stage 2, also known as moderate HS: more than one boil or abscess type lesion or area on the body. There is limited tunneling.
- Stage 3, also known as severe HS: multiple boils or abscesses, extensive scarring, and tunneling. Involving entire and multiple areas of the body.

There is no such thing as stage 4 HS. There are other staging criteria but Hurley staging is the most commonly used by physicians to diagnose and determine what treatment to use (Smith, Nicolson, Parks-Miller, & Hamzavi, 2017).

HS-related Comorbidities

Comorbidities associated with HS such as metabolic syndrome, polycystic ovarian syndrome (PCOS), diabetes, heart disease, dissecting cellulitis, acne conglobata, inflammatory bowel disease and spondyloarthropathies (Smith, Nicolson, Parks-Miller, & Hamzavi, 2017). Suicide and suicide attempts rates are high in the HS population.

Social Impacts of HS

People with HS struggle to obtain sickness or disability benefits due to lack of awareness, education, and policies, which has extreme and dire social equality impacts on the person with HS and their families. Awareness, education, guidelines, and policies need to be urgently put in place as people with HS are falling through safety nets and being failed. The process itself for applying, trying to provide medical evidence, which with high rates of misdiagnosis even with a diagnosis is hard to provide, is very stressful and stress is an aggravating factor to flaring and the progression of HS. Many people with HS go through the process to be declined even though they are severely impacted physically, emotionally and psychologically. In the UK the Department of Works and Pensions need to recognise the condition as people with HS have been refused when applying for Employment and Support Allowance (ESA), Disability Living Allowance (DLA) and Personal Independence Payments (PIP) as the assessors are not educated enough about the condition resulting in people with HS being failed by the system that was put in place to help them when needed. They then have the choice to either appeal or accept being declined. If they do appeal this leaves them with no income and the stress causes a worsening of their HS! Or they can apply for Jobseeker's Allowance. As they are not fit for work but are not recognised that they are not fit for work results in that they are put under extreme pressure to search for work and attend meetings at the Jobcentre. Due to the unpredictable nature of HS and that it can erupt suddenly causes issues in their capabilities to seek work and attend appointments. This results in them being sanctioned. This can result in administrative punishments called 'SANCTIONS' due to not being able to fulfil their Claimant Commitment Contract and losing their benefits for fixed periods of times. This is a contract that they have to sign to receive benefits and is a contract

of the claimants responsibility to look for work for a determined amount of hours each week and keep a record that is determined by their work coach. This is a failure of the system and urgent action is required to prevent people with HS falling through the cracks due to lack of policies, education, and misinformation. People around the world are having the same issues due to the lack of policies, education, and awareness of HS.

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