

Looking For a Pony

by Patti Suler

TWO YOUNGSTERS WERE PLACED IN IDENTICAL rooms that contained a shovel and large pile of manure. Their reactions were noted: The first boy touched the shovel, looked at the pile of manure and then sat down and began to cry. The second boy spotted the shovel, grabbed it and began shoveling as fast as he could. Both boys were then interviewed. The first boy explained that he was crying because there was nothing in the room but a huge pile of manure and he just couldn't deal with it all. The second boy shared that he began shoveling as fast as he could because with all that manure there must be a pony in there somewhere! I love this story because it not only highlights how perspective can influence our actions but also because poop has a major role in it.

Previously I had written my story while shielding myself emotionally. This time I wanted to be honest and transparent. Storytelling is a powerful tool and requires the teller to be present.

Now, ready or not, here I begin. My story has new journeys and adventures. I love every good and bad moment of it!

The frustration and pain were unceasing. Everything I ate seemed to come right through. Three months after my 44th birthday, I continued to deal with unending diarrhea and all the messy side effects (raw butt, soiled clothing, and missed events). I had tried everything I knew and nothing worked to stop or slow it down. I waited forever for my first gastroenterologist visit. Something had to give. Luckily a friend who had recommended her doctor to me gave up her appointment and I got in a month early. I was a seasoned self-advocating patient. I worked with my doctors and followed instructions. I already had an impressive resume of chronic diseases that I managed well. I found my latest specialist to be knowledgeable and honest. He spoke to me and discussed things; big points in any doctor. I was told I probably had ulcerative colitis and that a colonoscopy would help confirm the diagnosis. I was thrilled. This thing had a name and was no longer an unknown. I was on my way to recovery!

This is not my first rodeo! A common expression in Texas that indicates I am not a stranger to whatever I am faced with. My initial research with my personal librarian Ms. Google revealed that ulcerative colitis (UC) was a chronic inflammatory bowel disease (IBD); one of two recognized diseases that had no concrete cause or treatment. I was considered a late bloomer with my diagnosis as UC usually shows its ugliness

early on. I recalled being told I had a nervous stomach, food allergies, and should have invested in Pepto Bismol stock, as it was my go to self-medication throughout high school.

I had already accumulated over half a dozen chronic illnesses, so I reasoned, what is one more? My ignorance was soon less blissful. One of my existing chronic illnesses had an aversion to my new one. The medication regime that most IBD patients undergo is based on immune suppression via one or more drug combinations. The logic is clear. IBD is caused by an overactive immunological response in the bowel so suppression will help lead to remission aka management, except when the patient already has an unrelated immune system deficiency. It was akin to opposing sides on a chessboard: as one approached, one retreated. One gained strength as one lost, with me in the middle losing on both sides.

My two specialists began a systematic treatment approach cou-



pled with a lot of blood work. I spent the next year and a half emailing Excel spreadsheets with weekly potty trips and diet highlights to one doctor. My other doctor managed monthly multi-vial blood draws. Specialist co-pays are not cheap. My initial symptoms continued without relief. I continued to lose weight and rack up impressive bathroom time at work, home and anywhere I went.

I began 2005 with an anal abscess that I thought was related to my UC. Same area right? The colorectal surgeon was amazing. After the surgery I was advised it was really deep and had been there for many years. Removing the two miles of packed gauze was impressive. Bad news though: the abscess removal created scar tissue in my sphincter muscle which weakened its sealing capability. I now leaked all of the time.

A few months later, my gastroenterologist ordered a CT-scan to see what else might be going on in my abdomen. It revealed a mass on my left ovary. He lined up an oncologist / gynecologist / surgeon for me and the benign mass, along with my ovary and attached tube, were removed.

Except for the surgical recovery periods, I worked the entire time I was undergoing this never-ending flare-up. As I single person, if I didn't work, I didn't have insurance that I needed to manage my health. I had to leave or miss meetings and often was found in the ladies' room. Some folks suggested I have a network connection added so I could still work from the bathroom. I did not see the humor although admittedly my staff often looked there first when trying to locate me.

After I donated my dignity while fleeing to the restroom with my gown just a flapping during my first colonoscopy, I begin to talk potty and share my diagnosis and journey with all who would listen. I felt anyone going through this or who knew someone going through this should not be alone. This was my advocacy in its infancy.

A co-worker heard of my plight and shared that he too had been diagnosed with UC and had a temporary ostomy before getting a j-pouch (whatever that was). He attended a support group of similar folks called 'ostomates' and recommended I attend a meeting. I took his advice and went to the Ostomy Association of the Houston Area (OAHA) meeting.

A vendor representative shared products by passing them around

like a show and tell presentation. Although I really wasn't sure what they were talking about I noticed I was the only one not enjoying the tasty refreshments being served. By this time I had lost over 40 pounds due to malabsorption. Everything I ate caused pain and perpetuated endless bathroom trips.

Whoever these ostomates were, they ate and enjoyed it! Insert a touch of foreshadowing here in the form of lyrics taken from a favorite Rolling Stones song 'you don't always get what you want...but you get what you need'. I am blessed with getting what I need even though I did not realize that I would need it at a later time. This group meeting was just one such occasion. Less than six months after my exposure to an ostomy support meeting my colon perforated.

My colon blew apart while I was undergoing my fourth colonoscopy in less than two years. As with my last two scopes, I prepared some fun music for the team to listen to while they traversed my intestines with the all-knowing camera. I believed this was my new normal and that I would have a new medication or process to try when it was over along with a new set of photos that one really doesn't share with just anybody. Hey, check out this ulcerated portion of my colon! – Naw.

My gastroenterologist reported to his nurse afterwards that the procedure was smooth, no problems. He had noted a small stricture that would require removal at a later time yet something was bothering him. The escaping gases began distending my abdomen during recovery. His concerns were quickly validated and a suspect perforation was verified by an x-ray taken while I was still in the recovery area.

My roommate Barbara was present and carried my power of attorney; however, she was frightened by the decision to take me into immediate surgery to remove my entire large intestines. She requested that I be woken up and advised of the situation. As I became conscious I was consumed with pain from the intestinal leakage into my abdomen and expanding gas. I was hearing 'your colon perforated, we have to take it out now. We have to do an ostomy.' I struggled between the pain and the procedural anesthesia hangover. Ostomy? I knew that word. Fate had placed me in the right place already. "Please, do something, whatever, please stop this pain. I know about ostomy, I went to a meeting recently, consent provided." I was given some pain medication and transported to the hospital for surgery. It was Friday, January 13, 2006.

Immediately, my gastroenterologist started looking for a surgeon. One agreed to do the surgery although it was not in his field. I later teased the surgeon by presenting him with a basic embroidery kit so he could improve on his stitching as my scar had a very defined dogleg in it.

I remember tremendous pain unlike anything I had ever experienced. Deep pain that screamed inside my head. I had been sedated after consenting to the surgery but I have snips burned into my memory. The jarring of every speed bump the ambulance went

over, the sounds of the gurney as it was navigated through the hallways, murmurs, questions, answers, and then one 'Oh my God, look at her stomach!'

As a child I grew up in a very difficult environment. One of my self-saving practices was to close my eyes and go to sleep. Things were usually better when I woke up. Although sleep wasn't overcoming the pain this time, I kept my eyes tightly closed throughout the transport process and surgical prep.

True healing begins within. My initial surgery was dirty. The wound was deemed 'dirty' due to the perforation and I literally had to heal from the inside out. No pretty thin line scar. My belly looked like a restaurant lobster tail for over six months as my body slowly healed.

My colon perforated. It literally shredded from the unchecked disease progression. Had I not been cleaned out and in a sterile environment, just six blocks away from a major hospital, I would not be sharing my story. My disease had progressed so quickly that my colon could have blown apart at any time, any place. Yet, it came apart in the best possible time and place while extraordinary people surrounded me.

I remember waking up and being without pain for the first time in what seemed like forever. I was even more amazed two days later to find out I was carrying a pouch on my tummy alongside an abdominal drain tube and catheter. I walked down the hall with my loaded IV cart. Surely I was glowing in the dark with all the antibiotics being administered to combat the dirty wound. The morphine altered my awareness and perception greatly as there were times I confused events from the news as directly affecting me. My surgeon had prescribed a heady dose indeed. Playfully I asked my surgeon when he came to inspect my sutures if I could still play the piano. He smiled with a knowing grin, "sure" he replied adding, "but only if you could play it before".

These memories are like old friends now, distant but still present and a part of me. My early battle with inflammatory bowel disease was clearly difficult and seemingly endless yet looking back now, this battleground provided the fertile growth medium and opportunity I needed to become the person I am now. I wouldn't change one moment of the journey. I had been given a second chance.

My surgeon and gastroenterologist told me I was not eligible for a j-pouch or similar system because even though my age and initial diagnosis supported it, pathology found only patchy portions of disease throughout my colon. My UC was renamed to indeterminate colitis or more clearly inferred as perhaps UC perhaps Crohn's. The thinking at that time was that people with Crohn's disease were not candidates for a j-pouch perianal replacement because the disease process can affect anywhere in the gastrointestinal system (mouth to exit point) as opposed to just affecting the large intestines. So my ileostomy was permanent.

I need to admit that I absolutely do not like hospitals. The staff

found me sitting in a chair within hours of getting into my room. I immediately wanted to know when the nose tube, the abdominal drain, the catheter along with everything else were coming out. I was told my lungs were not strong during surgery and I had to take breathing treatments every four hours. I was told I had to have abdominal noise indicating my remaining guts were active and awake before I could have anything by mouth. The nose tube stayed in until my other parts were awake and I was no longer at risk for nausea. In order to gain strength, I had to walk with all this stuff. Every time I took a step, in my mind, I was walking home. I had to be off the morphine and IV antibiotics in order to take pills in their places at home.

Let's return to the 'I don't like hospitals' part. I was admitted on Friday after emergency surgery and released to go home on Wednesday. The hospital is over an hour from my home on a good traffic day. I was told if I had a problem with my ostomy to call and set up an appointment to see the hospital nurses. I had declined all home health care and support. My first ostomy change took over three hours as my shaking hands navigated the new accessories, pouching and gaping wound. Although I had attended a support

meeting the prior year, I was now not able to travel right away. My ostomy support came from the Internet and in the form of calling and ordering product from the big three manufacturers. One in particular had a great staff person who listened to my issues and provided not only product overnight but also follow-up and tweaking over the phone.

For the first five months, I managed my pouching by trial and error. I took some photos to an ostomy support meeting in May. Approaching the WOCN after the meeting I asked her if she could make some recommendations based on the photos. She smiled and said that she could do better in person and we set up

an appointment. Her support and the group helped me overcome many obstacles during the first year.

I followed through with my colorectal surgeon after six months and she advised that she reviewed the pathology, confirmed there would be no J-pouch and also believed it to be Crohn's disease versus the colitis. She told me that people lived quite well with a bag despite the bad press. I took that news and a pepperoni pizza home.

It took me almost a year to understand all that she had implied but I wasn't too concerned because all I no longer had pain or diarrhea and I could eat. I ate and ate and ate. No one ever told me to go easy on the weight gain nor that my stoma wouldn't stretch as my belly did with the extra weight. Disease had starved my body for two years and it was hungry. I ate my way back to my original pre-disease weight in no time at all. Unfortunately my stoma became a pouching nightmare in a recessed nest surrounded by its own belly moat.

I named my stoma Junior. It was much easier to say 'I need to take Junior to the bathroom' than 'I need to empty my pouch' when

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JR AND PATTI ZIPLINE 2017

I was out with friends. I still watch strangers look around me for 'Junior' - that is just too much fun.

Junior settled into his post surgical size within six months and was the shape and size of an almond. He required convexity, a full wafer and broke his seal any time movement occurred. Talk about a little pooper. Movement defined as bending, twisting, sitting, and standing. I learned to sleep sitting up as effluent surrounded him when I lay down. I slept in small batches of time so I could get up and empty throughout the night. I changed my pouch often, even sometimes in the bathroom at work. I carried a change of clothing and full emergency replacement kit. Yet I went back to work within three months of surgery (the wound closed six months after surgery - remember no work, no eat, no insurance). I managed this lifestyle for almost two years until a stoma revision in 2008.

The emergency surgeon was unaware of my sketchy colon at the time he was removing it and had left ten inches of rectum behind in case they could use it for a J-pouch connection. This became a major source of new issues. Coupled with the indeterminate diagnosis of colitis, I was considered at risk for cancer and required a colonoscopy every year. Oh so not fair. The first one required the usual no food, sedation and recovery. The second one I opted for no sedation because I really liked eating and thought I could handle the procedure while awake. Never, ever consider this option. Take the drugs.

My remaining rectum oozed constantly, a bloody, mucus goop that required pads or diapers. Flash back to the blown sphincter muscle seal. I was alive, I was not in pain, I could work, I attended meetings and supported others but come on. Through my group support and learning there were better ways, I conceded and scheduled an appointment with my colorectal surgeon regarding my remaining rectum. I took Junior selfies showing him nestled in his

little belly moat. I had my dialogue about the bleeding and annual invasive probing all ready to share.

I presented my request for the removal first. My surgeon reviewed the surgical notes and said she didn't think it was the right thing to do just yet. But, upon looking at the photos of Junior, she simply stated, "I can fix that".

I was scheduled for surgery with a full complement of ifs written up. It could require another abdominal incision, scar tissue from the previous surgeries could complicate things, and it could require a new stoma. There could be all sorts of different circumstances. It actually required none of these. The stoma popped out, she reshaped and resealed it and was done. I was in an overnight observation room and got to enjoy a sandwich and crackers afterwards. I went from a cocktail wienie to a full-blown beefeater. My new Junior was a pouching dream sporting a one-inch round diameter.

The revision was life altering. I began moving, doing, sleeping and living. I could bend over, sleep flat, and make hundreds of movements folks just plain take for granted. This was just in time to pay back my roommate Barbara for her care and support through four years of IBD. Her ovarian cancer returned, our roles reversed and I became the caregiver.

Hurricane Ike hit the Houston area in September of 2008 just a few days after Barbara had her first chemotherapy. We lost power in the storm. This doesn't seem really bad at first until you add on that we were dependent for water on a well system that required power. It was hot, humid and we survived for almost three weeks without power or water. I used information I had previously read to change my pouching system by flashlight. I was still working and pulling emergency shift hours, twelve on - twelve off. Yet we were blessed as co-workers assisted us with securing one hundred pounds of ice each shift for me to take home in a large cooler. Enough ice to provide support for food and chemo medications each day.

We received so much support in during those difficult weeks. Time passed as we recovered from the hurricane and she settled into fighting the cancer once again.

I returned to my colorectal surgeon in 2009 with a fresh rash of bloody butt tales and continuing cancer risk concerns and she finally agreed to remove my rectum. Unfortunately she could not take it from the rear, she had to make a new abdominal incision on top of the old one and go through the top. I thought this would be my last surgery, but nope.

The new incision was tiny and closed up nicely. I was excited and left the hospital the day after surgery complete with twenty or so staples. One would think I would know better and maybe stay a day to make sure all was good. I noticed hardening in the abdominal area two days after the surgery. So I sat with a warming pad on the incision area to soften it up. The abscess that had formed there popped through the sutures. I made it to the bathroom as the wound opened up and drained into the tub. The smell drove my roommate out the door. I packed it loosely in sterile gauze and went the next day to my surgeon's office. She was not pleased and removed the

lower staples, cleaned it out and now I had an open wound to heal from the inside out. It was not quite as deep as before but a good size triangle that created a hard area of scar tissue as it healed.

I took on the role of Newsletter Editor in 2009 with our ostomy group. I wanted to give back by providing fresh ostomy news stories to help people navigate their choices easier than I had. I enjoyed the role of writing, collecting and sharing stories for many years. It brought me closer to my community and advocacy.

There is a saying that things may not get better but you will. 2010 started off with reorganizational work challenges as Barbara's health declined. I needed to be available to provide caregiver support to my best friend. The job was demanding more commitment and responsibilities increased exponentially at the same time my dear friend needed me the most. People first. I took a leap of faith and chose early retirement. Two weeks after my final day at work she had a stroke. Complications lead to her death within five months. I found myself alone and without a job before I rang in the 2011 New Year.

The final months of Barbara's struggles had led me back to my church. I found their informal Saturday night service to be very accessible as I left the hospital or rehabilitation center. I was welcomed by very loving and supportive strangers who watched me cry softly during the services.

The strengths I had discovered as I dealt with my ostomy and chronic illnesses became the foundation for my new life. I moved forward. I took my love of gardening and enrolled in a county based Master Gardener program. I reconnected with my love of photography and leveraged these passions as I continued to become more involved with my church.

I took big, risky steps too. Determined to overcome all of my ostomy fears at once; No guts, all glory, I booked a trip to Hawaii by myself. I arranged airfare, hotel and entertainment for a week. I snorkeled, went to a luau, explored, climbed Diamond Head, managed airports, security, transportation and shopping. I later shared my independent insights at support groups to encourage others to fight their own fears.

I thought I had experienced the last of my ostomy-related surgeries with the removal of my rectal stump but my surgeon had chosen a sphincter-saving procedure over a 'Barbie butt' (complete removal and sewing up the anal area). That old sphincter seal damage showed up again. It wouldn't hold any seal now, which resulted in a gooey end product that seemed to be never-ending.

My newly developed self-confidence was propelling me towards re-entering the exciting world of dating and seeking companionship yet gooey butt was holding me back. One more trip to the colorectal surgeon and I hoped the resulting 2012 surgery would pave the way for me to successfully pursue a dating life. I was grounded during my anal tract excavations (intended to reduce/remove the gooey) for two months so I went where everyone goes in this new era: dating sites.

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I joined one, then another, then another. There is no slot or question field for missing parts, ostomy type, what is your favorite adhesive or pouch brand on these dating sites. I tried most of them, even spending time on an ostomate site. I found after a summer of active online pursuit and research that I was a part of the too old or too young for this type of venue. Having retired from an IT environment I was able to navigate sites, monitor profiles, develop an evaluation standard and run profile comparisons while I healed. The few matches I ended up going in closer for always seemed to be dead ends. I experienced a disastrous relationship for a while that had nothing to do with my ostomy but lasted far too long because of it. 2013 was a bad year that became a foundation for better years to follow. Allow me to explain.

I had not dated for many years, mostly because I worked hard professionally and was ill for so long before the ostomy due to my other chronic illnesses. Now retired, comfortable, and healthy I found my desire to have a relationship was premature because I was immature. My inexperience with mature (adult) relationships cost me greatly. I was so lonely and needy. When I did begin a relationship I found that having gone so long without someone in my life that

I was willing to put up with a crummy relationship rather than be lonely again. I lessened myself and tolerated being treated poorly rather than risk being alone.

I learned a long overdue lesson in that this can and does happen to others regardless of circumstance or missing parts. I didn't get what I wanted but I got what I needed. I was given a chance to begin healing myself emotionally from the inside out. I realized after this very painful experience that I wasn't as together or as mature as I thought I was. I needed to work on me. If I wanted a better person in my life I had to be a better, more whole person first. I looked at life and myself through a clean lens. I examined and defined what I wanted and what areas I needed improvement.

I thought about where I found the best of the circumstances and identified where I was not happy. I began to lighten my load, remove the negative stuff. A process I still enjoy today. Review, revise and act accordingly; some behaviors from my work background that are still good.

Back to my early, no fear agenda. Starting from the what do I want or need now questions. I wanted more real friendships and good people in my life. I went to my church leadership and laid it out. I wanted to be more connected: tell me how. The first recommendation was to join a small ladies' bible study. I joined, I learned and interacted. 2014 began a time of applied self-awareness coupled with cleaning out my mental closets. My master gardener talent was utilized in landscape renewal projects to help others recover their exterior landscaping that were lost due to illness or other circumstances.

I joined a photo club near my home to improve my technical skills. I went on group photo outings and competed against others.



Sometimes I chose to not participate in outings because of my ostomy. I do understand the limitations of being the owner of an ileostomy. I know that I need to be hydrated and am aware of its unpredictability after eating. Long outings without the benefit of restroom facilities disqualify me. I do know ostomates who will not eat or drink to reduce the need for restrooms and I have tried this. It is a choice not a restriction.

I took time to get to know me. They call it being comfortable in your own skin. It sounds so simple, yet it is the hardest thing I ever started and continue to work on. One New Year's resolution for me involved not saying 'no' when invited to go somewhere. I felt this was a way to encourage myself into trying new things. I ended up going to a boat show, photographing a sunrise on the beach in a new town, rooming with strangers, traveling to Oregon and attending countless family related events.

I found my calendar filled with endless commitments and volunteer activities. I next learned how to say no and set boundaries (this is still under construction). Once I repaired and expanded my personal life, I transitioned to self. I became comfortable being single and even told my friends that if God wanted me to have a man in my life, he would lay one across my doorstep with a note on his chest that stated, "Patti, this one is for you. Love God."

My ostomy advocacy is shaped through my interactions with others. I boldly share my disability. I am not disabled. I have a disability. After a recent photo club competition we gathered at a late night Mexican restaurant for margaritas and a meal. Some of the guys were discussing traveling by air and the hassles of going through TSA and security lines. I laughed at one man's story about being patted down due to metal implants in his body placed there to repair various broken things. I shared that I when I went through the x-ray one time they pulled me aside and gently patted my abdomen after seeing something on the scan. What is this they inquired as they patted my pouch gingerly. I responded that I had an ostomy, would they like to see? Several laughed around the table as they tried to recall what an ostomy was. I have learned to share my ostomy tales just like others share their tales of accidents, near death events, stints, strokes, and assorted chronic illnesses. Sometimes I explain more if asked. More often than not, my shares allow for

conversations to begin, sometimes helping others in the process. I have been contacted for follow-up from simple shares to help someone with this or that related to colon issues or just plain poop talk. I have found no better stigma buster than this.

I kindled new friendships, refreshed some old ones and pruned some that were not supportive or kind. I found the confidence to enter a Lay Chaplain program and began learning more about my faith. I believe that whatever we are, whatever we believe, we need purpose and faith in something more than ourselves. We all have gifts and as an ostomate I knew what it was to receive and give back. The Chaplain program allowed me to serve in new ways.

I decided during the program to take a cruise all by myself, to enjoy and reflect. I wanted to expand on my no fear goals by trying to return to my youthful sense of adventure. A sabbatical cruise was just perfect. I planned shore excursions to go snorkeling in underground caverns or cenotes. Additionally, I signed up to swim with the dolphins in Cozumel and enjoy meeting and interacting with new people from all over the world. If I didn't like someone, odds were I would never see them again.

It is physically impossible to pick up something if your hands are already full. To be comfortable in my own skin I had to learn that it was okay to not be a part of nor cooperate with anyone else's expectation. I like flannel shirts, not wearing make-up and comfortable shoes. When I first met my husband I was wearing just that. I share these bits and pieces because I find truth here. Being myself, true to myself, makes me whole. My comfort level reflects my inner light and shares it with others. My journey led me to a closer relationship with my Lord. My confidence in this spiritual journey, coupled with my emotional stability and healthy lifestyle create the wholesome being I strive to be. My life saving ostomy surgery became my 'life restoring, life renewing and source of life surgery'.

Just about every ostomate's story is comprised of what it was like before the surgery, why the surgery, during the surgery and after the surgery. Each story is unique to its writer yet they all contain common elements surrounding the event. Giving back. Many of us tell our stories to help ourselves heal, help others facing similar situations, to debunk stereotypes and fight stigma. We become part of a new survivor tribe.

I publicly share my story or parts of it often for two reasons. The first is because sometimes, I can address ignorance, educate, or connect and be of support to others.

The second reason is more personal. I officially joined my ostomy support group six months after my colon was removed. I remember hearing about a woman who had surgery over two years prior. She had not left her apartment since her surgery because she was afraid, embarrassed, could not cope, nor adjust to having an ostomy. Imprisoned by shame? No one should feel this way about themselves, their bodies, or their right to just 'be'.

Relationships are tough. It's a lot like the two types of SCUBA divers. The ones who tinkle in their wetsuits and those who lie about not doing it. Relationships are difficult for everyone. For people with ostomies, the concerns involve both inside and outside of your clothing and their real importance is often reflected in the top questions after surgery.

Top post surgical questions: What can I eat? Can I bath, shower,

swim? What can I wear? Can I have sex?

The best answer would be sure, if you did it before the surgery. If not, you will have to learn how to do it.

I once wrote a story about a lady marathon runner with ulcerative colitis. She successfully competed in the Boston Marathon with her ostomy. In my research, I came across an article that advised against running for ostomates based on having had abdominal surgery. Mind boggling!

I love scuba diving but was told by someone that I couldn't do it anymore. Moving forward before I could grieve the loss, I gave away all of my custom gear, keeping only my mask, fins and snorkel. Remember to fact check information that is important to you. Last summer in 2017, I went diving for the first time since my surgery in the Florida Keys. I had a blast and plan to pursue more diving in the future.

Another ostomate I knew continued long tubing adventures with their family each summer. Another went hunting in Alaska, another took an African safari, and another, and another. Ostomates continue to overcome and pursue their passions.

Ostomy surgery does give birth to another shared commonality: fear. Many of us face surgery or death scenarios and having survived the surgery find that we still have fear left behind. Fear. That basic instinct is great when in physical danger. Our bodies are equipped to produce adrenalin to prepare us to fight, flee or freeze when in danger. Uncertainty, insecurity, fear of failure, risk are created fears based in what if scenarios. Screw fear; look what you have already overcome. Fear should pale in your awesomeness.

Okay, I will step off of my soapbox and return to the good stuff. Let's return to my cruise of independence in the fall of 2015. "Hi, I'm Billy Jack Pickett from Sulphur Springs, Texas!" This man wearing a nice dress shirt and tie introduced himself around the dinner table the first night of the cruise. As the meal progressed various people shared tidbits about themselves, where they were from, what they did, and general stuff. Proudly sitting there in my Army sweatshirt and non-matching sweatpants, I advised I had just completed a lay pastoral course and was in the process of digesting all the training. Billy Jack advised he was a Christian poet. Really? I inquired. Bring any samples? I challenged as I looked at his smiling blue eyes.

Later in my cabin I thought about him. Where is Sulphur Springs Texas anyway? I did not return to the table the next night having made reservations elsewhere on the ship. Coming back to the shared table on the third night, Billy Jack proceeded to give me a new Christian poem written on the back of ship flyer titled 'Righteousness'. It was good. I started to wonder if this was a note from God.

We eyed one another over the dinner table for a week. As the cruise neared an end, we spent the last night talking about ourselves as we walked the decks. Fiercely guarding my newly formed self-image I advised him that I was an amputee as I prepared to explain my ostomy. He shared that his granddaughter was born

with a birth defect and had one created at birth for a time. He knew what that was. OK. Time to start at the end; we took turns over coffee the last night laying down our respective chronics and weaknesses. Failures, victories and rejections. He had one more specialist than I did but I had more chronic illnesses.

We began a long distance relationship, as Sulphur Springs was a 4.5 hour drive from Houston where I live. We burned up the phone lines. He sent me a card every day from the moment he got off of the cruise ship until our first date on New Year's Eve. We brought in 2016 together.

He turned out to be the one and I accepted his proposal of marriage in October of 2016 after he sang, 'Cross My Heart' by George Strait in a Karaoke bar aboard a cruise ship.

We were married at sunrise on the beach in Galveston, Texas, on May 7, 2017.

With one kiss, I became a wife, mother and grandmother. Four months after we married, Hurricane Harvey hit the Southeast Texas coast. Our home was spared. Billy went through the same Lay Chaplain program I did and commissioned in 2018. At that time, an ultrasound detected a large mass on my remaining right ovary.

Due to scar tissue from my previous two abdominal surgeries, my surgeon requested a colorectal surgeon clear a path to remove the mass. He ordered a CT-Scan and found I had a hernia as well as adding he may have to relocate my stoma, my Junior, to my left side.

The mass was benign and was removed along with my remaining ovary and tube but my uterus stayed behind encased in scar tissue. The hernia was repaired without relocating my stoma but my colorectal surgeon took several hours to unstick my

small intestines and layer them in Suprafilm; a new product used to prevent scar tissue from forming that later dissolves into a gel that will absorb into the body. My stoma was re-shaped and a new pouching strategy had to be developed.

Recovery was a bit slower too. However, he fixed my three level belly button back into one and removed that nasty triangle of scar tissue below. If I can get my firm abs back this year, I might just start sporting a two-piece! Once both surgeons gave me the green light, I rebounded back into activity and completed 2018 more busy than ever with my awesome beloved at my side.

We brought in the New Year quietly with our animals and began having a slower more enjoyable year. Billy suffered a cardiac event on January 12, 2019, and spent the next several days in ICU. They found the cause and he now has a defibulator implanted in his chest along with some new stents. He has a second chance now. We plan to enjoy it.

No more procrastination – and there seems to never be a closing point so that is my point. Life goes on. Make yours a good one. For me, I not only found a pony, I found a herd of them. ■

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Patti is Media Coordinator for the Ostomy Association of the Houston Area.
