


The Phoenix

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By Amy Sloan Nichols

Part I

When I run along some of my favorite trails, I am mesmerized by nature's ever-changing display of colors. It is the perfect setting to reflect upon the many seasons of my life, personal transformations and appreciation of being able to live in the moment.

I have always been a healthy athlete, enjoying all kinds of sports and activities. My husband, Jon, a fellow athlete, and I were married during the summer of 1989. With mixed, but inspired feelings, we bid farewell to our family and friends and relocated from western New York to southeastern Michigan where greener pastures lay ahead; an automotive engineering career for Jon and a high school teaching position for me.

The following summer, we decided to drive west for a second honeymoon. It was a magnificent trip filled with camping, hiking, biking, running, swimming and exploring – life couldn't get any better than this! We returned home and I suddenly became very ill, but I speculated a parasite was to blame. I was not prepared for the diagnosis of ulcerative colitis.

"In sickness and in health..." As a 30-year-old health nut, this was the first time that I was truly sick. My symptoms included a chronic urgency to use the rest room, blood loss and unremitting abdominal pain and cramping. These symptoms, coupled with a significant amount of weight loss, resulted in very limited activities - running was no longer an option.

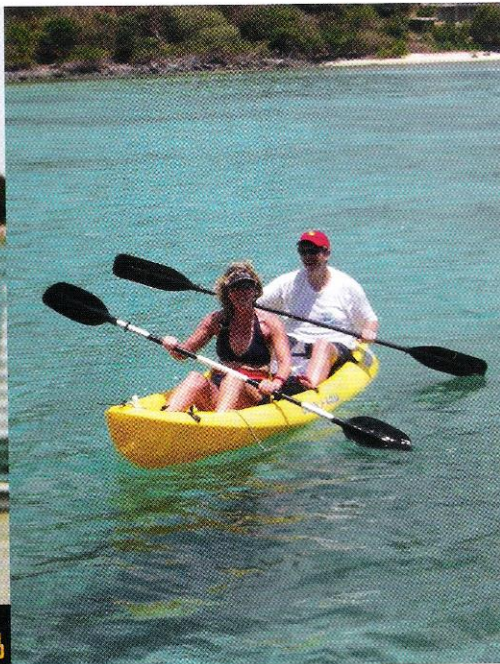
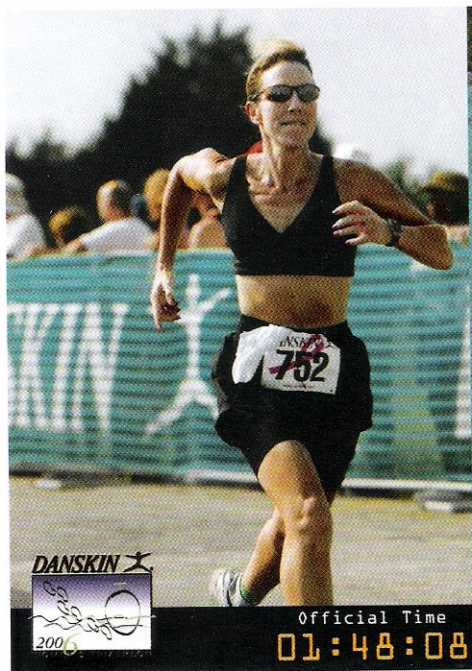
As summer turned to fall, I went from a sense of serenity to that of uneasiness and sadness. I was not

Seasons of My Life

Positive Reflections on Trials and Tribulations

Left: Running in the Aspen trees of Telluride, Co. Below: Enjoying the view in Telluride, CO.





Right: Amy and Jon Sloan kayaking in the British Virgin Islands. Finishing the Danskin Triathlon in Austin, TX.

responding to medication. My spirit was weakening and defenseless. My feelings of despair were like the first gusts of wind that blow the beautifully colored fall foliage from the trees leaving them barren and exposed. Intuition told me that surgery was the next step...and so it was.

The surgery resulted in the complete removal of my large intestine, rectum and a small portion of the small intestine requiring a temporary ileostomy until a second surgical procedure, a j-pouch, could be performed the following spring. At 5-ft., 4-in., I weighed less than 100 lbs. and needed to re-introduce food to my digestive tract. As winter arrived, this lifelong athlete was unable to participate in any physical exercise except the occasional walk down the driveway to fetch the mail.

Unfortunately, I had several complications throughout the winter, spring and following summer resulting in multiple hospital stays (my new "bed and breakfast") with IVs, liquid diets, continued weakness and further weight loss. My doctor told me that I needed to gain weight. I knew this intellectually, but a diet to add weight was both a paradox and foreign concept to me. As the fall arrived, my strength, endurance and weight gain slowly increased and soon my spirits were awakened.

My husband, family and friends showered me with their love, understanding and humor, "Buy some shoes to match your bag?." This entire experience changed my

as the first sign of spring after a long, harsh winter.

I ran a 5K the following spring of 1991, a year-and-a-half after my surgery and have since completed two marathons, several half marathons, plenty of charity road races, mini-triathlons, duathlons and charity bike rides. I participated in a few 100k team trail runs – good fun and great company. I returned to college and completed my Ph.d. This led to a rewarding career as a school administrator with opportunities to teach as an adjunct professor at nearby universities.

I've also had the opportunity to comfort people experiencing similar struggles and surgeries. A myriad of feelings are associated with this kind of surgery that many people are uncomfortable discussing. I am proud to be somewhere near the top of my gastrointestinal surgeon's "shit list" by sharing my story of a painful, but successful recovery while empathizing with others. I am told that I inspire others and it is this appreciation that embraces all that I do.

Part 2

I want to preface by saying my quality of life is great, the human body is an extraordinary machine and I am thankful for each day. I know that I am capable of giving and receiving love. I am surrounded and supported by my wonderful family, friends and my remarkable husband, Jon. I truly understand unconditional love.

I've experienced several setbacks starting in the fall

of 2000 and continuing through the spring of 2007. Actually, I am currently home recovering from my January 2007 surgery at the Cleveland Clinic. Let me backtrack a bit. For more than 10 years I was a j-pouch poster child. Then, in the fall of 2000, I underwent surgery for an abdominal mass that was a combination of an ovarian cyst and scar tissue. The mass attached itself to my small intestine and the doctors were quite concerned. I had just entered a new school year with my staff and was at peak physical performance, having completed a ten-mile race that fall.

The surgery resulted in the removal of the mass, my right ovary and fallopian tube. The mass, which was the size of an orange, was benign. All was fine within a few months and I re-engaged in my activities.

Now I'll fast forward. Jon was aggressively recruited by an engineering firm in Austin, Texas during the winter of 2005. We created a wonderful life in Michigan with sixteen years of personal growth and professional success. Our decision was to accept the job offer in Austin, say goodbye to Michigan, and see what life held for us on our next journey. Sadly, we closed one door and bravely walked through this new door with open minds, ambition and excitement.

One of the most difficult decisions was leaving my surgeon of 15 years. I began struggling with complex fistulas in my j-pouch from 2003 through 2005 resulting in several medical procedures, interventions and surgeries. Crohn's was ruled out and we thought we had it healed that May prior to my move. By the summer of 2005, our move to Austin was complete and I was ready to begin a new job in the corporate world that fall.

Prior to our move, we planned a multi-sport summer vacation in a place we love to visit – Telluride, Colorado. We experience such peace there when the majestic mountains and panoramic views surround us. We had a great time, were very active and ended each day with a glass of wine and a soak in the hot tub. Within two weeks of living in Austin, I was sitting in my new surgeon's office with a temperature and in terrible pain. Yes, the fistulas were alive and well. During my first office visit, my new doctor released the fluid, addressed the pain and reconfirmed the fistula diagnosis and ongoing internal infection.

I was not responding to medical interventions. Just six months after moving and starting a new career, I was prepping for yet another surgery in the winter of 2006. This surgery was to create a temporary ileostomy fifteen

continued on page 57

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continued from page 45

years after my initial one. The intent was to divert the small intestine for internal healing of the fistulas and infection. So let's see, I was 30 and a newlywed for my first ileostomy and 45 for my second.

I couldn't believe I was at that juncture again. The thoughts that flowed through my head were like winter clouds swirling dark grey with sadness. Although I always say it could be worse, I am thankful that I've never been diagnosed with cancer. However, I've often wondered just how much more my body can take.

I adjusted well to the ileostomy and increased my strength and stamina. I stayed very active and fit, traveled for business, joined a golf league, started yoga, entered bike races with Jon, completed a mini-triathlon, sailed in the British Virgin Islands with friends and participated in my first adventure race with a girlfriend. Life was so very good and I was thankful for each day.

It was now the fall of 2006. Comprehensive medical tests indicated the following: fistulas and infection still existed, significant weakness in muscles and incontinence. My Austin surgeon was discouraged. He recommended a second opinion from either the Mayo Hospital or Cleveland Clinic (my choice) where the atypical and complex are the norm. I was given all my options, did my research and realized that I really only had two alternatives remaining: a permanent ileostomy or a Koch pouch (Kock pouch, K-pouch or continent ileostomy).

A Koch pouch is an internal pouch created from the small intestine (like the j-pouch) and attached to the abdominal wall.

You empty the pouch by inserting a catheter through the stoma. The stoma is flush to your skin and covered by a bandage. This is an uncommon and often unpopular surgery because it is technically complex and often associated with complications. It has virtually been replaced by the j-pouch or by a permanent ileostomy. Interestingly, a childhood friend had Koch pouch surgery over 23 years ago before j-pouches were available. He has coached and supported me (and Jon) since the very beginning in 1990.

An internationally renowned surgeon at the Cleveland Clinic is recognized for his technical expertise with Koch pouches. We went to get his professional opinion and to determine if I was a possible candidate. I was and underwent the surgery in January of 2007. This was a very difficult surgery with large amounts of scar tissue that further complicated and extended the length of surgery. I write this article while recuperating at home. The recovery is slow and often painful, but I am increasing my stamina and endurance each day. I have far to go, yet I have come so far. I won't allow this to hamper my Pollyanna outlook...spring is in the air.

We love living in Austin. There is plenty of sunshine and the mild climate invites you to play outdoors. I'm excited about wearing form-fitting clothes again and maybe a two-piece bathing suit this summer. Equally, I thrive on the endorphin rush I get when I eventually go back...no, go forward to my full and active life. My next goal is to participate in a sporting event and only wear my Ipod® by choice and not an ileostomy bag by necessity.

One of the many lessons I've learned through all of my trials and tribulations is this is life, your



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life, my life. It is fragile. You don't get a dress rehearsal. It is how you choose to reflect on all that happens that allows you to be your best self and live your best life. One must maintain a positive outlook and healthy spirit, understand the mind-body connection and respect the human body as a fascinating machine.

I will continue to reflect, recognize and appreciate all that I have and all that I am. Jon and I will celebrate 18 years of marriage this summer and are planning our next trip to Telluride. I am delighted to say that at age 45, the changing, multicolored seasons of my life continue to flourish and follow trails of their own leading to places that resonate my past, welcome and respect the present moment and guide the path to my future. ☺