
HS Action Together
VOLUME 1
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

“Debris”

by Seraphim Yoho, USA

The first time I bloomed I blamed myself. I pointed the finger at my own habits, deciding the painful weeds in my garden had to have stemmed from lack of watering, or from my fertilizer not holding enough nutrients. I stayed silent as the harvest died and returned.

The fifth time I bloomed, my garden began to wilt. The soil turned dry and lost its color. I finally showed someone my acid flowers when they became too unbearable to tend to alone. It was a long road of pain; my garden was uprooted and my weeds were mangled and trimmed. The landscaping left me limping, slinking like a wounded animal. I was humiliated, exposing myself to others, cloaked in a heavy sheet of blame, insisting that this still had to be all my fault.

The sixth time I bloomed, I was too weak to keep waiting. I spent hours by myself, combing through the words of every doctor I saw, every diagnosis they had given and every medicine prescribed. In the end, I alone would find the source of the weeds in my garden.

The tenth time I bloomed, I painted a picture. In the place of blotchy patches of skin, tunneling wounds and tacky rings from bandage adhesive, I painted what they really ought to be.

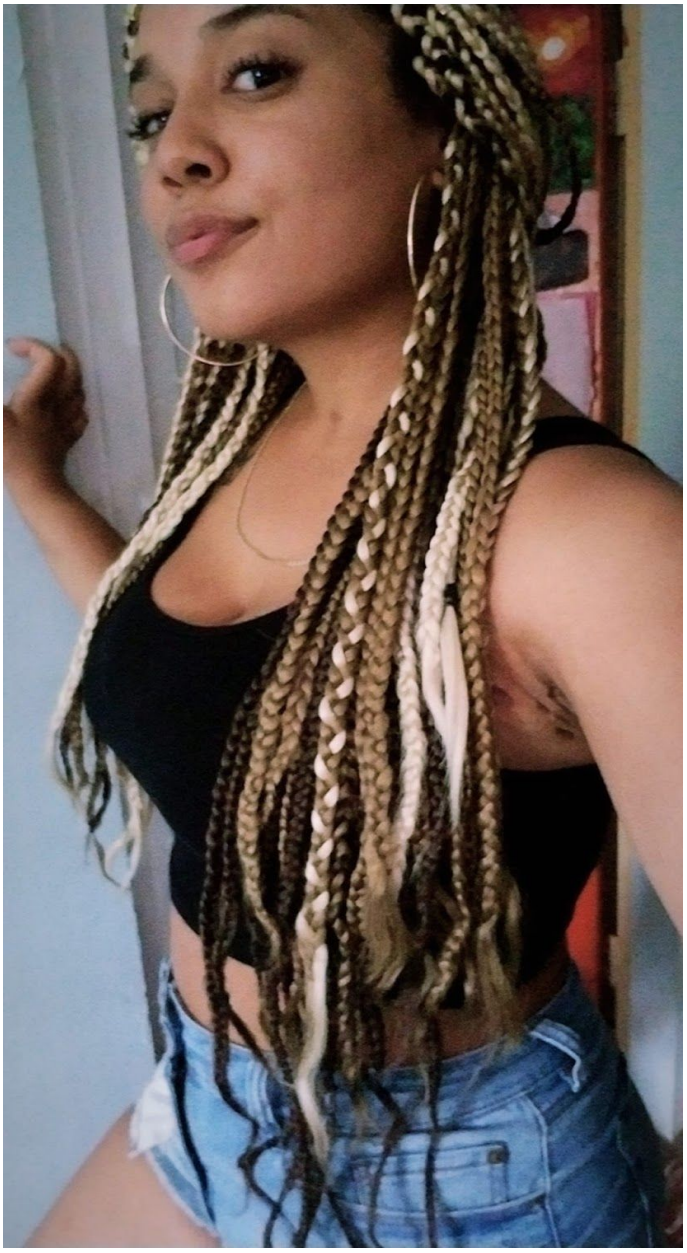
Flowers.

My garden is my own, and I share the damage in the wake of its episodic harvest with many others. I refuse to let this landscape taint me as a barren wasteland. Its acres are both my grace and my pain. I have learned to find the beauty in their seasons.

I am fifteen and was diagnosed with HS approximately a year and a half ago.

Have Courage and be Kind to Yourself

by Kiara Pagán from Puerto Rico.



Today I shaved my armpits, knowing that it might cause new abscesses. But I didn't care! I wanted to do it because, despite all the scars I wear, my armpits look pretty with them. I have decided to accept myself as I am and use sleeveless shirts, even if the scars can be seen.

HS Led Me to Where I Am

by Suzanne Moloney, Ireland

I don’t clearly remember my first experience of Hidradenitis Suppurativa, but I think I was about twelve or thirteen years old. It was like a dark cloud that followed me around. I would ignore it most of the time and get on with things, but when I got home I would look at myself and worry about what was going on. I used to Google skin lumps, abscesses, boils and carbuncles because I didn’t know what it was. I would read about it and tinker with different home remedies and sometimes they worked and my skin would clear up. I never told anyone, because it was very embarrassing and I thought there was something wrong with me.

When I was seventeen, things progressed for the worse and I showed my Mam. She brought me to the GP, who prescribed me with antibiotics. Over the next four years I would be prescribed antibiotics regularly - almost monthly - to treat the abscesses.

Life went on and I finished school, started college and trained as a chef. I had regular HS flares, I took a few painkillers, ignored them and somehow went to work.

At twenty, I was sent to A&E with what my GP thought was massive cellulitis. I had surgery that afternoon to remove the affected skin and was left with a painful open wound which required a lot of aftercare. I was then referred to another surgeon who thought I might have Crohn's Disease.

After several tests and investigations, Crohn's was ruled out and I was sent to a dermatologist. He began treating me with more intense antibiotics and steroid injections directly into the lesions. This was an unbelievably painful experience which became the norm for about another year.

At twenty-two, I was referred to another surgeon, who eventually diagnosed me with HS. I had a radical surgery to remove extensive areas of damaged skin. I was left with large open wounds that required a twice-daily visit from a home care nurse. I was out of work for eight weeks after this surgery.

Things settled down for a while after the big surgery and I left Ireland to travel to Asia, Australia and New Zealand. HS reared its ugly head several times during my time away. My emergency supply of antibiotics quickly ran out so when I got to Australia, I sought treatment. In Brisbane I was treated with steroid injections in my thighs, groin and chest. Then I set off on the road travelling with my sister. We had an amazing trip, but my HS caused frustrating delays in our schedule in order for me to see a doctor on several occasions.

When I got to Melbourne, I attended their A&E with a massive flare and was prescribed more antibiotics. I sought out a GP and she kept an eye on me while I was there. On my return to Ireland, two years later, I went straight into hospital for another surgery.

Since then, I have tried every antibiotic combination possible, steroid injections, androgen blockers, insulin regulators, immunosuppressant therapy and have had about thirteen surgeries, I have honestly lost count! While some treatments temporarily quell my symptoms, nothing has lasted for more than a year.

At twenty-eight, I became self-employed, opening a bakery in Dublin, and I began to accept HS as part of my life, something that I would have to manage forever. I had seen how HS had impacted my life. I missed days and weeks of college, work and so many social occasions. I had my travels and holidays disrupted. I had lived a life of taking painkillers and all sorts of medications. HS has affected my self-esteem and limited me in my clothing choices, physical activities and hobbies. I began to look for something that I could use to manage my symptoms every day.

One of the worst consequences of living with HS for me was managing the lesions and wounds every day.

Each morning would deal a different blow. I would spend a lot of time trying to bandage myself up. I would be late for - or prematurely leave - so many occasions due to dressings. Ensuring my dressings were in place and secure was next to impossible so I lived with the inevitable leaks and lost dressings.

I was at a party one day and while shaking someone's hand, my armpit dressing fell right out of my top. As it fell to the ground, I honestly thought I was about to be the first documented case of death by embarrassment.

That night I was angry. I was angry because there was nothing suitable for me to use to dress my armpits. I was angry because I was trying my best to get on with my life and not let HS hold me back. I wanted to be able to get up and go like all my friends and family do. I hated that I had to spend so much time out of my day managing these lesions, and that the products I was using didn't even work properly.

People living with HS are very resourceful and are improvising dressings all the time. I had tried a few improvised dressings myself, so when I was twenty-nine, I approached a product designer to help me develop my idea into a dressing that I could use. This set me on a trajectory I never thought I would be on, but here I am.

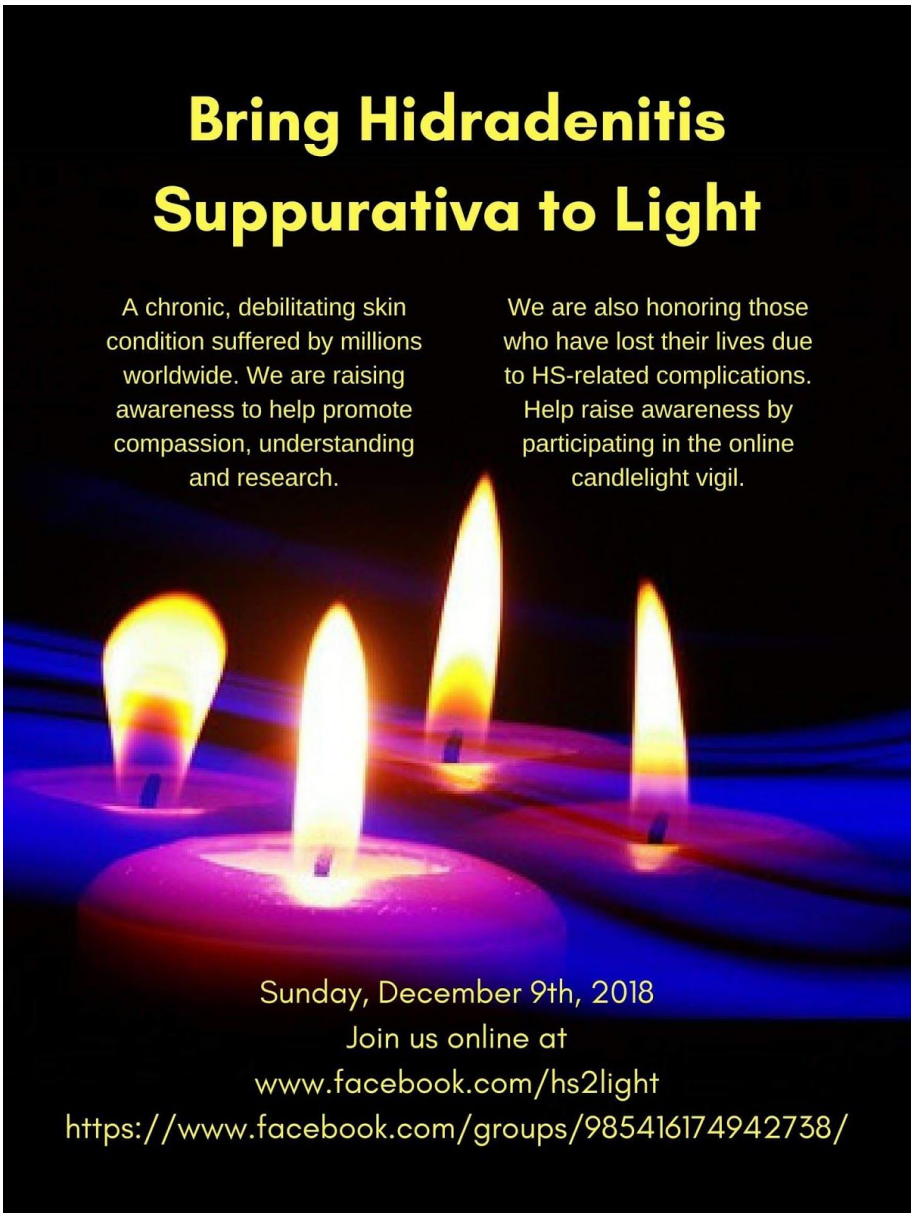
Five years later, I have left my bakery behind to work full time on my new company, HidraMed Solutions. We created an innovative wound dressing product that provides secure dressing placement and retention. Users can apply, adjust and remove a dressing quickly and easily. Dressings falling off or leaking will no longer be a worry for people with HS and other chronic skin lesions.

I have received so much support from the med-tech community in the development of my idea and we are aiming to launch the product in June 2019. We have received funding and support from BioExel, EIT Health and Enterprise Ireland and we are working with industry experts to make this a reality!

My main goal in life now is to promote HS awareness and to develop my company, in order to make a meaningful improvement in the quality of life of people living with HS.

The Day Life Ended

by Penny White, United States



October 14, 2015.

Life as I knew it ended.

It was during a drive back to Atlanta from Tennessee. I felt this tingling sensation in my right thigh. I knew what it was: Hidradenitis Suppurativa (HS).

The surgeon from three years hence told me it would never go away. I didn't believe her.

I was in between jobs at that time. Little did I know I would never be able to work a conventional job again.

Within a few days to a week, I was unable to sit due to the pain by this latest flare. Walking and standing were equally painful. No more data entry for me.

I struggled, ending up losing my beloved apartment of twelve years and moving in with my mother. No more independence for me.

I was denied treatment due to no insurance and no money.

When I got disability, the first thing I did was made an appointment with a doctor who was supposed to "specialize" in HS. He took one look at mine and refused to treat me.

And charged me $200 for the privilege of refusing.

Did you know that if you get private health insurance, it will not cover a pre-existing condition for a full year? I felt it was pretty pointless, not to mention expensive.

So I waited.

While I was waiting, changes occurred.

I was able to get the apartment next door to my mother. At least I had a place to myself.

Not so fast.

Life ended again about a year ago.

Mind you, I am still in severe stage three HS.

But the building in which we lived was being sold. New owners were raising the rent far beyond what any of us could afford.

The result was moving into a house with two other family members.

I thought I had already lived through hell. Silly me.

Now I am in a "prison" where my poor 90-year-old mother and I are manipulated, and emotionally and psychologically abused so that we remain in our individual rooms with doors closed. Granted, the "prison" is a house with doors and windows and we can come and go. But "the wardens" ensure we are "under control" while we're here.

No, it isn't doing my HS any good.

After finally getting Medicare (government health insurance), I was scheduled to see a dermatologist, but, due to the growing tension in this prison and my mother's being defenseless against the wardens, I canceled the appointment. I know that when I do see a dermatologist, surgery will be scheduled. I am my mother's keeper and she must be protected at all costs.

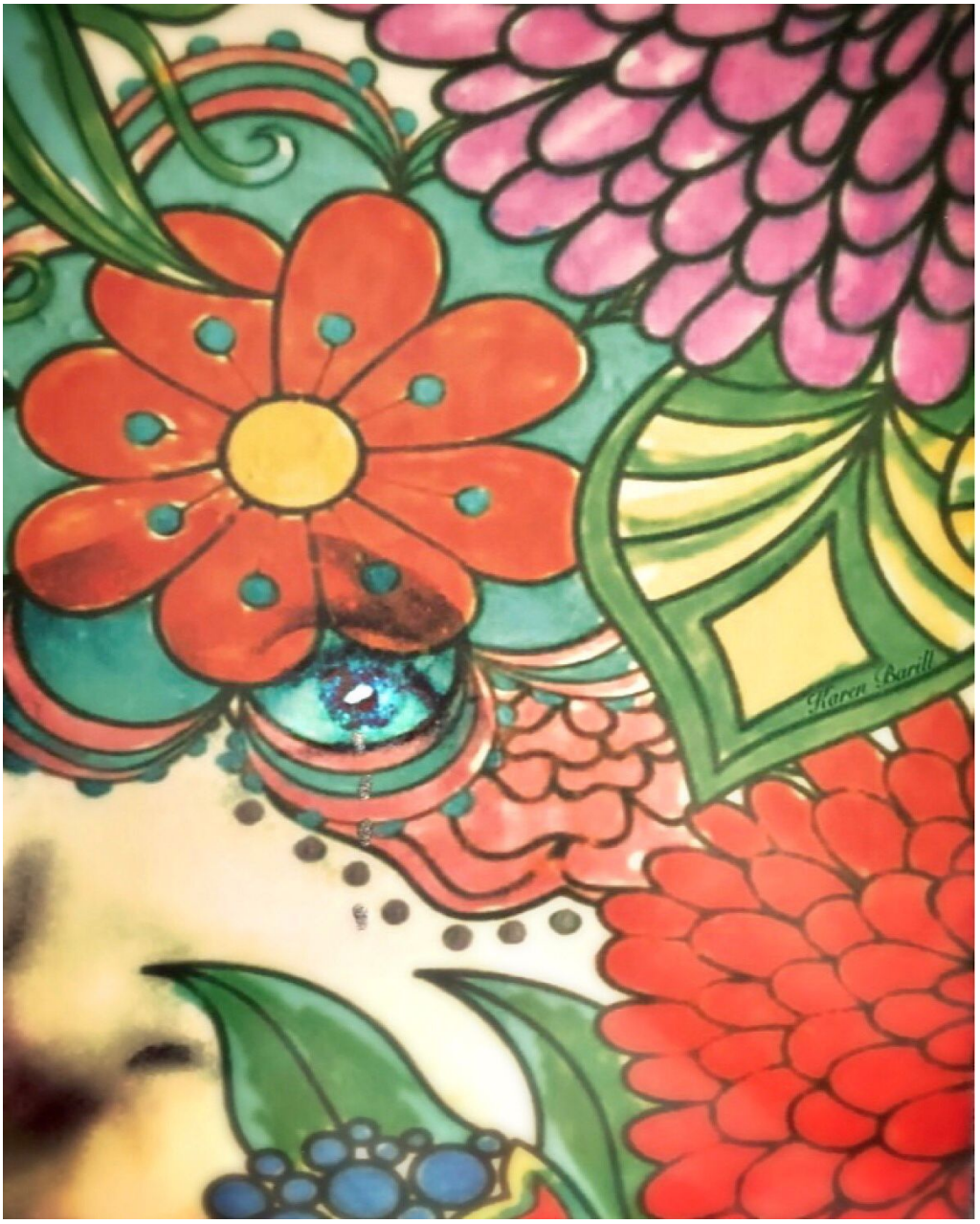
I do what I must to ensure my survival. I write and I raise awareness of HS. Those are the rocks I cling to in the murky, tumultuous waters of what my life has become.

Each time pain rips through me, I write a little more, work a little harder.

And hope, with every breath I take, that – someday – there will be a cure.

HS Doesn't Have Me

by Karen Boley Barill



It was 1977 when I had my first lesion.

Like so many of you I had never sought care, never had seen a single doctor - I could not seek help because I had secrets to keep at all costs. I was embarrassed. I could not even speak of my own health issues with anyone for so many years. I had the flu a lot, so I told

them. When I finally did it was immediate family members and very difficult to explain especially when I didn't totally understand exactly what I was dealing with.

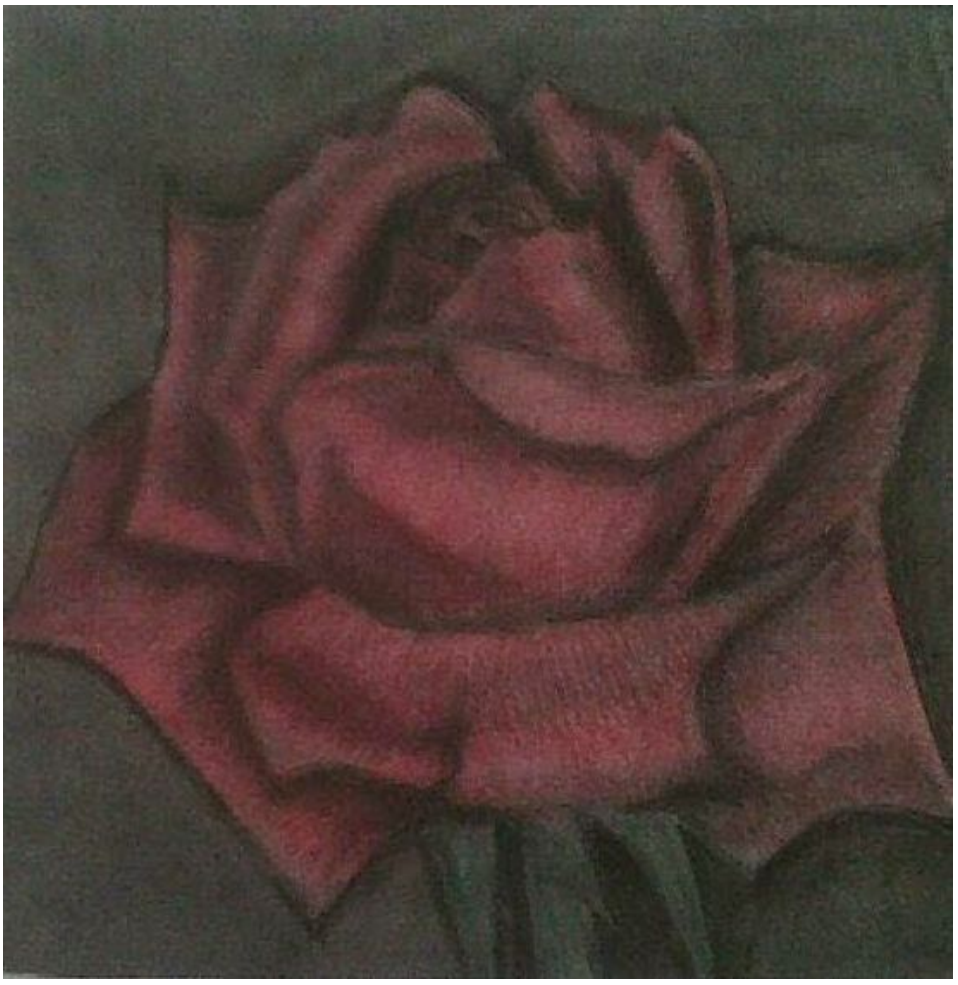
Years passed when I made a change. I not only learned what HS was for the first time, but other issues I have or had, like Type 2 diabetes and thyroid issues. I sought care and help everywhere I could.

Fast forward to today. I have seen over twenty-five different physicians for my care. I'm fortunate now to only have three wonderful doctors. I have been through multiple major surgeries and skin grafts. Now I'm extremely proactive (when I'm not sick) as a self-advocate and - most importantly - have been overly attentive to the accuracy of my medical records.

If I have any advice at all it would be to allow yourself one, maybe two, bad days, then pick yourself up and say, "HS doesn't have me"

THE MANY NAMES OF HS

by Michaela Parnell, Manchester, UK. Founder of HS Action Together



There are many names for HS; Hidradenitis Suppurativa, Acne Inversa, Verneuil's disease,
Hidrosadénite Suppurée, Maladie de Verneuil, Idrosadenite Suppurativa to name a few,
Even worse there is no cure or effective treatment that works for all of us.

Millions of adults, teenagers, and children across the world are living a life of HS Hell;
Am heartbreakingly aware, their desperate cries resonating like echoes within our HS community,
Not many medical professionals, the public, and even those with HS have ever heard of it,
You wouldn't believe the health and social inequality that it brings us.

No one understands. It's easier to judge; oh, how we're the stigmatised, the **#MillionsHidingHS,**
Are you aware, heard its name, that there are different HS types and stages, not due to infection?
Misinformation, 7 years of misdiagnosis and fighting for a diagnosis are our norm,
Exacerbates the mental, emotional, and physical damage on top of the HS Chinese water torture;
Stigma and discrimination cause millions of us to hide, feeling ashamed and fearful of judgment.

Oppressed in our betraying bodies as the HS insidiously invades us, hidden behind our fake smiles,
Forsaken and isolated due to HS, ignorance, misconceptions, lack of education and awareness.

Hopeful for a future of understanding and compassion, for HS to be known about and understood,
So internationally, we are, together, trying to **#BringHStoLight** for **#MillionHidingHS** worldwide!

This poem is dedicated to the millions of adults and children living with HS worldwide.

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.

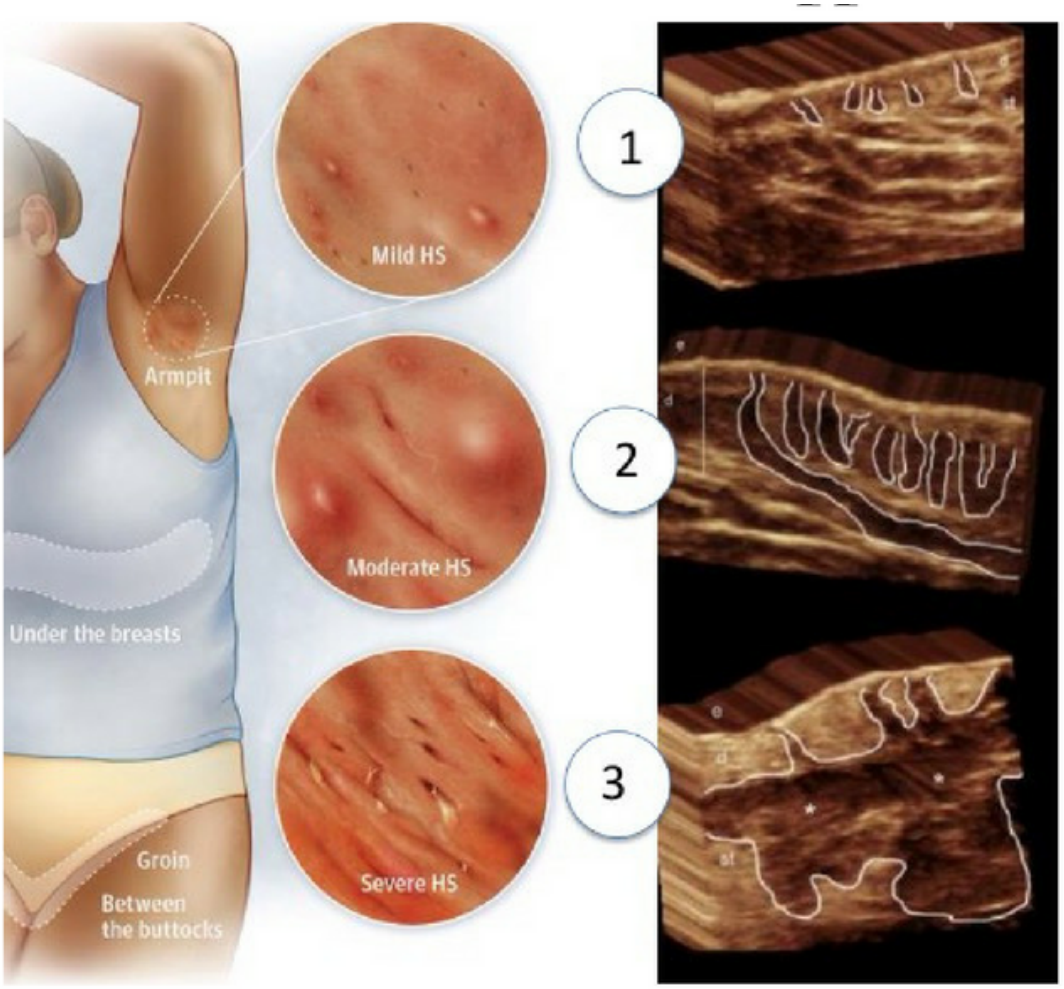
Fluctuations between HS flares varies and it can affect the person continuously as one or multiple flares, flares subsides, and another or multiple flares erupt. There can be different stages of HS on various parts of the body. Due to the various types and subsets of HS it is difficult to determine each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