



VOLUME 5

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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"500 Miles of Meaning"

by Kenton Bailey, Kentucky, USA



My name is Kenton. I am a person. I have interests, hobbies, duties, responsibilities, likes, and dislikes, loves and hates. I have pain, discomfort, problems, and imperfections. I have flares, swelling, holes, bruising, sores, and scars.

And yet, I am not my body. I do not feel ashamed of my body, but it remains my burden to bear. I am a person. I am a soul.

When I first decided, in what will now be called an “attempt” to walk across America, I had become consumed with the idea, driven by a need to run away, and the dream fueled by the

online journals of walkers past.

When I watched videos and read articles of people who had travelled the 2000+ miles, I saw free souls who had found a way to escape the day to day monotony of life. In many cases, the walkers felt unfulfilled in their ordinary lives. In many cases, they were merely adventurous and lead otherwise happy lives.

One tip I had consistently heard was to walk for a cause. A good reason being for the additional motivation and to do something good with your time. To not waste the exposure. To take something good and make it great.

At first the thought of walking for an ailment that I myself suffer from seemed selfish to me. After all, there are so many great people that need help with their struggles.

Not too long before the walk, I had started frequenting Facebook groups for people that suffer from Hidradenitis Suppurativa. Although it was great to have a community that made me feel not so alone, it was obvious that HS was a black hole, with little treatment options and even less awareness. It only felt right to choose HS for my awareness campaign. It allowed me to form a bond with friends I didn't know I had. Friends that I could share an intimate issue with and be understood.

Depression wasn't going to stop me, my flares weren't going to stop me. Nothing was going to stop me.

But then I stopped. In Panama City Beach, I had finally decided to give in to what my body was telling me. I had developed an umbilical hernia from pushing the heavy cart so long away, and it was only getting worse and I would need to keep the cart and load it down even heavier with water for crossing the desert. Not only that, but it turned out being with myself 24 hours a day seemed to only bring out some of my worst thoughts.

While I didn't complete the walk, and I didn't find in myself what I was looking for, I did make it over 500 miles and crossed two and a half states. Georgia, Alabama, and the

panhandle of Florida. Along the way I was guided by irreplaceable friends in the HS community, who volunteered their time to find me food, shelter, and safety along the way. So in the end, I found more than I was looking for, though it was something unexpected altogether. Something better.

Despite it's quick end, the awareness campaign was a massive success, and the spirit I saw in the HS community was like none which I have ever seen. So remember, life is a walk. A long and hard walk. But you are not your body... You are a person, you are a soul, and your soul can walk forever.

If you would like to learn more about my journey across America then please see my Facebookpage Kenton's Walk for HS and my Youtube Channel Kenton Bailey https://www.youtube.com/channel/UCdkbabDJqYHz3_SJXUzKF5Q

A COMMUNITY REMEMBERED

by Rob Howes Melbourne, Australia.

Oct 26 2018.

"A 36 year old African American woman living in Portland, Oregon, a woman named Stesia first developed HIDE in 1986. Courageous, feisty & determined, Stesia reached out past the stigma and fear and founded a world-wide community."

1. Internet Archive H.I.D.E. website 31st March 2001:

<https://web.archive.org/web/20010331155442/http://www.hideintl.org/>

On June 17, 1997, H.I.D.E. CANADA (Hidradenitis Information Development and Exchange of Canada) was established as a volunteer Internet resource group established in 1997 by Canadian sufferers of Hidradenitis Suppurativa, co-founded by Canadian's Michael Bonnar & Sylvia Shawcross. HIDE developed a website and an internet support group for Hidradenitis sufferers in Canada and abroad with the following mission statement: 'To develop, promote and facilitate the exchange of disease information for sufferers, medical professionals and the public. To provide a forum for sufferers to openly communicate and support each other. To advocate and encourage the advancement of disease research and treatments to find a cure for Hidradenitis Suppurativa.'

By 2000 HIDE had supported members from 14 countries and developed 'The H.I.D.E. International Network' with at least four prominent and active affiliates:

- a) H.I.D.E. La FRANCE
- b) H.I.D.E. NETHERLANDS
- c) H.I.D.E. U.K. & IRELAND
- d) H.I.D.E. AMERICA



In 2001 this global HS Community known as HIDE developed a nonprofit organisation for members, by members: the Hidradenitis Information Development AND Exchange INC. / Hidrosadenite Information Developpment et Echange INC., Mississauga Ontario, Canada. Dr. Gregor Jemec, Denmark, was one active medical member of this organisation.

Members of the original HIDE community were involved in the creation of HS-USA Inc. Brighton, Michigan, United States. HS-USA was a non profit patient & caregiver focused organisation that raised awareness, provided support, encouraged, stimulated, facilitated and funded medical research. Michelle Barlow, a person with HS from San Diego, California, was, very briefly, a member of the board of trustees of HS-USA late 2003 or early 2004.

The Hidradenitis Suppurativa Foundation, Inc., San Diego, CA., began life as a United States non profit corporation October 12, 2005. Founded by two European doctors Dr.'s Ralf Paus and Christos Zouboulis from Germany, and two people with HS- Michelle Barlow from the United States, and myself, Rob Howes from Australia. Dr. Gregor Jemec was a founding medical board member of this organisation. Sylvia Shawcross, Canadian citizen and co-founder of H.I.D.E. accepted our invitation for honorary membership of the HSF Management Board.

Today's global medical/scientific non-profit organisation's dedicated to Hidradenitis Suppurativa (HSF, CANADIAN HSF, EUROPEAN HSF, SWISS HSF & RESOVERNEUIL may be the spiritual sons and daughters of H.I.D.E., a patient-led initiative. **Remember.**

A HS Shadow Free From The Darkness

by Michaela Parnell, Manchester, UK



4th December, 2016.

It is only recently that I was brave enough to start being more active publicly about having HS.

I still struggle mentally and emotionally sometimes trying to come to terms with having HS. But I realize now that being an HS shadow just lurking in the background won't help any of us and that by speaking out I can help others.

It pains me to see so many people suffering. I want this to change and for people to get the help they need. So much needs to change.

Today I have been deep in thought. Thinking about all the people with Hidradenitis Suppurativa (HS) and their personal stories I have read.

These inspiring people have bravely shared their stories about their personal experiences living with HS: the heartbreaks and challenges they have faced due to living with HS and the effects it has had upon them.

I would like to say a heartfelt thank you to each of you who has opened up about your experiences with HS.

I know it isn't easy to share your intimate experiences of living with HS. But in doing so you are helping so many others with HS in so many ways, as well as raising awareness.

Reading your stories made me think more about my own lifetime of living with HS, which I have for a long time tried not to think about and forget. I have been thinking about my own story and remembering the last twenty-one years of living with HS. The battles and challenges I have faced because of the effects HS had upon me and my life. Which, sadly resonates with so many others like a desperate cry for help within the HS community.

I hate that others have HS and the pain they go through. The positives of each person sharing their personal stories is that it helps others and myself feel less alone.

Trust me, I have felt alone most of my life because of HS.

I was a shy and self-conscious sixteen-year-old, just married. Weeks after giving birth to my daughter, HS reared its ugly head.

I felt dreadful. My joints ached and I felt absolutely exhausted. I was afraid it was an infection because of where it was.

I had a traumatic time giving birth and required stitches and thought maybe that was what caused it.

I was told it was a boil, to be more clean and prescribed antibiotics. I reacted badly to the antibiotics and couldn't stop being sick. I stopped taking them and it went away, but it kept coming back. Every time I saw a doctor I was told it was caused by not being clean enough.

I felt it was my own fault and that I was dirty. I was clean and couldn't understand why it kept coming back. It didn't make sense and I knew something wasn't right.

I began trying to figure out what it was.

In my early twenties, I used the Internet to research what it could be and I found information about HS. As I sat reading about it, I knew it was what I kept getting.

I printed the information off and when I had my next flare up I went to A&E (Accident and Emergency) armed with it.

Sadly, the doctor with whom I pleaded for help dismissed me, gave me a lecture about personal hygiene and prescribed me antibiotics. I broke my heart crying for days. I was so frustrated and angry.

It was about six months later that I awoke to a massive knuckle-sized monster abscess that appeared overnight in the crease of my groin/thigh. I was sweating in agony and the slightest movement was torture.

I was rushed to hospital and admitted. I was put on an intravenous drip and intravenous antibiotics, met the surgeon, was told I needed emergency surgery and signed a consent form. I pleaded to go my Grandad's funeral the next morning, but they couldn't let me go. The doctor had to sedate me with morphine because I was going berserk and trying to leave. I had my surgery later that day: at the same time I should have been at my beloved Grandad's funeral. I hate that HS cruelly took that away from me.

When I awoke in recovery the pain hit me like a ton of bricks. I was grabbing the bars on the bed, screaming the place down. The nurse who sat looking after me, immediately gave me morphine and it knocked me out.

I awoke again later back on the ward and the pain took my breath away. The nurses were wonderful and did their best to ease my pain and comfort me about my Grandad, but I was inconsolable. I cried a river of tears that day.

The next morning a nurse told me she needed to change the packing in my wound and redress it. She told me that a bath would help make it easier to remove the packing once it was softened by the water. She said she would give me an injection of morphine for the pain.

I asked if I could go home and she told me that while I was having morphine I would have to stay in hospital. I refused the morphine because I just wanted to go home. She tried talking me out of refusing the morphine, but I was adamant.

She had to help me out of the bed. She had brought a wheelchair, but I refused to use it. She respected my wishes and kindly helped support me walking to the bathroom.

It was agony, the slightest movement caused breathtaking pain and I was sobbing. I had to keep stopping. Again, she tried to convince me to have morphine and for me to use the wheelchair, but I kept saying no and shaking my head.

Finally, we reached the bathroom. She helped me sit on the toilet and I watched the bath filling as I cried. She went and brought me a clean hospital gown and the stuff needed to unpack my wound. She put the morphine injection on the tray and said it was there in case I changed my mind. She helped me undress and get into the bath. She was so gentle and tentative.

I was lying back in the bath looking at the huge dressing in my groin/thigh area. I was taken

aback at how big it was. It went around both the inside and outside of my thigh and across the bottom of my tummy. The size of it confused me.

The nurse gently splashed water on the dressing to help make it easier to remove. She asked me if I was ready for her to remove it and I nodded.

I took a deep breath and prepared myself for it to hurt. She gently started removing it. I began sobbing with the pain. She immediately stopped and asked if I wanted the morphine. Yet again I shook my head and asked her to just do it.

I grit my teeth and closed my eyes. She removed my dressing and tears rolled down my cheeks. I opened my eyes and gasped at the size of the wound that still contained the packing.

The nurse asked if I was okay and I just nodded. She asked if I was ready for her to start removing the packing and I took a deep breath, grit my teeth, and nodded. She began gently splashing water on my wound to soften the packing and it hurt. I was whimpering and crying with the pain.

She again offered me the morphine and again, I refused. I told her I just needed a minute. She told me to let her know when I was ready for her to begin removing the packing. I nodded and said I was ready.

She began removing the packing. I grabbed the rails on the sides of the bath and couldn't stop myself from screaming. I pleaded for her to stop. She immediately stopped and began comforting me. I was shaking and sobbing.

She pleaded with me to have the morphine. I agreed. She immediately administered the injection and I could feel the effects of it coursing through my body, relaxing my tensed muscles and hitting my brain, making me feel fuzzy and woozy. But most of all easing my pain and helping me feel calm.

She smiled at me and asked if I was ready. I nodded yes. I closed my eyes and grit my teeth. Preparing myself for the pain I had just felt to hit me again. She removed the packing and it hurt, but it was now bearable.

She told me that she had removed it. I opened my eyes and looked at the tray. I was confused by the amount of packing that had been removed. There was a lot and I couldn't understand why. I looked down at my wound and immediately put my hand to my mouth in disbelief and broke my heart crying.

The wound was huge and it was deep. I had a massive gaping hole where the monster abscess had been. It was wide and it was deep. I don't know how I felt, but I couldn't stop crying. It was a shock. I was confused and asked why it hadn't been stitched shut?

The nurse explained that it had to heal by secondary intention by its healing from the inside-outwards and that was why it had to be packed. I asked her what she meant and she explained that she needed to clean and repack the wound, then put a dressing on it, but she would do that when I was back in bed.

She helped me out of the bath, helped me to dry myself and put the hospital gown on. Even with the morphine it hurt and it really upset me that I needed her to help me.

She helped me into a wheelchair, took me back to my bed and helped me get into it. She went and got what she needed to tend to my wound. I lay there dreading what she was about to do. I quickly looked at the gaping wound again and bit back my tears.

She returned. As gently as she could, she packed and redressed my wound. It hurt like hell. She had to keep stopping because I kept wincing and crying out in pain. After she had finished and left, I broke my heart sobbing.

I was kept in hospital for four days because I needed morphine injections for the pain throughout the day and night. The nurses always timed my morphine injection just before each time they needed to unpack, clean, repack and redress my wound. It filled me with dread when they said they were going to change the dressing.

On the fourth morning of being in hospital I refused to have any more morphine injections because I so badly wanted to go home. The doctor prescribed me liquid and tablet painkillers.

I was able to just bear the excruciating pain the wound was causing me. It hurt like hell having my wound unpacked and replaced. I sobbed the whole time, but I wanted to go home and managed to get through the torture of my wound being tended to.

I was released home with strong painkillers and into the care of the district nurses that came to tend to me daily. The wound took four months to heal by secondary intention and district nurses visiting me, unpacking and packing my wound every day.

They visited twice daily at first (with some extra visits needed some days). After a couple of months, they went down to once-daily visits. The nurses were lovely and tried their best to be gentle and as fast as they could.

I dreaded them coming as it hurt so much. It was like a daily torture session I had to go through so that my wound would heal from the inside outwards.

I would take the painkillers beforehand and lay in the bath sobbing, dreading the knock on the door, announcing the arrival of the nurses. I always tried to put on a brave face and hide

how I felt behind a smile. But as soon as they left I would break down and cry.

I finally received my appointment with the dermatologist. This was when I was finally diagnosed with HS.

To be quite frank, even though I knew it was HS, I burst into tears when the dermatologist confirmed it. He was shocked at my reaction. He prescribed a combination of two antibiotics and told me that it would get rid of the HS. I took the tablets and I reacted badly to them. I couldn't stop throwing up and had to return to A&E. I was told to stop taking them.

I didn't take it at all well. I cried and screamed the house down for days. I felt like my life had ended because I knew what having HS meant, what it was capable of doing to me and that there was no cure. I didn't want to have to face another monster flare, having another piece of me cut away; the months of daily torture of having the wound packed.

I was in a lonely and dark place. I was already hurting due to losing three of my grandparents to cancer in the previous two years, my marriage falling apart and going through a divorce. Now this on top just extinguished the light at the end of the tunnel.

I felt so lost and alone. I made it worse by bottling it up and hiding how I was feeling.

Sadly, no one understood when I did finally get upset in front of them.

How could they understand when they didn't know what HS is? I think they thought I was overreacting because I had boils and they tried to help me by saying to be more clean.

I mourned for the life I had planned that had been cruelly stolen from me. My future now filled me with fear and dread because I had no choice but to face and live with having HS.

Every time I had a new flare I was terrified in case it erupted into a monster and would immediately go to A&E, which often resulted in emergency surgery to remove them and more visits from district nurses to pack the wound.

Even with a diagnosis, I faced an uphill battle with GPs and A&E doctors not knowing what HS was.

I remember going to A&E with a flare up on the inside of my thigh. I had scarring, too, from previous flares and surgeries. I told the doctor I had HS. He left the cubicle and I thought he was going to look it up.

I was not prepared for what he said when he returned. He accused me of being a drug user and it was okay to admit it.

I asked him how he had come to that conclusion and he said he knew this due to the scarring I had caused by injecting and that was why I had the abscess on the inside of my thigh due to where I had injected getting infected.

I went absolutely nuts and was screaming at him that I was not a drug user and that I had a condition called Hidradenitis Suppurativa, that if he looked it up he would have realised what the condition was, but instead had chosen to ignore this and incorrectly accuse me of being a drug addict.

The consultant heard me screaming and came to calm me down. I told him what had happened and he took the doctor outside the cubicle.

I could hear the consultant giving him a stern telling off. Luckily, he knew what HS was and told the doctor that he should have looked up what HS was instead of ignoring the diagnosis of HS and accusing the patient of being a drug user.

The consultant came back and apologised for the doctor's treatment of me. He was so compassionate and respectful towards me. He took bloods, gave me morphine and admitted me to the surgical ward for surgery. I was very angry and frustrated.

I spent years arguing with medical professionals that had no clue what HS was, couldn't even pronounce it, and had no idea how to treat me. I tried to my best to educate them and raise awareness of HS with them by providing them with literature with the hope that no one else would be treated the way I was.

Some doctors took the time to listen and learn. Sadly, others dismissed me and refused to listen.

It upset me knowing there were others like me facing the same battles too, and that was what always gave me the strength to keep fighting to raise awareness of HS.

I got fed up to the back teeth of knowing more about HS than the medical professionals who were failing me and others with HS.

It just wasn't good enough. It had to change, but how? How could one person make a difference? That I didn't know, but I knew I had to try.

That was when I decided I had to try to find a way to change this.

The idea how to begin changing things came to me when I watched a film called "Patch Adams." The film was based on the true story of one man trying to make a difference to help

others and the battles he faced. His message reached me and he inspired me.

If I became an HS researcher they would have to listen to me because I could back everything up with research; to hopefully inspire more knowledgeable researchers to investigate HS; to help educate the medical professionals and hopefully help others with HS understand what it is, to stop blaming themselves, feeling it was their fault and stop feeling dirty and ashamed.

I went back to college to obtain the GCSEs (General Certificate of Secondary Education). I needed one at a time to enable me to enroll in an access course so I could apply to University.

I have just started my third year of a biology degree at the University of Salford. It has been an uphill battle every step of the way and I almost quit University last year.

But some of my lecturers refused to let me quit and supported me so much. They helped me believe in myself when I had lost all hope and felt beaten. Without their support I would not be doing my third year at University.

I gave birth to a beautiful little girl a week before my second year at University started. I went back full time when she was four weeks old. Then my uncle passed away from a Glioblastoma brain tumour. I was devastated.

The combined hormonal changes from giving birth caused my HS to begin flaring more and in new places. My HS, the stress from juggling a newborn, losing my uncle, attending University and doing my coursework became too much by the Easter holidays. I was having panic attacks and crying all the time.

I was diagnosed with postnatal depression and was not well enough to do my exams. I felt defeated.

I was going to quit University as I couldn't cope. But two of my lecturers that have been my rocks at University refused, point blank, to let me quit. They arranged for me to do the exams in August instead.

I broke my ankle just before the August exams and couldn't do them. I was distraught.

My lecturers once again stepped in (pardon the pun) and the Dean of my school took all my medical evidence and circumstances of the previous year into consideration. She supported me and arranged for me to be able to attend the second year at University again full time.

I passed the second year with flying colours. I cannot thank my loved ones, all my lecturers, the laboratory technicians and the lovely ladies in the school office enough for their belief in me and their support.

I am looking forward to my third year and am excited by the content of what I will be learning. Fingers crossed, I want to do a Masters degree and then a PhD because my aspiration is to be an HS researcher. My loved ones are always there supporting and encouraging me. They are my world, my precious everything. I love you all eternally.

I am worried that I might not be able to do it because of my HS. But I am determined to try my best because I want to help be part of the changes that we need to see happen.

I am constantly reading journals about HS on top of the research I have to do for assignments at University. I constantly think about HS from the moment I wake up until I go to sleep.

Pass or fail in my aspirations I will continue to help others with HS any way I can.

It was only recently that I became more active in the HS community because I had always been an HS shadow hiding and feeling ashamed, only occasionally reaching out to the HS community by posting. Others always rallied 'round offering support but I would always return to the comfort of being in the shadows.

I met so many others with HS online. I began for the first time opening up and sharing with them my story of living with HS and my dreams and ambition to become an HS researcher because I wanted to help others and be part of the change we so desperately need to see happen, sooner rather than later.

I was gobsmacked at their reactions. They told me that my story would help and inspire so many others.

At first I was hesitant because I feel a deep shame about my HS. I was afraid of what others would think of me and didn't think anyone would be interested in what I had to say.

I guess I had grown too comfortable being an HS shadow, quietly working away towards my goals, silently and determinedly, not telling anyone what I had planned for so long.

At University when people asked what I wanted to do, all I said was that I wanted to be a researcher. I didn't want to share that I had HS because I was afraid of what they would think of me.

I joined many Facebook support groups on an international scale and I spent my summer holidays getting to know other amazing and inspiring people with HS. They helped me begin to deal with the emotional and mental aspects that HS has had – and still has – on me.

I began reading the stories others have shared and I began to realise that my personal fears

were hindering me. This was the opportunity to help others I had been waiting for.

Then sadly Angela Sams passed away suddenly after just after sharing her story. Even though I had never met her, reading her story touched my heart. I watched the YouTube video she had made wanting others to know what it is really like to live with HS.

I cried my eyes out for her because I could see the pain and distraught in her eyes, and her story reached out to me. It pained me deep within my heart that she had suffered so much; that people had cruelly judged her instead of offering her understanding and the support she so badly needed.

That was when I made the decision that I had to help publicly be part of the changes we need to see because too many people are suffering and not getting the help they need.

Angela wanted to make a difference by sharing her story to try and help be part of this change. She was a friend to many in the HS community and she was a beautiful, kind, caring, compassionate, thoughtful and passionate person that I think about. She was the final push I needed to step out of the shadows and become a public, passionate HS advocate that I have been for many years, but did in my own way, hidden in the shadows.

When I have a rare moment to myself, I sit and think about Angela and all the others that have shared their personal HS stories. They all give me the strength I need to keep fighting in any way I can to help us all.

Life is not easy with HS. It hits you and pulls the rug from under you when you least expect it. It is like living in the eye of a storm, knowing it will return but not knowing when or how bad it will be.

The pain it causes is the worst. It hurts like hell regardless of the stage you have. It is like Chinese water torture: relentless. Yet you have no choice but to live with the pain and get on with things the best way you can.

Trust me, I have spent months at a time hiding how much pain I am in, just wanting to rip my own face off; crying rivers of tears when I am alone; lying in bed exhausted but unable to sleep due to the pain tormenting me and keeping me awake, with only distraction to help take my mind away from the pain.

Headphones listening to music helps while I read things on my iPhone; usually journals for University coursework or HS-related journals. It doesn't take the pain away but helps me cope with it better.

What upsets me most is that everyone else with HS feels the exact same way about the pain

that HS causes. They, too, feel that not enough is being done to help ease it. Instead, they have no choice, like me, but to grin and bear it, live with it and deal with it the best they can.

It upsets me knowing that HS not only affects the person with it, but also their loved ones and friends, too. It is hard to see someone you love or care about suffer and not be able to do anything about it.

This is an area where these people need help and support too. Thank you to all of you who are there for, and support, your loved one with HS. It is by no means easy, but you mean the world to your loved one with HS.

It has not been easy writing this and I hope that by sharing this I will help others out there with HS (diagnosed and undiagnosed) and raise awareness of what living with HS is really like.

You see, we with HS are so used to hiding this and people tend to not really see what we are truly dealing with. We do this because we know it hurts our loved ones seeing us in pain and we don't want our HS to hurt you, too.

If you have HS, please do not blame yourself. It is not your fault. There are many of us who have felt this way.

There are so many people with HS in various HS support groups that help and support each other. If you have HS please do not suffer alone. We are here to help and support you in any way we can. All you have to do is reach out and there will be others who will reach back out to you and help you in any way they can.

I know it is hard to reach out because I was an HS shadow, afraid and alone in the dark. Reaching out was scary but it was the best thing I ever did.

I have met so many others with HS and they have helped me so much in dealing with the emotional and psychological impacts that HS has. They have given me so much advice on things I can try to do to help ease my HS and vice versa.

But most of all, I'm not alone anymore and I have my HS friends and they have me. We help each other in any way we can. Thank you to each one of you. I love you all dearly.

If you are a family member, loved one or friend of a person with HS, we are here for you, too. Please reach out to us and we will try our best to support you as well. We know how hard it is seeing a loved one living with HS and what it does to them. We have groups for you too so that you can ask for advice, support or just have a chat.

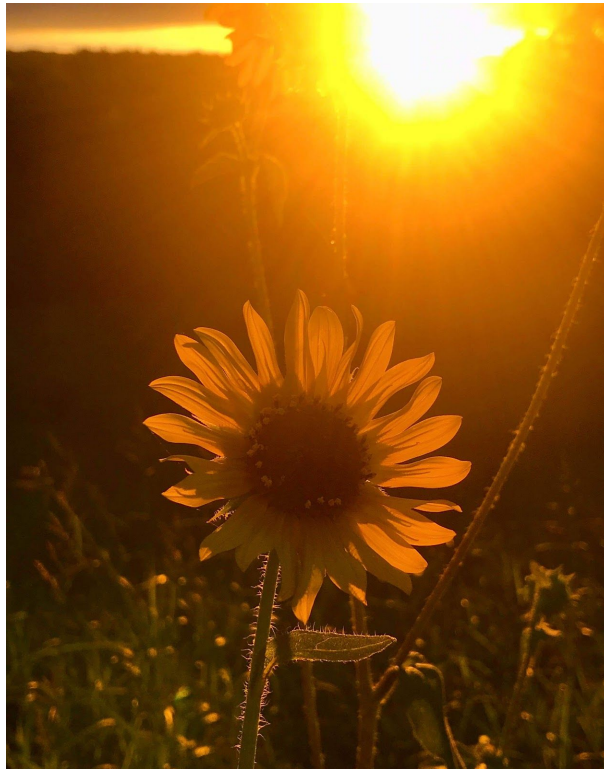
I shared this story in the hope to help others and raise awareness. I do not share my story for sympathy, but to try to get HS out of the shadows and into the public arena to be discussed and debated. That is the first step to enabling the changes we need to happen. Please support our **#HSMillionsMissing** and **#BringHStoLight** campaigns in December 2018 to help us find others suffering alone with HS and raise much needed awareness of the world wide health and social inequality that we - adults and children with HS - live with. You do not have to have HS to participate. Please check out HS Action Together Facebook and Bring HS to Light Facebook Pages.

Much love

Update: I am no longer a cofounder or member of HSAwareness.org or HSSupport.org and am no longer affiliated with them. I am setting up a HS social enterprise HS Action Together and a HS Citizen Science Project. I have completed my BSc (Hons) Biology degree and am now doing a part time MSc Science Communication and Future Media Masters at the University of Salford as the next part of my journey. I have just completed my first year.

She Can't Let You Stay

by Amber Taylor



The mirror shows her scars and bumps, and all the tracks that HS has made,
But despite the fact sadness creeps in,
She can't let it stay

The odor from her flares are stronger than her perfume
She looks around the room and wonders if anyone else can smell HS too
But despite the fact self-doubt creeps in,
She can't let it stay

The red mark across her skin left behind from gauze and tape, her finger traces,
As she wishes today she didn't have to go to so many places
But despite the pain that HS brings on,
She can't let it stay

Another Epsom salt bath, another weekly biologic injection, another antibiotic downed all in hopes just to get better
She begs for a moment just to feel normal
But the HS hurts too much, it won't let her
But despite her despair
She can't let it stay

Her family wonders why she doesn't want to get out of bed
"There's nothing wrong with you, you're just lazy," her stepdad once said
"I don't see anything wrong with you," her friend once stated
"I can't even look at you without clothes on," said one guy she dated
But despite the ignorance of so many others
She can't let it stay

Another visit to a doctor who doesn't seem to understand
"Lose some weight, take a bath, make sure you wash your hands."
That's the advice doctors give to treat a raging condition
"You really think my weight and hygiene put me in this position?"
She asks the doctor as he walks away
But despite feeling dehumanized
She can't let it stay

All the money she's spent on her medical care
Would be enough to buy a house on a deserted island somewhere
But despite the dip in her finances
She can't let it stay

She's better than the sadness, the odor, and the pain
She's more than what HS tries to make her believe
She's a fighter, a warrior, and brave to her very core
She won't let HS take her down in life
She's going after more

There's all her hope

There's all her faith

There's going to be a cure

Deep in her heart, she believes that for sure

Awareness is key and a role we all play

I'm sorry Hidradenitis Suppurativa

She can't let you stay!

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.

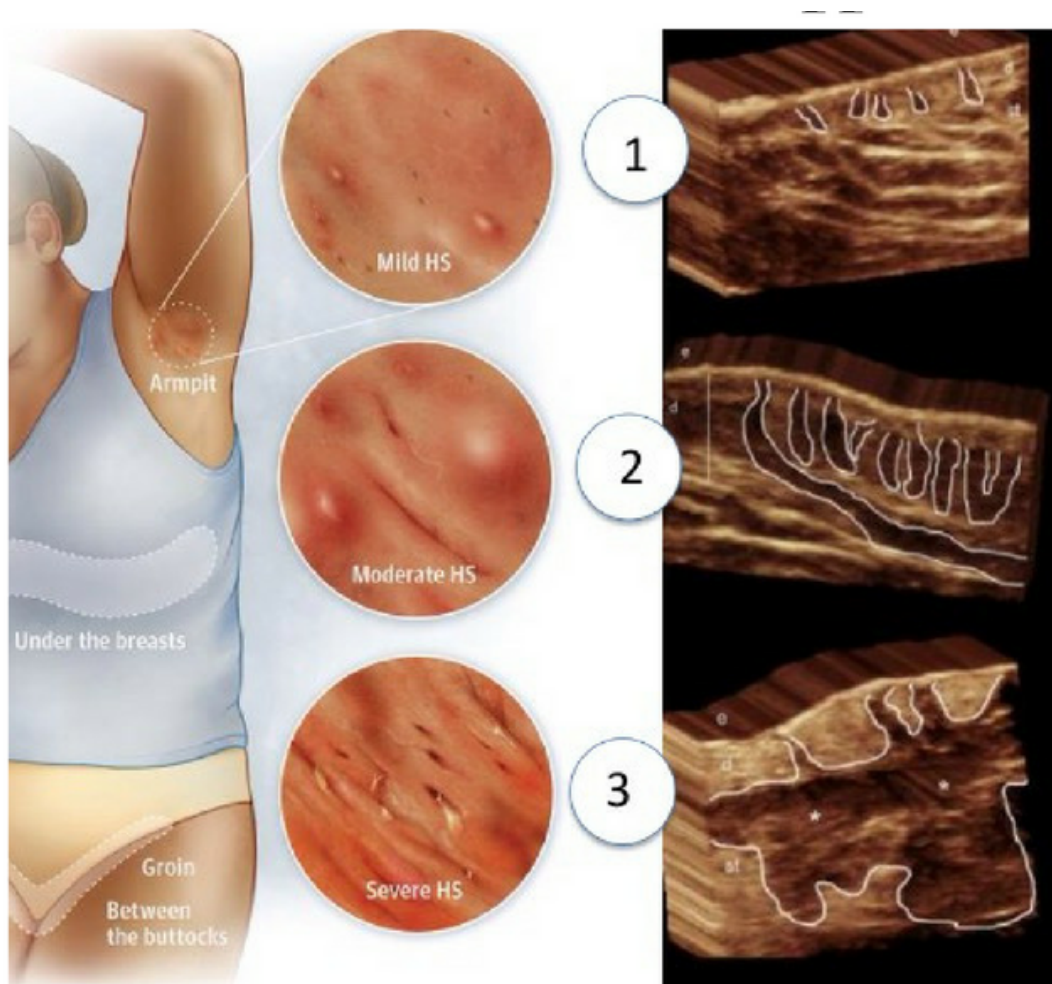
Fluctuations between HS flares varies and it can affect the person continuously as one or multiple flares, flares subsides, and another or multiple flares erupt. There can be different stages of HS on various parts of the body. Due to the various types and subsets of HS it is difficult to determine each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