

Ken Whitley's IMPACT Story

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“DON'T GIVE UP!! THERE IS HOPE! Put one foot in front of the other; keep moving forward; Define and pursue your goals while putting your trust in God. Doctors can treat. They can't heal. God does, however, work through doctors, scientists and the EndBrainCancer Initiative's Team. Don't give up! New GBM treatments are around the corner and the EndBrainCancer Initiative's team can provide IMMEDIATE ACCESS to these specialists and these new treatment options.”

- Ken Whitley, GBM patient, and 2018 EndBrainCancer Initiative National HOPE Award Winner

In 2016 I was at the top of my game professionally, physically, and I thought spiritually. I was successfully growing a multimillion dollar business and had the respect of peers, friends, and family. I was exercising at a high level, had a new home, was teaching adults and high schoolers at church, and had two wonderful daughters and sons in law. In December of 2016, for the first time in my life, I suffered migraines. The physician's assistant gave me a shot in the bum, scripted a dose pack of steroids and sent me home. The treatment worked and I credited the pain to end of the year stress. **On Super Bowl Sunday of 2017, life was turned upside down and my faith journey became supercharged.** I entered my brother's house for a party and he insisted I go to the hospital immediately. While I didn't feel bad, he and others noted an imbalance in my gait and trouble with my speech. My then girlfriend, Cathy, took me to the hospital and a CT scan revealed a tumor. After admission to Neuro ICU, a surgeon removed a tennis ball size tumor from my right temporal lobe. The surgeon told Cathy I had been close to brain herniation and that I was 24-36 hours from death; the operation saved my life.

My Journey through 2017 had many hurdles and blessings. After my craniotomy and transfer from Neuro ICU to a regular room, a friend insisted I call the EndBrainCancer Initiative (EBCI - formerly the Chris Elliott Fund). Talking with the EBCI team was one of the more significant events of my journey. Their team was factual, frank, and encouraging, providing guidance and insight that changed my and Cathy's approach to my treatment, and connected us with key doctors in North Carolina. Cathy and I had embarked on a faith journey that **no conversation could prepare us** as glioblastoma (GBM) creates challenges at a fast and furious pace.



Ken and his wife Cathy living life to the fullest

As 2017 progressed the challenges and hurdles continued to stack up like playing cards. In March, we visited:

1. Duke to find I was **NOT A CANDIDATE** for either the polio treatment or the CMV targeted-therapy clinical trial.
2. Wake Forest Medical Center to find nothing was available for my tumor biomarkers.
3. The Levine Cancer Institute in Charlotte where I qualified for, and started, a Nivolumab Clinical Trial.

In April, acid reflux from the drugs inflamed my sinuses to the point of fluid draining from my ears. In May, a routine MRI showed swelling and midline shift. I was back in the Neuro ICU with a dexamethasone drip and told a second craniotomy was urgently needed. Cathy and I took a cautious, conservative, and urgent approach seeking counsel from multiple surgeons and oncologists in the Charlotte area and the team at EBCI. We concluded it was serious though a second craniotomy was less urgent than my admitting neuro oncologist had painted.

In June, we went back to Duke where a new regimen of chemo was scripted. Also, in June, I proposed to Cathy, and she accepted. Since she had been walking with me since the tumor was first found, she knew the prognosis and I was blessed with her "YES."

August proved to be a monumental month. We found through a routine MRI, the tumor was still growing; at the same time, we also discovered and Duke had a **clinical trial showing promise and that I was a candidate!!** This Duke trial was new hope as my tumor had grown through radiation, a clinical trial for Nivolumab and multiple rounds of Temodar. On August 31, 2017 Cathy and I stood before God, the preacher, and many friends to say "I DO". God had blessed me with the love of a wonderful girlfriend and now He gave her the courage to enter a covenant relationship with a guy carrying a brain tumor.

While tumor growth was a concern, the side effects of having a GBM tumor continued to bring hurdles and frustrations to my daily life. I had difficulty reading as I would lose the left 2 inches of the computer screen and inch of a book. I also lost the first 2-5 letters of some words. "Women", for example read "Men" leaving me with two men's restrooms. Loss of left peripheral vision also caused me to run into doors, walls, store displays, AND people on my left side. Most people were understanding, but some were offended. Before GBM, I was using reading glasses and experiencing some loss of hearing. After the craniotomy, my vision deteriorated further and reading a shelf tag became a challenge. Deterioration in hearing, and sight were compounded by "brain fog." **I had gone from top of my game to "can't find the game" in a few short months.** I quickly identified the hearing and vision declines, but was slower to pick up the significant reduction in cognitive processing speed which became a significant point of frustration. **Not only did I struggle with things that were once easy, everything took longer and I couldn't understand why.** With the frustration of these changes, the emotional impact from the tumor, and emotional impact from drugs, my moods were shifting like the spring weather. My mood would change in a few minutes or a few hours **and I couldn't understand why.** My challenges were further compounded by extreme dizziness when I stood after sitting for a while. I would get so dizzy I had to hold onto something. A couple of times I thought I was going to fall down while holding onto the car or parking sign. We believe this was due to low cortisol caused by long term use of dexamethasone.

September brought the clinical trial at Duke. On the 19th, Dr. Allan Friedman drilled 4 holes in my head and started a 72 ML drip of bacteria into the tumor area. As I write this, my journey continues and I fully expect the challenges of GBM to continue. I know, however, that my God, Jesus, walks with me and with my family on this journey. GBM is my disease, not my identity. I am the adopted son of a loving god.

I started this journey believing I was at the top of my game on all fronts. I am now closer to God than I have ever been and am physically stronger than any time in the past 5 years. Through this, I have experienced the true meaning of grace (from God, friends, and family) and have come to realize where my faith should rest. In January, I had relied on me and Me LET ME DOWN. The day after each operation, I was too lethargic to feed myself; within a couple of weeks I was doing cardio and strength training. The **ONLY** thing I did was try over and over again. Don't quit!! **THERE IS HOPE!!**

Throughout this journey, I have learned to put one foot in front of the other; keep moving forward; and trust God. While I had trusted him with my soul, this journey has taught me to trust Him with my everyday life. I get to face the unknown with a known god that knows and loves me. This week I got the results of my latest MRI - "no measurable change in the tumor!" **The 3 previous scans showed tumor reduction and dissipation!!** A "NON DUKE" NEUROLOGIST SAID "I HAVE NEVER SEEN GBM DO THIS. Additionally, Hydrocortisone supplements took care of the dizziness; my peripheral vision is getting better; AND I can read again!!

I urge YOU to support the work of the EndBrainCancer Initiative today so that they can provide HOPE to more brain cancer patients like me and get more brain cancer patients into advanced treatments and clinical trials. Please, donate today at www.EndBrainCancer.org and at this Event right now!

In deep gratitude,

Ken Whitley