
HS Action Together
VOLUME 3
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.

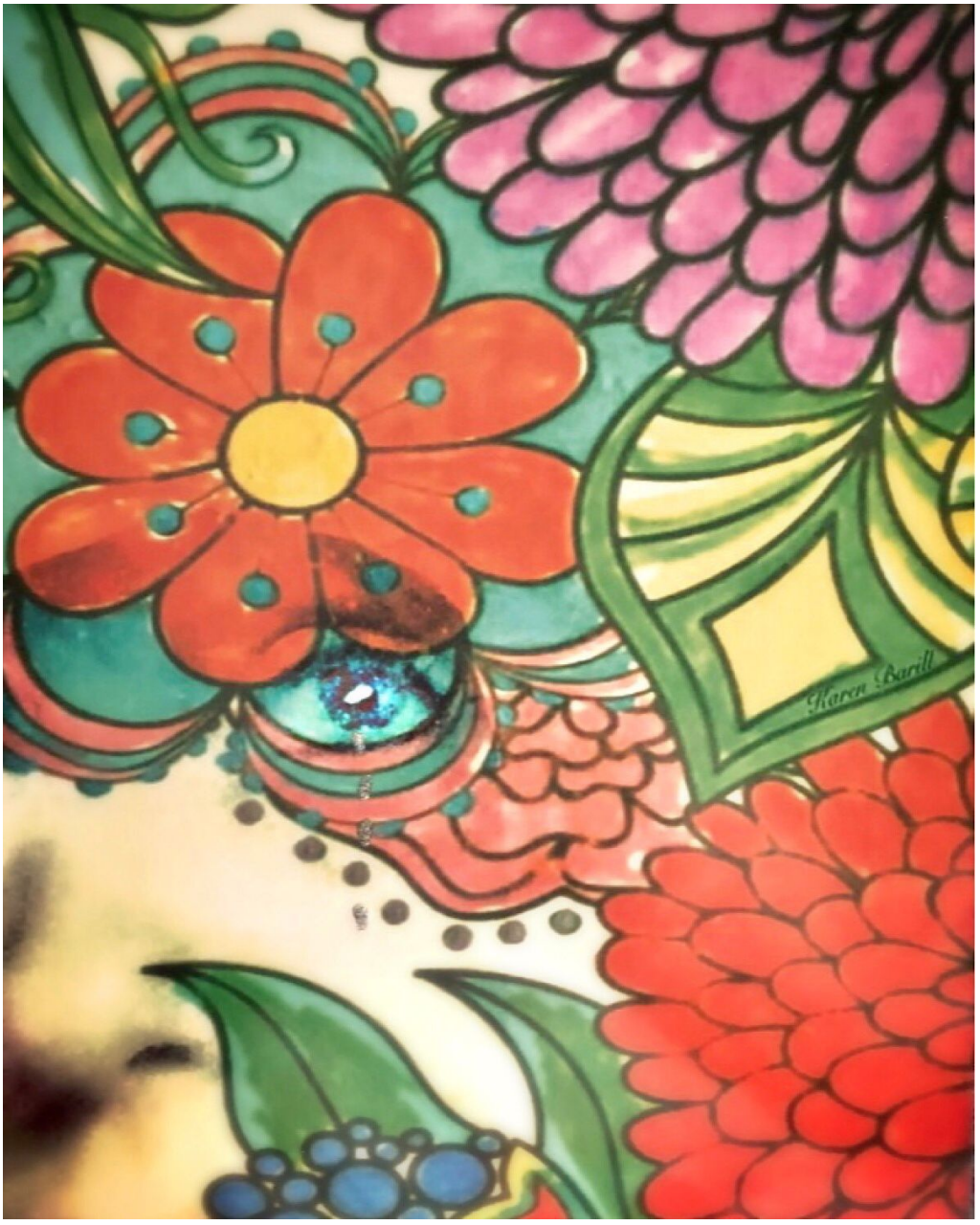
Thank you,

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

Contents

Never stop fighting

by Karen Barill, from Michigan, USA



My name is Karen Barill. I suffer daily from Hidradenitis Suppurativa (HS) Hurley Stage 3. I have suffered from HS since my preteens; I'm now fifty-six. Doctors have cut, pinched, and drained me. They put cortisone injections in my groin, and nothing has worked. I've had over forty-two surgeries in my groin and bottom, and that only accounts for the surgeries for which I have paperwork.

In January 2016, I had another surgery in my right groin. I was attached to tubes and a wound Vac and required a visiting nurse. My surgeon said I had no skin left, so he did a skin graft with urinary bladder matrix. In 2017, I was admitted again for the opposite side and another skin graft, but this time it was larger and much deeper, closer to bones and nerves. August 2018 I endured another skin graft in my groin, and the same routine, resulting in another three-month recovery to finally come back to life.

In October 2018, my Dr. informed me that I have more masses on my left groin, gluteal fold, and bottom. My body cannot withstand being cut again at this time. I'm undernourished and underweight. So I have decided to resort to infusions. I'll start infusions of Remicade, originally used for breast cancer patients to shrink tumors, in the coming months. I'm nervous but absolutely positive it will help me.

I find inner peace drawing, painting, coloring, and in photography. It takes my pain, thoughts and emotions and I focus on my art. I call it moment mindfulness. My form of meditation. I don't focus on the end result, it's what my experience is right in the very moment when I'm experiencing it.

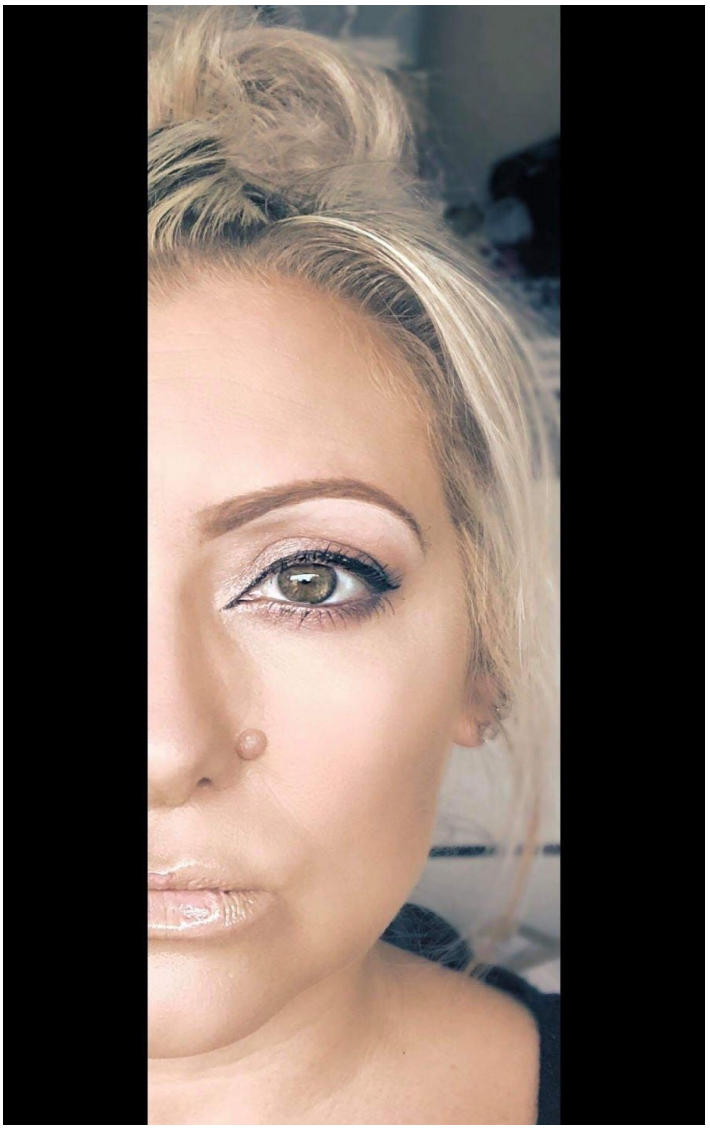
To this day I continue to get lesions and I cry every time. I cannot disembark from this horrible roller coaster and ask God to just make it stop. I cannot sit for long periods, take comfortable plane rides or walk long distances, and I'm in horrible pain every day, but I'm ALIVE. I believe a positive attitude is an essential part of healing, but sometimes I cannot help but feel like the whole world is going on around me, without me.

With very little knowledge and research people will continue to die with this disease. Please help others with this dreadful disease. We need more knowledge, research, awareness and most of all results.

Just remember you're not alone.

HS. I’m a Professional Secret Sufferer.

by Claire Walker, Leics, UK. Age 37.



My first experience with “boils” happened around 1999. Age eighteen. Irritated, angry lumps would appear in my groin or in my armpit. Several doctors checked them, prescribed me the usual antibiotics and sent me on my way with a, “try these for four weeks and come back if they don’t disappear.”

Safe to say I saw a doctor every month for approximately eight years after that. That in itself is a depressant. You have no safe place, no professional, no person, no reason, no diagnosis, no name . . . the depression that comes with that is immense. You feel like a leper. No one

knows why you have these hideous lumps that ooze and smell, not just monthly but daily. Day in, day out.

Then in 2008, two weeks before I was due to fly to Greece to marry my husband, I had two lumps so big and infected, he gave me no choice. He drove me straight to A&E and demanded someone saw me immediately. My arm had swelled to double its size and I couldn't sit down due to a plum-sized boil in my groin. I was in agony.

They took me straight down to surgery and cut them out. I woke up groggy, frightened and with two large holes in my body. My husband and bridesmaid had to be trained in packing them and keeping the wounds sterile as I refused to cancel my wedding.

Upon returning to the UK, I had my check-up appointment at the doctors. A GP I'd never seen before, took one look and said, "That's Hidradenitis Suppurativa" and nodded her head, looked at me with an, "I'm so sorry" look. "Ermmm... it's a what?!" I had never heard those words before that day. Now it's become part of my daily vocabulary.

I studied, read, researched, found the HS Trust, emailed them, tried to find people with the same condition . . . everything I could do to become an expert in the disorder. I managed on constant antibiotics and visits to change them when I had a flare. I swear I'm immune to them! I think I actually visited my GP just so it was "on my records" how frequently it happened.

This disorder has made it difficult to wear certain clothes. It crushes any self confidence you have and the pain, oh my goodness . . . the pain! It became a secret condition that only my mother and husband knew about, and that's only because I would become bedridden and I needed help. Not just to help me with my babies but little things like putting my hair up in a ponytail, doing my bra up, lifting the plates down from the cupboard, driving me around because I couldn't bear the pain of using a manual gear stick. They have been my angels. They don't judge; they are just there and that is everything.

I have never ever told anyone else.

1. Because the embarrassment that comes naturally with the symptoms. How do you tell people you have “boils”?
2. I needed an escape. I had unconsciously built a character away from HS, a life where the words never crossed my lips because I was so sick of it at home.
And 3. I’ve always been a “girly girl”; hair, makeup, nails, lashes, clothes . . . they are my mask and if people look at those, then there’s no way they would guess what I’m hiding beneath it all.

In June, this year, 2018, I hit my biggest wall. A monster of a boil under my left armpit. From my elbow to my shoulder, the left side of my neck, my face, my ear all became heavily infected. Within four days of having a tender armpit to being completely bedridden and disabled. It knocked me for six.

The doctors had to get the infection down so I was on the highest level of pain killers I could take and antibiotics: fourteen tablets a day. I lost count of what I’d taken and when. I had to have an alarm set on my phone, a list at the side of my bed and a pill box. Absolutely ridiculous.

My husband - my rock - bathed me, washed my hair, fed me and gave me fluids. My mum - my best friend - took care of my girls.

I couldn’t have told you what the time was let alone what day. I was in so much pain my body shook.

I had to call my husband to come home from work one day because I had rolled onto my front in bed and couldn’t roll back or off the bed and I was desperate to go for a wee. He carried me to the bathroom. I sobbed. And sobbed. And sobbed some more. I couldn’t tell you how I got through the next week.

We are strong, strong people and no one will ever take that from us. We are true survivors. And I am proud of every single person I know (all online, never met anyone in my current social circles with HS): they are a force to be reckoned with.

My GP changed my tablets and I tried to walk up to the doctors the week after (in flip flops, in the rain because I could not reach down and put shoes on) and I collapsed on the village green.

The pain takes over you.

A week into taking these tablets and I was told to change them again. I took two before I went to bed, then two in the morning. I was due to drive to work. I said to my husband I had a little headache behind my left eye, but shrugged it off.

Five minutes down the road and the most terrifying thing happened. I lost sight in my left eye, everything went white, my body convulsed and I had no feeling in my neck, chin or lips. I dialed my husband on loud speaker and pulled into a residential road. I then panicked, thinking if I was going to have a full-fledged fit, no one would see me. I screamed to my husband to come find me. I drove through pure panic to a main road where he whisked me straight to hospital. I thought I was going to die. I have never experienced anything like it and I never want to again.

Turns out I'd had a reaction to the new meds. This disorder is such a trial-and-error condition you have no idea what your body will take or reject.

At this point I felt the need to share my story. So, I'll say bravely - but I really didn't feel that way - I shared my story in a Facebook post of my history and my HS fight to all my friends. I was terrified of the reaction but also I've run out of excuses. I'm exhausted from hiding.

The feedback I've received has been truly inspirational: People are kind, people care and people are shocked. People need to know about HS and what we go through.

As I get older I've realised you just need to put yourself out there.

I am so pleased I have had the courage: People are more compassionate, more considerate and are thankful to have awareness of the disorder. And I feel less guilty. I can now say, “Sorry I can’t make it today because I have a flare,” instead of, “I’m just so busy.” It’s a breath of fresh air.

And I will encourage everyone to do the same. Don’t hide, you have nothing to be embarrassed by. Twenty weeks on, I’ve seen a private specialist, three dermatologists, four GPs and I’ve met numerous nurses.

I’m now, fingers crossed, on meds that are helping calm things. I still have three holes under my left armpit, a lump, and have to change my dressings twice a day, but I can cook, I can wash myself and I can play with my children. I can’t reach up, I can’t lift and driving using a gear stick hurts. But I’m thankful I’m over the worst, with this one anyway. I woke up yesterday to two lumps in my groin . . . I’m meditating to get myself ready. Because, God help me, here we go again.

Living With Feeling Helplessness - And Building A Warrior

by Hollie Tenerowicz, North Augusta, SC

As parents all we wish/hope/pray for our children is for them to be happy and healthy. It is really an unsettling feeling to have no control over what happens to your child.

We had just moved from Massachusetts to North Augusta, SC in the summer of 2016. Looking forward to new house, new school, husband's new job: so much to look forward to. Veronica (seventeen) developed an "ingrown' hair in her left armpit on the ride to SC (August 12) for the closing on our house (August 15). Sunday, the 14th, Veronica mentioned that her underarm area hurt and a "bump" was visible at that time. We/I treated it with warm and cold compresses, Tylenol and rest. My husband and I were focusing on the closing of our house and, unfortunately, brushed off the armpit.

After the closing on the 15th, the cleaning and lifting etc., Veronica couldn't relax her arm. The next day we went to Urgent Care and the doctor there told us it was indeed an abscess and it needed to be lanced. He couldn't do it in the office due to the size and pain associated

with it. He referred us to Doctor's Hospital/Jeffrey M. Still Burn and Wound Center in Augusta, GA.

August 17th, Veronica was supposed to begin her senior year at her new high school. Instead, we were at Doctor's Hospital where we first heard the words Hidradenitis Suppurativa. I had NO idea how our world(s) would be changed, forever.

Yes, that sounds dramatic; however, sadly it's true. My daughter, though mature for her age, would be forced to GROW UP. She turned eighteen in Sept and was now considered an adult for all decisions regarding her health. We were blessed with a wonderful surgeon, who would end up advising me/us on procedures as though Veronica was his daughter.

Veronica had to grow up and I was now "on call" as nurse, caretaker, home health care provider, chauffeur etc.

Over the next few months (Aug. 2016 - May 2017) Veronica would endure eleven surgeries: four of which were two-part grafting surgeries to both armpits and groin areas.

Through ALL of this she trudged through studying and completing assignments in order to graduate in June 2017. She had been accepted to five of her six colleges (Auburn University and Purdue being two of the schools) ultimately deciding on attending Auburn University in their Pre-Vet Med program at the College of Agriculture.

All the dreams I had for Veronica as a little girl seemed to be gone in a FLASH.

Much to my surprise, Veronica isn't letting HS define her. She is trying different activities and opportunities and finding out IF she can or can not do something, rather than assuming she can't, due to HS. She is *trying* to be happy. She has a great circle of friends. She has also leaned on the support of her cat, Syd and her horse, Tigger.

To this day, Veronica is dealing with a pressure wound which began as a pilonidal cyst. It has been over two years, but if an issue arises she knows to go to the PA at the school clinic or, if

needed, to come home and we go to the surgeon for an opinion or option for care. I had written her a note at one point last year commending her on how much she has gone through and how she has persevered. I signed it, "You are my Hero."

Last fall, while visiting her sister, Veronica had those words tattooed on her forearm. She brought me to witness and I bawled my eyes out.

I LOST a year of unpacking, setting up and decorating the new house, but I gained such deep respect and insight into how strong my daughter is. I don't have to worry about her being okay: I believe she will regardless of HS.

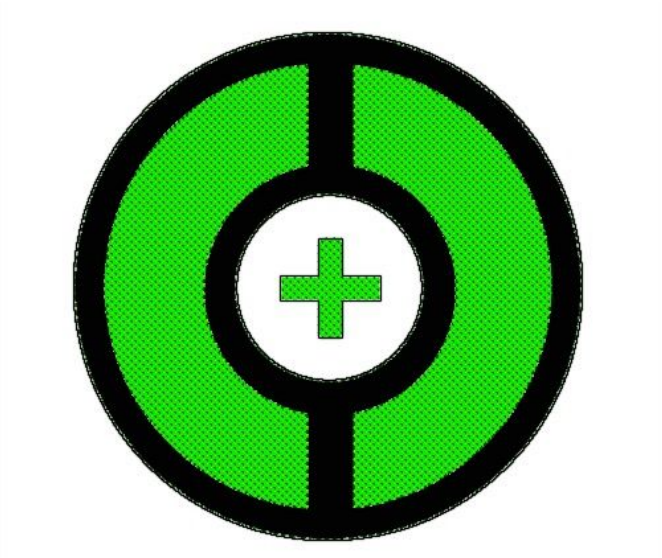
I WISH there was more information available to educate people on the condition. More information about cures, temporary relief options, remission options and not so much trial and error. Nothing works the same for everyone affected with HS. Frustrating is another term and feeling you become familiar with. There NEEDS to be more SUPPORT available to HS Warriors!!

Regards..... hopeful parent....

Hollie Tenerowicz.

Human Again

by Adamimmune, Kansas, USA



Just 13 when I first felt this sickness
Doctors warned me there is no cure
Without hope, sorrow became vicious
But a fire lit inside me, so I studied the obscure
With lots of trial and error, I can finally say
I'm in complete, 100% remission today
The healing started in my tiny, empty kitchen
No more dairy, no more grains
Not even the nightshades either
Gone the symptoms, gone the pains
I finally feel like a human again, not the creature
Now I devote my life to something bigger
Spreading the good news
That the foods we eat can be the trigger

We Have To Keep Fighting

by Megan Carline

I was 11 when I first experienced “HS”. My doctor just kept telling me to clean myself thoroughly, hot wash towels, only use them once & cover them with dressings, take a 7–10 day course of antibiotics.

“They are just reoccurring boils”. I was clueless. I was hygienic, I couldn’t understand why I kept having this problem. I felt frustrated, embarrassed, different & extremely alone.

Fast forward 7 years later in 2015, I was still suffering, except it kept spreading, HS was appearing in other areas of my body. I was now 18. I was dating, I was always busy, more social & always trying to keep up with my friends. HS was starting to slow me down.

After many trips to the doctors, after many different antibiotics, surgical scrubs, creams, natural remedies & having no such luck I returned back to the doctors. This time I saw a new doctor. She explained to me that I have a condition called

Hidradenitis Suppurativa. The relief to hear a diagnosis was life-changing. I now have friends all over the world with the same condition, I am not alone.

I am now nearly 22. I have now suffered for 11 years. It is an extremely draining condition. I have had multiple minor & major surgeries. Some of my surgeries have been life changing & some have been unsuccessful. HS has no cure.

I am just lucky I have been able to have at least some relief from surgery. HS is a very difficult & painful condition to live with. I am currently on the waiting list for another surgery.

We need more answers. I know I am not alone. I know we have to keep fighting. We are warriors. 💜

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, Nicolson, 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.

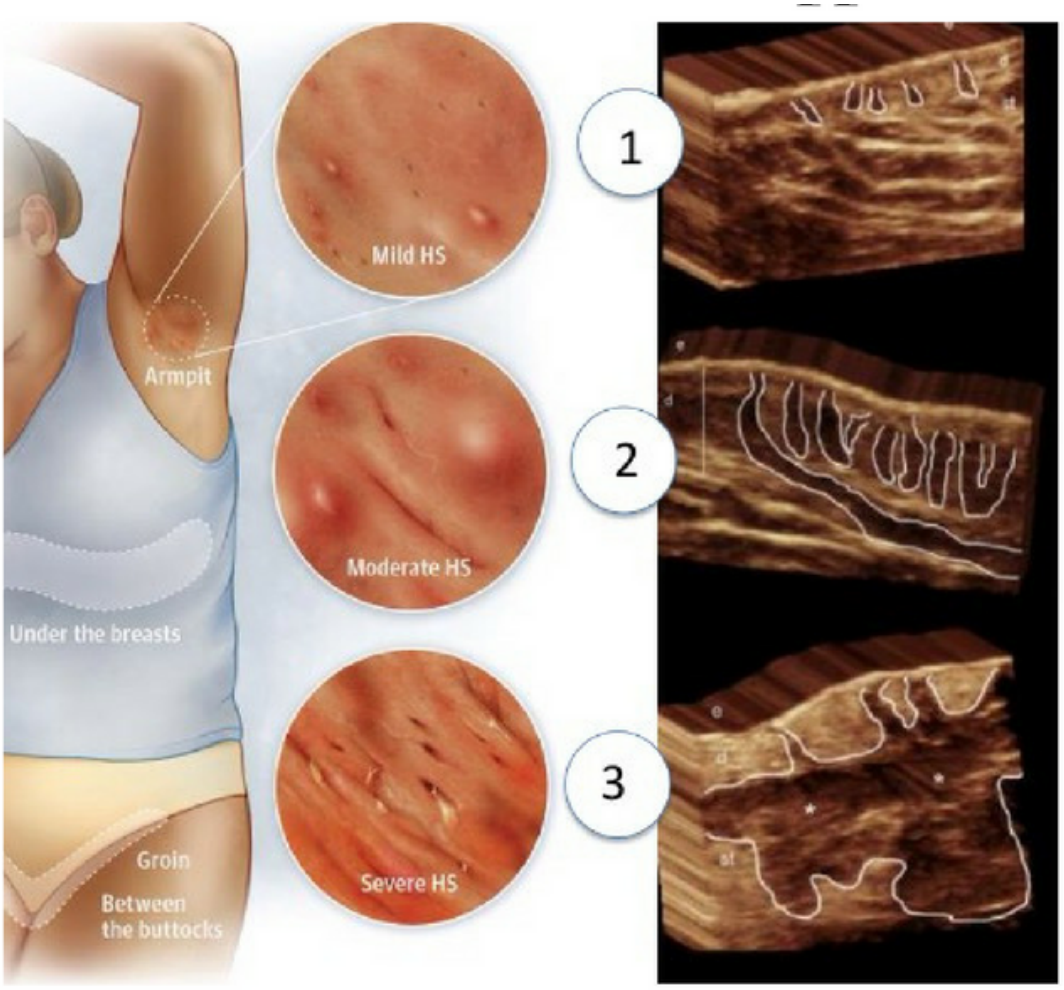
Fluctuations between HS flares varies and it can affect the person continuously as one or multiple flares, flares subsides, and another or multiple flares erupt. There can be different stages of HS on various parts of the body. Due to the various types and subsets of HS it is difficult to determine each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