

## Ken's IMPACT Story

03/16



My family will never be able to express our gratitude to the entire EndBrainCancer Initiative (EBCI) team, but thank you. **Just when my father was starting to lose HOPE, you found a way to give it back to him.** Ever since we started at Swedish my father has had new HOPE and has kept the fight going. We have been having very good news so far with the Nativis Voyager System device ([www.nativis.com](http://www.nativis.com)), and we even had one MRI come back to show the tumor looks like it may have shrunk a bit. You have given so much to my family, my father, and me.



My father's battle against cancer began in October 2014. One early morning my father, Ken had felt a bit dizzy, he had fallen asleep in the living room the night before and once he tried to get up and come to go to bed he collapsed in the living room, and fell unconscious. Once he came to, he was awoken by medical staff that were called by his now Wife Shelly. My father was then rushed to Northwest Hospital. He was in the ER all day, and they were running what seemed like every test in the book. When they finally decided to go in for an MRI they discovered he had a tumor in his brain, and he collapsed because he had had a seizure. They weren't sure at the time what type of tumor it was, but they knew he needed surgery. My father started his battle on that day.

After his surgery, they broke the news to my father that he had a tumor called anaplastic astrocytoma, and he was going to need radiation, and chemo. He was transferred over to the University of Washington for his radiation, and before they were able to start they noticed something didn't seem right, and decided to double check his original diagnosis. Once they ran the tests needed they had discovered that my father's tumor was actually quite worse than originally thought. The original surgeon from Northwest Hospital had only actually taken out 30% of the tumor, and there was still 70% there. His new diagnosis was that he actually had a Glioblastoma multiform, and he had to go back under the knife once again. My father this time did his surgery at the University of Washington medical center. He also remained there after for treatment.

My father went through six weeks of radiation in Nov. 2014, and was after put on Temodar chemotherapy. From November to April my father stayed on Temodar, it seemed to be working, but one day we received bad news, and that was that his tumor had a little growth to it, and they wanted him started on a new treatment. They told him they would like to go ahead and start on a treatment called Avastin. That day changed our family's life forever.

After every appointment, and any change in my father my favorite person to talk it out to was my then girlfriend, and still amazing friend, Laura. She always had a way of explaining what was going on with my father in which I could better understand. She helped me through all the tears, anxiety, and pain, and it's because of her that we came to meet with Dellann and the team at the EndBrainCancer

Initiative. When Laura heard the next treatment option for us was Avastin she expressed some concern, and asked if we would be open to setting up a meeting with EBCI/CEF to discuss all options my father had. It was an easy sell for us, and so Laura went ahead and got us all scheduled up for a conference call meeting.

During the call we got to meet two delightful patient navigators. Both from the beginning were very kind, and inviting. They expressed the same concern they had for my father going to Avastin at that time, and told us about a few other options that they thought we would like. One was a very new clinical trial called the Nativis Voyager device. It is a device that looks like a halo that you wear around your head. The device is connected to a small wire that is plugged into a little thing that looks very much like a pager. This device creates a magnetic field around your head and kind of simulates chemo, but without actually putting any poison in your body. Once my father heard that he was 100% on board. The EBCI team got to work right away and set us up with the head of the clinical trial at Swedish Hospital. After we met with him, he approved my father was a candidate, and so set us up with the Neuro-Oncologist on campus. The Neuro-Oncologist gave my dad other options as well as the Nativis device, but in the end we all decided Nativis was the best option, however since the device is so new in clinical trial she decided it best to also be on some chemo as well, and so prescribed the Chemo pill CCNU to be taken once every six weeks along with the Nativis device.

I'm so grateful every day for the EndBrainCancer Initiative. Their dedication to brain tumor patients and their families is a blessing, and their "Direct Connect" program connecting patients like my dad with top brain tumor specialists made it possible for my dad to be here still, and in great spirits.

I hope that one day we are able to find a way to end brain cancer. That hope is why I support the EndBrainCancer Initiative! Please join me in supporting this organization.

If you would like to support the EndBrainCancer Initiative and their "Direct Connect" Program, please go to: [EBCI Gift and Donation Page](#)

For more information about the EndBrainCancer Initiative and their important work, please see: [www.endbraincancer.org](http://www.endbraincancer.org)

**THANK YOU Everyone!!**

Josh Frost, Ken's son