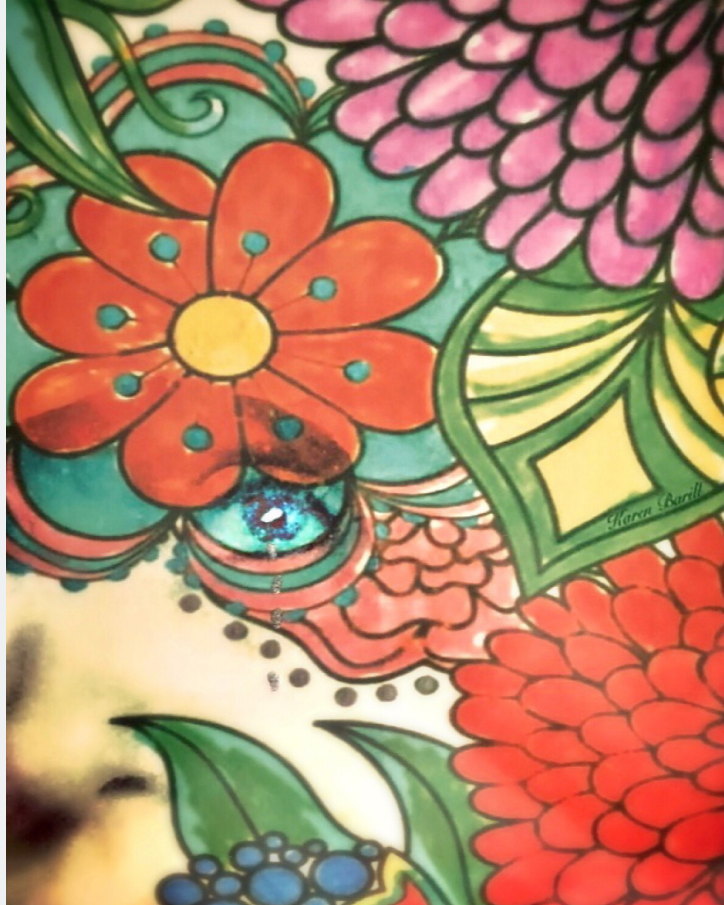


# Never stop fighting

by Karen Barill, Michigan, USA



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

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

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

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

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

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

**Just remember you're not alone!**