



VOLUME 2

# 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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## **“On the edge”**

by John Herbert, California, USA



We all feel alone sometimes. For me, it's like standing on the edge of a great expanse. You feel small, insignificant, like if you were gone it wouldn't be noticed. That's how I felt when I painted this. But lucky for me, I have people that care about me and helped me to just enjoy the view. There are so many of us that have no one to help them through tough times. Awareness is the only salvation. HS is not deadly. Living with HS is so hard without support. The choice to end it is a prevalent thought in all of us. If we can't find a cure at least let us find some empathy.

## HS Warrior

by Penny White, Georgia, USA



I am an HS Warrior.

I wield pen and brush and voice as swords and daggers. Words and images are arrows that pierce through my isolation to allow in light where once darkness reigned.

My heartbeat is the drum, calling all to join the fight, knowing victory lies upon the horizon. We need only to see the dawn to exult in our triumph.

Hope is the steed upon which we ride into battle. Determination is my battalion. Courage is our battle cry. None of us knows defeat.

We ride with heads held high, pride resting upon our shoulders. Our strength lies, not only in our numbers, but also in our individuality: That which makes us each unique is also that which sees each of us through the storm of battle.

We survive the pain, the anguish, the desolation thrust upon us. A Warrior knows the challenges. Though the Warrior may be struck down, the true Warrior stands again, ever vigilant in the fight.

Some Warriors will fall. They will be mourned, on and off the battlefield. Their loss will pierce the hearts of kindred Warriors and loved ones alike. Those Warriors remaining will continue the fight in their honor.

Because this is a fight we cannot – must not – lose. We will fight until we stand victorious in the brightening rays of the new dawn of freedom: Our freedom from this enemy which shows no mercy and therefore deserves no mercy. We will fight until this enemy is vanquished.

We are stronger than our enemy. Our power lies within our voices, our hearts, our very spirits.

That power overpowers all and empowers all of us.

I am an HS Warrior. I am a force to be reckoned with. I will not be defeated by this tyrant, this coward, which dares attack without provocation. I will be the one victorious, wielding my pen, my brush, my voice as weapons against the brutality of such a vile and despicable monster.

I am an HS Warrior.

We are HS Warriors.

In our fight, we are already victorious.

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



## For the Lost Kids of HS

by John Herbert, California, USA, 50 plus years of dealing with HS.



I am writing this for all the young people thinking that their lives are over because they have HS. My hope is by the end of this you will realize it doesn't have to be. I am not saying your lives won't change or you won't have to make sacrifices - a lot of sacrifices - but you can have a full and happy life.

I was diagnosed with HS about eighteen years ago but I have lived with it for over fifty and I am still here.

Hidradenitis Suppurativa (HS) is a common (though rarely diagnosed), chronic skin disease characterized by clusters of abscesses or subcutaneous boil-like "infections" (oftentimes free of actual bacteria) that most commonly affect apocrine sweat gland-bearing areas, such as the underarms, under the breasts, inner thigh.

I have been employed in hundreds of fields for over forty-five years including a career of eighteen years. Currently living on a bit of land the bank, I, and my wife (a lifetime sufferer

of Lupus and its cousins) have owned for almost twenty years. Now that's a lot of years and not all good for sure.

If I had to put into years how often HS or other health issues have put me down completely, I would say less than two. The way I see it, most of the time the pain is there if you are on your back or on your feet and I can cope better if I am occupied. Even with stays in the hospital and numerous surgeries, I refused to stay on my back (the breakouts on my butt hurt too much) so I busted through therapy and got mobile asap. I learned to apply dressings one-handed, left or right. I became adept with a scalpel, packing and a drainage wick. Whatever it took to keep my life regular, I did. Sure I would be missing employment - sometimes paid and sometimes at the cost of the current job - that's why I have had hundreds of types of work.

I am lucky I found a partner. Living as two is easier in a lot of ways if you act as a team. But I met her in my mid 30's so both of us had a life dealing with our diseases alone, basically. I hid mine from everyone and hers was ignored. Although we are both disabled now we manage to keep goats, chickens, dogs & cats, plus my wife maintains a vegetable garden. Not bad for two people with Hidradenitis Suppurativa and Lupus. Not easy either. We have our days when we are down. Between us we make almost a whole person. A partner is the best. Not a bad life.

There are so many afflictions in this world many times worse than mine or yours. I know that now, but I spent a life knowing only my pain and shame. I want to you know what it took me some decades to learn.

First off, although, at times you will wish yourself dead I have never known or been aware of an HS-caused death. Just death from giving up. Now, Sepsis, yes, so take care of open wounds.

HS is NOT your fault! HS is a disease: a disease with a stigma in league with leprosy but, unlike leprosy, it cannot be transmitted and as of yet there is no cure. I make it sound bad



because it is. You all are in for a fight, but if you are reading this now you are halfway to victory.

“Awareness is the cure.” Not just for those with HS, but everyone in their lives. You will be embarrassed, shunned, people will be revolted by you. That is a fact. Hindsight is for the old to share with the young. I have lived it so I can give you some pointers.

I was at a party once when a big bastard under my arm burst open. What a mess! I acted like I was drunk and fell in the pool to have an excuse to go home and change. I rode a bike so I wouldn't be close with people. In gym I dressed early or late. The only way I could have sex was fully dressed. Does any of this sound familiar? I had no idea at the time what the hell was wrong with me so how could I expect anyone else to? So I kept it hidden.

### **Some pointers:**

Panty liners or feminine pads, not just for women, they work all over your body so always carry some.

Mentholated jelly (don't put near wound) covers up smell very well and people stay back if they think you have a cold.

Always carry some extra clothing and wear dark colors.

Loose clothing. I would go with a Moo-Moo if I could get away with it.

One-handed armpit bandage.

1. On clean surface lay out enough overlapping gauze pads to cover the area needed.
2. Cover gauze with paper-tape (I found this best for skin irritation).
3. Let tape extend 1 inch or so over all 4 edges. Turn it over.
4. Put a nonstick-pad with medication in the center.
5. Reach for the sky and, with one hand, slap it on and pat all edges to stick.

There are adhesive pads for large areas but I have found them to take skin with removal.

Purchase a scalpel and keep it with you for emergency lancing. If I have the time I use hot compresses to bring it to a burst.

Get a good dermatologist or at least an internal medicine doctor.

If you find a good employer let them know what is going on. They may work with you on time off and activities that you can do.

And most important - something I wish could have done - is talk to everyone you care about and let them know what is going on with you. This is where you will find out who really cares about you. Let them help you.

HS is different for everyone who has it. The effects and the treatments aren't set in stone. Try not to treat yourself from what you hear or read. Talk to a doctor.

I am currently on Humira, Dapsone, Dutasteride and Doxycycline. I guess you could say I was HDDD. I have to be very careful to not overexert myself or stress out: both cause breakouts for me. I am still hoping for a cure and the more we all learn about this the closer we will be.

You can have a full life. It is hard and painful but is it worth the effort.

It always helped me to help people that have it worse than me. It gives me a perspective which is hard to attain in solitude.

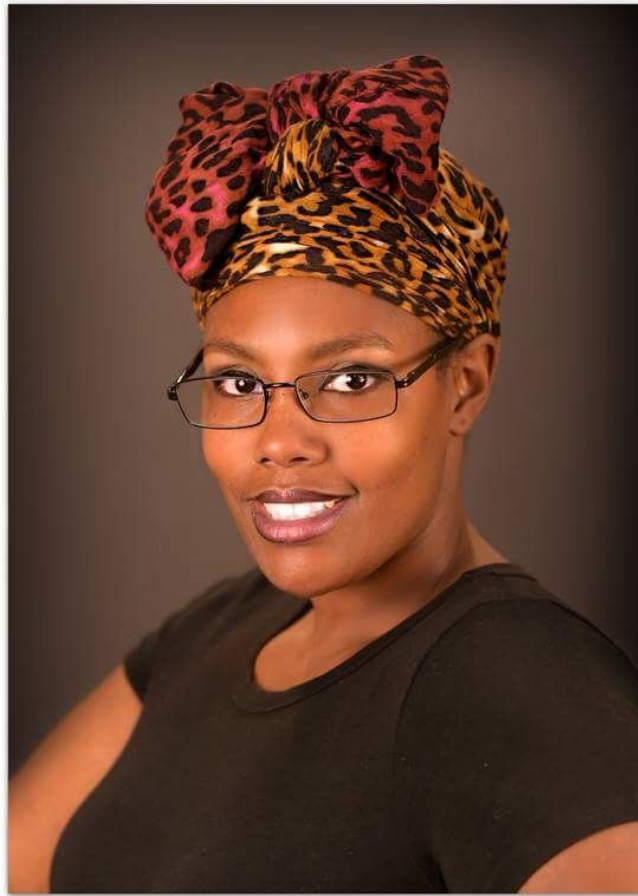
Please get out there. Don't keep yourself isolated. Humans don't do well by ourselves. We need people around us for support, guidance, companionship and love.

Every day think of one thing you would like to do and then find a way to do it. At the end of the day you may not have figured it out but you will find that your pain subsided a bit, simply because your mind was occupied and not dwelling on it.

Don't lay there in despair letting HS take your life away. Learn all you can about it and keep going past the pain. You will have a happy life.

## **My Journey I Don't Know**

by Francean Kennedy, California, USA



My Hidradenitis Suppurativa began at age thirteen. I had no knowledge of this disease or its effect no one knew what it was I was covered in lumps and bumps and all the doctors could tell me was that they were boils and the ones that were open they said I had scabies. I was very clean, so I knew there was no way.

They tried different antibiotics and medications.

When I moved to Redding, California at age nineteen, the lumps and bumps became worse. It seemed real bad with pregnancy, but I was told they were just boils, so I did nothing.

I don't remember my exact age, but sometime during my twenties, I finally got a doctor down in Vallejo, California; I thought maybe he would know what was wrong with me. Four kids and finally, some help! So I made the appointment with doctor Carlton.

He came in and all he did was look at me. It was like God himself sent him: He knew! He said, "You have Hidradenitis Suppurativa," and did some swabs of my wounds to run some tests to check for infection . He told me that HS is caused not by infection and that swabs from HS wounds normally came back clear of any infection. I was in disbelief that I had Hidradenitis Suppurativa until he had proof from the tests that it was not a skin infection..

A week or so went by then he called me and told me I had stage three Hidradenitis Suppurativa, skin cancer and Rheumatoid arthritis. It was a lot for me to take in, so much going on with me. It had gone undetected for so long.

After my appointment I fell into a deep depression. I didn't want the surgery he offered. I felt that was a waste of time.

Then I got up and I decided I had to live.

I had surgery first on my right armpit. It took my whole armpit, and I was thinking it was over and then I end up having three more operations on the same arm. They didn't staple it this time; this time they left it open, so it can heal.

It healed a year later. I became pregnant with my now four-year-old son. It got worse while I was pregnant and they couldn't treat me. No more surgery no more meds just pain, and I was riddled with bumps and sores.

After the baby was born they removed my left armpit down in Butte County I ended up there because of the skin cancer and my mom was helping me with the baby and my daughter. I had a better doctor, and he did the surgery right the first time; he left it open.

Fast forward to today my cancer is in remission. I do have small relief because of Humira except for a couple of weeks ago the left arm burst open and my thighs are riddled with bumps and some sores that prevent me from walking long distances.

The one improvement was weight loss I used to weigh 390 pounds. I dropped the weight and I don't have as much pain as I used to. And my energy is somewhat back.

Living with HS is like being possessed. My body is not mine. I feel ugly. My legs are bruised and bumped up. I'm always tired, and I'm still in pain. I just want to be able to play with my kids and I can't. I don't have the energy.

Awareness needs to be raised because no one understands or knows what I'm talking about. When I tell them about it or if I say I'm tired, they see me as lazy. This disease drains you.

It took me forever to find out what was wrong with me and I'm glad I never gave. NEVER gave up because now I know what is destroying my body and has left me scarred.

I go to school and it's very hard to sit in pain or just tired and not be able to finish. My kids want to do road trips and I can't because it hurts too bad to walk so we stay indoors. I was supposed to do a Pageant, but I quit because my arm ripped open.

It ruins your whole life and sometimes I want to quit.



# **I woke up**

by Rose Ortiz, Puerto Rico



Today I woke up with more scars. Scars that, besides being physical, are also emotional. I woke up and today and I can not move. Around me, they do not understand the reason for my immobilization, but I do understand. I bring my hands to my face and I cry. I cry because, like yesterday, I do not tolerate the pain.

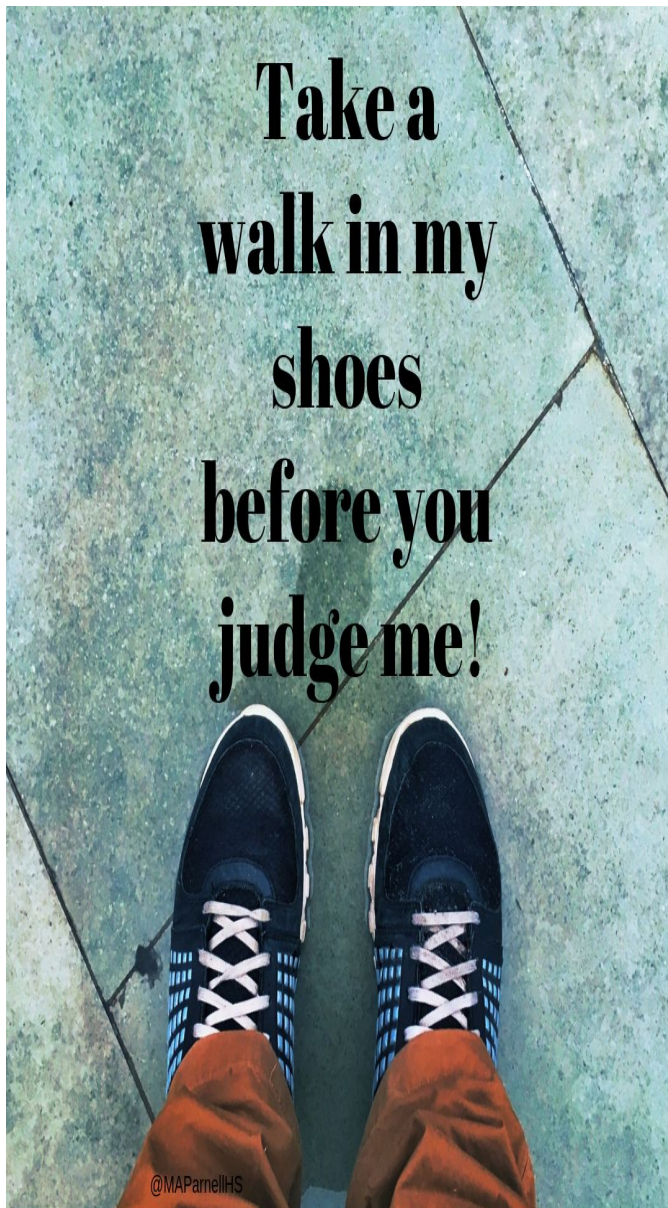
This pain gnaws my insides and I feel that I have lost everything. I have lost the desire to fight, to smile and to enjoy. This is my life, this is our life . . .

I have Hidradenitis Suppurativa and this is my story. This is our story.

Rose

# **What Hidradenitis Suppurativa means to me**

by Salvador Galindo, California, USA



**Hurts**  
**Irritation**  
**Depression**  
**Redness**  
**Autoinflammatory Disease**  
**Discharge**  
**Embarrassing**  
**No cure**  
**Injections**  
**Tender**  
**Imperfections**  
**Smells**

**Scars**  
**Underarms**  
**Pus**  
**Painful**  
**Unbelievably Enormous**  
**Reality**  
**Alone**  
**Tunnels**  
**Intense**  
**Very painful**  
**Ass**

## **40 years with HS**

by Maria Scharff, Sweden



Today I am sixty years old and just last year in August 2017, I saw the name of my disease in my journal, Hidradenitis Suppurativa, Hurley III. That was very late, since I have suffered from it since the late seventies. Totally confused, I called my chief dermatologist and asked her what she had written. She explained and for the first time I realized that I didn't just suffer from severe abscesses, but that I actually had a skin disease with a name.

Since then, I have studied HS a lot, mapping my own life, trying to figure out the reason for its outbreak and then, of course, trying to live with it, having/leading a so called normal life with this painful disease.

Apart from the fact that HS is a genetic disease, I am today pretty convinced that a long-term overdose of antibiotics at a young age had a lot to do with its outbreak. I was on antibiotics from the age of three until the age of eighteen, when they finally removed my tonsils. A year later, I also became PC allergic.

Other reasons that may have caused my HS to deteriorate are grief, sorrow and stress. Looking back at my life I can clearly see that after divorce, deaths in the family, and stress at work my HS has become worse.

I have gone through most treatments for HS that there are today: ordinary surgeries, plastic surgery, laser treatments, CO2 laser, long-term antibiotic treatment and Humira treatment. I can only draw the conclusion that none of the above treatments can - nor will - cure HS. It is, today, a very painful disease WITHOUT a cure!

Today, I fight HS by trying to change my lifestyle: what I eat and drink i.e. diets, I take frequent Epsom Salt baths, I eat a lot of vitamins, and I try to lead a stress-free life. So far, I managed to keep my inflammation level down to a reasonable level. That means at least keeping out of bed gives me a better quality of life.

For me, exercising is more than difficult. I have had to give up most sports that I love, e.g. skiing and horseback riding. The only sport that works for me now is swimming.

The future is unsecure. I have been on sick leave from work now for over two years. I have difficulties walking due to my abscesses and scars that constantly are painful and draining. Just three weeks ago my local municipality granted me a handicap parking permit. Just having that has been of great help coping with my daily life, e.g. grocery shopping etc.

Living with HS is PAINFUL and HARD but through raising awareness around the globe, we can at least hope and pray for a cure!

## **My personal story about HS.**

by Johnny Karnier, Belgium



I am a thirty-six-year-old dad of five-year-old twins (two girls). During my childhood, I was not really spared on an emotional level.

When I was eleven years old, my mother died of Hodgkin's lymphoma. She had just turned thirty-nine.

My dad died at the age of fifty-five in March 2016. He had an operation on the veins of his legs. The operation went well. The day of the operation I went to the hospital after work to visit him. He was in an artificial coma and I spoke to the nursing staff.



I went home with peace of mind. The next morning at 6.34 a.m. I received a phone call from the hospital with a request to go to the hospital as soon as possible. It is not going well with your father, they said on the phone.

I jumped into my clothes and went to the hospital. When I got there, the wife of my dad was present (they were in the process of a divorce). The doctor told me that my dad's cause of death was due to a hepatic shock. The surgeon did not understand how it was possible and was mystified.

Since they were officially married, his wife arranged the funeral and consciously chose to have him cremated instead of being buried.

Two months later in May 2016, I was hit for the first time by an abscess at the top of my tailbone. This was operated on with an open wound as a result and weeks at home nursing to take care of the wound. I was told by the surgeon that it was an ingrown hair that caused the inflammation.

June 2016 I was again hit by an abscess, this time on my buttock. After the operation, I was told again that it was an ingrown hair.

In September 2016, another abscess was removed surgically but in a different place. Again, I got an ingrown hair as a reason for the inflammation.

In November 2016 it occurred again. I consulted with my physician to show the inflammations. My left armpit, right earlobe and my buttocks had inflammations this time. By then my doctor knew enough and told me that he suspected I have HS.

On the advice of the GP, I got an appointment with a dermatologist who is familiar with HS. (not many doctors know about HS). It was well understood by the dermatologist but he advised me to also do a test of my intestines. He suspected that I also had Crohn's.

I then immediately made an appointment with a gastroenterologist at the hospital. A colonoscopy was performed and it showed that I do have Crohn's.

I will never forget the date of this diagnosis: 6 December 2016 (especially a personal gift from Saint Nicholas).

A few weeks later I returned to the dermatologist for the test results. It was early January 2017, when I was told that I not only have Crohn's, but also HS. I did some research on HS because nobody in my immediate environment (family, friends) had ever heard of it. At the beginning of February, I started a biological treatment (Remicade). I receive this infusion every two months for fistula formation.

A few weeks later, the mum of my children left me.

In March 2017, I was again operated on my buttocks, again an abscess was cut open, again with weeks of home nursing as a result.

I can confirm to you that it was not always easy as a single dad of three five-year-old twins. But it is also rewarding ;-). The support and love that I received from my children gave me the strength and courage to make the best of it.

June 2017 I was operated on again, an abscess at the buttock removed and weeks of home nursing.

August 2017 I had an inflammation in my left groin. A fistula of 15cm was removed and again the home companion had to come daily for the care of the wound. The size was large and I searched the internet for a patient association in Belgium. There was an association "La maladie de Verneuil and Belgique," but it existed only in French so Dutch-speaking Belgians were not helped.

I contacted the president of this association and proposed to help Dutch-speaking companions. After a few days, I became the contact person for Flemish fellow sufferers with HS.

In September 2017, I gave my first interview in a newspaper and a few weeks later my first interview for a regional television channel became a reality. Little by little, I really got to know the disease and people started to know me, too.

At the beginning of this year I went to Rotterdam to attend a meeting of the EFPO (European Federation Patients Organization). I got to know the presidents of the associations of Italy, the Netherlands, France and Denmark.

Meanwhile, I have made contacts with fellow sufferers in many countries: England, Canada, and the United States have joined. In May, the Belgian association decided to stop the association for fellow sufferers. I did not like this and have set up a private Facebook group "HS in Belgium."

I have a good relationship with Abbvie, the only laboratory that works for HS. They printed information flyers with the link to my private FB group. A short film was made thanks to the cooperation of Abbvie, which can be seen on the site of Abbvie HS online.

During the worldwide awareness week around HS in early June, I gave an interview in two newspapers (*Het Nieuwsblad* and *Het Laatste Nieuws*) and I was invited for a live broadcast of a regional television channel of *Brussels BXI*.

Since there is no longer a patient association in Belgium, I decided to set up one myself. Such an association I personally find very important to be able to increase pressure to research in the medical world. I have received the necessary information from the notary for the foundation of the association.

Within a few weeks "HS in Belgium" becomes a reality. Once the association officially exists we will receive subsidies with which our own flyers will be printed and there is money available for a posh campaign.

HS *must* and *will* become a recognized disease. Positive thinking ;-) Together we achieve much more and we stand stronger !!!

I thank you for your attention.

Kind regards, Johnny Karnier Tuinwijk Buizingen Belgium

# **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.

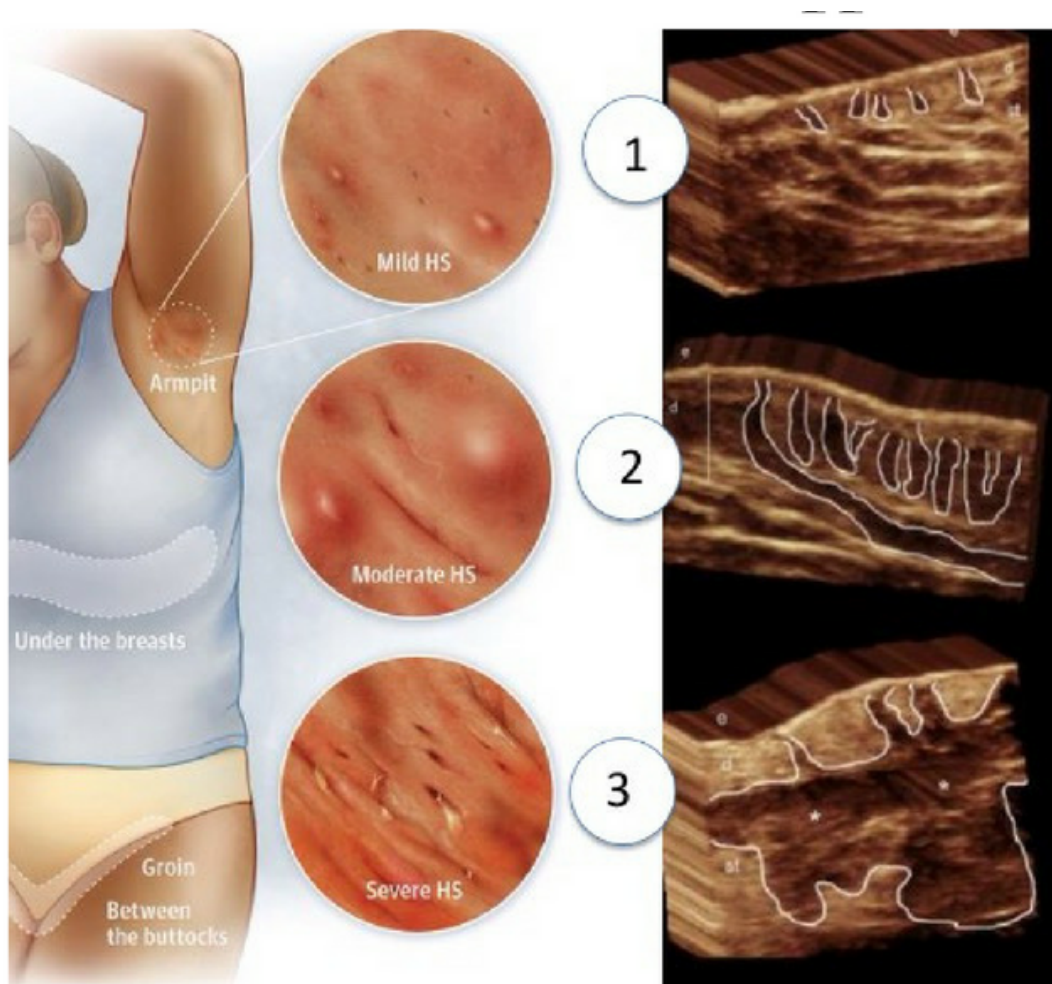
Fluctuations between HS flares varies and it can affect the person continuously as one or multiple flares, flares subsides, and another or multiple flares erupt. There can be different stages of HS on various parts of the body. Due to the various types and subsets of HS it is difficult to determine each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