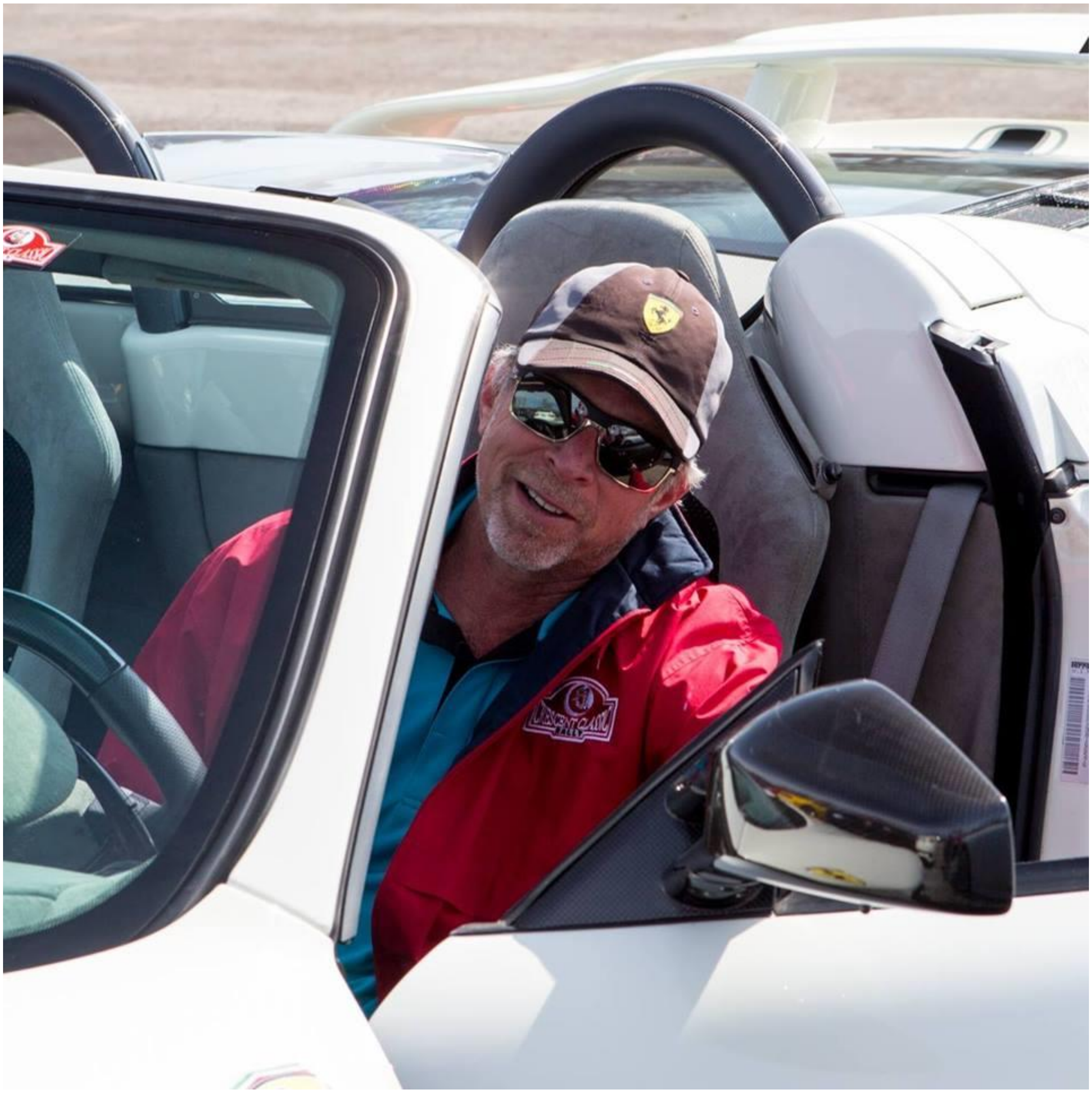
MY STORY

by Chad Shaffer, Co-Chair of Step Beyond Celiac 5K Run/Walk and Car Show



Just sitting here in bed taking it easy before my next gamma infusion. Infusion #117 is only a few days away. Thinking about the past few years and the upcoming Step Beyond Celiac 5K run/walk and car show.

Almost 8 years ago, I was hospitalized for an unknown illness that had taken its toll over the prior 3 months. I was at the top of my professional career, working two jobs and loving every minute of it, 80-100 hours a week, and had many hopes and dreams.

Then it came crashing down.

I barely weighed 110 pounds, could not walk without leg braces and crutches, and spent a lot of time in a wheelchair. I needed help to get out of bed, get dressed, even go to the toilet. Oxygen tanks and buzzing machines for apnea surrounded me. I was dying, plain and simple.

I developed a life threatening heart arrhythmia that was the last straw and put me in the hospital.

I remember thinking that I wouldn't reach my 50th birthday, but strangely enough, I didn't care as I was just so sick and miserable.

Several months of hospital stays followed, including over 20 times to shock my heart back into normal rhythm

Right before Christmas I suffered a cardiopulmonary arrest at home. My wife performed CPR and revived me from laying lifeless on the floor next to my bed.

The source of my illness was unknown at the time and treatment options in my hometown were exhausted. The best doctors simply didn't know what I had or how to treat me.

We began a snow packed icy drive to Mayo Rochester MN. I will never forget that drive. Lots of time to think. Never felt nervous or worried the entire trip, as if guardian angels were guiding the car every treacherous mile.

We spent a lot of time at Mayo but fortunately, were able to overnight with two of our best friends. I remember telling him that it would be too much trouble to coordinate all the oxygen equipment and oxygen machine at the house. He would have no such words.

When I arrived, very sick, they had a special room prepared for me, and all the oxygen equipment and supplies were sitting there ready to go. I don't know how they managed all of that, but having a bed to sleep in at your best friends' house instead of a hospital or hotel bed is a comfort that is beyond description. I am forever grateful.

I was so tired of tests, pokes, needles, biopsies, shocks, and procedures that I couldn't imagine going thru another one.

What followed was three weeks of the most intense round of evaluations, testing, and procedures at the Mayo. But first priority, try to fix the heart.

A 13 hour heart procedure and operation took place to fix the damaged electrical circuits. I've seen a lot of amazing medical procedures in my career, but lying there awake for almost 2/3rds of it was an amazing and humbling experience. The technology, state of the art equipment, and dedication of those health providers was a small miracle.

I got tearful at one time and the anesthesiologist asked me if I was in pain. I told him no, just thinking about life and how drastically it had changed. He told me that God had plans for me and not to worry. That was a turning point in my attitude toward my illness and will never forget it. He was right.

A set of autoimmune diseases were diagnosed, triggered by a severe form of Celiac Disease. Gluten? Are you freaking kidding me? Can it be that simple?

It wasn't that simple. The disease had probably been there most of my life but some kind of trigger put it into overtime mode. My body's immune system had launched an attack throughout my body, muscles, nerves, gut, skin, brain, and heart.

A precursor for a rare untreatable form of lymphoma was found in my gut biopsies. Surprisingly, I wasn't scared. Challenge accepted.

That's when I first thought of the quote "Some days the Dragon wins and some days the Dragon Slayer wins". It has been the most difficult battle of my life and it continues to this day.

Experimental treatments were tried. Terribly expensive and they were not covered by insurance initially. That was a hardship, but nothing like the social isolation that took place.

Almost everything I did prior to getting sick was ripped away in one form or another. My work, career, friends, social network, activities, hobbies, sense of self worth, ego....you name it....gone.

After another operation on the heart and a trial of high dose steroids, things had improved slightly but the lymphoma precursors had progressed.

I spent over a year in physical therapy to learn to walk again and take care of myself. The PT Director was a colleague and personally took care of me. Daily PT at first in the swimming pool because I wasn't strong enough on land.

During that phase of rehab from my own philosophy of never quit, never lose, always give 110%, I tore the rotator cuffs in both shoulders, ruptured 4 discs in my neck that have pinched my spinal cord space in half, damaged the nerves to my right arm and shoulder, and developed paralysis of the diaphragm that moves air into and out of my right lung. Those are ongoing daily battles that most people are unaware of to this day.

We switched to a type of treatment for one of my other autoimmune diseases known as immunotherapy. A former Docent teacher of mine took me under his wing and set to work. He prescribed gamma globulin immunotherapy. It's a bit like chemo for your immune system, only different. We hoped it would have an effect on my refractory celiac disease and lymphoma precursor cells as well.

A number of my friends and even family had gone thru chemo, so this would be a battle but it would have an end and hopefully a favorable result. It's good to see the light at the end of a tunnel to help you get thru things.

Unfortunately for me, "chemo" has never ended. Every 3 weeks for the past 8 years. Getting ready for #117. Two days of IV "flu in a bottle" initially, now one long 13 hour infusion day. When I stop to think about it, that is just mind boggling. Although I hope and pray that someday I will have my last gamma infusion treatment when a cure for celiac is discovered. It is what it is for now and to be honest, I don't really have any big complaints. The alternative simply isn't acceptable.

My lymphoma precursor cells have gone away for the time being. This particular form of enteral associated T cell lymohoma has a dismal prognosis of less than 6 months survival time from diagnosis. My form of celiac carries a 5-year mortality of 60%. Well, I obviously made it past 6 months and blew by my 5 year mark. There is much more going on here than science can reasonably explain. I'm gonna take it and run with it! Further research is greatly needed for celiacs and others like me.

Most of my acquaintances and friends knew me before I got sick or after I started some recovery. I let very few people in my circle when I am sick. Always been that way. Never let anyone see you down or less than 110%. A lot of people that casually see me now would never know anything is wrong. That's the face of an Invisible Illness in a strong willed person that never wants to be seen as anything but positive and strong. Weakness is the enemy. But it comes with a price.

That's part of the reason I am writing this note. It's more for me than for you. Feels kind of good to not be quite so hard on yourself and set realistic expectations while not being afraid to dream big even though you might fail. In the past, I would have never dreamt of such a crazy philosophy on life.

That one day of energy and smiles that you see was preceded by 1-3 days of preparation and rest and followed by varying durations of "paying for it". Every battle results in wounds that take a while to recover and get ready for the next one. It's not something you can do every day, or even every other day. My mom says I wasn't born with frown muscles in my face and have always had a smile no matter what. Returning to work has not been an option in my career and it's one of the most devastating consequences of this whole damn illness. But how do you fill such a huge void?

I can say without hesitation that getting together with a local car club as my health began to improve somewhat is what probably saved my life as much as anything else. Treatments can only do so much. Social interaction and a feeling of self worth and positivity is an amazing healer. Without my connection of car friends, I would be dead by now. No question about it.

One of the first times I went out of the house socially after this severe illness was a visit to a car event where I met our car show hosts for the first time. I felt welcomed and they were a beaming source of positive thinking and energy. They are hosting the car show to benefit Step Beyond Celiac. Couldn't think of anyone else I would rather have working towards a cure for celiac.

Next, was a charity auction to benefit a local charity foundation. They sponsored that event too and it's where I bumped into another person for the first time. Wow, what a character! We knew right away we would be lifelong best friends.

I sold my daily driver, changed our financial focus, and we bought a car we had always wanted. Live a little I thought. It's just a car but it can't hurt. Right? Even though you battle every day, there is still that little nagging dragon in the background that reminds you that life isn't simple any more and it is likely to be significantly shortened. So let's make the best of any given moment.

That car led me to the car club where I began to meet some of the most genuine, generous, and fun people I have ever been around. All of them accepted me for what I was, what I could do or couldn't do, and made me feel welcome.....always.

Even though I was fighting dragons at probably less than 50% of what I could have done before my illness began, and had such terrible mental fog it was hard to focus on anything, they accepted me like the real nut that I am. I am forever grateful to this group of friends that have become family to me.

I tried to keep the goal simple.....just take a green flag in one race. Please God, don't let me screw that up. It was against all medical advice and considered unobtainable.

The couple who started this race series worked with my limitations and were supportive all the way. A pro race driver instructor was my biggest fan and believed in me. Powerful stuff when you don't have a lot of confidence after what I had been thru. We modified the approach to fit with my capabilities after the illness. Not only did I take a green flag, I took a checkered flag! And then did it again one more time.

I had more satisfaction from that event than any other single personal goal I have ever achieved. Ever. Thanks to all who made it happen.

Amongst many new dear friends, one couple have been especially amazing and have given me wise advice and unending, no-strings-attached support and love. I don't know where I would be without them.

Yet another friend makes sure I always have the right attitude and gives me frequent doses of his amazing positivity that is nothing shy of contagious. He is deep in my inner circle and is an amazing source of energy for me. He has "never had a bad day in his life". He hides things well too. That's why we get along so well and are like best friend brothers.

Mom remains my biggest fan of all and would gladly accept my illness upon herself if it would make me better. She has a special place in Heaven waiting for her. Saint Bernadette for raising us three boys. Mom is celiac too but thankfully, not the severe form that I have. Dad has the celiac gene but the disease has not shown itself in him yet. My two brothers do not currently have celiac.

My forever pets have been our children over the years and have given an immense amount of love and support these past 8 years. Days of lying in bed, just wanting to cry, but those dogs never left my side and the tears would always just dry away. Those two have recently gone to heaven and now I am blessed with five more dogs to lead me through life’s challenges and occasional tears.

Most of all, my wife has been my biggest support of all. It's easy to forget how much this illness has taken away from her too, changed her lifelong dreams, and pushed her to new limits each and every day. From not having kids to little hope of early retirement, she has given so much. I have always been good at being a pain in the ass. But this illness brought it to whole new levels. She has been a faithful companion thru thick and thin, in illness and in health, til death do us part.....for the past 27 years. Little did she know the past 8 would have turned out the way they have. I love her more with each passing day and look forward to every tomorrow with her. So here I sit before my next infusion, thinking about life and purpose. That anesthesiologist was right. God does have a plan for me. He pulled me out of the rat race, allowed me to try and enjoy life to the fullest each day, and has given me a set of forever friends that most people can only hope for.

Sometimes you have to accept battles to get where you are going in life. I'm not exactly sure where that is, but if these past years are any guide, then I welcome another year!

These experiences have brought me to help create the nation's first Step Beyond Celiac 5K run/walk and car show to benefit research towards a cure for celiac disease. This is about friends; new and old, giving back to community, participating in something bigger than yourself, setting high goals and reaching them, and winning....winning in life thru a cure for celiac.

Thanks to all who are making this happen. Your friendship and support is truly amazing!