Recovery is a Marathon, Not a Sprint

The sun hadn’t even thought about rising yet. It was Sunday, September 18, 2010 in Appleton, Wisconsin and it was cold. Cold enough to see your breath and jumping around in a group of fellow team members was the only way to stay warm. It was a good hour before the start of the race and we were doing just that, huddling close together and jumping up and down to try to get the blood flowing through our veins. I looked around our group, all wearing Team SJS or Super E shirts in bright royal blue, and realized that this was the day that I had been dreaming of for 9 months.

It all started with a silly invitation to my local friends on Face Book, asking if anyone would want to run the Fox Cities Half Marathon with me on Sunday, September 18, 2010. I had never run that distance before, either before or after my battle with TENs in June, 2008. My husband and I had run for years and I dabbled in triathlons and duathlons, but I had never even considered that I could actually complete a race of that magnitude. That is until January, 2010 when I had decided I was tired of living my life with SJS and decided to live my life after SJS. It was time to put some closure on that part of my life and to make new memories that would allow my heart to heal along with my body and my spirit.

It wasn’t long before I had a list of people who were planning on running or walking it that day to help raise awareness in my town. The local paper did an article on me and the Team in July and it covered the front of the Sports page. I was so excited and couldn’t believe that this many people wanted to make a difference with me. I figured then that there was no backing out for me. There were too many people that knew I had committed to doing his darn thing! I couldn’t weasel out of it now!

And then I started making more and more friends on Face Book with fellow survivors and a few of them helped me to see that this could be so much more than just a half marathon if we all did it together! Rachel Corley Guiterrez flew in from Boston, Catherine Walchl flew her husband and son from Atlanta and Ethan Maidl drove with his parents from Val Paraiso, Indiana in hopes of meeting others like them. People that understood their every day struggles, their fears and their wants for the future. We all knew it was going to be great and exciting, but we never dreamed that it would be more than what we ever could have imagined!

Not only were there 4 survivors here at the same time, but they each brought their families and friends. People came from Phoenix, Washington state, Milwaukee, Marquette, MI and, of course, the Fox Cities. The group had grown from me and my husband to about 50 in just a few weeks time. It was going to be bigger than we had anticipated!

We spent as much time together as we possibly could during those few days leading up to the race. We shared hospital stories, tips for skin care, as well as fears, frustrations and tears. We talked about SJS, but we also talked about our families, our goals and dreams, our lives before the illness and how we were doing after wards. My husband, Mike, and I educated our out of town guests on cheese curds, brats and local micro brews. Wisconsin has so much to offer! It was so much fun to share our town and our lives with our new friends, and so much fun to learn about their lives and where they
come from. We made plans to visit each other and promised to stay in touch. And I can happily report that that has remained true! Plans are in the works for a visit to Val Paraiso yet this winter.

So as I looked around on that early race day morning, waiting for the news crew to interview us before the start, I prayed a prayer of thanks to God for bringing us all together for a cause that I will forever hold near and dear to my heart. I thanked Him for the strength and the courage to try, for the condition my body was now in considering two years before I had been in a wheel chair, for the love and support of my husband through the months of intense training and for all of the people that felt it was important enough to come to Wisconsin and plow through 13.1 miles. And before I knew it, the gun went off and we were running!

Along side of me was my husband and coach, Mike, and Super E’s mom, Heidi. My older brother, Sean, had borrowed a bike and was riding along the route to stay with us throughout the race, just as he had through my hospital stay. We laughed a lot, saw people along the route wearing their Team SJS t-shirts cheering us on, heard a stranger yell that he had seen us on TV that morning and that we were “looking good”, and were asked by other runners what our shirts meant. We put one foot in front of the other and counted the miles as we moved forward. There were Team members throughout the entire route, some running and some walking the half and some braving the full marathon. SJS was represented all over the place in our bright blue shirts, and Heidi’s pink hat with signs sticking out of her head!

The miles passed by at our 12 minute pace and I thought at times about the fight that all of us survivors have been through. I thought about all of the people that I had spoken to on Face Book and those I had spoken to on the phone. I thought about their struggles with their eyes, with nerve damage and fatigue. I thought about my own struggles with the same things and how I had pushed through the pain and discomfort for all of us. I had never believed in something so strongly and I was going to get to that finish line no matter what!

It wasn’t until mile 11 that I started to notice the signs of my SJS. I had struggled with intestinal issues, nutrition and dehydration throughout my entire training season and I thought I had kicked them all. Eating certain foods, avoiding others, eating a certain number of times a day, not eating after certain hours, hydrating with diluted Gatorade in order to avoid stomach upset from too much sugar, and salt tablets every half hour while running longer than an hour. Things that I never had to deal with before my illness, but things that will forever be a part of my new life. A minor irritation compared to losing my life during the summer of ’08 and minor compared to many of my other friends with similar stories. The cramping in my belly intensified and we slowed to a walk over the bridge that ran alongside the hospital where I had been taken when the rash had covered my body. I had spent two days there before being transferred to a burn unit in Milwaukee. I looked up to the windows and thought again of why it was I was doing this. Why these incredible people that I had never met in person would travel halfway across the country to do it with me. It was then and there that we began running again and I knew we weren’t going to stop until we crossed that finish line.
As we rounded the final corner of the park, I could see the sign hanging over the heads of runners and hear the thump, thump, thump of the music calling to us to finish. I could hear my family and friends cheering and then I heard nothing. Not a sound. It was as if someone had pushed the mute button on the TV remote. All I could hear was the sound of my own breath and the pounding of my feet on the concrete. I reached my hands to my sides grabbing hold of Mike and Heidi’s hands and we raised them up over our heads. As we stepped onto the finishers mat, recording our final time, I realized that we had done what I had thought I would never be able to do. I had, with my friends, family and total strangers, conquered 13.1 miles all in the honor of those who had fought and won and those that had fought yet lost their lives to the most devastating illness I know of. We had done it for them and we had done it for all of those that have never heard of Stevens Johnson Syndrome. We did it to put SJS on the map and to hopefully let people know what all of us already know, that it can happen to anyone!

It was decided at a breakfast table in a little café that very next day that this was going to happen again next year, and the year after that and the year after that. Team SJS will be represented at the Fox Cities Marathon for as long as I can do it and maybe even after that. Not everything that comes from SJS is bad. I know that now better than ever before. I learned that there are incredible people in this world who feel the same way as I do about this illness. I learned that I am stronger than I ever thought that I was and that my new friends mean more to me than I know how to express. I am hoping to add more people to that list of friends next year! I hope you will think of joining us here in the great state of Wisconsin. Run it, walk it or cheer from the side lines. We don’t care how you get here, just get here and share in the magic of a glorious day!