

And So It Begins Again

My life with brain cancer



Beginnings

Posted on **November 18, 2012** by **VAD**

My name is Vince DiCroce. Sometime ago my wife told me I should write about my life. Maybe it is time.

In October 2004 I ran the Chicago Marathon. It was an incredible experience. Emerging from a painful and difficult divorce, 42 years old feeling like life was just beginning. I was on top of the world. Chicago represented a new start. I set my sights on qualifying for the Boston Marathon. High aspirations for someone who just a year earlier was so out of shape that he couldn't run a mile.

A month later I was in the hospital. Diagnosed with brain cancer. Initial prognosis was grim. No cure. 3 – 5 years to live. Life was just beginning indeed.

I refused to give up. After all, life expectancy is just a number. It did not dictate my future. I resolved to fight and to be stronger than before. I would defy the odds and live. I would more than live. I would be faster, stronger, and better in every way. I continued running. I ran through the incredible pain and debilitating weakness of chemo therapy. Six

months into chemo I ran a half marathon. Two months post chemo I ran the Duke City Marathon setting a new PR. I refused to let up and kept going.

Each year a new PR. During my brain surgery I told my neurosurgeon that I would qualify and run the Boston Marathon. I am sure I sounded crazy at the time. In April of 2008 as I crossed the finish line on Boylston Street in Boston, it didn't seem so crazy. And I was just taking off.

Pushing myself to faster marathons wasn't enough. I signed up for an Ironman triathlon—a 2.4 mile swim, 112 mile bike ride, and a marathon. I didn't know how to swim, but it didn't matter. I completed Ironman Wisconsin on my 44th birthday, September 7, 2008.

Since being diagnosed with brain cancer I have completed almost 30 marathons and 7 Ironman triathlons. All the while, to the amazement of everyone, doctors included, my tumor was shrinking. With each race finish I felt I was defying death. I was getting faster, stronger, and better than before.

For the last several years, at the beginning of the year I type out an event schedule with my major races and tape it above my desk. After I complete each event, I make a check mark and write how I did such as my time, place (AG or overall) and whether it was a PR. For 2011, next to each event there is a check mark followed by "PR". In January I began to prepare my schedule for this year and I thought "how can I top 2011?" I turned 50 this year. Between advancing age and setting the bar so high last year, improvement seemed improbable if not impossible.

"Anything is possible" is a motto of Ironman. 2012 proved that to be so. What seemed impossible in January was accomplished on Saturday November 10th when I ran the Richmond Marathon in 3:03:39. My last race of the season, a 6 minute marathon PR from last year, and an exclamation point to a season where I once again set a PR in every event.

2012 had been a good year. A great year. Better than I had dreamed and hoped for. Although my event results were nice, it is what they represented that was important. A PR is just a time. Meaningless in the grand scheme of life. To me, my constant improvement in races was a reflection of my life. I have been damn lucky. I was more healthy than anyone could have expected, my life with my wife Linda had never been better. We were very happy in our home. All of the kids were doing great. We were starting to even think about a future retirement—something that was unimaginable just a few years ago. On the flight home that night, for what seemed like the first time I felt at peace. I could afford to let my guard down and let up on this insanely strong internal drive to push forward in order to convince myself and everyone around me that I am alive. I was diagnosed with brain cancer eight years ago last week. Linda and our daughter Leah had a surprise celebration for my anniversary a couple days before I left for my race. We reflected upon how fortunate we were. We talked about the sign I made just after being diagnosed and hung on my office wall that reads "I will not just survive. I will be better than before." We smiled

in contentment at how what seemed mostly as false bravado at the time turned into reality over the last eight years. Truly, we did not just survive, we were better than ever before. As the plane landed in Denver Saturday night, with the post marathon soreness beginning to set in as my 3:03 celebratory beers began to wear off, I wondered as I did before, "how could I possibly top this year?"

My question began to be answered three days later 9:00 Monday morning as Linda and I saw what we had come to believe impossible. The monitor in the exam room revealed something we have never before seen—on the MRI were two very bright and unmistakable areas of new tumor growth.

Maybe it is time to start writing about my life.

I haven't mentioned this to anyone else other than my immediate family and a couple of close friends. I am still trying to absorb it. My friends in my running group (Runners Edge of the Rockies) are still in disbelief about the 3:03 and wondering how soon I will break that 3:00 barrier. Soon enough they will know that I am not Superman.

I suppose it is from the greatest challenges that rise the greatest successes.

And so it begins again.

And So It Begins Again

My life with brain cancer



Ignorance is Bliss

Posted on **November 22, 2012** by **VAD**

I met with my neurosurgeon on Monday and the oncologist on Wednesday. Both confirmed what I already knew—my tumor is growing. The sleeping giant stirs. My course of treatment will be long. Longer than I hoped. Six weeks of radiation with daily chemo. A month break followed by another 12 months or so of chemo. About 15 months in all. It really depends upon how long my body can hold up.

I learned a lot about brain cancer and various treatments over the years. I don't obsess about it. I simply try to keep up-to-date on new developments. It doesn't take a lot of time. There isn't a whole lot of good news in the world of brain tumors. The cancer lives in your head with the singular purpose to kill you. And it is very good at it. There is no "cure." Some forms kill you fast. Others more slowly. To make matters worse, as it grows in your head to fulfill its mission of death, it destroys your brain along the way. Your sense of sight, smell, hearing, balance, coordination, cognitive ability, and emotions are all controlled by your brain—in essence, the core of your being; your very existence. Depending upon how fast the tumor grows and where it is located, any and all of these can be affected.

Standard treatment is a combination of surgical removal of as much of the tumor as possible, radiation, and chemotherapy. Basically treatment is creating a balance between quality and longevity of life.

In 2004, I was diagnosed with a stage two oligodendroglioma. Fairly rare, but if you have to have a cancerous brain tumor, not a bad one to get as they are slow growing. More importantly, my tumor has what is called 1P 19Q deletions. The details of the pathology don't matter here. What does, is a study published in June that provided the biggest development in brain cancer research in years—people with tumors having the 1P 19Q genetics, treated with radiation and chemotherapy appear to have a dramatically increased rate of survival and decreased rate of recurrent tumor growth.

My tumor currently lives in my right occipital lobe. The area of the brain that processes vision to the left side. In 2004 – 2005 I was treated with chemotherapy. My tumor was fairly diffuse. Surgical removal would have meant a significant loss of vision at best. And it may or may not have increased my life expectancy. Even with surgical removal, these tumors come back. In short, the balance between quality of life and longevity did not necessarily support surgical intervention. Temodar, a new chemo drug at the time, offered some promise. It is taken in capsule form and was reported to be easily tolerated with few adverse side effects. The thinking was “let's give it a shot, monitor with an MRI every three months, and see what happens.” For 8 years the plan was working.

When you are young you feel immortal. Death is a mere concept, not a reality. For me, that changed when I was diagnosed with brain cancer. I remember very distinctly the day it hit me that there was not a big “S” on my chest and I didn't have a red cape. It hit me so hard that I physically hurt from the impact. I spent the next eight years trying to convince myself and everyone else that I really was superman. I was good at it. Over the years my tumor shrunk. My MRI looked better 3 months ago than it did 6 years ago. There was no explanation for it, but you can't argue with the MRI. I improved my diet, exercised every day, did my best to get rest and reduce stress in my life. I was in good physical condition at 18. I was in better at 50.

Before being diagnosed with brain cancer, I knew nothing about it. Like most people, I knew that generally cancer was bad. I had some familiarity with different types of head and neck cancer from my days as a Navy Corpsman working in an ENT clinic. I seemed to remember that most types were treatable if caught early.

I knew pancreatic cancer was bad. It killed my grandmother—one of the strongest people I have known. When she was around my age she suffered from appendicitis for days, refusing to go to the doctor because she had too much to do—ironing clothes, cooking and such. By the time she made it to the hospital her appendix had ruptured and she nearly died. The doctors said one more day and she would have. A few days later she was back home running the house. Tough as nails, but pancreatic cancer took her quick. Twice as long as the doctors predicted, but quickly. As I laid in an E.R. bed in November 2004 waiting

for the doctor to tell me what was going on with my head, I knew Lance Armstrong had overcome testicular cancer and had recently won the TDF for the 6th time; but, I knew absolutely nothing about brain cancer.

When the doctor returned to the room, he told me he wanted to get a CT scan. My symptoms were pretty bad. I couldn't walk without bumping into the walls, I was unable to do simple tasks such as read or type and I had this mind splitting headache that would not go away. He said they were looking at three possibilities—MS, a stroke, or a brain tumor. I thought to myself “I hope it is #3. They can remove a tumor. The other two are permanent.”

The first indication that my reasoning was flawed occurred shortly after my CT scan. I was back in the E.R. room waiting for the doctor to give me the initial results. A nurse, who apparently thought I knew the results, walked into my room and broke down into tears as she told me how sorry she was for me. She attempted to provide me with some reassurance and told me that there were some promising results with “snake venom” trials in Israel. She gave me a hug and told me to not give up hope. That night I was admitted to the hospital for observation and to get an MRI and a PET scan the following day.

My next clue was when they wheeled me back to my room after my MRI. Apparently the results made it back to the floor before I did. As the attendant wheeled me down the hallway, Linda by my side, I felt like “dead man walking.” It seemed all of the hospital staff were awaiting my arrival. They looked at me without looking at me. It was eerie. What followed was a whirlwind.

Later that night a neurosurgeon met with me and my family. He explained that he was relatively sure that I had a tumor. He explained he could operate on me the next day and remove as much of the tumor as possible. He said another option was to go to University Hospital where I could be evaluated by an entire team. The gravity of the situation was starting to sink in. But I still had no idea.

Within a week, I was in surgery at University Hospital. The biopsy confirmed cancer. My neurosurgeon recommended against a full resection and suggested instead a course of chemotherapy. He described Temodar and the promising results of some trials. Within another week I was with an oncologist and beginning chemo. Despite my best efforts I still did not fully understand what I was dealing with. Between, the pressure in my head from the growing cancer, the trauma from the surgery, and the steroids to reduce brain swelling, it was difficult for me to understand simple thoughts, forget trying to understand forms of brain cancer and what it everything meant. It was all moving too fast.

What I did understand is that the chemo was supposed to be relatively easy. Take a pill for seven days, take a couple of weeks off, repeat. Sounded simple enough. The reports were that it was easily tolerated. No real side effects. Should be able to do everything as normal. Maybe some constipation and a little fatigue. Much better than previous forms of chemo. No big deal. I didn't know any better. Ignorance is bliss.

For me, chemo was a big deal. I won't claim to have my grandmother's toughness, but I'm no cream puff either. I went to the hospital before my appendix ruptured. I was in 4th grade at the time. Granted, I couldn't stand up straight because of the pain and they did rush me into surgery because it was about to rupture. But the chemo kicked my ass, plain and simple.

I convinced the oncologist to put me on somewhat of an accelerated cycle—5 days on, 16 days off rather than the then standard 5 on 23 off. Days 1 – 3 were OK. Days 4 and 5 not so good. Days 7 – 14 were awful. I could barely walk up stairs, at some points I could not comprehend simple sentences I tried to read. I heard it called “chemo-fog.” It is what it felt like. Like I was enveloped in this increasingly dense painful fog. Time seemed to stop and disappear at the same time. By day 14 I just wanted to get through to the other side. The fog would seem to lift for a couple of days, and then it all started over again. Each cycle was increasingly worse. My body atrophied. During each cycle I became incredibly constipated causing my bowels to distend. At times, I looked like I was pregnant. The drug killed the natural ph. balance in my mouth. I gave “dog breath” a whole new meaning. Worse, during the most intense part of the cycle, I just smelled of bad chemicals. At times, I could not eat. I could not drink. I could not think. But I muscled through it. I still tried to run. Shuffle was more like it. At the end of the cycle, on my good days, I could even get in some distance.

I started chemo in December of 2004. I survived through 8 cycles. By July, my body simply could not recover. My blood levels failed to improve enough by day 21 for me to start a new cycle. We waited an additional week and my levels were still too low. We made the decision at that point to halt chemo for a while and take a “wait and see” approach. Despite my desire to eradicate the cancer from my body, I was good with the decision. I knew that I could not mentally or physically continue the way things were. By the end, the fog never lifted. Although I continued to fight and never missed work, I knew I could not sustain it. I was spent. I looked, felt, and smelled like death. The chemo destroyed any semblance of balance between quality and longevity of life. I was done.

It is against this backdrop, after rebuilding my mind and body to be stronger than ever before, that I face the next 15 months with my old friend Temodar. With 6 weeks of radiation/chemo as an opening salvo. I have been training for this day for 8 years. It is why I do what I do. I knew this day would come. During the middle of an Ironman when I was throwing up and felt like I could not go on, I kept going. During those races when I was physically depleted and felt like I could not take another step, I kept going. No matter how tired I was, how sick I felt, how much I hurt, I kept going because I knew I would need to know how to overcome when it was needed the most. I will be on a lower dosage of chemo this time. In theory, people who react to the Temodar the way I do have better success. The theory is that their bodies, including the cancer cells are more sensitive to the drug. I will keep that in the back of my mind.

I do not look forward to what I will endure for the next 15 months. It is not what I wanted to face now or ever. I don't think I could be any better prepared mentally or physically. I do know that I will not quit. Grandma DiCroce would be proud.

1. Jenny Davies-Schley on November 24, 2012 at 1:59 pm said:

We're devastated to hear of your recurrence, Vince. But we feel confident that if anyone can face cancer with ferocious strength and graceful dignity, it's you. Please know that your extended DiCroce-Schley-Davies family has you in our thoughts and are pulling for you. Let us know if there's anything Charlie and I can do for you, Linda and Leah while you're undergoing treatment.

2. Kathy on November 26, 2012 at 11:24 am said:

Vince, I am so sorry to read this. I feel as though I've just been gut punched.

You are, indeed, a man who truly lives and lives truly.

3. Dad on November 26, 2012 at 5:54 pm said:

Vince, the last eight years you have managed to prove what the importance of perseverance, a healthy strong body, and a very positive attitude can achieve. I have no doubt you will be just as successful this time around. We have always had a very close family and have worked through some very difficult times the last few years. We continue to be there for you.

4. Alexis on November 27, 2012 at 10:51 am said:

Know you through Runners Edge.

Have continued running post treatments (surgeries/chemo/radiation/ loss of eye) for Stage IVb cancer. Each run is my knowing I am preparing my body/soul to fight again.

You are a warrior. Chemo/radiation is a journey you can move through . You have prepared yourself for this journey. You have prepared to do battle in the finest way.

Blessings.

Alexis

5. John Shults on November 27, 2012 at 2:58 pm said:

Your fighting spirit is an inspiration. I just passed my 4 year anniversary cancer free and it's difficult to think of the return of cancer. Just like at all your races, we're here rooting for you and wishing for the best results.

6. Karen on November 27, 2012 at 5:12 pm said:

Vince— I linked to your blog through David's posting of the link. Thank you for your honesty and willingness to share your story of endurance, resilience and perseverance. Continue to write. You are a great writer. Your story is one that can give many of us encouragement and hope as we face our own obstacles. Running can be a literal lifeline. Forget that trim waistline, it keeps us sane and gives us a modest amount of control over lives that seem to spiral out of control. I agree with your wife— it is time to write it down—and my thoughts and prayers will be with her and with you and your entire family and medical team as you all approach this next battle in the war together. And know that there are many silent warriors cheering you on as well! Run when you can, write when you can, and when you feel weak, we'll be strong for you. And if you wouldn't mind sharing a bit of that PR I sure could use it!

7. Michael Klee on November 28, 2012 at 5:34 pm said:

Vince, about four and one half years ago, you sat down with me and assured me that my herniated disc would repair itself with time and with proper exercises. Knowing that you lived through this ordeal of back pain and that you came back to run even better than before meant so much to me. I too came back from that injury better than before. At the time of our conversation I had no idea of the extent of your other, larger challenge of dealing with your brain cancer.

Your story is eloquent and inspiring. I am able to deeply understand what drives you to run faster, dig deeper, endure greater pain, and harden your body so that you are prepared for anything your cancer may throw at you. At my age of almost 67, I run with every ounce of energy and guts I can muster because I know that I too must harden myself against the incremental effects of the aging process. Thank you for giving so many of us fellow runners your story of what positive thoughts, an undying will to live and persistent training will accomplish.

Your resolve to keep fighting will pull you through. Here's wishing you all the best. Keep writing.

8. Luis Corchado on November 29, 2012 at 11:56 am said:

Vince, curiously, you have been on my mind all day today and now I just learned this terrible news. Whatever influence I have in the unseen realm of this world, I will now redirect your way. I met you in the 1990s and then was lucky enough to work with you for years in the 2000s. Through all that time, you have been a super person, one of the good folks on this earth. Your life proves that terrible truth that it rains, downpours even, on very good people. But, because of your golden heart, I have hope that you will be rewarded with healing. I cannot imagine how difficult it will be, but I know you are an iron man and so disciplined that

you have powers beyond the normal person, certainly beyond me. So, may your recovery be swift and full. God bless!

9. Erik Skirmants on December 2, 2012 at 10:45 am said:

Vince,

In a group like Runners Edge of the Rockies, everyone is in many ways extraordinary. I have used the word hero about a few of our members, not a word I take lightly. Yet in RER I have used it 3 or 4 times this year. I found particular inspiration from those that demonstrated strength and confidence; with an eye towards anyone in my or an age group my senior. I remember the first (of several) time you ran the group down after starting late. Every time you appeared out of nowhere, like it was no big deal...to catch the fastest group in the best running club around. I am pretty sure you were the first person I called a hero in RER! You seemed to just be out there running while fools like me stressed out over pace and miles and endlessly chattered about nothing important. I look up to your mental calmness and strength (exhibited physically as well...you run with great power). Your results and endless PR's, an age group above me, encourage me so much. (I only joined in 2012...so I missed a lot of the prior progress). This was all an opinion formed BEFORE knowing about your cancer history. I admire your outlook and openness, and would love to come by / visit sometime when you could use a distraction!

10. jen mclellan on December 2, 2012 at 11:57 am said:

Thanks for sharing & you are an inspiration!
Sending u all good thoughts & energy.
My fav quote: "To give up enthusiasm wrinkles the soul."

May your recovery be beyond your bliss!

11. jeffrey, amanda and reef on December 10, 2012 at 8:06 pm said:

We love you. Kisses to you and your family.

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Anticipation

Posted on **December 2, 2012** by **VAD**

Confident exhilaration, nervousness, fear, and a quiet calm. All part of the mix of emotions during the week or so leading up to the start of Ironman.

Confident exhilaration because I want it to begin, to give it my all to see if I have what it takes, believing I have trained and prepared as well as I possibly could. Nervousness, wondering if I didn't. Maybe I should have trained more. Run harder, biked farther, swam longer. Or maybe I over trained and didn't let my body rest enough. Did I forget something? I check my gear bags, my bike, and my equipment to make sure I have everything I need for the race. Then I check it all again. And again.

Fear. Fear because I know I will feel intense pain. Leg cramps, stomach cramps, bloating, nausea, vomiting, dehydration, complete and utter exhaustion with seemingly no relief on the horizon. I have experienced it all. Sometimes in the same race and all at once. Perhaps the most intense pain is when I force my mind to will my body forward

through it all. Quitting simply is not an option. No matter how bad the pain. Then the calmness. Because at some point you just have to let it all go. Let it go because the time is here. There is nothing left to do but to relax and let it begin. All of this is not unlike what I have been feeling this past week, the days leading up to the start of my treatment.

This past week, I met with the neuro-oncologist and radiation oncologist. Each appointment went pretty much as expected. Both reiterated that because surgery is not a good option, we should hit the cancer with 6 weeks of daily radiation and chemo therapy, to be followed by a month off, then monthly cycles of a higher dosage of chemotherapy. Most likely a year or more.

In terms of getting everything ready, on Wednesday, I went to the pharmacy and picked up my first month of chemotherapy and anti-nausea medication. I also picked up some of the mouthwash and toothpaste I use to counteract the effects the chemo drugs have on my mouth. Carrying it all in the house, my wife said I looked like I was bringing in a bag of groceries. I made the requisite phone calls. Let friends and family know what is coming next. Explained to the people at work what was going on. It is never easy telling people. It makes it real. You can't live in denial and open-up at the same time. And yet, it helps me come to grips with what I face.

Finally, on Thursday I went to the hospital to have my radiation mask made. The mask fits over my face and upper torso so they can secure my head as they irradiate my brain. The hope is to get started with the first dose of chemo on Tuesday night and the radiation sometime on Wednesday the 5th. It takes a few days to get the exact protocol set up so that certain areas of my brain will get more radiation than others. After Thursday, the wait began. A lot like the days right before an Ironman, I went on a couple of runs, a swim, and a couple of rides on the indoor bike. There is no real purpose for any of it other than to give me something to do, burn off some of the nervous energy, and attempt to keep the fear at bay.

I suppose the most difficult thing for me is the medical professionals explain each time we meet that this is "serious." I understand that. I also understand that they need to tell me. It is their job. People start getting a little jumpy when a nice quiet grade two tumor begins to upgrade to a more aggressive grade 3. I get that. And I get that someday it will most likely kill me. I prefer to put that day off for a while. A long while. To cope, I focus the battle on keeping life good till that day. Maybe it is easier for me to deal with it that way. It is like Ironman. The distance is crazy really—140.6 miles. A 2.4 mile swim, a 112 mile bike ride, and a marathon. Overwhelming when you think about doing it all. It is better to focus on bits at a time. Sometimes during the swim leg of the race, I focus on one stroke at a time. I simply cannot think about doing the full 2.4 mile swim. It is not just the distance. It is in open water with 2000 other athletes kicking, fighting, and scraping to get out of the water before the next guy. I know I can do one stroke. If I focus on each stroke, I don't worry about getting kicked, hit, or drowning, I know I will eventually finish. When I finally get out of the water, I always seem to think "that wasn't so bad." Same with the bike and the run. It all makes for a long day. To survive, I live in

the moment. Each pedal stroke, each step, each breath, each heartbeat. I become very focused. I enter this strange Zen like meditative state. When I focus on a each pedal stroke, or the way my foot lands with each step, or my heart beat, I am not focused on fear or pain. I know what lies ahead but I don't worry about it. If I did, I would quit. I know to finish, I need to pay attention to what is now. And without fail, when I finish, I know that no matter how hard it hurt or how bad I felt, I will have enjoyed the ride. I will have discovered more about myself as a result of the journey.

I guess I am trying to do the same thing here. Not worry about the finish. Think about each pedal stroke, each step. If all goes well, when it is over, when that day comes, I will have enjoyed the ride and learned more about myself. No matter how bad I feel along the way, when I cross that finish line, I know that I will think "that wasn't so bad." Until then, I want to enjoy every step, every breath, every heartbeat. I want to enjoy and appreciate every moment.

For now, I just hope to remain calm as I wait for it to begin.

1. Charlie Davies-Schley on December 3, 2012 at 6:00 am said:

Anything you need to make it easier? We can cover a lot of errands, holding hands, just name it. Take care,

2. Woz on December 3, 2012 at 2:04 pm said:

I still remember that same strange sensation for the first time at Ironman Wisconsin – a month after our first half at the Boulder Long Course, where we wondered, "how the hell are we going to swim TWICE that far?!" We bumped into each other in T1 and, with a smile, you commented that it was a nice warmup! It was, as you said, all about focusing on the present and relaxing so that the pain and suffering become a background to the calm flow of the experience... And later in that same IM, I remember spotting you ahead of me on the run – I was suffering more than flowing at that point. I threw a mental rope around you and you towed me back to my focus on every breath, footstep, and heartbeat. You'll be tackling a lot of miles, so to speak, in the next year or so. I'm looking forward to seeing you in transition or 'out on the course' so I can flash a smile back and offer a tow to help you back to your flow, too.

Let the race begin.

Woz

1. Spencer Mamber on December 3, 2012 at 5:52 pm said:

Vince,

We've been friends a fairly short time (8+ years ?). It's so strange to discover how much I

admire your writing skills, via this process.

Looking forward to having a lot more time to enjoy your writing, as well as your friendship.

2. Jenny Davies-Schley on December 3, 2012 at 5:57 pm said:

Do take us up on it, Vince. We're very good at cooking, running errands, picking up kids, and holding hands. We'd be honored to do any of it so Linda, Tony, Chris and your immediate family can focus on you and we can feel useful during a really trying time. XOXO

3. Sarah Bay on December 3, 2012 at 6:53 pm said:

Vince,

We just wanted to let you know that you are in our thoughts. If there's anything we can do please let us know.

Sarah & Gabor

4. Julie Westfield on December 3, 2012 at 7:03 pm said:

Vince,

You are many things.....an absolutely brilliant writer, and more importantly you are an amazing husband, father, son, friend, colleague, son in law, brother in law, neighbor, running partner, athlete, fighter, warriorI don't want to leave anything out! While I am so sorry to hear this recent news, I am really happy that I was able to learn about your blog (through Gina) and look forward to your updates when you are able to do so. I will check in with Linda/Toby and see if there is anything I can do for you all. You have so many fans....and they are all fighting for you and with you – and I am one of them for sure!

5. Pam DiCroce on December 3, 2012 at 9:12 pm said:

Thank you for sharing your inner most feelings and hope and fears. What an inspiration you are to everyone. Our thoughts and prayers are with you through your brilliant writings on your journey to that finish line~~

6. Tenley on December 3, 2012 at 9:16 pm said:

Vince I loved and hated your update all the same time. I loved the passion and detail you wrote on the ironman. I think it's the first time i really understood the emotions you go through in training-i could feel what you were saying. When you related it to cancer, you put the emotions in a whole new light. I have never heard your experience explained in the way you have and it was so powerful and yet so meaningful. Good luck, you are in our daily thoughts and prayers.

7. Stewart Schley on December 5, 2012 at 9:44 am said:

Damn, man. You have some serious writing chops. Inspired by your words. Thanks for sharing them.

8. Susannah Thompson on December 5, 2012 at 2:27 pm said:

Wow – tough to know how to express how deeply your words have touched me. You have an incredible spirit, a delightfully mesmerizing way with words and clearly a heart wrenching/warming/inspiring story. I have shared a good chunk of your 7th paragraph with colleagues and friends and have received countless replies. You are leaving an important mark on the world. I am a friend of your sister Lori in Golden, CO. My husband and I are song writers / musicians. If you ever want to collaborate on a tune let me know. I would love to put your words to music. Warm wishes – thanks for the the gift of your thoughts.
Susannah

9. kd on December 7, 2012 at 7:06 pm said:

every stride was a prayer,
each stroke a hope.

every inhale was a gift,
each exhale a cleanse.

every heartbeat was the filling of love,
and then the flowing of life.

and he was learning,
learning to fly without wings.

And So It Begins Again

My life with brain cancer



The Start

Posted on **December 9, 2012** by **VAD**

I love the start of a race. It is a blast. No matter how big or small, or how long or short the race, I love the excitement, the anticipation, and even the nervousness. There is an electricity in the air that seems to intensify as the minutes and seconds tick by leading to the starting gun. It is one of those moments in life when I feel "alive." Maybe it is why I race so often.

The start of Ironman is something else altogether. There is nothing like it. It is incredible. If you get a chance, watch one. Better yet, do one. 2000 of some of the fittest people on the planet assembling for what has been called one of the most grueling single day endurance events in the world, gathering together at the water's edge in anticipation of what is to begin. One by one, they slowly swim out to the starting line—a long rope stretched across the water some 50 yards or so from the shore. Silently treading water, they wait for the cannon blast that signals the start of the race and which will unleash a fury of arms and legs, churning the once calm water into a froth of bodies as each competitor desperately fights to gain seconds upon the next in a race that may last up to 17 hours. Before that blast, as if in suspended animation, they wait. Barely moving. Barely making a sound.

The stillness of sight and sound is deafening. Like a dense morning fog, fear and pent up exhilaration permeate the air. In the eyes of each is an unparalleled intensity. Each one is there for a different reason. Some are there to win. Some just to finish. Others, like me, are there to prove to their inner demons that they have what it takes to keep going and keep fighting in the face of overwhelming adversity. And, to paraphrase what has been said by another, "For all, it is a chance to see what you are made of on this day."

Tonight is a much different start. Tonight I start my chemotherapy. It is tonight I begin anew my fight against my brain cancer. I will not be surrounded by 2000 other competitors with eager anticipation of a cannon blast. Rather, in a couple of hours I will simply walk up to the kitchen sink, fill a glass of water, and wash down a 140mg Temodar capsule. There will be no fanfare. No electricity in the air. No event at all. No, I will just quietly swallow a pill and wait. I will wait for the drug to begin to flow through my body into my brain to do its job as I start to figure out how to do mine. I will go to bed and hope to get some sleep. And tomorrow I start my radiation. This will be my treatment regime for the next 42 days. Chemo by night, radiation by day.

This was not a race I signed up for nor a start I love. For the past 8 years it is something I have fought every minute of every day to prevent. For the past three weeks I have experienced a wide range of emotions, from anger to despair and even helplessness. None of which are unexpected when you discover a cancer is once again growing inside of your head with the singular purpose to kill you. But, they are not necessarily helpful or productive.

Today, for the first time I began to feel something different. I began to feel something more focused, more intense. I began to feel a sense of burning defiance deep within me. And I could feel it begin to grow. I liked it. I yearned for it. I grabbed on to it and would not let it go. It is something I have been wanting to feel, terrified because I did not. I am sure that in the coming days and weeks this intense defiance will ebb and flow as the chemo and radiation ravish my body when they go about doing their job attacking my cancer. But as I sit here tonight waiting to take my chemo so it can start its fight, I know that no matter how weak or tired I become, nothing will extinguish this strong angry defiance that is beginning to burn inside of me.

The start of this race, this fight, may be quiet as I swallow my first dose of Temodar alone in the kitchen when I get ready for bed, but the defiance growing within me is loud. It may not be one of those moments in life where I feel "alive" but to that cancer inside of me, make no mistake, I will live.

I know what I am made of.

It starts today.

1. Gina Warner on December 9, 2012 at 7:24 pm said:

I know what you're made of too, Vince. We love you and are so proud of your guts. Get it done.

2, kd on December 9, 2012 at 7:58 pm said:

Emotions have purpose. Your anger will propel you to fight. You are a warrior. You will win this battle.

3. Michael Spry on December 9, 2012 at 9:58 pm said:

Vince

Our paths really did not cross until after you had a path cast for you and you had already made the choice to forge that brave other high road to push the limits of what you could accomplish in the face of tremendous adversity. We have never spoken directly about this most important road you are now navigating but I am honored to have witnessed a few miles of your journey on this path you continue to travel whether it be by foot, bike or by water. Those many miles, I know, mean a lot to you and demonstrate the power of your will, determination and conviction. There is nothing that I can say or do that will directly affect the outcome of the race that you are undertaking at this moment but please do know that I am here holding out a cup for you. You know the cup. You have seen thousands of these along your path. The cup I am holding, contains support, hydration, nourishment, encouragement or whatever you may need. I hold just one of many cups that are available to you. They are all along your route and held out by many people, some of which you recognize along the way and sometimes they are held out by total strangers who just want to be an aid along the way. As you push on to put those treasured strokes, miles and step behind you, know that there are no shortage of those cups on the road ahead. Grab what you need. Keep on pushing and we will all be there cheering loudly as you break that ribbon. It may not feel right now like there are thousands with you on this race but there are thousands of cups all along the way.

4. Lori and Doug Fugate on December 10, 2012 at 9:39 am said:

Our thoughts and prayers are with you as you begin this fight. You are inspiring.

5. Barbara Hill on December 10, 2012 at 5:56 pm said:

Vince, you may have been physically alone in the kitchen but spiritually you are surrounded by a group of people. We are all treading water in our own way with our own challenges. I believe that group has you surrounded with love and healing energy.

6. kd on December 10, 2012 at 8:07 pm said:

Amen.

7. Emily Burt on December 10, 2012 at 8:10 pm said:

Vince, we are thinking of you each day and especially this evening.

You are enough!

8. Andrew Auerbach on December 12, 2012 at 7:57 am said:

You are an amazing writer. I feel like I'm living the ordeal with you.

9. Meg on December 13, 2012 at 9:49 pm said:

Vin,

As I've read your posts over the last few weeks, I've been moved and inspired. I've wanted to post comforting "replies"; words of encouragement and support, but have found myself at a loss. What does one say to someone facing such a battle? Words seem so small at the base of such a mountain.

I only know that as I sit and read your posts, the tears silently fall. They are tears of sorrow for what you are facing, tears of admiration for your strength and courage, and tears of relief over your ability to stand up, yet again, and fight with determination.

You are never alone. You have the love and support of all us.

Meg

10. Oza Klanjsek on December 19, 2012 at 8:56 am said:

And yes, we know what you are made of too. We've seen it, Vince this summer when you did grueling Ironman Mt. Tremblant with the smile on your face. And we know you're going to win this race. Milan and I are so proud of you and we're thinking of you every day.

You're our inspiration!

11. Billy Kinneer on January 22, 2013 at 9:16 pm said:

Vince just heard from you Dad that your cancer had started up again. Here is hoping that the treatments are working and it will soon be stopped again. Hang in there and fight it like it is and Ironman. Billy

And So It Begins Again

My life with brain cancer



Time

Posted on **December 23, 2012** by **VAD**

Time is funny. It is constant, yet your sense of it is constantly changing.

Ten years ago, time didn't mean much to me. Then in a moment, a lifetime turned to 3 – 5 years. Suddenly, time meant something. At that point every event in my life seemed that it might be my last. My last birthday, my last anniversary, my last Christmas, my last marathon. Then over time, something changed. I kept living and getting better. Time lost its urgency.

Six weeks ago, time changed again. It was then we learned my cancer was growing. For a moment, it seemed time stopped. I wanted to somehow turn it back. Back to when I felt safe. But time is constant. It keeps going.

Two weeks ago tonight I took my first dose of chemo. Prior to that time, it was nothing for me to climb out of bed on a Saturday morning, run 14 – 20 miles, do some work around the house in the afternoon, drink a couple of beers at night as I planned how to balance my Sunday to include the additional household chores, time with the family, and a 50 – 100 mile bike ride. Most days during the week started out with a 3 mile run with my wife

followed by a 40 minute swim before work. Lunch was normally a 6 – 10 mile run or a 45 minute ride on an indoor bike depending upon the day.

Two weeks ago time was different. My days were ruled by my calendar and every minute seemed filled. More often than not, time was measured in minutes per mile or minutes until my next meeting. I was physically strong and mentally sharp.

In the time of one week that all changed. It was in less than one week that chemo and radiation changed time. Changed me. That was all the time it took for me to go from being able to run 20 miles with no real soreness or fatigue to being able to only slowly trudge through 3 miles.

That first week I still tried. A couple of mornings I still ran with my wife. A couple mornings I still made my swim if I didn't run. I could not do both. And I didn't attempt to run during lunch. I was able to ride lightly on the indoor bike a couple of days I even drank a beer one night. By Saturday, a long run was out of the question. So was a beer. Most everything for that matter.

In the time frame of one week I went from being in tremendous physical condition to feeling like I was barely alive. I described it as feeling as if I was hung over and had the flu at the same time.

It is now another week. After tonight, I will have completed 14 doses of chemo and 9 radiation treatments. Last week I wondered if it would get worse. Now I know. It does and it will. Most of the time I feel miserable. I still have the strength to make it through a day of work, but that is about it. I come home after my radiation treatment and fall asleep on the couch. I lay there in pain as I wait to take my chemo and drift off to sleep for the night so I can do it all over again. Get up. Maybe eat something. Make it to the office. Make it through the day. Do the best that I can. Make it to radiation. Make it home. Make it to the couch. Make it to dinner. Make it to chemo. Make it to bed. Just making it. Everything I once enjoyed now seems un-enjoyable. I can't eat. I can't enjoy a beer. I can't run. I can't spend time with my family like I used to. I can barely watch a movie without drifting into a painful sleep. My wife and daughter don't know what to do. They try to comfort me. It is hard. I hate what I see in their eyes. I am not the man they saw two weeks ago. More than what it does to me, I hate what this cancer does to them. I hate that in order to live, I have to slowly die and then get stronger. I hate that they have to watch it.

My wife tells me that in this blog I describe what I go through but not what I feel. That I don't peel back the onion. Maybe that is because I am afraid. Afraid to talk about it. And just afraid. Superman doesn't cry. I do. Sometimes I can help it. There are times when I simply feel like hell. Actually, more times than not. I'm hungry but I can't eat. I have a constant horrible taste in my mouth. I can't run but can't lay around all of the time. I am weak, I feel like throwing up. My bowels feel like they are shutting down. I can't go to the

bathroom without a laxative or a stool softener. I cry because I don't know how I can continue doing this for another 4 weeks but know that I must.

I used to obsess about time. How many minutes per mile. How many seconds faster this year than last year. Now, time is a blur. Time is a measure between radiation and chemo. It is a measure of one treatment to the next. It is a measure of how many weeks more to endure. Time is something I don't like to think about anymore.

Sometimes at night I dream that I did turn back time. I dream that I am strong and in a race. I feel like I am running as if I am flying without wings. I feel amazing. Then I wake up.

Time. In time, I will get back to where I was. For 8 years, every minute of every day I prepared myself for this test. Hopefully, before I know it, I will again be measuring time in minutes per mile. It will just take time.

1. Gina Warner on December 23, 2012 at 10:14 pm said:

Vince thank you for sharing – even the parts that are painful, both physically and emotionally. As you know I'm a Jesus freak, and in less than 48 hours I celebrate His birth. I'm so struck by your Christ-like courage, Vince. Regardless of whether or not you consider Him your God, no one can deny the courage it took for Him to willingly and publicly carry His Cross – literally and figuratively. Seeing your willingness to share your vulnerability with us in this blog is an act of courage greater than any I've personally witnessed. I'm so proud to call you my friend. This Jesus freak prays for you every day.

2. Chris on December 24, 2012 at 8:48 am said:

Vinny, Congratulations on getting through your first two weeks!
Your right that time only seems to be relative to the person living it. It is different for everyone in their own way. During an Ironman, it seems like time will never end and the race, pain, torture will go on forever. However, as you know, when you finish it seems like it wasn't so bad and time flew by and you can't wait to do your next one. You will get through the next day, the next week and the next month! Remember, you are stronger than you think you are and you can do more than you think you can (Ken Chlouber). In the end, time will have passed you by before you know it. You will be back strong and hungry and I will be there with you at yet another starting line with both of wondering how much time it will take to finish!

3. kd on December 24, 2012 at 11:21 am said:

VAD, This is your time to heal...

Ecclesiastes 3 (NIV)
A Time for Everything

There is a time for everything,
and a season for every activity under the heavens:
a time to be born and a time to die,
a time to plant and a time to uproot,
a time to kill and a time to heal,
a time to tear down and a time to build,
a time to weep and a time to laugh,
a time to mourn and a time to dance,
a time to scatter stones and a time to gather them,
a time to embrace and a time to refrain from embracing,
a time to search and a time to give up,
a time to keep and a time to throw away,
a time to tear and a time to mend,
a time to be silent and a time to speak,
a time to love and a time to hate,
a time for war and a time for peace.

“Breakdowns can create breakthroughs. Things fall apart so things can fall together.”

Love and peace.

4. Barbara Hill on December 24, 2012 at 9:10 pm said:

Vince,
Having been on the other side, I can tell you what you see in your wife's and daughter's eyes is LOVE.

5. Mia on December 27, 2012 at 2:40 pm said:

Vince -
You are stronger than you think you are. Remember that.
Don't worry about what you can't do right now. Look at what you are doing. Each day for you right now is like an Ironman. And remember that you have trained well for this. Trust in your training (the past 8 years) and BELIEVE that you are strong enough to endure this. Picture all of us cheering you on – and picture yourself at the end of a long, hot race crossing the finish line with your arms in the air.
Prayers for less discomfort rapid healing coming your way!
Mia

6. Jenny Davies-Schley on January 3, 2013 at 8:39 am said:

We knew you were having a bad time of it when we didn't see you on Christmas Eve. You were missed but all of us are sending thoughts of healing and strength to you, Linda and Leah.

7. Michelle on January 6, 2013 at 1:13 pm said:

You are simply the single most amazing person I have had the honor of knowing....your strength, courage, fear, vulnerability, love of family, life, and health are nothing short of inspirational. YOU WILL GET THROUGH THIS my friend...I only wish I/we could take some piece of this painful yet necessary journey for you, but even saying that, I know I could not do it as well as you can. I am with you...you will defeat this...AGAIN....much love my friend.

And So It Begins Again

My life with brain cancer



A New Year

Posted on **January 6, 2013** by **VAD**

A good friend sent me an email recently to tell me that "I am sure there are a lot of people like me reading your blog posts but not commenting because we really are at a loss for words. I want you to know that you are being heard by your friends and fans, and how much I appreciate your sharing the details of your ordeal. It just makes me feel closer to you, which can only be good thing."

Truth is, when I started writing this blog I did not contemplate people commenting. The "comment feature" was merely built into the software package I used to start up the webpage. I was a little surprised and a little unsure of what to do when I started getting comments. So far I haven't responded to any comments. It is not that I don't appreciate them, but find I am at a loss for words regarding the kind things people have said.

I did not start this blog to develop support. It was really to sort through and record for myself what I anticipated I would go through. The first time around, I kept thinking I should write this stuff down. For the most part I never did. As it happens in life, you think you will remember events and moments forever, but, in reality you rarely do. Now that I have a second chance, I figured I wouldn't make the same mistake twice. I hope my

current course of treatment will beat my cancer into submission to such a degree that I will have a much longer break where I can again focus on living life before I begin round three.

I also hoped by writing about my experience, that maybe I could help some others. The world of brain cancer is not filled with great success stories. That was probably the single biggest eye opener for me 8 years ago when I was initially diagnosed. The world of brain cancer appeared to me to be a world of carnage. It was something that I was completely unprepared to see, let alone accept. I don't mean to discourage anyone reading this who has or knows someone with brain cancer. But it is a fact, brain cancer is merciless.

Early on I decided that I had to accept that this disease would likely kill me, but resolved that until it did I would live. That I would dream big, set the bar high, and feel alive. I vowed that my cancer would never be an excuse for failure; rather, it would be my reason and motivation to excel and succeed.

This time a year ago, I was getting ready to spend a week in Maui with Linda. It was to be our first vacation alone together that wasn't planned around one of my events. I promised her that we could take a trip without me doing a marathon or an Ironman. As it turned out, a couple of weeks before the trip, she was on the internet looking for things to do on our vacation and found out that there was a marathon in Maui the Sunday after we arrived. No one believed me, but I truly had no idea when we planned the trip. Yeah, I know, you don't believe me, but it is the truth. And Linda insisted that I run it. Really. It actually worked out very well. We had an amazing vacation. I didn't even think about the race, and ended up winning my age group in a race for the first time.

This year, instead of getting ready to head back to Maui, last week I shaved the remaining hair off of my head. A little over two weeks into radiation and it just started falling out in clumps. I am now about halfway through my 6 weeks of radiation and chemo. I honestly feel worse than I ever have in my life. At times, I wonder how I will make it through the next three weeks. But I know I will. Between the chemo drugs, laxatives, stool softeners, anti-seizure pills, anti-nausea meds, and others, I feel like a toxic chemical dump. I can barely eat, I constantly feel like throwing-up, nothing tastes or smells good. Everything about me tastes, smells, and feels like chemicals. It sucks. I don't even think about the ensuing year of the monthly cycles of a higher dose of chemo. What keeps me going are the resolutions I made eight years ago. I need to dream bigger, set the bar higher, and strive to feel more alive than ever before.

The other thing that keeps me going is I find myself getting closer to the people around me and as my friend said, "Which can only be a good thing." Indeed, that may be the one good thing about cancer. The comments left here, as well as the words of encouragement, voicemails, emails, positive thoughts and prayers are truly humbling and appreciated more than I can ever describe. Thank you.

I look at 2013 not as a new year but as a new beginning. I enter it the way I entered life—bald and in need of the help of those around me to just get through a day. Although I am miserable most of the time, I am truly happy to simply be alive. As the saying goes, “tough times don’t last, tough people do.” I will make it through this.

Look out 2014, here I come.

1. Stephanie Longcope on January 6, 2013 at 10:08 pm said:

I am in awe of your strength and determination, Vince. You are truly an inspiration!

Like most, I’m at a loss for words. I’m so sorry you have to experience this dreadful beast. We wish we could help. We wish we could make the pain subside. We wish we could just make the whole ugly thing go away. But all we can do is wish and hope and pray. Please know that you are in our thoughts and prayers daily.

2. Mike on January 6, 2013 at 11:31 pm said:

You are the strongest person I know. You inspire me and everyone around you to strive to do better in life, to keep pushing through when times get tough, and to never give up. As you told me earlier on the phone, and is the saying you live by, I promise

“ I will not just survive, I will be better than before”

Keep on fighting; you are my role model, hero, and the type of person I inspire to be as I grow up. I love you

Mike

3. Mia on January 7, 2013 at 7:18 am said:

Vince -

I was so proud to see you on the course Saturday at the RER run. What I saw was not a guy on a casual Saturday run. I saw a man – with intense focus – on a journey. When I said “hey Vince” – I seemed to break your concentration for a moment and I realized that you must have been pushing through a wall. Maybe you were looking back at the wall you faced last week with treatment. Whatever you were pushing through, you were doing it with a vengeance. I wouldn’t have wanted to be that wall.

There is nothing like standing at the finish line of a marathon and watching those, who appear to be average human beings, finish 26.2 miles with the look of pure tenacity in their eyes. This is what I saw when I ran into you on Saturday. Keep pushing and NEVER let doubt creep into your vocabulary. You got this!

Prayers,
Mia

4. kd on January 9, 2013 at 5:01 pm said:

"Suffering and joy teach us, if we allow them, how to make the leap of empathy, which transports us into the soul and heart of another person. In those transparent moments we know other people's joys and sorrows, and we care about their concerns as if they were our own."

~Fritz Williams

5. Andrew Auerbach on January 16, 2013 at 1:46 pm said:

Vince—Thank you for this window. It's reassuring to hear your voice (yes, I can hear your voice in your writing, loud and clear) and to catch a glimpse of what your life is now. Your blog helps me more than I can ever help you, which is unfair.

6. Cathy Maslowski-Yerges on January 16, 2013 at 2:29 pm said:

A while ago inspirational running quotes were requested to share with you, Vince. I think this one nails it.

"Your body will argue that there is no justifiable reason to continue. Your only recourse is to call on your spirit, which fortunately functions independently of logic."

- Tim Noakes

Professor, runner in more than 70 marathon and ultra-distance events

Keep fighting! Stay strong!

Cathy M-Y

RER member since 2003

7. Kris on June 3, 2013 at 5:45 am said:

Just found your blog and am reading through all the posts. My husband is a marathon runner and has run Chicago, New York, Houston and others. April 2013 he was diagnosed with grade II Astrocytoma. Thanks for writing.

And So It Begins Again

My life with brain cancer



Six Weeks

Posted on **February 12, 2013** by **VAD**

Several nights back I had a nightmare. I woke up in a panic stricken cold sweat only to find that when the fog cleared from my head, the nightmare was my reality.

In the dream it was near midnight on Christmas Eve and I had the startling realization I failed to purchase a single gift for a loved one, family member, or friend. I had not even realized that the holiday season was upon the world. As a result of my chemo and radiation induced fog, life began passing me by. I became a mere observer, not a participant in life, mentally and physically unable to connect with the world around me. Neither my mind nor body possessed the strength nor stamina to interact with my surroundings. It was as if I were a child, helplessly standing on the a playground watching all of the other kids laugh and spin around on a merry-go-round. Unable to stop it or hop on and enjoy the fun, I could do nothing but stand there and watch it go round and round. As the dream cleared my head, I came to the realization that this had been my life for 6 weeks.



The start of one of my radiation treatments. I was secured to the table by the rigid mesh mask over my face and shoulder

For 6 weeks I ingested a handful of pills every night of the week. Included in the mix was Temodor, a chemotherapy drug used to treat brain cancer. It is used because it is one of a few drugs able to pass through the blood brain barrier. Because it can pass through that protective barrier, it is able to attack the cancer cells. If only those were the only cells it attacked. It is a drug that once again proved to be particularly powerful to my genetic make-up. In short order it atrophied my muscle tissue, destroyed my mouth, stomach, and entire digestive system. Coupled with my daily chemo regime were radiation treatments Monday through Friday. Each day I could feel my body and brain slowly shutting down. My mental and physical reserves drained further and further almost by the hour. At the beginning, my mind and body regained a little strength during my weekend reprieve from radiation. The last three weeks I steadily descended into a dark abyss. I slowly sunk into a mind numbing and painful pit of quick sand. There was no escape. I never felt worse in my life. I felt barely alive, barely human. I existed in a constant state of nausea and overall physical discomfort. My body a toxic chemical cesspool. Unable to eat solid food most of the time, many days I struggled to simply drink a glass of water.

Previously, a normal day would start at 4:30 a.m. with a 3-4 mile run with Linda, a good healthy breakfast followed by a 30 minute swim, and off to work. I packed into the day as

much as I possibly could. My mind was always going. I was rarely at rest. My lunch breaks consisted of a 6 – 10 mile run or a 45 minute intense spin on the bike, then back to work. Throughout the day I fueled my body and mind with healthy foods such as fruit, greek yogurt, nuts, and berries, but I was not one to pass up a good pastry or three. I never made it home by the time I said I would, but normally in time to eat dinner with Linda and Leah. After some family time, Linda would put Leah to bed as I caught up on work. Normally asleep by 9:00 and back at it again in the morning. The weekends were for 20 mile runs, 80 – 100 mile rides, zoo adventures, science fair projects, dinners out, pizza in, a few relaxing beers, projects around the house, fun and laughter. Life was good. Over night it seemed, everything changed.

Soon after starting chemo and radiation I could not make my morning runs or swims. At first I was able to eat some breakfast, but not for long. Basically my days became a fight to survive one hour to the next. I struggled to simply get out of bed each morning. Once I did, I moved slowly, waiting for my head to clear from the drugs I consumed the night before. Almost immediately upon starting treatment I felt like I had the flu and a hangover at the same time. Then, after a week or so it got worse. Time stopped.

My active and intense days turned into an exercise to survive. After managing to get to work, I suffered through the day, pacing myself so I could be mentally sharp enough to handle meetings or what were once simple mental tasks such as reading and writing. Anything that required mental focus exhausted me, causing increased nausea, and necessitating a period of "recovery." It proved increasingly difficult and painful to make it through a day. I came to work to maintain a sense of normalcy in my life. It helped keep my mind off of the misery. At the end of each day, completely exhausted, I drove to University Hospital for my radiation treatment. Always a difficult drive as I never knew if I would make it without throwing up. Linda urged me to use the valet parking at the hospital. I refused. I wanted to walk the 3 blocks or so from the parking garage to the clinic—my defiance to the way I actually felt.

It terrified me at first to be strapped to a table by my head so that radiation beams could invade my skull with precision to fulfill a mission to kill cancer cells while minimizing damage to healthy tissue. In each and every treatment, to keep myself calm, I slowly counted backward from 100. As the radiation began, I would see a nonexistent blue light and smell a nonexistent sickening odor. Apparently these experiences are common. Something to do with the radiation stimulating parts of the brain. As the radiation entered my brain, I forced my heart and breathing to slow in an effort to keep completely calm and at peace.

The individual treatments were relatively fast and non-eventful. After each one, I would get dressed and slowly trudge back to my car as a headache and mental fatigue set in. Each night as I made the drive home I felt more physically sick and mentally cloudy by the minute. Unable to eat or drink, I invariably curled up in a fetal position on the couch immediately upon walking through the door. It was too difficult to watch TV so I simply listened to it in the background as Linda and Leah carried on around me. Homework,

dinner, feeding the dog, and all the normal things in life still needed to be done. I just couldn't do them. Life around me continued on. I participated less and less. Each night I laid on the couch waiting for time to pass by.

Normally, at 7:30 I started my evening protocol. First, I took 3 types of anti-nausea medication and stool softeners. I then mixed up some laxative with Gatorade. Choked it down and waited as I felt all of the medications slowly seep into my body. I could feel it and taste it. Thirty minutes later I would take the chemo and fade off to bed, hoping to get some sleep so I could wake up 10 hours later to start it all over again. The highlight of my day often was having a bowel movement. It was a rare occasion. The treatments shut down everything including my digestive system. I don't know what was worse—the struggle to get calories in or the struggle to get out what little I was able to consume. By the end, I dropped below 135 lbs. My body a shell of what it once had been. The Ironman who could run and ride forever with ease wasted away to a child like figure curled up in a fetal position most of the time to ward off pain, fatigue, and nausea. I couldn't eat or drink. My stomach was in a constant state of pain. My entire digestive system felt shut down. My sense of taste and smell became extremely heightened and deadened at the same time. My brain became numb in an effort to protect me from the constant onslaught of overwhelming and total discomfort.

I felt terrible for what I was putting Linda and Leah through. Whatever energy I could muster up, I expended at work and to make it through my radiation treatment. At home in the evening and on the weekend I was barely able to interact with my surroundings. I didn't feel like a father or a husband. I didn't really feel alive. I began to seriously question how long I could continue this existence. More than once I was at a near breaking point. I felt completely defeated. A feeling I have never really experienced before. No matter what I had been through in my life, I never lost my "will." For the first time in my life I feared I was losing it. That scared me.

Eight years ago when I was diagnosed with brain cancer, I knew to survive I needed to be mentally strong. Unyielding. I could never allow a glimmer of weakness to develop. I told Linda that all my life I had tried to be the best at everything I did. I was usually good, but never the best. Now it was time. I needed to be better than the best. I needed to be perfect. I had kept that strength for over 8 years. Never wavering. Until now. As I finished my 6 weeks of radiation and chemo I seriously wondered whether I had what it took to continue this fight. My nightmare was my reality and I was scared.

It has been nearly three weeks since I finished my chemo and radiation. Slowly, I have started to feel human again. I am starting to regain my appetite but still struggle to eat. This past week I started to run with Linda in the morning a little and did some light spinning on the bike during lunch a couple of days. Today I weighed more than 135 pounds for the first time in a couple of weeks. I am starting to regain a little strength. I am able to interact with the world. I feel almost human again. More importantly, I know I haven't lost my will. I made it through the six weeks and out the other side, stronger as a result of the struggle. I made it not because I am perfect. I made it because I am not. I

made it because of the love and support of my family and friends. Thank you for your thoughts, prayers, phone calls, emails, gifts, and just saying "hey."

The day after I finished my radiation a good friend came to my office and brought me a book of quotes she assembled from family and friends. The book is absolutely beautiful and entitled "Words to Live By." She described it as a "literary hug." And that it is. The timing could not have been better. The effects of the chemo and radiation do not end immediately. Instead they seem to intensify as the treatments progress (and linger on far afterward). It is a cumulative effect. The end is far worse than the beginning. It was at the end, indeed even after the treatment was complete, when I was at the absolute lowest point. It was then when I began to question my will. The book of quotes, that literary hug, helped pull me along when I could no longer pull myself.

I am not out of the woods yet. I start my monthly chemo cycles soon. But I'm glad to have those six weeks behind me.



With my family after completing my final radiation treatment

1. Christy Burns McLaughlin on February 13, 2013 at 8:46 am said:

Vince

You are an incredible man. I haven't seen you in a long time but I want to tell you that you are the first runner I ever ran with when I joined a Runners Edge complimentary run many years ago. It was the Lowry run and I think I had gotten lost (not a rarity) after stopping off at a bathroom. When we ran into each other I remember meeting you and our conversation led to your battle with brain cancer. I was so amazed and could not understand how this fit athlete I was trying to keep up with had battled something so scary so recently. I think this was shortly after your return back. Anyway, since that meeting I have told so many people about this incredible and inspirational runner who had beat brain cancer and was living life to the fullest. I still see that and am touched by your will and strength to keep at it. I've followed this blog and heard through the runners grapevine and will continue to send healing thoughts to you and your family. Your strength (physical strength as I think you have more mental strength than most people will ever find) will return and I know you'll be setting more records and blowing people's minds once again. Thanks for inspiring me and for reminding me that life is to be treasured. Always. Keep healing up and letting others support you. You are in my thoughts.

1. Barbara Hill on February 13, 2013 at 9:04 am said:

6 weeks can seem like an eternity. I am so glad it's over and you are feeling better. I want to give you words of encouragement! I was so overwhelmed by this last post... Brings back memories of a loved one who struggled in the same way. Vince, you are truly amazing.

2. Teresa Stitely on February 13, 2013 at 10:26 am said:

Vince,

It has been a long time since we have talked. I am praying for you and your family.

3. kd on February 13, 2013 at 1:36 pm said:

VAD-

You are truly blessed. In addition to being a remarkable man with an indomitable will, you have the most incredibly amazing family. Love you, love them ALL!!!

4. Ty Godwin on February 13, 2013 at 4:46 pm said:

Vince: You never cease to amaze me as a runner, an ironman, and a person. I am sorry we haven't run in a while and didn't realize what you were going through. I know you have a lot of family and friends supporting you. I'll make a point to tell your story of bravery over

the dinner table and send a prayer your way. Hope to see you out on the road running, riding, (or in the water) soon. Ty

5. Oza and Milan Klanjsek on February 13, 2013 at 10:16 pm said:

Vince,

You are definitely an inspiration to us and you are in our thoughts more than you think. So glad that radiation 6 weeks is over and that you're regaining your strength. Yes, it does bring lots of memories of loved ones who struggled fighting cancer.

You and your family are truly amazing!

6. Kari Jensen on February 14, 2013 at 8:57 am said:

Vince, you and your family are in my thoughts daily. You are such an amazing inspiration to so many. Thank you for telling your story. I hope as you write it is healing for you. Continue the fight. You are not just human. You are an Ironman!

7. Dad on February 17, 2013 at 8:47 pm said:

Vince, I don't think there will ever be a father that could be more proud of their son as I am of you. And it isn't only because of your present battle. I remember when you graduated from boot camp and Mom and I flew out to attend the ceremonies. You were so proud to have graduated and to be in the Navy. I will always remember you telling me how much you enjoyed boot camp. I had never before heard anyone say that about boot camp. I think that is when you confirmed my belief that you were something special. You went on to finish college while still in the Navy and then completed law school and graduated with honors, all while raising a family. You have tremendous determination and strength. I know you will prevail and become healthy again. Love, Dad

8. Jalice Vigil-Kelly on February 18, 2013 at 7:09 pm said:

Vince,

I just recently heard about this return of your cancer. You are in my thoughts and prayers. Thank you for your courage to share your journey in this blog. I wish the best for you and your family. Please do not hesitate to ask if you need anything. Food, car rides, support, someone to just listen and/or sit with you and your family. Take care.

-Jalice

9. Frank Ingham on February 18, 2013 at 8:43 pm said:

Vince, it's been just over 4 weeks since I left the CA's office. Until I read your post I was thinking how fast time has flown with my new challenges. It's funny how one's perspective of time can be so different. Just know that I think of you often, and wish you the best. Now that you're no longer my boss, I can say I'm proud to know somebody capable of making it thru this. Keep it up and God bless! Frank

And So It Begins Again

My life with brain cancer



A Taste of Normal

Posted on **March 1, 2013** by **VAD**



A picture from a ride through Torrey Pines State Park outside of San Diego taken during a bike trip with friends last March

Nearly six weeks after I completed the opening barrage of the chemotherapy/radiation and almost twelve weeks after I began treatment, my body felt like mine again. During the past week, I ran a little, biked a little, and swam a little. I started slowly at first, growing stronger each day. I ate without worry of my stomach rejecting the food or my digestive system shutting down. We went out to dinner a couple of times. I met a couple of friends for a beer. I gained some weight. We watched a couple of movies. I even enjoyed helping around the house. I had a taste of normal. It was a real treat.

The original plan called for me to start my monthly cycles of chemotherapy 2 weeks ago. My body refused to cooperate. The chemotherapy drug attacks fast growing cells. Cancer cells are fast growing. So too are the bone marrow cells that produce blood cells. My body appears to be very sensitive to the chemo. Four weeks off of the drug and my platelet and white cell counts were still too low to begin my monthly cycles. I have another blood test on Monday. Given how I feel now, I am sure I will be good to go and will be starting my first round next week. Until then, I will continue to enjoy feeling more normal.

Feeling "normal" goes beyond feeling good. There is another side. Deep in the throes of treatment I felt so miserable I could focus only on getting through the day or, at times, the

hour. I didn't spend much time thinking about what life once was, or what it might or might not be. I was in survival mode. I simply did not have the strength or the energy. Now I do.

Last March I went to southern California for a bike trip with some friends. I had never done anything like it. Each morning we enjoyed a leisurely breakfast then rode all day through the beautiful SoCal countryside. Our longest ride was a little over 100 miles and the shortest was around 40. I think I rode more than 350 miles over the couple of days I was there. After returning to the hotel each afternoon, I ran for an hour along the beach before dinner. It was great. We planned to make it an annual event. Because of my cancer and treatment, I can't make the trip this year. . . maybe in 2014. If all goes well, I will be able to make the trip for many years to come. Feeling "normal" has caused me to think about life in this way, about how life was and what it might or might not be. It has also caused me to have renewed appreciation for what life is.

Feeling "normal" has reminded me to enjoy those ordinary things in life that over the last couple of years I started to take for granted—putting away laundry, cooking dinner, spending time with family doing nothing in particular. All things you don't necessarily appreciate until you start thinking about what life was and what it might or might not be. Sometime after I was initially diagnosed, someone asked "what it felt like to have brain cancer?" I replied it was like driving down the highway and seeing a bus in the distance coming directly at you. You are unable to get out of its path. You cannot avoid it. It will hit you and it will kill you. You just don't know how fast the bus is going or when the impact will occur. It is absolutely terrifying to think about. The best thing you can do is to relax enjoy the ride while it lasts. Don't worry about the bus. You have to learn to live in the moment.

After being diagnosed with this terrible disease, it took me a while to learn how to enjoy the ride. I tried to live in the moment but could not free myself of an incredibly strong underlying fear that I was dying. It is difficult to live when you have a constant fear of dying. It wasn't that I was afraid of death; I just wasn't ready for it to happen. For a long time, I feared that every family event, every birthday, every vacation, and every race would be my last. I suppose that is one of the reasons why I started running a marathon every couple of months after I completed chemo back then. That and because every time I finished a marathon, I would reason to myself, "How could I be dying if I am getting faster and stronger?" I struggled with the fear for years. It is one thing to recognize the reality that at some point life will end; it is another altogether to see the bus racing toward you. It puts a whole new perspective on the notion that "we are all going to die someday."

I'm not sure when it happened exactly, I suppose it was more of a process than an event, but at some point a couple of years back, I became very comfortable living in the moment. So good, that eventually it turned into living in denial. I succeeded in convincing myself the bus did not exist. I was enjoying the ride with no end in sight. It was very freeing. Routine things such as the concept of a future retirement progressed from something that "was" to something that "might" or even "will be." This past November my denial evaporated like an early morning fog at sunrise. And when it did the bus emerged clearly into my vision,

bringing with it the realization that while I was blissfully enjoying the ride, the bus was traveling closer to its final destination with new acceleration.

The past week or so has been good for me. I had some fun and regained some strength. More importantly, it reminded me that the bus is still there headed for me, and that while I am still here I can't take anything for granted, not even putting away laundry or spending time with the family doing nothing in particular. This time gave me a chance to reflect and regain perspective. It reminded me to enjoy the ride and live in the moment. Death will come. It always does. But now is the time to live.

It was important to have this little taste of normal.

1. Cynthia Yakely on March 1, 2013 at 9:18 pm said:

I have had several friends battle and beat cancer the last few years- 2 with lymphoma, and one who has been battling for years. She beat bladder, then lung(hard to beat) and then breast. She is 70 and is healthy. You are a fighter and inspirational to everyone that knows you and hardly knows you (like me). Good luck, my friend- looking forward to your blog when you can say you beat it again!!!

2. kd on March 3, 2013 at 10:01 pm said:

Carpe diem!!!! Glad to hear you are enjoying normal.

2. Chief Dan George on March 7, 2013 at 10:41 pm said:

"The beauty of the trees,
the softness of the air,
the fragrance of the grass,
speaks to me.

The summit of the mountain,
the thunder of the sky,
the rhythm of the sea,
speaks to me.

The strength of the fire,
the taste of salmon,

the trail of the sun,
and the life that never goes away,
they speak to me.
And my heart soars.”

Chief Dan George

And So It Begins Again

My life with brain cancer



My First

Posted on **March 12, 2013** by **VAD**

Below is from a letter I wrote in 2008 to a friend after finishing my first Ironman and my first year of triathlon. That period of time was the beginning of my recovery from the initial diagnosis and treatment of my brain cancer. It is good to reread it now. Last night I began my monthly cycles of chemo. I know that I have a long and difficult road ahead of me. The next year will be a constant intense struggle to maintain some strength as the chemo ravishes my body and attacks the cancer. I know that the cancer will never be gone. The fight will never end until I do. I simply hope to emerge from this next year ready to become strong again. Rereading this letter reminds me that nothing is impossible, that I must believe to succeed, and that no matter how low I sink, I can always climb back higher than before.

I was pretty pleased all around. Just before the race, I was very nervous that I would not be able to make it. I had never before swam 2.4 miles or ridden 112 miles, let alone back-to-back followed by a marathon. My longest ride was a couple weeks before the race. I rode about 105 miles. I nearly passed out when I got home. Similarly, my longest swim was a couple of days after that ride. It was a little over two miles. When I got in the car to

drive home, a couple of blocks before my house I had to pull over on the side of the highway and throw up. I pushed both of those trainings harder than I planned to do in the actual race, but still, they left me a more than a little apprehensive. One thing about Ironman Wisconsin is that it is an open water start. You have to kind of float and tread water for a while with 2000 other competitors as you wait for the cannon to go off. Safe to say, all of these things caused me to be a little nervous about even being able to finish the race right up to the opening cannon shot.

Once the swim started, I felt pretty good. A couple of funny things happened. As I took my first stroke I realized I left my wedding band on. I have lost a little weight over the last couple of years and it falls off in the water. So, I had to immediately begin clenching my fingers together on my left hand. Unfortunately, as the swim progressed, the cold water made my fingers shrink even more and my ring kept sliding off. I had to continuously use my thumb to get it back on my hand. I remember debating whether I should simply let it fall off or struggle to keep it on. Apparently this mental exercise kept me pretty distracted. After a while I started thinking I was out there for an awful long time without making a turn (the course consists of completing a 1.2 mile rectangle twice). It was about that time I heard the announcer and realized that I had in fact completed an entire loop and was half way done. How I made it around three turns without noticing I will never know.

The second loop of the swim went pretty well. I did not feel as smooth as I did during the first, but must say that I had more energy after a 2.4 mile swim than I did after swimming a lap in the pool when I first started learning to swim. My goal during the bike was to take it easy and consume a lot of food and fluids. I was pretty successful on that score. I finished the bike with plenty of energy and felt pretty fresh as I started the run. In fact, I had to try to slow myself down during the run because I was going too fast and did not want to bonk at the end. The run was amazing. The crowd support was thick and loud. It was a double loop of 13.1 miles. The half and the finish were in front of the Wisconsin State Capitol building. It was amazing running through this crowd with everyone cheering you on. It was more intense than Boston. I felt pretty good when I finished. I was a lot less tired than I anticipated. But, I didn't push my limits throughout the entire event. My goals were to finish and to enjoy myself. I achieved both. Most of the day I had a huge smile on my face. From the moment I got out of the water I knew that at the end of the day I would be an "Ironman." It was pretty cool coming through the shoot at the the finish line with huge cheering crowd and hearing the announcer say "Vince DiCroce. . . you are an Ironman."

This has been a tremendous experience. The process reinforced my firmly held belief that our minds are our biggest limitation. If we believe, then we can succeed. Six months ago I could not swim a length of a pool without grabbing hold of the side gasping for air. There were times when I tried to simply float in the pool and kick that I would actually move backward. At the beginning of June, when I attempted my first open water swim experience, I was too afraid to go in the water deeper than my waist. It was a week later when I made my first real attempt at an open water swim. I signed up to do the Stroke-

and-Stride in Boulder. It is a half mile swim followed by a 5K. I did it with my brother Chris, his wife, Sarah and my friend Randy. It took me 24 minutes to swim the half mile. I was so tired from the swim and had swallowed so much water that during the first half of the 5K was coughing up green junk the entire way. I could barely jog. I figured the green was from the algae in the water that I had swallowed. By the end of the run I had coughed so much my throat was raw and I was coughing up blood. But I finished. Over the course of the summer I did the Stroke-and-Stride 6 more times, did 3 other triathlons of increased distance, and improved my swim to the point that my best half mile was just over 15 minutes. We had a lot of fun laughing about my exploits after the race last weekend.

I was diagnosed with brain cancer 4 years ago November. I had just finished my second marathon. It was Chicago and I finished it in 3:34. Shortly after being diagnosed I hung a plaque on my wall that states "I will not just survive. . . I will be better than before." During my surgery that December, I told my neurosurgeon that I would run the Boston Marathon. I don't know if he actually believed me but it added a little levity to the moment. The August after I was diagnosed I was "better than before" in that I ran 3:33 in the Duke City Marathon in Albuquerque. The fact that the race was for the benefit of cancer research made it a little sweeter. Although it was a new PR, I did not qualify for Boston.

I ran Duke City 3 months after my last chemo treatment. In retrospect I probably pushed things a little too quickly. My body was weakened from the chemo and consequently I began to battle a series of injuries. First, my lower back started causing me problems. So much so that by December of 2004 I could not walk upright. I began working on my core strength every day for at least 30 minutes. Although my back improved, I again probably pushed things to early and I developed stress fractures. When I ran Chicago again in 2006, the pain was so great in my right lower leg that I could barely walk after most of my training runs. I was surprised that I was able to finish the race. I refused to give up however. It was about that time that Linda bought me a bike so I could start cross-training. My injuries continued however. I began to develop a stress fracture in my other leg. Consequently, last year I was un able to run Chicago.

Since then, the tide has turned. It was September 8, 2007 that I signed up for Ironman Wisconsin. When I was diagnosed with cancer, my then boss gave me a inspirational sticker with a quote from Winston Churchill that states "never never never give up." At the time I signed up for Wisconsin I could not run because of the stress fracture in my left leg, I did not know how to swim, and I had barely ridden the bike Linda had given me the year before. A month later, after bagging Chicago, I ran the Denver Marathon. In what set out to be a long training run turned into a new PR and a BQ of 3:30:00. In December I ran the Tucson Marathon in 3:24, in April the Boston Marathon in 3:25, and in May the Colfax Marathon in 3:26. In June I did the Boulder Sprint triathlon, in July the Bolder Peak Olympic distance triathlon, and in August the Boulder Long Course Triathlon (half Ironman distance). To complete the year I finished Ironman Wisconsin in 12:43 with a 4:02 marathon time. Throughout the year I have not just survived, I am better than before. I feel stronger mentally and physically than I have at any point in my life. My cancer

continues to stay in check. When I was diagnosed I told Linda that all of my life I have tried to be the best at something. I was good at most things, but never the best. I remember thinking maybe all of those times throughout my life where I came up just short were training exercises for this fight. For this time when it matters most. With this fight I can never give up. So far I am doing well. I am starting to truly believe I can win.

Oh, and remember that moment of levity in the operating room. Well, my neurosurgeon now runs with me as part of a group on Saturdays. He ran his first half marathon last October when I qualified for Boston. This year, he is running his first full marathon in Twin Cities.

I have learned a lot about myself this year. The Ironman was an amazing experience. It taught me how to begin to truly believe. That nothing is impossible.

The best part of the day was that after 12 hours and 43 minutes, 2.4 miles of open water swimming, 112 miles on the bike, and 26.2 miles running, I crossed the finish line an Ironman, with arms raised in the air, and my wedding band still clenched firmly on my left hand.

2. Ruth Mares on March 13, 2013 at 9:12 am said:

Behind you 110%, Vince! Best of luck with this next part. I know you can do it!

1. kd on March 23, 2013 at 11:07 am said:

Mind is the master power that molds and makes,
And we are Mind, and evermore we take
The tool of thought, and shaping what we will,
Bring forth a thousand joys, a thousand ills.
We think in secret, and it comes to pass –
Our world is but our looking glass.

~James Allen

2. Lindsay Dolce on March 31, 2013 at 8:53 pm said:

Keep sharing and we will all keep praying and sending good juju into the universe for you. You are an inspiration to all of us...

3. Scott Larson on May 14, 2013 at 8:30 am said:

Vince,

My dad sent me the link to today's Denver Post story, and needless to say it brought a torrent of emotions and many, many memories. Your grace and strength are utterly remarkable, and your message so powerful. InVINCEable!

And So It Begins Again

My life with brain cancer



Good to be Bad

Posted on **May 15, 2013** by **VAD**

According to my treatment plan, this past weekend I should have been completing my third cycle of chemotherapy. My body had a different plan.

Prior to each chemo cycle it is necessary to check my blood counts to make sure my body is ready to endure another round. My original treatment plan called for 6 weeks of daily radiation combined with daily low dosage chemo, 4 weeks off to recover, then 12 monthly cycles of a higher dose of chemotherapy. The monthly cycles are 28 days consisting of 5 days on chemotherapy and 23 days off. I tend to start feeling pretty weak and sick the last couple of days taking the drugs (days 4 & 5) and increasingly worse for the next two weeks (days 6 – 19 or so). Around that time, I slowly start feeling better as my body recovers enough to start the next cycle.

My first monthly cycle of chemotherapy was delayed a couple of weeks because my body was unable to sufficiently recover from the 6 weeks of daily radiation/chemo. Eventually, my blood counts came up enough for me to start. But because my counts remained pretty

low, my oncologist decided to keep me at the lower chemo dosage rather than doubling it according to normal protocol.

Despite my oncologist's firm yet polite insistence to the contrary, I initially intended to limit my chemo cycles to six rather than twelve. She explained what I already knew, that she wanted to keep me alive as long as possible and that the protocol provided me with the greatest chance of longer "disease free progression." She was right. Intellectually, I knew it. Emotionally and physically, I just wanted to be done with treatment and with cancer and get on with living and enjoying life. I have since resigned myself to completing the full 12 cycles. I need to keep in mind that although I have brain cancer, it does not define me. I have control over who and what I am no matter what I might be going through at any given moment. Being alive is a state of physical existence; feeling alive is a state of mind.

My body has repeatedly proven to be particularly sensitive to the chemotherapy drug. And so it was, after just two monthly cycles, I found myself sitting in my oncologist's office being told that my blood counts were too low to start my third. I wanted to cry. As I sat there in the exam room contemplating it all, I began to accept that my 12 cycles would not be 12 months. For me, it seems 12 cycles will take much longer. I suppose it is a "good news bad news" situation. The bad news is I most likely will be on chemotherapy well into 2014. The good news is that, in theory, if my body is hyper-sensitive to the chemotherapy, then so is my brain cancer. That's the theory anyway. In other words, bad blood counts lead to good results. Let's hope it is good to be bad.

Having brain cancer and going through treatment can feel at times as if life is put on hold. With the words "your cancer is growing," life changed. In the wave of the initial shock, I thought of seemingly trivial things such as vacations needed to be cancelled and plans for the coming year had to be adjusted. As the blow of the initial shock began to wear off, it was as if cancer regained its grip upon my life and began to pull me closer to death. Instead of boarding a plane for a sunny destination we were sucked into the world of radiation and cancer treatment. Training plans were replaced by treatment plans. In short order, Linda and I knew that once again, like 8 years ago, life would not be what we thought it would be.

On a deeper and more personal level I again began to contemplate "will I live or die?" I try not to go there very often, but it is unavoidable. When I find myself there, I focus on the simple fact that we all will die. It is just a matter of when and, and more importantly, how we choose to live until the end. We may have little control over when we die; we have almost total control over how we choose to live.

Originally, upon learning my cancer was growing, my goal was to make it through treatment as quickly as possible in order to minimize the amount of time my life was placed upon hold. But I came to realize that that my life is not on hold. It is just different. Linda and I may have cancelled our trip to Hawaii and I won't be able to compete in an Ironman

next month, but life around me keeps on keeping on. I am still alive. Despite actively fighting a disease that is trying to kill me, I began to better understand that I still needed to appreciate life around me. I needed to appreciate being alive. I needed to live life.

Shortly after I learned of my new cancer growth, a friend came up with an idea she called "Run with Vince." The idea was for people to challenge themselves by running one of the races at the Colorado Colfax Marathon on May 19th. In addition to a full marathon, there is a 5K, a 10 miler, a marathon relay, and a half marathon. She challenged people to choose a race outside of their comfort zone to emulate my belief that "you can do much more than you think you can." What started as my friend and a couple of others challenging themselves by running one of the races spread to my family, co-workers, colleagues, friends, and friends of friends. They created a t-shirt for everyone to wear in the race. Come race day there will be around 200 "InVinceables" out there running, including my wife and oldest daughter who will be running their first marathon. My youngest will be running the 5K. A friend who lives in Hawaii made the trip out to run the marathon. Another made the trip out from California to be part of a marathon relay. People who never before toed the line at a running event are stepping up to have a go at it, pushing limits in ways they never thought possible. Even my neurosurgeon will be running the marathon on Sunday. And all of these folks will be sporting their bright blue "InVinceable" shirt.



The "InVinceable" Running Shirt

As race day draws nearer, I find myself more and more moved by the tremendous support growing around me. The pinnacle occurred this past Saturday morning at a little before 7:00 a.m. as I walked with my wife to meet our running group. At the starting spot, I was met by a group of 20 or more of my friends looking very similar to me—they had all arrived early and shaved their heads in what they called “Vanity for Vince.” There have been very few times in my life where I felt completely unable to express the depth of emotion I was feeling. The moment when it sunk in that all of those guys had shaved their head in support of me was indeed one of them. These are not young kids in high school or college, these are professional men in their 30’s, 40’s, 50’s and 60’s, all of whom decided it was worth it to shave their heads as a way to show support for me.



Vanity for Vince. A handsome and inspirational crew.

It is hard for me to describe what I feel and the impact all of this has had on me. People have told me that I inspire them. I don't really see it that way. We all have our obstacles to overcome in life. I simply do what I need to do in order to survive. It is the people around me, all of those “InVinceables” out there who are inspiring. They have selflessly chosen to provide inspiration and support for a fellow human being. They have chosen to make a difference in the life of another.

It is against this backdrop of "Run with Vince" and "Vanity for Vince" that I contemplated what it meant for me to appreciate life and feel alive. I thought about what it meant for me to do much more than I thought I could and about making decisions on how to live. Back in December when Run with Vince was just beginning as a concept, I was deep in the throes of daily radiation and chemotherapy. At the time, doing anything more than simply watching the various races at the Colfax Marathon was unthinkable. My weight had dropped below 135 lbs. and I spent most of my time at home curled up in a fetal position on the couch.

Two weeks ago, after a morning run, over a cup of coffee a couple of friends in my running group (both of whom are now both sporting nice bald heads) asked me what if any part of the race weekend I would participate in. I thought for a moment, and replied I was thinking about running the half, but now that my blood counts were too low to start chemotherapy maybe I would use it as opportunity to run the marathon. And so I will.

I might be slow, but that is OK. It is not about running a race. It is about refusing to place life on hold. It is about choosing to feel alive. It is about being inspired by and honoring all of those who have done so much in support of me. It is about celebrating life.

When I am out there on Sunday and see the flow of blue inVinceable shirts running on the course and cheering on the sidelines, I can't imagine the flood of emotion I will feel. What I do know, is that on that day, it will be good to be bad. If my blood levels would have been good enough to begin chemotherapy this past week, I would have missed the opportunity and honor to run a marathon among a river of blue shirts and would not have experienced another one of those rare moments in life where I find myself completely unable to express the depth of my emotion.

1. kd on May 15, 2013 at 5:59 pm said:

Wonderful post!!!

"Excellence is never an accident. It is always the result of high intention, sincere effort, and intelligent execution; it represents the wise choice of many alternatives – choice, not chance, determines your destiny."

— Aristotle

2. Lori Di Croce on May 15, 2013 at 9:55 pm said:

Vince, not only will I wear the shirt proudly but I will be sporting my new tattoo on my arm reminding me with every arm swing that our lives have not been easy these last few years in many facets but ultimately PAIN IS INEVITABLE. SUFFERING IS OPTIONAL. let's do this thing!!!!

your lil sis Lori

3. Mike on May 16, 2013 at 3:26 pm said:

Dad, I wish I could be there with all of you and show my support! I know your emotions will be running high, and I envy how strong of a man you are, and can only hope I'm half as strong as I grow older into my adult life.

4. Dad on May 16, 2013 at 3:45 pm said:

I'm grateful you feel up to the challenge of a full marathon. You'll do great, you always do. All of us "InVinceables" will be so proud to be out there with you. Please don't show us up too much! Love ya! See you at the race.

5. Karen on May 16, 2013 at 8:49 pm said:

Even though I won't be in Denver for the Colfax run, my thoughts are with you. I wish you the very best. You are strong and will make it through these hard times. Please keep in touch.

6. Woz on May 16, 2013 at 9:30 pm said:

Vince,

While I won't be running in the wave of blue at Colfax, look for me out on the bike – another (nearly) bald head shouting out to you and the InVinceables!

7. Jan Messervey on May 17, 2013 at 9:20 am said:

Dear Vince,

You are, indeed, inVinceable and I am proud of all your accomplishments through this long journey. I often think that "Life is NOT a bowl of cherries". You are handling this whole situation in a very positive manner.

Your Dad (bless him) sent me the article which was in the Denver Post. I hadn't read the papers yet so I was so glad he sent it to me. I would have seen the article as I peruse the sports page, but anyway, I was so impressed that I forwarded it on to other family and friends with a notation that I knew you and your whole family as we are next-door neighbors with your parents in Grand Lake. I wanted to share some of the comments which I received back from them. There were a lot of "amazing person, inspirational, courageous, nice article, thanks for sharing this article, WOW, and this person is something else". Vince, you are surrounded with loving friends and family who are boosting you on. I know from experience that this is most difficult but you are never alone as our hearts, thoughts and prayers are with you on a daily basis.

Good luck to you and all the "inVinceable" members as you run the Colfax Marathon. By the way, I love the shirts and I know everyone wears the shirt proudly. You are one "amazing" person!!

With love and a gentle hug, Jan

8. Gretchen on May 18, 2013 at 6:55 am said:

Vince,

I am running tomorrow because your sweet sister Lori invited to be part of this group. If someone had just asked me to run a 1/2 for the fun of it, I would have had my answer "can't" and my reason, "way too busy" put before they could have finished the question. But after reading your blog, I quickly realized how ridiculous that sounded. Thank you for sharing your journey in a way that inspires people. Thank you for demonstrating strength and grace under pressure. Your impact is has a ripple effect that is never-ending. See you tomorrow! Gretchen

And So It Begins Again

My life with brain cancer



Enjoying the Ride

Posted on **August 11, 2013** by **VAD**

Life keeps moving. Just not always in the direction or the way in which I want.

I fight this cancer in the way that I know how. I fight it with all the strength I have. It is exhausting at times. With no end in sight, it can be overwhelming and consuming. Sometimes I need a good reminder to take a step back and simply enjoy the ride.

The entire weekend of the Colorado Colfax Marathon was a good ride. Family and friends out in support running the 5K on Saturday. A stream of blue "inVinceable" shirts along marathon course on Sunday. It was one of the most humbling and inspirational experiences I have have been through. I will forever owe a debt of gratitude to each and every one of you who were out there with me in body and spirit that weekend. Thank you.



Part of my wonderful support crew running with me to the end of the Colfax Marathon

The race was exhilarating. I probably pushed things harder than I should have. Post race festivities at the house were wonderful. The day could not have gone better. I went to bed that night, feeling good, but knowing I would start my next round of chemo and regiment of drugs the following day. It is all part of the game. Build me up; break me down. Never give up. And hopefully take out some of the cancer in the process. It is how I fight. It is how I roll.

My post marathon chemo cycle turned out to be a somewhat of a rough round. Snuck up on me really. I didn't slow things down much after the race. Truth is, I started to pick up the pace. Started to increase my intensity. Started to believe those shirts that I was "inVinceable." Started to believe there were ways I could get my body stronger and faster while I was consuming a cocktail of drugs destroying my body. I rested, I ate well, and thought I maintained balance, but through it all I slowly started to push more and more.

Deep inside I just wanted my life back. I have been fighting this incurable disease for too long. Eight years ago I underwent 7 months of chemo and I was done. I was able to live again. This time, after 7 months of chemo and radiation I wasn't even halfway through. In retrospect, I realize I was starting to get angry. I was growing impatient. My mindset was to push harder, to not let up for a moment. I wasn't going to let this defeat me. I didn't take time off from work. I didn't slow down. I pushed. I pushed through the cycle. I pushed to get stronger. I don't lose. I win. I will beat this I told myself.

I ran The Colfax Marathon on May 19th. On May 20th I was on chemo for a week, drugs eating away my body and flesh, blood counts dropping, muscle falling off my body by the day. And each day I am at it fighting to get stronger. A month later, Father's Day June 16th, my body still recovering from my last chemo cycle, I was back at it competing in the Boulder Sprint Triathlon. I figured it was "just a sprint" I would have fun and not push it too hard. Who am I trying to kid? Despite my weakened state, I still fared well in my Age Group. After the race in the beer tent, I joked "Triathlon by morning; chemo by night. And that is exactly what I did. I began my next chemo cycle that night. Not surprisingly, this cycle was a little harder than the last one. What was it that I said before . . . "snuck up on me really."



A view from the ride up Squaw Pass

A week later, three days off of chemo, with my brother and some friends, I rode my bike pretty hard from Evergreen, up Squaw Pass, around and up Floyd Hill and back to Evergreen. Some pretty good climbing and we rode it at a pretty good clip. I had a lot of fun. Beautiful views and great company. I enjoyed the feeling of struggle as my mind and body pushed me up the climbs and feeling of free falling exhilaration as I hugged the road at 40 mph plus down the descents with the wind whipping around. In a word, I enjoyed feeling "alive" again. Throughout the ride though, I could not shake this nagging notion that the strength was gone throughout most of my body. Not gone in the sense that I was

coming off of chemo and other drugs as I have grown accustomed to feeling over the months. Gone in the sense that I was unable to get my muscle tissue to “fire” correctly. My muscular strength was just gone. More concerning (and embarrassing), once back at the car after the ride, still in my bike kit, I lost control of my bladder. I simply could not stop my bladder from emptying. It wasn’t the first time in the past week either. At least this time I was out-of-doors in bike clothes rather than in my business suit pulling into my driveway.

I started noticing other things as well. So did others.

Over the course of the next two weeks, an incredibly deep fatigue set in throughout my body. I have never felt so physically tired or spent. The fatigue wouldn’t lift. Each day it drove deeper within my body. On separate occasions my brother and wife commented that when I was running I held my left arm still and at an odd angle. I noticed that I was starting to drag my left heel when walking. I attributed these things to the fatigue. I found it increasingly difficult to concentrate and stay awake at work. My fingers weren’t hitting the keyboard just right. Simple tasks were not so simple anymore. As the days passed, walking became a purposeful deliberative act rather than a natural unconscious one. I started to feel enveloped by a mental fog. My anger over this long course of treatment dissolved into depression and sense of hopelessness. The ride wasn’t so fun anymore.

My treatment has a cumulative effect in that each chemo cycle is progressively harder on my body. Each month, while on the drugs my body weakens and withers away. It is a two step backward one step forward process. I am always losing ground. By the beginning of July, I had completed 4 cycles. Probably lost more steps than I wanted to accept or acknowledge. Add to the mix the intensive radiation and chemo I underwent for 6 weeks beginning in December, my desperate desire to push and fight, a perfect storm was beginning to develop within my brain.

Radiation is a tough friend. Like the chemo, it kills cancer cells—and more. As one of my most treasured members of my treatment team noted, “It is one of those gifts that keeps on giving.” I may have completed radiation in January, but it wasn’t done with me.

Pushing forward, intense as ever, eager to start my 5th chemo cycle on July 14th, I met with my oncologist on July 2nd. She expected me to have an easier month. I explained how I actually felt worse and watched as the concern emerged across her face. I related to her my extreme fatigue, the feeling of weakness on my left side, and how I was beginning to feel less mentally sharp. During the exam it was clear something was amiss. Although my blood levels were high enough to begin my next cycle, I performed poorly on my neurological tests so it came as no surprise for me to hear her say that we better get an MRI within the next week or so and delay the chemo to make sure that everything was OK.

Everything wasn’t OK. My symptoms quickly grew worse. My motor skills seemed to diminish by the hour. Walking began to require intense concentration. Typing became an

exercise in mental gymnastics. It was becoming impossible for me to stay awake throughout an entire day. The breaking point for Linda occurred when she realized that I was unable to make it through a day without saturating at least one pair of pants with urine. Out of love and concern my brother and Linda both reached out separately to my neurosurgical team who decided the MRI couldn't wait a week. Within two days I was sitting in an exam room looking at some fairly concerning scans. My brain was starting to bleed and swell. I don't recall the exact non-technical phrase that was used to describe what we were looking at on the monitor, but in essence my brain had transformed into a bloody swollen mess. No one was sure why. Just sure that something needed to be done fairly quickly. There were two options: "A" surgery to remove the blood and debris or "B" a heavy course of steroids for 2 weeks, then rescan and reevaluate.

No surprise, we decided to try option "B" first. It is my preference to have my skull cut open and portions of my brain removed only when absolutely necessary. In addition to the normal risks of brain surgery, because of the location of my tumor, any surgical intervention comes with it a risk of vision loss. If that did happen, I could probably, in time, recover and compensate enough to read, type, and adequately do other routine daily acts. Descending down a hill at 40 mph on a bike and other activities that require quick eye-hand coordination may be a different story. In other words, those things that I have come to rely upon to feel alive, to feel like I am defeating death, might be gone. That scares the hell out of me.

I have come to understand that the most important part of my treatment team is that they have come to know who I am. They know what makes me, me. This closeness that developed over the years, a friendship really, was somewhat foreign for me at first. Throughout my life I had developed an inclination to keep a distance in many situations. I have come to realize over time that that characteristic in me can be a fault, not a strength. I suppose it was born out of a fear of emotion clouding sound decision making. I have seen it and experienced it far too often in much different situations. Here though, I came to appreciate the tremendous benefit a closeness brings. It brings a sense of trust—the absence of fear. One of the most valuable lessons I have learned along this journey is to trust others. I trust these people with my life. And I know that they understand that to live I must feel alive. To do their job well they must know who I am. They do their job very well. They are the best. I am a very lucky man. If surgery became the best option, I have absolute confidence in the skills they each possess to do it in a way so as to minimize the risk. I also have absolute trust that they will only go down that road if they thought it completely necessary knowing who I am.

Although option "B" avoided surgery for the time, the prescribed steroid, Decadron, is both friend and foe. It is very effective in reducing brain swelling, but that is only part of the story. Side effects include an inability to sleep at night, (I rarely slept more than an hour at a time, or more than 4 hours a night but I certainly was able to get a lot of work done), facial swelling or what some call "moon face" (my athletically gaunt face transformed into a rounder and more swollen version of me that no one has seen for since I was 50 lbs heavier) intense acne and skin sores, emotional swings, intense appetite swings, extreme

fatigue, and dramatic muscle loss (my muscular quads and calves melted into sticks with skin loosely hanging on).

The other part of option "B" was for me to agree to dial it back. The cause of the hemorrhaging and swelling was not entirely clear. It could be from new tumor growth. The MRI did show some new areas of enhancement. But it is not easy to tell exactly what is going on. The hope was that it all was result of what is called "treatment effect." My body has clearly established that it is particularly sensitive to the chemo. It may well be that I am particularly sensitive to the radiation as well. Some patients, about 6 months after radiation start to develop what amounts to a breakdown in the surrounding brain tissue. It is a result of the combined cumulative effect of the chemo and radiation. And maybe, my unyielding nature, always pushing hard mentally and physically was also taking a toll. It was time for me to take a step back and relax and enjoy the ride. And so I did.

For the next two weeks, as Linda and I anxiously awaited the next MRI, I focused on remaining relaxed and calm. I focused on living in the moment. I gave up "training" and took up "exercising." Morning runs became nice relaxed jogs with Linda. Swim practice became short dips in the pool simply working on my stroke. I stayed off the bike entirely. I tried to release all stress at home and work. Becoming "Zen" became my mantra. We went out for happy hour a couple of times. Watched some movies at home. Enjoyed a beer on the front porch. I really started to enjoy and appreciate life again. Despite the horrible side effects of the steroids, and the concerning MRI, life was good. I was once again enjoying the ride. I told Linda that I felt happier and more content than I had in years, maybe the happiest in my life. As the reality set in that this horrific disease remained on its singular mission to kill me, a renewed appreciation for the beauty and wonder of life filled my soul. After all, I am not dead yet. I still have a lot of living left to do.

My follow-up MRI was very encouraging. Gone were some of the areas of enhancement that might be evidence of new tumor growth. The swelling and bleeding were greatly reduced. Quite simply, it was the best news we had received since November when this ordeal began again. It appeared that the Decadron had done its job. I dodged the surgery bullet for moment. I began to taper off of the steroids. I felt better by the day. Almost by the hour. We did have to cancel a vacation, but it was OK. Linda and I had both learned to remember that even during the tough times, there is a lot in life that make it worth living. That even when life is not going in the direction or in the way you want, it is still possible, necessary really, to enjoy the ride.

It was an important lesson for us to learn. Over the course of the past 2 weeks, many of my increased symptoms have returned. An MRI last week showed renewed hemorrhaging and swelling. It is not as bad as it was a month ago, but it is now time for option "A." No dodging the bullet this time. In a week I will undergo brain surgery. Not a pleasant thought. As I said, it scares the hell out of me. But I am thankful for the past couple of weeks and the reminder to take a step back. As I move forward, I will keep this at the forefront of my mind. I will stay calm, relaxed, and zen as much as possible. Most

importantly, I will try to always remember to appreciate the beauty and wonder of life around me. No matter what direction my life will go, no matter how difficult the struggle, no matter how overwhelming the journey, I know it is important to enjoy the ride.

1. Erin Brumleve on August 11, 2013 at 8:47 pm said:

Vince,

Your courage, honesty, and ability to be in the moment and still appreciate beauty in the face of this hellish challenge is beyond amazing. My family and I are sending positive thoughts your way.

2. Michelle Wolcott on August 11, 2013 at 9:40 pm said:

And yet somehow, Vince, you still find the time and energy to come out and cheer us on. You truly are an inspiration and thank you for being out there with us. Beat of luck with the surgery. I'm not really a spiritual person but praying for you in my own way every day.

3. Steve Renda on August 12, 2013 at 6:53 am said:

Vince,

You already know how much I admire you, so I won't muddle up your blog with all that – besides, it will make us misty.

But I have to tell you, I am amazed at how clearly you can see through a very, very difficult situation. I've learned so much from you, and am lucky to call you my friend.

We're all pulling for you here in Georgia.

Steve

4. Kari Jensen on August 12, 2013 at 7:48 am said:

Vince, I am continuing to send "Zen" your way and to Linda. I loved seeing you (although briefly) at GTIS this weekend. Thank you for being out there to cheer us on. You are an inspiration to all of us to live well now. Will be praying for you and your family as you begin your next ride.

5. Steve Honda on August 12, 2013 at 1:03 pm said:

Vince,

Count me among the many, many folks who probably haven't directly told you (because of the self-conscious fear of possibly saying the wrong thing) that we're right there consistently praying, thinking, hoping, wishing as your ride through this.

Your words continue to inspire and encourage. Rest assured that you have a whole team of people pulling for you — including those of us who still may not have figured out the best way to show it.

Steve

6. Rose on August 12, 2013 at 4:06 pm said:

Vince,
I'm repeating what so many others have said before but you are truly an inspiration and a wonderful example of how to live life to the fullest! I'm so amazed at your strength and ability to surge forward even with all the chemo and radiation treatments. Thanks for sharing your updates on the blog. I get so much inspiration from your courage to battle cancer. My thoughts and prayers are with you.

Rose

7. Bonnie Pichler on August 12, 2013 at 9:36 pm said:

I understand the fatigue and the depression when our bodies fail us and we don't know what the future brings but, you were named "Vince" for a reason ... you are "InVinceable" and you bring inspiration to so many people ... my prayer is the inspiration you bring to others will come back to you in ways that cannot be measured and lift you to new heights that will bring healing and strength to your body...albeit it slowly, but healing nonetheless! There are survivors of this terrible cancer, and you will be one of them — you already are! This is a momentary detour in your journey ... and you have so many people being your bumper rails in the meantime.... prayers are sent forth to you and Linda and your family from the Pichler's, Anderson's, and Raymond's next week.

8. Ruth Mares on August 13, 2013 at 3:39 pm said:

There are no words to express how much I admire you, Vince. Best of luck next week. Fight on!

9. Sharon on August 13, 2013 at 7:44 pm said:

Vince,

When I met you on a 20-mile run 8 years ago, you shared your story with me as we wound through the Wash Park neighborhoods. I was speechless (which never happens!), my heart bursting with awe and admiration.

My prayer is that your body be healed, your spirit be uplifted, and your struggle be at an end. My prayer for your wife and family is for peace in their souls and comfort of their hearts.

Fight the good fight and enjoy the ride!

Sharon

10. kd on August 14, 2013 at 1:58 pm said:

your words are beautiful
full of hope
gratitude

like a confession

they acknowledge an unthinkable
truth
they reveal a special
grace

a body ravaged
a heart opening
a soul ascending

fully loved
fully living
life to the full

a living prayer....just breathe

11. Stewart Schley on August 19, 2013 at 4:43 pm said:

Vince, I had to smile when I read that part about you enjoying a cold one on the porch. Thinking about you this week.

And So It Begins Again

My life with brain cancer



Game Change

Posted on **August 30, 2013** by **VAD**

GBM

The acronym I never wanted to hear to describe my cancer. Now it does.

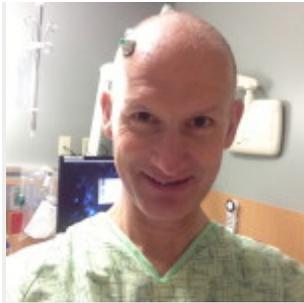
Look it up. Scary stuff. Seriously, look it up. This new road scares the hell out of me. It would scare anyone. I have feared this day for over eight years. I hoped it would never come. Convinced myself it never would. Now it has.

GBM is a Glioblastoma Multiforme Stage IV tumor. It is the most highly aggressive, invasive, and deadly form of brain cancer. It is what my cancer now is.

It was quite a week. The game has changed.

My surgery took place on Monday the 19th. It was a long day. I arrived at the hospital at 5:00 a.m. for my pre-op MRI. I felt remarkably calm and upbeat. The first step was to have electronic markers placed on my head to assist the surgical team guide the tools used

to resect my brain tissue. Next was the MRI to map my brain in relation to the markers. Then off to pre-op to get ready for surgery. All around a pretty easy and orderly process.



Ready for pre-op MRI

Originally, surgery was to take place in the morning, but, I have been having a problem with my platelet level. For reasons yet to be determined, my platelet level continues to drop fairly low. It could be a result of what the chemo is doing to my body, could be something else. It is something we will have to figure out. The morning of surgery, my platelets were lower still. Consequently, I spent a good part of the day getting platelet transfusions to raise my level high enough to safely conduct the surgery. Ultimately, they were able to raise it and I was in the O.R. sometime around 5:00 p.m.

The surgery was more aggressive than I had original thought it would be. My surgeon wanted to go after the "enhanced" areas on the MRI. His concern was that my MRI showed two different areas of enhancement which may be active tumor. You really can't tell from the MRI whether those enhanced areas are active tumor or an enhancement from some sort of treatment effect or other cause. At this point though, if you are going in, it is probably best to get out what ever tissue you safely can that may be active tumor growth. The risk and my biggest fear about the surgery was that I could suffer permanent vision loss to my left side. In theory, if that were to occur, my brain could compensate over time so that I could read and write and do other similar activities. But I want to be able to ride a bike and run—activities that require quick reflexes and good vision if you are going to do them safely. The areas of enhancement were perilously close to areas of my brain, if damaged, could cause the type of loss I feared.

The surgery took about 4 hours. A remarkably easy process for me. Just prior to wheeling me into the O.R. they administered some meds that basically knocked me out for the duration. One moment I was in a bed in pre-op and the next I was coming to in the recovery room. As I started to regain consciousness, two things raised complete joy within me—I could see and my head felt better than it had it weeks. Not only did I not suffer any vision loss, gone was the hazy peripheral vision that had started to develop over the last couple of weeks. I truly felt great. I was elated. I remember at one point with my surgeon and brother in the room, I was so relieved with how I felt, I blurted out "lets go for a run!"



In the recovery room

The surgery was a tremendous success. My surgical team incredible. I truly do not possess the words to adequately describe the professionalism and compassion they showed for me and my family that day and throughout this entire process. I marvel at the skill and teamwork it must require to navigate surgical instrumentation through a brain to remove tumor from healthy tissues with millimeters of precision. Modern medicine and technology are amazing. But really, what makes the difference are the people involved. There are none better than those involved with my care.



Incision

I spent the two days immediately after surgery in the Neurosurgical ICU and then a couple more on the general Neurosurgical floor. I slept a lot. My body and brain slowly yet quickly recovered. The human body is amazing. Within forty eight hours of having a chunk of my brain removed, I'm walking a half a mile on a treadmill, albeit unsteadily, to regain coordination and doing logic games to regain mentally agility.

For the next couple of days, although I felt pretty lucid most of the time, there were certainly times where I had difficulty thinking. I seemed to go through periods of energy and what I can best describe as exhilaration. I also traveled through periods of extreme fatigue and weakness. All part of the recovery process. As I now think back about the week, I realize there is a lot that I don't remember and that blurs together. I also realize that I was a lot worse off mentally and physically in the weeks leading up to the surgery than I was aware of at the time.

By Thursday I was sufficiently recovered from the surgery to go home. One of the objectives of the surgery was to get the pathology of those areas of enhancement on the MRI. Were they related to treatment effect or active tumor? And if active tumor, what were the grade and type? It has been over 8 years since my original diagnosis and biopsy. What are we dealing with today?

My surgeon came to me in my room as I was getting ready to leave. He looked me in the eye and gave it to me straight—"the pathology came back, it's grade IV . . . GBM." There was nothing more to say. I admire and respect his directness. I would have it no other way. With those words though, recovering from brain surgery became the least of my concerns.

From the beginning I knew the likely progression of my cancer. I started with a grade II oligodendroglioma. A relatively rare and slow growing tumor. I may have had it for years before I was diagnosed in 2004. There is no way to really know. Over time, brain tumors typically increase in grade and severity until they develop into grade IV. It is how they kill you. It is what they do. My hope was to delay that progression from grade II to grade IV for as long as possible and to live life to the fullest along the way. I feel pretty good about what I have accomplished so far. Remarkable really.

Since being initially diagnosed in 2004 I have tried to live life to the fullest. To stay positive and upbeat. To encourage all of those around me to do the same. It hasn't always been easy, but all-in-all it has been a good ride. There is a line from "The New Karate Kid" that resonates within my core—"Life will knock you down, but it is up to you whether you stand back up or not."

Back in November when this journey began again, I was encouraged by a recent study involving oligodendrogliomas in individuals with my genetics. Those being treated with the Temodor and radiation had greatly improved life expectancy and increased periods of disease free progression. In other words, they were living longer, much longer, and they were living longer without new tumor growth or additional treatment. This study was the most encouraging news I had received since I was diagnosed in 2004.

The game changed for me last week. At this point, I am still trying to absorb and process it. Physically, I have been spending this week trying to recover from the surgery and taper down off of the heavy steroids I was on before and after the surgery. My doctors warned me that I would be exhausted for a couple of weeks as I work through this process. I am. My body decimated, I unsteadily walk our greyhound Buddy 3 miles each morning to clear my head, and begin to rebuild my strength. By late afternoon/early evening I sit quietly at my desk at work or on the couch at home, expending as little physical energy as possible, willing my body and brain to rebuild and regenerate. I find it necessary for the recovery process to consistently take in healthy calories throughout the day. My years of marathon and Ironman training have provided me with invaluable insight as to how to best approach this physical recovery process.

Mentally, I am struggling to just put everything into perspective. This time a year ago, I felt on top of the world. Sure, I had brain cancer, but it had become almost an afterthought in my day-to-day existence. Life had never been better. I was turning 50 in a week, had just completed my 7th and fastest Ironman and in the best shape in my life. Linda and I were starting to think more in the long term such as how and when we could pay off our house, retirement, travel—things that we really didn't think possible just a few years ago.

The game has changed. Everything is so unsettled right now. Time seems suddenly compressed and accelerated. Maybe it is. Maybe it isn't. We just don't know.

Initially, I remained calm upon learning of new the pathology. I let it slowly soak in. At the time, I was packed and ready to leave the hospital but still in my room. I sat down, called Linda to tell her that it was time for her to come out and take me home. Although I did not say anything, she could hear it in my voice and asked what was wrong. It was then that the first waive of emotion hit me. It hit me with such force that I could not speak. I could not get the words out of my mouth. When I did, my body and mind went numb.

We have been riding a roller coaster of emotion since. Over the past week, swings of disbelief, anger, overwhelming sadness, and helplessness have given way to acceptance and renewed resolve. Resolve to fight the fight wherever and whenever my cancer next raises its head. I know now that it will always be there ready to strike. I just need to be better, stronger, tougher, and faster than it is.

In the end analysis, it doesn't really matter—grade II oligodendroglioma or glioblastoma multiforme stage IV is not a choice I get to make. Life knocked me down with this new diagnosis. My choice is whether to stand back up or not.

Really though, there is no choice. It is time to stand.

1. kd on August 30, 2013 at 10:58 pm said:

And we will stand with you.

2. Ty on August 31, 2013 at 1:53 pm said:

Unbelievable bravery Vince. Our thoughts are with you.

3. Peter Strange on August 31, 2013 at 11:11 pm said:

Hey Vince, just wanted to write a note to say that if there is one thing I've learnt about the running community over the years is that you don't get a more terrific group of people. Dave regularly mentions your news in the pre-run talks, and everyone is thinking and praying for you. We all look forward to seeing you at REOTR Saturday mornings again, even those of us that don't know you so well. Keep fighting, that's all we know how to do and we're with you all the way.

4. Jeffrey Amanda and Reef on September 5, 2013 at 10:25 pm said:

Love you Vince. You are amazing, inspiring and kinda crazy. Don't stop.

5. Oza and Milan on September 6, 2013 at 5:44 am said:

Vince, you have no idea how often we think and talk about you. Sending you a lot of positive energy. Yes, you have to stand now!

6. Kari Jensen on September 8, 2013 at 1:08 pm said:

Vince, you continue to amaze and inspire not only me, but your entire running family. We can feel you in spirit each week and you are always in our thoughts. I do have say, not too many people I know would describe a major brain surgery as a "pretty easy and orderly process". You are incredible. My thoughts are with you and your family! We miss you and hope to see you soon!

7. Michael Klee on September 8, 2013 at 9:58 pm said:

Vince, having read your post-surgical blog I now know with deeper understanding why I am a platelet donor. I am so fortunate to be able to give this gift to courageous people like yourself. You are an inspiration to all of us. You teach us that every day is a unique blessing.

8. Justine on September 9, 2013 at 6:33 pm said:

Vince I have been keeping up on your blog and my prayers are with you and Linda and your family! God Bless You all!

And So It Begins Again

My life with brain cancer



The Line

Posted on **September 10, 2013** by **VAD**

In Vegas, the current line on the over/under for Broncos this season is 11.5 games. Optimists among us will take the "over" and hope that Peyton Manning guides the boys in orange to at least 12 wins.

Now that my cancer is a GBM, the current line on my over/under is about 15 months. My line is not set by Vegas. My line is set by the entire universe of people with a GBM. In the world in which I now live, people live on average 12 – 18 months. There is nothing magic about that number. It is just a number. It is a number that certainly puts things into perspective, but it is still just a number. It is a number that represents a dividing line. There are as many people over the line as there are under the line. And how far over or under the line people end up living can vary greatly.

Eight years ago when I was first diagnosed with brain cancer, Linda and I attended a monthly brain tumor support group. At the time, both of us were terrified with what we thought was my over/under back then—3 to 5 years. It was in the support group where we quickly began to realize how fortunate we really were. Those patients with less aggressive

tumors like I had at the time were in a completely different world than those with GBMs. What I was experiencing at the time was scary. What I saw in and heard from the GBM patients was terrifying. Our time with the tumor support group lasted only a couple of months. We found it useful at first, but the experiences of those other patients and caregivers were so different from what we were going through at the time that the group became more depressing than helpful. What I did gain, was an incredible appreciation for how fortunate I was and how precious each and every day can be. I learned how important it was to be able to focus on and live in the moment. It is easier said than done, but when you are faced with 3 – 5 years or 15 months, it becomes more of a necessity, a survival technique really, than some sort of abstract concept.

Shortly after joining the support group, a gentleman who attended regularly lost his battle with brain cancer. It was very sobering. Like me, he had been originally diagnosed with a grade II oligodendroglioma. Like me, at the time of diagnosis he was very active. I learned after his death that he was an avid cyclist before his cancer. When I met him, his tumor had already progressed to a GBM and very quickly took his life. Unfortunately, he was one who finished well under the line.

On January 25, 1998, the Denver Broncos lined up in Super Bowl XXXII against the Green Bay Packers. Denver had lost 4 previous Super Bowls and the AFC was on a 13 game Super Bowl losing streak. Green Bay was coming off a Super Bowl win over the New England Patriots and was poised to be repeat champions. Denver entered the game an 11 point underdog—one of the 5 biggest underdogs in Super Bowl History. The line set by the odds makers in Vegas represented the thoughts of the country and world. No one gave Denver much of a chance. But John Elway, who had lost three previous Super Bowls, had other ideas.

With only 3:27 left in the game, the score tied at 24, Elway raced to the 10 yard line, then the 8, then the 7. He refused to slide or go out of bounds. He knows his 37 year old body is going to take a hit but he doesn't care. This isn't the time to take the easy way out. This is the time to win. Two Packer defenders unloaded vicious hits on Elway spinning him around like a helicopter. He landed on the 4 yard line for a first down Broncos. Without missing a beat, he then jumps up as if the hits and resulting helicopter spin made him 10 years younger, runs back to the huddle, with his arm raised in the air and his fist clinched. At that moment, anyone anywhere watching the game knew the "line" didn't matter; the man did. Denver went on to win the game 31-24, well surpassing the 11 points they were supposed to lose by in line set by the Vegas odds makers.



John Elway Helicopters for a first down creating a pivotal play for the win and doing what it takes to overcome the odds

The line was just a number. What mattered, was the person.

Eight years ago, when attending the brain tumor support group, I was fortunate enough to meet a man who was living with a GBM. We shared some pizza together and talked about life with brain cancer. It appeared to me that his tumor was affecting him in some ways, but overall he was good. He spoke slowly but coherently and with great intelligence. He told me he had been a mechanical engineer by profession when he was diagnosed. He was not a spry man and moved slowly and with what appeared to me some deliberation rather than walking naturally without thought. He was in his early 60's and was a fairly large man. I never learned whether those characteristics were a result of what the GBM and treatment had done to his mind and body or if that was just the way he was and had always been. What I did learn from him that night was far more important, particularly now.

We talked about what it was like to get a devastating diagnosis of brain cancer and to learn that there is no cure, extremely limited life expectancy, and that the treatment can often be worse than the disease. Back then, the "line" on a GBM was worse than it is today. Treatment options were more limited. In essence a GBM diagnosis was a death sentence within a year. He explained to me how he did what many of us say we would do upon receiving a blow like a GBM diagnosis. He quit his job; he maxed out his credit cards, bought a new car, and travelled to exotic locations. He did everything and anything he could do to maximize his extremely limited time left on this earth. His advice to me, however, was to not go forth with wild and reckless abandon. Indeed, although he had an amazing time, his spending spree was his biggest regret. Within 6 months he was broke, unemployed, and in massive debt. And he was still alive. Despite the "line" he kept right on living. The night we shared pizza and conversation together was more than 12 years after his GBM diagnosis. He wasn't complaining by any means. Although those initial 6 months caused him years of financial struggle, he was thrilled to still be alive. He simply wanted me

to understand that life expectancy is just a number. And that I, like he, could be one of those who end up above the line. I quit attending the support group about six months latter. He was still going strong.



View from the top of the Lake Placid Olympic Ski Jump

Two years ago I competed in Ironman Lake Placid. I took my dad with me. We had a lot of fun and both really enjoyed the trip. Ironman Lake Placid is a amazing event held at the same venue of the 1932 and 1980 Winter Olympics. It is where the United States won the "Miracle on Ice." and the 1980 Olympic Gold Medal in ice hockey.

For me, the trip with my father two years ago took on unexpected significance. The town appeared to look much the same as it did in 1980. Being in that historic Olympic town for an Ironman, with all of the excitement and energy the event brings with it, was electrifying. I found simply walking around Lake Placid to be an extremely emotional and moving experience.

It spoke to me in the same way that Ellway helicoptering for the first down did. The sights and sounds of that famous Olympic city during Ironman weekend strengthened my deeply held belief that no matter the odds, adversity can be overcome. You may not be successful in every given situation, but you have to give it your best shot. To do anything less is to accept failure.

In the race, I gave it my best shot. Despite throwing up a couple of times on the run from dehydration and pure exhaustion, running in front of an oncoming bike and causing an accident, and feeling like I just needed to quit on multiple occasions, I kept going. I didn't

do as well as I wanted, but I gave it my best. And my best on that day was good enough for a new personal best.

On February 22, 1980, the "Miracle on Ice" took place during the medal-round men's ice game between the United States and Soviet Union. In what is widely regarded as one of the greatest and dramatic upsets in sports history, the U.S. team, made up of amateur and collegiate players and led by coach Herb Brooks defeated the Soviet team 4-3, which was considered the best hockey team in the world,

The Soviet team had captured the previous four Olympic hockey gold's, going back to 1964, and had not lost an Olympic hockey game since 1968. Three days before the Lake Placid Games began; the Soviets routed the U.S. team 10-3 in an exhibition game at Madison Square Garden in New York City.

Few gave the young Americans a chance to win. But win they did. I was a senior in high school at the time. I still have vivid memories of watching the game and hearing Al Michaels unforgettable call—"Do you believe in miracles?—YES!" as time expired. It was around that time in my life that I started to develop a strong unshakeable belief that nothing in life was impossible. When faced with seemingly insurmountable odds, I have always tried to stare impossible in the eye and not be the one to look away or blink.

So what do you do when you learn that you are faced with a line of basically 15 months? Frankly, I don't know. It is an incredibly short time. At this point it is simply incomprehensible for me. I can't wrap my mind around it. I have no way of knowing whether it could actually turn out to be 6 years or 6 months or what the treatment and disease will do along the way. I am somewhat paralyzed and thus just keep doing what I have done to this point—move forward and live life the same way I have been.

In a sense, life hasn't changed at all nor is it any different for me than it is for anyone else. Despite what we may want to believe and what makes us comfortable, there is no certainty in life or death. I suppose, in a way, I am lucky. I know the line on my over/under. People die every day without warning. It is almost as if when you get a diagnosis like this, you have more certainty. It is not information that you necessarily want or are prepared to deal with, but it is there and you have the opportunity to make decisions based upon it.

Never in my life have I faced the odds that I face today. I am afraid. But I move forward knowing that people overcome adversity everyday. Odds can and will be beat. There is absolutely no reason why I can't end up over the line. From all that I experienced in life, I know this to be true. I also know I will give it my best shot. If all goes well, maybe, 12 years from now I will be sharing a pizza with someone like me, telling him that life expectancy is only a number, and how in the end, the number really means nothing. But the person—the person means everything.

1. jeffrey, amanda and reef on September 11, 2013 at 7:01 am said:

My money's on you.

2. kd on September 14, 2013 at 12:18 pm said:

Vince- I've thought about this post all week and struggled to find the "right" words as a reply. There are no words. Your courageous response and strong will give us a glimpse into the thoughts of the great man that you are. Thank you for that.

"Forces beyond your control can take away everything you possess except one thing, your freedom to choose how you will respond to the situation."

— Viktor E. Frankl, Man's Search for Meaning

"As my muscles weakened, my writing became stronger. As I slowly lost my speech, I gained my voice. As I diminished, I grew. As I lost so much, I finally started to find myself."

— Neil Selinger

"In some ways suffering ceases to be suffering at the moment it finds a meaning, such as the meaning of a sacrifice."

— Viktor E. Frankl, Man's Search for Meaning

3. Sean on September 16, 2013 at 10:20 pm said:

Thanks for sharing your story with us Vince! I love and appreciate your perspective! Everyday is a gift and you are right, it is just a number.

4. Christy McLaughlin on September 19, 2013 at 9:05 pm said:

Thanks for sharing your journey. I only know you from several runs with Runners Edge and our conversations have been limited but I am amazed and touched by your courage and strength. I saw it in you as an athlete and this blog documents the courage and strength you have as a human being. My bets are that these characteristics you have that have kept you persevering in so many endurance events will carry you through whatever life throws you. I wish I had the right words to say but know you have so many thinking of you and hoping for the best. Thank you for writing and for your bravery. We can all learn a lot from you. All the best... Christy

And So It Begins Again

My life with brain cancer



Life is Different Now

Posted on **October 12, 2013** by **VAD**

I had no idea.

On November 18, 2012, I published the first entry of this blog. A week earlier I learned my cancer was growing.

I decided to write about "My Life With Brain Cancer" for a number of reasons. At a basic level I wanted to chronicle my experiences for myself and others. On another level, I hoped to feel sense of catharsis through writing about it. Also a large part of me wanted to inspire others dealing with brain cancer or other difficult obstacles in life. I thought I could begin to give back to others and raise awareness of this terrible disease by writing about my experience. Given where I was at that point, what I had accomplished since being first diagnosed, and where I hoped to go, I felt almost a responsibility or obligation to reach out to others. I thought I had a pretty good handle on things. I suppose I did at the time.

When I wrote the first entry entitled "Beginnings" I had been living with brain cancer for 8 years. I had been living with brain cancer in the sense that I had been living with a

cancerous tumor in my brain. But, really, I had no idea what it was like to "live" with brain cancer. I thought I did. Now, that seems foolish and naive.

Certainly, I had no idea what my life with brain cancer would become. I suppose I had an idea of what to expect if things took a turn for the worse. I talked with others worse off than me. I read about the experiences of others; and to be fair to myself and those close to me, there were some tough and difficult times over the years. My initial chemotherapy treatments were difficult to say the least. Emotionally, the diagnosis of terminal brain cancer was tough. It took years for Linda and me to come to terms with it. But this, this is different. This "life with brain cancer" . . . I had no idea. I really had no idea.

Even now, a year after learning my cancer is growing again, after 6 weeks of radiation and chemotherapy, after 4 additional cycles of chemo, after brain surgery, months of steroids, learning that my cancer progressed to a stage IV GBM, and trying to wrap my mind around a 15 month life expectancy, I am only just beginning to appreciate "life with brain cancer."

I do know a lot more today than I did in November 2012 and a whole lot more than I did in 2004 and 2005 when first diagnosed and treated. I know enough now to know I am going to learn a whole lot more whether I want to or not. There is no stopping this train I am on. It is simply a matter of how fast it is going to travel before it wrecks and how bumpy of a ride it will be.

For years I thought I was "living" with brain cancer. I was living. And I did have brain cancer. But for the longest time, the cancer did not have a significant impact upon my life. At some point, a couple of years after my initial brain surgery and chemo therapy, living with brain cancer became just living. I took Keppra, an anti-seizure medication everyday. I got an MRI of my brain every 3 months. Neither bothered me much. If I forgot to take my Keppra, I might get a little visual disturbance from a small seizure. Every week or so I would get one anyway. I always viewed them as a subtle reminder that I did have a brain tumor, because other than those infrequent mild visual seizures, I was "kicking ass and taking names."

I rather enjoyed my MRI appointments. I slept during the actual scan and after, Linda and I would get some breakfast together before heading to the Neurosurgery Clinic to view the scan and discuss the results with the doctor. Until November 12, 2012, the results were always great. Incredibly, my tumor seemed to look better each time making the appointments incredibly positive experiences despite the fact we were looking at a cancer in my brain. Afterward, we usually stopped at Starbucks to relax and celebrate life before we each headed back to work.

I worked hard and played hard. Men half my age couldn't keep up with me. That was my living with brain cancer for years. The cancer was always present in the back of our minds, but we kept it there. Most people who knew me didn't know I had brain cancer. For the most part, I refused to recognize it myself. Just a year ago, life with brain cancer was

running a marathon at a 7 minute mile pace without feeling tired or finishing an Ironman triathlon in 12 hours and drinking beers while I watched the rest of the field finish for the next 5 hours. I was enjoying a smooth ride on a slow moving train. At times I let myself believe the train had stopped.

Life is different now.

Today, I walk with a limp because I can't lift the toes on my left foot as I have lost nearly all the strength in my left calf. Apparently it is the result of some brain swelling that occurred before and from the surgery. Hopefully, I will regain most if not all of the use of my left side at some point. Because of the different body mechanics involved I actually find it easier to slowly jog than to walk. But, for other reasons, that isn't easy either.

For the past week, on a couple of mornings I have been able to muster up the strength to do a very slow 3 mile jog with Linda. "Jog" is an overstatement. It is more of a trot usually intermixed with a shuffle. I am physically unable to do more. One of the reasons is my blood levels are shot. I am anemic, my platelets, hematocrit, and hemoglobin have plummeted. No one is sure why. There are a couple of theories but no good thoughts on how to get my blood back to normal. The bottom line for me is the low levels make me incredibly weak and tired. Most mornings, after a couple of blocks of my jog/trot/shuffle I feel like my chest is going to explode as I gasp for air. My lousy blood counts also significantly limit my treatment options. Not that I have a lot of options anyway, but when your life expectancy starts to get measured in months rather than years, additional options would be nice. More important to me at this point, I would prefer to go through those months I have left with some energy rather than feeling like I am going to pass out every time I walk up a flight of stairs.

Compounding the destruction to my body by the surgery, radiation, and chemotherapy is the steroid I have been taking since July. The first week of July the doctors placed me on Dexamethasone (also called Decadron or "Dex" for short) to reduce the swelling in my brain caused by bleeding and treatment. Dex is both an effective and evil drug. It quickly reduces brain swelling. Almost as quickly it destroyed the muscle tissue in my arms and legs. This is another reason why I am physically unable to do anything more than a walk/trot/shuffle for more than a couple of blocks. I simply lack the muscle strength to do anything more. My leg muscles have deteriorated so much that most days I can't walk up a flight of stairs without pulling myself along grasping a banister. Dex also caused other body changes. It made my face swell up like a balloon (a condition referred to as "moon face"), it created an accumulation of fat on my stomach, back, and neck, it causes my stomach to bloat at times and my digestive system to shut down. Sometimes I have an insatiable appetite, others I have no appetite for days. My hands and feet tingle all day like they are "asleep."

Speaking of sleeping, it is an elusive concept while on Dex. Despite the complete exhaustion Dex causes me during the day, I am lucky to sleep more than 2 hours at a time

during the night. Making matters worse, while on high dosages of Dex, in the middle of the night I frequently experience an onset of incredible pain in my knees, ankles, and elbows. Some nights the pain so intense it literally reduces me to tears, like an intense gout attack in each of the six joints. I lay in misery unable to move as my joints ache, throb and cry out at the slightest touch. Try sleeping without allowing, either, knee, elbow, or ankle to touch anything. It is not possible. I know. I tried without success, intense pain proving my failure.

On the mornings following these Dex attacks, after I pull myself out of bed, crippled by the pain I am unable to walk without help for an hour or two. As I grasp the wall and hobble the 50 feet down the hallway from our bedroom to our kitchen, running a marathon in a couple of minutes over 3 hours or finishing an Ironman seem a lifetime ago. It is hard to believe it was just a year ago. That was living with brain cancer then. This is living with brain cancer now. I had no idea.

I have tapered down from high doses of Dex three times now. The first time was in August when it was hoped that I could avoid surgery. The significant negative impact Dex had upon the quality of my life was part of the reason we decided to proceed with surgery. After the surgery it was necessary for me to again take a high course of Dex in order prevent post-operative swelling. Fortunately, in short order my doctors tapered me down off of the drug over a couple of weeks. I was completely off of the drug for just a few of days, feeling better than I had in several weeks when, after consulting with a hematologist, they decided to put me back on a high dose in an attempt to get my body to produce platelets. I wanted to cry. I had just started feeling somewhat "normal" again.

After a couple of weeks of no sleep, painful Dex attacks, further muscle deterioration in my arms and legs, increased "moon face" and no real improvement in my platelet level, I convinced them to taper me down again. It didn't take much. At that point there did not seem to be a good reason to keep me on the drug. It was starting to completely destroy the quality of my life with no real benefit. When life is measured in months, the emotional toll from the weeks spent feeling they way that I have is far worse than the physical hell I simply endure. Although I desperately try to live in the moment and enjoy the ride, when I struggle to walk up a flight of stairs, or simply walk at all, I can't help but to think "time is a wasting."

. . .

I started writing this blog entry a week or two ago. I am not a fast writer nor do I have a lot of time to spend writing. Normally, my current daily life events are not relevant to what I am actually writing about. Consistent with the theme of this blog entry, life is different now. It threw me another curve. I thought it might be good to insert some "current events" and then continue on with where I ultimately wanted to go with this entry. I am currently writing from Neurosurgical Intensive Care Unit of University Hospital. A couple of days ago I

was admitted to the the NIICU with what started out as a little indigestion and diarrhea the night before and quickly moved to vomiting, high fever, and delirium by morning.

By midmorning I was basically non-responsive. Linda called my brother to help get me to the hospital. I don't have much memory of the day. I know that I was surrounded by medical professionals constantly who were very concerned. My temperature rose perilously close to 104, my white counts dropped dangerously low, and my red counts continued upon their downward spiral. Nothing was looking good. How or if this was related to my cancer and treatment is unknown. What I do know is it scared the hell out of me and everyone else. Everyone else because I was rapidly moving toward demise if things didn't get under control, me, because I don't know how I got there. If my immune system is that weakened, I will need to be all that more careful and balanced in how I live.

After a 4 day stay in the NICU, it looks like I will be discharged tomorrow. I have been on massive IV antibiotics, white blood booster drugs, poked, prodded and stuck with multiple needles, shots in my stomach and a PICC line which is basically a blood catheter that runs from my bicep to my heart. Truthfully, none of it bothered me much. None of it except I am back on a high dose of my nemesis Dex. The hematologist feels keeping me on a high dose until mid next week will help rule out some reasons why my blood counts are remaining so low. If they continue to remain low through mid next week he has agreed to let me taper down yet again. I will undergo a bone marrow biopsy. He said it is painful. I told him given what I have been through thus far, I am not worried. Where we go after that I don't know.

Life is different now.

I suppose the one good thing out of this brief interruption to my life is I was able to get an MRI of my brain. GBM's can be extremely fast growing tumors. That is why they can kill you so quickly. One theory as to why I am having trouble with my blood levels relates to fast tumor growth. I haven't had an MRI since immediately after my surgery. I have been a little worried that my cancer was starting to rapidly grow. Fortunately, the MRI showed that not to be the case. There may be an area of new growth, but it is a little early to tell yet. The bottom line is that my brain is not riddled with new tumor. My neurosurgeon is O.K. with the scan at this time. If he is, I am, though the area of enhancement concerns me.

They rushed me into the NICU on a gurney puking, delirious, and with a fever near 104. I walked out 4 days later after two blood transfusions, massive amounts of IV antibiotics and with no real explanation as to what happened or why and back on a high dose of my old friend Dex, for the 4th time, in a renewed and more urgent attempt to stimulate my bone marrow to produce blood cells.

And so goes my life living with brain cancer. As I said before, I had no idea. Back to rest of the story.

I pushed myself my entire life. "Driven" does not describe my odd behavior over the years. Maybe my DNA is just different. From a young age I thrived in adversity. I rarely took the easy path. If there was a way to challenge myself I seized it. I gravitated toward that which seemed difficult or impossible.

As a young kid I played baseball. I was pretty good at it. Better than most. Excelled at every position. I enjoyed it. Baseball came natural. My dad grew up wrestling. As fathers do, he encouraged me to wrestle. I joined a wrestling team but never became good at the sport. Built like a beanpole with the body strength to match, a natural I was not. I competed in both sports for a couple of years but my heart remained true to baseball. It did until the summer of 7th grade when I lost a wrestling match I knew I should have won. After the match, I stormed out of the gym, ran to the nearest pay phone, still dripping with sweat called my baseball coach, and told him I quit to wrestle full-time. From that point forward I never stepped on a baseball diamond again.

Despite years of working myself to death at wrestling, routinely staying for hours after practice to work on my strength and conditioning when all others were at home, living and breathing the sport for years, I never came close to the success at wrestling I obtained in baseball as a 5th grader. In fact, in the final week of my senior year of high school, I lost in a wrestle-off and did not even make the team for the final match of the season. Through all of the years of frustration, tireless work, and ultimate failure, I never once regretted the decision to take the more difficult path. I thrived on the challenge. It served not as discouragement but as intensified motivation and strength for future struggles.

Years later, after dropping out of college at CSU, I joined the Navy. The nation just a few years removed from Vietnam. Not surprisingly, my decision to enlist was not popular with the folks. I didn't help matters that I came home from the recruiter and informed them after the fact. Despite their concern they handled it fairly well. With angst on his face, my father sought assurance from me that I joined for only 2 years. I explained it was a little longer. "Three?" he asked, to which I replied, "no not for me" which was followed by the hopeful and inevitable "four?" At which point I explained that "no, for me it was six."

As with baseball, I did well in the Navy and could have easily turned it into a great career. I thoroughly enjoyed the Navy. I enjoyed everything about it. I even enjoyed boot camp. I served with pride.

As it turned out, my six years became eight so that I could put myself through college at night while I ran a department during the day. For four years I worked more than 60 hours a week, took 9 credit hours a semester, including the summers, at American University in D.C., and spent 3 hours a day commuting back and forth, all with the ultimate goal of gaining entrance into law school. The easy path was to remain enrolled at CSU and move on to law school after graduation or to stay in the Navy and enjoy a successful career.

Managing a department while muscling my way through school were difficult sleep deprived years. I often was so tired by Friday night that my bones literally ached. Simple pleasures such as watching a movie or enjoying a football game with a beer were virtually non-existent. To this day, I do not know how I survived.

My earlier life experiences served me well. I graduated with honors from American and then put myself through law school as I raised two kids, worked nearly full-time, and again graduated with honors. Those years even more sleep deprived than before. And as before, I never once regretted the decision to take the difficult road. I felt good about it. Something about facing adversity sits well with me. Maybe I was made for it.

This past week I have worked with my doctors to put together a treatment plan for the next month or so. Just prior to my hospitalization I began treatment with Avastan. The treatment is relatively simple. A weekly IV infusion every other week that takes about 30 minutes. Avastin blocks tumor blood vessel growth to create hypoxia (oxygen deprivation) in the tumor and shrinking it. It has shown mixed results. In some it has been effective to a degree. In others, the tumor finds new pathways and comes back with a vengeance. My Avastin treatment has been slightly delayed in order to get my blood levels stabilized at a level high enough for me to safely tolerate the drug. To accomplish this, next week I start weekly infusions of another drug called Rituxan. These infusions take longer. In the neighborhood of 4 – 8 hours. In the meantime, I will continue to take Dex, in stark contrast to the gaunt sinewy athlete I was but a short time ago, my body swollen like a balloon, unable to tie my shoes or fit into my suits, I will slowly walk a few blocks each day during lunch to maintain a sense of balance in my life and get in what little exercise I can manage.

While I wish I did not have to go through them, the infusions don't concern me greatly. The tenuous nature of my life does. This is nothing like one of those difficult roads in life I took on willingly as a challenge. This is not an adversity I relish. I want nothing more at this very moment than to wake up from this horrible nightmare, find myself on the easy path, sit back, relax and enjoy life. It is not to be so.

This "living" with brain cancer . . . I had no idea. And even if I did, it would not make any difference. My hope is that all my past life experiences in never taking the easy road will again serve me well and help me navigate the most difficult journey I have faced.

Life is different now.

1. Mia Migdall on October 14, 2013 at 9:10 pm said:

Vince,

You continue to share your story with us in a totally honest and uncensored manner. You are reaching so many people, more than you could possibly imagine, by sharing the

complete story of you. Thank you. Stay brave. I hope you can feel the love and support of those of us who surround you. Think of yourself in the middle of one massive group hug!!

1. Diane Davies on October 15, 2013 at 8:13 am said:

We are with you Vince.

2. Sean on October 17, 2013 at 9:52 pm said:

Hi Vince

Thank you for sharing your story with us. I admire your strength, courage and tenacity. Know that you are always in our thoughts and prayers. You are an iron man!

Sean

3. Ed Spear on October 31, 2013 at 5:48 pm said:

Vince, you were one of the best influences in my young life and continue to be so today. I knew that it was hard to live the Navy life and go to college at the same time and I always admired you for having the dedication to do it. Your determination and tenacity will always be something I aspire to. Keep fighting my friend and I'll join you at the finish line to celebrate!

And So It Begins Again

My life with brain cancer



Getting on with Living

Posted on **November 1, 2013** by **VAD**

I know I will die.

This disease will kill me. Nothing wrong with that. I accept it. We all die at some point. But for now I am still alive.

The news that I have a grade IV GBM growing in my brain hit me like a truck speeding down the highway. It knocked me down, beat me up, and took my breath away. After getting the news, I never really let myself emotionally release. I never broke down, never cried about it. I sure felt like it a number of times over the last couple of weeks. It is not that I am a tough guy impervious to pain or devoid of emotion. I just don't think I ever caught my breath enough to take it all in and allow myself to feel the incredible sadness and despair that surrounded me like a deep fog.

The news hit Linda just as hard or harder. The fog seeped into and filled our home. We both have seen the faces and looked into the eyes of those touched by this disease. We

wanted to believe, and because I had done so well for so long, almost started to believe, I was untouchable. But deep inside we knew I was not. Despite what we knew, we were unprepared for it to reach out and touch me. I am sure anyone who looked into our eyes during those first couple of weeks saw the same deep stare back of helpless despair that we had seen in the eyes of others so many times before.

The fact is Glioblastoma multiforme IV is probably the most aggressive, deadly, and least treatable cancer in existence. That it is now growing inside of my head affects me more deeply than any thing else has in my life to this point.

There is no denying the incredibly grim statistical reality of the disease. Approximately 50% of those diagnosed with a GBM die within a year. Only about 20% survive 2 years. The five year survival rate is less than 5%. And it goes down from there.

A number of factors can influence those percentages such as the person's age, location of the tumor, and an individual's responsiveness to a particular treatment. Some treatments, such as the Avastin that I am currently taking are thought to extend the quality of life for a couple of months, but not necessarily overall length of survival. Essentially, no matter how you cut it, those overall survival percentages remain.

It is not clear to me when my cancer became a GBM. It could be that my cancer progressed to that stage as early as November of 2012. There is no question that it progressed to that stage as of August 2013. It doesn't really matter. Either way, I am quickly moving within the expected statistical survival parameters.

All that said, the statistical reality is not my reality. I don't know what my reality is or will be.

Long term GBM survivors are loosely categorized as living 3 years or longer after diagnosis. Not a long time to be sure, but twice as long as the statistical average. I have read stories by those who have lived as long as 12, 14, and even 18 years, and are still living. Their lives have not always been easy. Almost all have endured multiple surgeries. Most are perpetually in some form of treatment. A few go a couple of years without either. All, regardless of the number of surgeries or the frequency and type of treatment are thrilled to be alive.

The answer to the question of "how do I get myself into that group?" remains elusive to all including the best medical professionals in the world. I don't know the answer. Like everyone else touched by this horrible disease, I wish I did. I do know there are certain things I can control and others I cannot. Mostly, I can control my attitude and mental outlook.

As I read the stories of long term GBM survivors, it occurs to me there is a consistent theme among them. Long term survivors all seem to possess the attitude that they will continue to live life. It is the attitude I developed after being diagnosed with brain cancer in 2004 and it is the attitude I need to firmly reestablish today.

Although nowhere near as grim, my diagnosis in 2004 was nevertheless devastating at the time. It took me a while to come to terms with it, but I did. And when I did, I refused to accept the statistics in the sense that for the most part I kept on living life as I had before the diagnosis. Absolutely I made adjustments to my long term thinking. I could not ignore reality. To do so would have been unfair to myself and those close to me. But I did not stop living life. Instead, I pushed with all of my might in the other direction and did my best to live life to the fullest. I developed a personal mantra of sorts, "Dream big, set the bar high, and feel alive." I repeated the mantra to myself over and over again, day after day. I lived it. It became part of me. I refused to allow brain cancer to keep me down. It would not define who or what I was. I did.

I am not one of those people who will tell you that getting cancer "was one of the best things to happen to me." It wasn't. It sucks. But is an incredibly humbling experience that led me to considerable introspection and caused me to make many positive changes in my life. Without a doubt, the years since my initial diagnosis in 2004 have been the best of my life. Not because of cancer, but despite it. And because of the changes I have made within myself as a result.

It was during these years that I began to understand I was not alone in this world. For much of my life I lived with a sense of isolation. I kept a certain emotional distance between myself and others. I suppose it was a protective mechanism I developed out of necessity as a result of circumstances that previously existed in my life. My cancer enabled me to better see the capacity for good in others. I learned to accept the help and incredible kindness offered by those around me. I realized that in many ways I was giving back by receiving. I learned to trust people. Most importantly, I learned that people truly cared about me and that I had an impact upon them.

Brain cancer forced me to take control of my life. A cancerous tumor growing inside of your head reminding you everyday of your mortality can have that effect. It taught me to look for the positive in everything and everywhere. Where others see obstacles I look for opportunity, rather than accepting excuses for failure, I search for reasons to overcome and succeed. It is not that I am better or stronger than anyone else; it is because I feel I am perpetually at a fork in a road leading to either life or death. To take the path to life, I cannot accept failure or allow negative emotion to guide me.

When diagnosed in 2004, I attacked life with a vengeance in every possible way. I relentlessly pushed my mind to work harder and my body to be stronger, faster, and fitter. I succeeded on all fronts. I embarked upon a mission to defy death, to defy the cancer. In many ways I did. I far surpassed initial life expectancy and cancer progression

expectations. But that was not enough. I hung upon my office wall a personal mission statement which reads "I will not just survive I will be better than before." And so I did.

In terms of my running, prior to my initial brain cancer diagnosis my goal was to qualify for the Boston Marathon. After I was diagnosed such a lofty goal appeared unattainable to many but not to me. I reached the goal within 2 years, and after going through brain surgery and nearly a year of intense chemotherapy and treatment. I went on to run a Boston Qualifying time in every marathon I ran thereafter. I never let up. Over time, I completed more than 30 marathons improving my time each year. At some point, running a fast marathon wasn't dreaming big enough or setting the bar high enough in my death defying pursuit to feel alive.

Without knowing how to swim, I signed up for an Ironman triathlon—a 2.4 mile swim, 112 mile bike ride, and a marathon all within 17 hours. I finished it in just under 12 hours 45 minutes. Over the next couple of years I went on to finish 6 more Ironman triathlons and numerous shorter ones in which I often placed in or won my age group. In so many ways, personally, professionally, and athletically, I accomplished more in the 8 years after being diagnosed with brain cancer than I did in the prior two decades of my life. It was a good ride.

It has taken me a while to get up after the GBM truck knocked me down. I am not completely on my feet yet, but I am getting there. As much as I would like to continue to defy death and my cancer, I am realistic. The challenges of today are different than those in 2004. I know I must take a different approach.

I still repeat my daily mantra of "Dream big; set the bar high; and feel alive." Each day when I walk into my office at work, I still read my personal mission statement hanging on the wall: "I will not just survive I will be better than before" and think about what I can do to carry it out on that day. As I often tell my children to ask themselves, I ask myself, what can I do today so I will be better tomorrow than I was yesterday?"

I believe the answers today are not, nor should they be, what they were 8 years ago. Pushing my mind and body to the limit is not necessary. To do so is probably counter productive to my overall physical and mental health. Taking things down a notch is not giving up. Rather, I am redefining what it means to "feel alive." It doesn't have to be crossing a finish line in an endurance event faster than before or faster than someone else. Feeling alive can appear when and where I want it to. I feel it as I jog with Linda in the morning, the sun rising on the horizon, birds chirping as we pass by, our feet softly padding along. I feel it as we prepare and enjoy dinner together after work. I feel it when I am around family and friends. I feel it every time someone reaches out and does a kind act or expresses a kind and supportive thought to me. The kindness people have shown me has made me feel more alive than all of my Ironman and marathon finishes combined.

I don't know how much time I have left in this life. None of us really know. I will give it my all to finish this race better than the 80% of GBM patients that only make it 2 years and better than the 95% that don't make it past 5 years. My goal is to finish better than anyone else. To be the best.

I don't know how to reach that goal. I do know that I only reach it if I get on with living. Getting on with living means once again refusing to allow cancer to define me. It means appreciating the beauty of life all around me. It means continuing to see opportunity for success rather than obstacles or failure. It means facing life with a positive outlook and letting go of any negative emotion. I may have the meanest, badest, most aggressive cancer in existence, but I am still alive. And while I am, I plan on enjoying life.

After I was first diagnosed with brain cancer in 2004 our life was a whirlwind of activity between surgery, appointments with different doctors, chemo therapy, steroids, and just trying to figure out how to cope with what we were dealt. It took a couple of years for everything to calm down to a point where we were able to simply live what felt like a normal life. We have much of the same whirlwind of activity this time around without the luxury of a couple of years to figure things out. That is okay though. There isn't that much to figure out at this point. For the most part the fog has left our home. Linda and I are mentally in a better place. I am feeling better physically than I did a couple of weeks ago. We will take things as they come and do our best to not worry about that which we have no control. We will continue to live our lives together as we know how.

The years since first being diagnosed in 2004 may have been best years of my life so far, but they aren't my last. Nor will they remain my best.

Like all of those long-term GBM survivors, I am thrilled to be alive. I look forward to joining their club someday.

I am excited about getting on with living.

1. Jeffrey Lippa on November 1, 2013 at 10:55 pm said:

Thank you, Vinny. I needed to read your words tonight.

2. Steve Renda on November 2, 2013 at 7:43 am said:

Vince,

I know deep down that you have plenty of time – probably enough to even see me qualify for Boston – which in my case is two or three generations out.

But one thing I'm even more certain of – because of who you were before cancer, and the way you have handled life since, you've touch so many people that you'll live forever.

Love you brother

1. David Collins on November 4, 2013 at 1:12 pm said:

Vince,

Wow bro. Thank you for sharing.

3. Kevin Bommer on November 5, 2013 at 8:24 am said:

Vince:

Your attitude and spirit is infectious, which I am sure you've heard from lots of other people. In your quest to be better each day, remember that the way you are living your life and the positive impact you have on those around absolutely counts toward that goal. Rather than just simply sinking away, the stone you cast is sending ripples out to other people and making them better, too. I am glad to be one of those people, and I love watching you embrace life!

Kevin

4. 44mom on November 23, 2013 at 4:06 pm said:

Thank you for posting this. I was just diagnosed 3 weeks ago. I am 44 with a family. Your story really touched me and motivated me. I wasn't even looking for this but am so thankful I ran across it. Thank you again.

5. Mike Spry on November 25, 2013 at 8:18 pm said:

Vince, thank you for all your open thoughts and sharing your journey. Your re-iteration of thinking positive and living life in a positive way is an epic example of a role model. You are certainly a role model for me.

6. Liz on November 30, 2013 at 7:40 am said:

Vince, I always read and never comment – but thanks for writing this. This holiday season has once again reminded me to treat each day as a blessing. Living in a body that is, compromised, for lack of a better word, allows me to let go of past hurts, grudges. We are here now – and that is what matters.

7. Michael Klee on December 5, 2013 at 2:36 pm said:

Vince, what Steve Renda said resonates with me too. You have left a part of yourself with all those who know you and thus you will live on as a guiding light in their minds. The ripple effect is endless. Also, what you said about everyday you are at a fork in the road choosing either life or death. Don't we all have that choice to make every day, choosing to overcome some obstacle instead of letting it destroy our lives? Thanks again for all your writings. Keep living deeply!

And So It Begins Again

My life with brain cancer



Six Weeks

Posted on **March 28, 2014** by **VAD**

Six weeks.

Those were the worst words I had ever heard. I was in 4th grade at the time. Baseball was my life. Spring was in the air and the season was just beginning.

A few days earlier, despite my refusal to acknowledge my severe stomach pain to myself or anyone else, and my strong denials to the contrary, my parents knew something was wrong. Not surprisingly, my inability to eat, drink, or even walk upright did not escape them. The following 24 hours were a blur. Partly because of the pain and partly because of the flurry of activity. I remember my parents taking me to the pediatrician and a subsequent hurried drive to the ER. I remember being rushed into emergency surgery that night and hearing from the surgeon the next day. He explained I was lucky he was able to remove my appendix before it ruptured. I really didn't care much. I just wanted to get out of the hospital and back to the ball field.

A couple of days later, after willing myself to make countless laps around the ward with my IV pole in my hand, I convinced the doctor I was doing well enough to go home. A short time later, all my hard work seemed for not when, during my discharge, the doctor uttered two unimaginable words: "6 weeks." I could play baseball again in 6 agonizingly long weeks. To my young mind, the season and therefore my life, was over.

As a kid, summer vacation seemed to last forever. It was when I lived life. No school, no homework, no worries. Just having fun and enjoying life. Throwing and hitting a baseball, chasing and catching butterflies, wading in a river and catching fish. Just three months, each summer created a life time; those 6 weeks I could not play baseball, an eternity.

Time is funny that way. We have standard units to measure it: seconds, minutes, hours, days, weeks, months, and years. Yet, depending upon where we are in our life, time and the units we use to measure it, take on entirely different dimensions. As a kid, 6 weeks seemed an eternity; as an adult, not so much.

On January 29th, 2014, a doctor again told me those two words: six weeks. At that moment and stage in my life, that very same measurement of time affected me in an entirely different way than it did when I was a kid to whom the most important thing in life was playing baseball.

With cancer, I am constantly using different measurements of time to judge where I am and how I am doing at any given point. Though really, I am doing nothing different than what we all do every day when we think things such as, "I have to be out the door in 15 minutes," or "this project is due in a week," or "I have 20 weeks to train for my marathon. It is that with cancer, the same measurements of time take on different dimensions

Nearly 10 years ago when I was first diagnosed, my life expectancy was thought to be around 3 to 5 more years. Significantly longer than the 6 weeks I had to go without playing baseball in 4th grade, but at the moment I heard it, it seemed a whole lot shorter. And the same measurement of a 3 to 5 years to live, so devastating to hear when I was diagnosed in 2004 would be welcome news today.

Almost 18 months ago, in November of 2012, we learned my cancer was growing and progressed to a new stage. We know now that is a stage IV GBM. Over 50% of the people diagnosed with a GBM die within the first year. Only 20% make it past two. It probably has the worst overall 5 year survival rate of any cancer. In the last year and a half I have endured six weeks of daily chemotherapy and radiation, 4 additional monthly cycles of chemotherapy, two hospitalizations, brain surgery, months of steroids, more radiation (this time stereotactic surgery), and biweekly Avastin infusions for the last six months. My blood counts—white, red, hematocrit, and platelets—plummeted and slowly crept back up to almost normal again. For months I was unable to sleep at night, then for months I was unable to stay awake. I watched helplessly as my body transformed from a sinewy athletic build to a bloated and swollen blob. My weight fluctuated over 30 pounds and I lost half of the hair

on my head . . . twice. I went from running a 3:03 marathon to struggling to walk a couple blocks as my left foot dragged with every step, as if tethered by a ball and chain. All of which brings me to January 29, 2014, and those two words, that measurement of time: "6 weeks."

I completed my second course of radiation in December while undergoing biweekly Avastin infusions. I was physically and mentally spent. I felt nothing like the man who started this odyssey in 2004 nor remotely like the man in November 2012, who I had worked so hard to become. In speaking with the oncologist after I completed radiation, her thought was to start me on a different course of multiple chemotherapy agents in conjunction with the Avastin. I explained to her that at my next appointment, when we did my first post-radiation MRI, I wanted, for the first time, to have a discussion about the quality versus longevity of my life. I told her I wasn't giving up, but I was tired. It had been a long and difficult road. And I wasn't sure I was willing to endure more and increased misery only to buy myself a couple of months in the end. We scheduled my next appointment and MRI for January 29th.

In the meantime, Linda and I hastily scheduled a desperately needed trip to Maui. While there we relaxed, enjoyed the sun, spent time with friends, and relished our time together. I gathered strength and regained use of my left foot and hand. I spent a lot of time contemplating the quality versus longevity of life. It is not an easy decision. It is not an easy disease. It is cruel. There is no cure. What it does and will do to me is the easy part. The impact to those around me is nearly unbearable.

Getting an MRI with a GBM reminds me of the movie "The Deer Hunter" where prisoners of war are forced to play Russian roulette. You never know if there is a round in the chamber and you never know how long you will be in the game. On January 29th, I pulled the trigger resulting in nothing but the click of an empty chamber. The MRI revealed no new or at least significant tumor growth. The heavy discussion of quality of life versus longevity was delayed. When Linda and I met with the oncologist, all three of us decided to simply stay the course for a while. No additional chemo. Just the bi-weekly Avastin infusions. I was granted a reprieve of sorts, for "six weeks," at which point I would get a new MRI.

Six glorious weeks.

It has been more than two months since that appointment. The latest MRI again revealed no new tumor growth. I have been running a little and riding a little every day. Nothing much or too fast. Nowhere close to racing a marathon or competing in an Ironman, but I have come a long way from not being able to type with both hands or walk much.

Considering that nearly 80% of the people in my shoes would not be alive today, let alone lacing up a pair of running shoes for a 14 mile run, make no mistake, I have nothing but the deepest gratitude and the most profound appreciation for the opportunity I have every minute of every day.

In fourth grade "6 weeks" were the worst words I could imagine. On January 29th, I couldn't imagine hearing anything better. Two weeks ago, after reviewing the incredibly surprising results of my most recent MRI, my oncologist said to us that she was willing to wait 12 weeks this time before another scan. Without hesitation, Linda and I simultaneously replied, "no, 'six weeks' is fine."

That was 3 weeks ago. As I told my friends and family back then, it was incredibly good news but by no means am I out of the woods. The fact remains I have highly aggressive and incurable brain cancer; yet, a more important fact remains: I am still alive.

And while I am, as long as I possibly can, I will continue to lace up my running shoes to enjoy early morning runs with my wife and friends; clip my cycling shoes into my pedals to climb a mountain or two on my bike; and jump in the pool whenever I can to do a few laps, pretending I know how to swim. Every step of the way, appreciating how lucky I am.

Even if I am living "six weeks" at a time.

And who knows, maybe, just maybe, I will be able to get in a race sometime.

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1. Frank Ingham on April 12, 2014 at 8:02 am said:

Great stuff Vince...Frank

And So It Begins Again

My life with brain cancer



Physicality

Posted on **May 12, 2014** by **VAD**

Physicality.

It is a real word. For the longest time I didn't think it was. I looked it up. I was wrong.

I thought it was a word sportscasters made up in an attempt to sound intelligent during a broadcast, as in "he plays with great physicality" or the game today takes great physicality."

I looked it up partly, because of my natural curiosity in language and word usage, but mostly, because I suddenly found myself without it. "Physicality" that is.

I found it defined as: "Intensely physical; of or relating to the body as distinguished from the mind or spirit."

All of my life I have been physically active and fit. From the time I was a young boy I involved myself in organized sports, such as football, baseball, and wrestling. If it wasn't one of those, it was something else. I was always in motion and always dreaming how to get better. In seventh grade, in an attempt to become stronger for wrestling, I began playing a game each night before bed that I called "push-up poker." The game consisted of using a deck of cards, placing the deck face down next to me on my bedroom floor as I readied myself on my hands and knees. I would then turn over a card and do the number of push-ups indicated on the face of the card. Aces were 11 and Jokers 20, all face cards 10. I wasn't a strong kid. "Spindly" a better description. The first night I attempted a game of pushup poker, as I finished the last card I collapsed to the floor in a trembling sweaty mess. I pulled myself into bed and promptly passed out. Strong no. Determined yes.

Undeterred, I continued to play the game each night before bed. Ultimately I was able to go through three decks of cards in less than five minutes. turning three cards at a time. I still looked like a spindle but I could sure do a lot of push-ups.

It was around that time that I also started to run in order to get into better shape. My classmates probably thought I was a freak. Every night after school as they headed home to do those things that middle school kids do, I ran up and down the stairs inside the school for hours. No one asked me why or really paid me any attention. It was just something I did. Later, I started running for distance. I didn't know what I was doing. I just ran. It was not unusual for me on a Saturday afternoon to head out our front door and just start running. I went nowhere in particular. I just ran until it seemed like it was time to turn around and then headed back home. I ran in all types of weather and all times of the day. Sometimes I returned home in the dark of night covered in snow and ice, other times, I set foot out the door with the temperature over 100°. The one constant, I always enjoyed it. I loved it. People often remarked they saw me out running along the street with a big grin upon my face. They thought it odd both because I was out there running at all—this was before the first big running boom hit in the early 80s and because I was doing it with a smile. I imagine it was pretty unusual to see anyone out running at all, particularly a scrawny little seventh grader grinning ear to ear, no matter the time of day or the conditions. In a strange way, the worse the weather, the tougher the run, the bigger my smile

It was few years later when I started riding my bike more. I had always ridden my bike to and from school and around the neighborhood. It was how I got around. For some reason, I don't really know why, I started riding my bike in much the same way I ran. I frequently headed out the door for hours with no particular plan or destination in mind, and when it felt right I turned around and headed home. Pushing myself all the way, enjoying the mind-body experience. I guess a sportscaster would have said I approached life with great physicality.

I had my most recent six week MRI on April 23rd. For the obvious reasons, Linda and I were fairly nervous going in. Throughout most of the six weeks, I felt pretty good. I started to run a little every day, rode the indoor bike for about 45 minutes everyday, and

even got in the pool now and then. I felt like I was finally starting to gain back some strength and get a little more normal.

And then it hit. The loss of my physicality. It was odd. It both came on gradually, almost by the day and hour, and seemingly struck me overnight. I began to first notice it when I met my friend Gina for coffee around April 10th. I found it difficult to walk up a couple of stairs while holding a cup of coffee on a tray. I felt strangely uncoordinated. It was as if I was unable to navigate up two steps without losing my sense of balance and direction. Over the next couple of days I noticed I was having difficulty using some of fingers on my left hand. I noticed that typing, something I had done virtually, all day long every day. and was as second nature as breathing, became increasingly difficult.

The day after I had coffee with Gina I ran 16 miles and felt great. The following Saturday it was more difficult. My body felt out of alignment and I could not move with the fluidity I had grown so accustomed to and so much enjoyed. I tired easily. It was a struggle to make it 10 miles. The next Saturday I barely made it six. Within days I was unable to run at all. Today, two weeks later, I am unable to walk without a cane. I am only able to type with my right hand and through the assistance of a dictation program. Thank goodness for modern technology. More importantly, thank goodness for my wife. She gets me dressed in the morning and gets me into bed at night.

I cannot imagine how difficult it must be for her to watch her once seemingly indestructible ironman reduced to a childlike figure who cannot put on his own pants or shoes without assistance.

One of the more frustrating aspects to all of this is that cognitively I am as sharp as ever. Completely aware of my physical decline while feeling utterly helpless to stop the regression.

On a positive note, the MRI on April 23rd revealed that there did not appear to be new tumor growth. My doctors believe these new symptoms are a result of what they call treatment effect from the radiation I completed approximately 5 months ago. Apparently, radiation is one of those gifts that keeps on giving. They believe I am experiencing tissue breakdown, or what is termed "radiation necrosis" along the motor and sensory strip in the parietal lobe of my brain. The hope is I will be able to regain some or most of the functioning on my left side, but it is too early to know for sure. It is pretty clear; however, if any gains are to be made they won't come fast or easily. I am currently doing physical therapy and trying to teach myself how to use my left hand again. I do this by completing repetitive simple tasks such as attempting to pick up a child's block and stack it on top of another, something that would have been thoughtless task two weeks ago now takes tremendous concentration and focus for me to be able to complete the act at all.

Last Sunday, I was fortunate to experience the incredible moment of being at the finish line of the Colorado Marathon as my good friend Jim Lynch completed his 100th marathon. As I

watched him cross, my heart filled with joy that I was able to be there for such an amazing accomplishment. The truth is, more than a couple of tears ran down my face as I was overcome with the enormity of what Jim had accomplished at that moment. Undoubtedly, a Sunday afternoon sportscaster watching him cross the finish line would've commented on the great physicality required to complete 100 marathons. It truly is a remarkable feat necessitating tremendous dedication, discipline, commitment, and a level of fitness achieved by but a rarified few.



100 marathons come to an end

Truth be told, it was not the physicality of the accomplishment that overwhelmed me. Indeed completing 100 marathons is an intensely physical feat. What moved me to tears and filled my heart with joy was not the intensely physical act; it was the mind and spirit of Jim Lynch. As I embraced my old running friend, propped up by my new cane, I knew my marathon running days had likely come to an end. But as I looked into his eyes I felt great hope rise within me. I was reminded of what I already knew. What I learned as a spindly kid heading out the door for hours on my bike or a run. What every marathoner or endurance athlete knows. What we can accomplish in life. What is really important in life is not who or what we are physically. It is about our mind and spirit. My body may be broken. I may not be able to walk without assistance or get dressed without the help of my lovely wife. But make no mistake, my mind and spirit remain strong. To you Jim Lynch thank you. Thank you for reminding me what is truly important in life. Like you, it appears my marathon running days are over. You chose to "retire" from the game.

I simply lost my "physicality."

In both of us our mind and spirit will carry on and burn with far greater intensity than our bodies could ever maintain.

1. Travis Burmaster on May 12, 2014 at 10:05 pm said:

It was so great to see you at Colorado marathon! You are such an inspiration to us all!

2. Ty on May 13, 2014 at 8:21 am said:

Vince. You continue to amaze all of us with your courage and wisdom. As I sit here, the things I thought were stressful in my life now seem insignificant. Keep on truckin' and keep on writing!

3. Donna W. on May 13, 2014 at 10:41 am said:

Thank you for sharing your journey with us. You are a class act, Vince. Sending you lots of love & strength.

3. Lindsay Dolce on May 13, 2014 at 12:10 pm said:

Vince, you are such an incredible and inspirational person. In the face of something awful you have managed to seek and find joy, we can all learn from your attitude that it's just as easy to find the positive as it is the negative. Thank you for sharing your journey with so many. Sending prayers for strength and a continued positive outlook in your journey.

4. David Fine on May 13, 2014 at 12:26 pm said:

Thank God He has blessed me by putting you in my life. Your words are not what awes me, it is the life you live that inspires me to be courageous and overcome my fears.
Thank you Vince!!!

5. Katie Tiernan on May 13, 2014 at 2:34 pm said:

I found your blog through Lindsay Dolce. I'm inviting you to come race and win Leaves of Hope, Lutheran Medical Center's annual National Cancer Survivors Day 5K/10K Run/Walk in Wheat Ridge. Register here: <http://www.leavesofhope.org>. I hope to meet you.

6. Dad on May 28, 2014 at 11:00 pm said:

Vince, Your strength and courage has touched hundreds of individuals; many with serious illnesses. You have made a difference in all of our lives and especially those of whom are also suffering. For all of us that are close to you and some that have only heard of your fight - you are our hero, you have been so incredibly courageous. You have fought a very difficult fight for so very long without every losing you dignity or perseverance. You are an inspiration to so many people and will be for years to come. Not many achieve the admiration of so many individuals as you have. You truly have made a difference in our lives. I am so incredible proud that you are my son. I love you so very much.

Dad - May 28, 2014