

Chris' Story

This is my story as told through my wife, Dellann, about my battle with Glioblastoma brain cancer.

My name is Christopher Stewart Elliott. I am 39 years old, have a daughter who just turned 8 and a son who just turned 5. I was fortunate enough to meet my wife on a blind date 12 years ago. We have had a lot of fun along the way and I know I have been blessed. We often pinch each other just to check in to make sure that we are truly living such a wonderful life. I've got my health, am still very athletic, have good lifelong friends in my life and have had much success in the telecom industry. Life was good and I knew it.

It was a beautiful Sunday morning, August 27, 2000. My family and I were up at our cabin at Crystal Mt. when I had a sudden urge to go home and work on the arbor that I had been building off of the back patio and work in the yard. By the way, working in the yard was one of my favorite passions. That and playing golf!

So, we left the cabin and came home. I spent the afternoon building the arbor in the backyard and mowing my large yard on my pride and joy, my riding lawnmower. Dellann left the house around 5:00p to get propane and stuff for hamburgers for dinner. Barbecuing hamburgers and eating outside sounded like the perfect way to end a perfect weekend. I continued to work outside in the front yard while my two children ran around playing.

All of a sudden, I felt nauseous and I kept smelling the most awful smell. A very strong smell that smelled like very old sneakers. The smell was so strong that I could almost taste this horrific smell. I felt weird. I sat down and asked my daughter to run inside and get the phone. My kids sat with me while I tried to decide what to do. Just then, Dellann pulled into the driveway. She saw the phone in my hand and could tell something was wrong. Her first thought was "oh, no, someone has died". I explained to her that I felt like I had the flu, told her about the strange smells and thought that I needed to go inside and lay down. She helped me upstairs and laid me



down on the couch. She then went downstairs to fix the kids dinner. About 15 minutes went by when all of a sudden I knew I was in trouble. I started pounding my hand on the coffee table to get someone's attention. Dellann ran upstairs and I told her to call 911 right away. She did and the emergency personnel arrived right away. They thought that I had meningitis, that Dellann and the kids had been exposed and that they would just be driving me to the hospital in a leisurely manner. Dellann said she would get the kids packed up and meet them at the hospital about 10 minutes after the ambulance arrived.

The ambulance pulled out of the driveway and about 3 minutes later, Dellann heard the sirens. She prayed that it was not me, but it was. I had a grand mal seizure while in the ambulance. EMT's are not able to administer certain drugs and one of the drugs that I needed to control my body was a drug they could not legally administer. So, they called in the Paramedics and the siren that Dellann heard was the paramedics coming to meet the ambulance that I was in. About this time, Dellann was stopped in traffic and couldn't see why, but she had a feeling. She pulled out of line a little and saw a police officer and flashed her lights. He indicated for her to bypass all the traffic and come to talk to him. She did, told him who she was and he indicated that Chris had had a seizure and that the paramedics had to be called in and that the ambulance would meet us at the hospital. Dellann beat the ambulance to hospital. She asked the kids to stay in the lobby while she waited for the ambulance with me in it. When I was unloaded, she was not prepared for what she saw. I was unconscious, pale and had a breathing tube inserted. I was immediately whisked away for a CAT scan of my brain. After seeing this, Dellann KNEW something serious was wrong and started calling friends for childcare. The on call neurosurgeon showed Dellann the CT which indicated that I had a primary brain tumor about the size of a quarter in my right temporal lobe. The neuro-surgeon indicated that if you're going to have a primary brain tumor, that is the right location to have it as it is easily removed.

Dellann will tell you that the next many hours were some of the longest and most heart-

wrenching ones she has lived. The drug that was given to me controlled my grand mal seizure by paralyzing my body from the neck down to my waist and takes several hours to wear off. I remember the worst part being that as the drug was wearing off, I found myself in the hospital, I saw Dellann and my dad in the room, I had a tube down my throat and I couldn't move or speak. As the drug wears off, it is awful because you feel like you are choking. The only way that I could communicate was with my eyes. I pleaded for Dellann and my dad to help me, I tried to get out of bed and as the drug wore off more, I found that I had more use of my hands and arms. So, I tried to pull the breathing tube out! I'm a strong guy, so I was no match for Dellann and my dad. They couldn't hold me down anymore. I watched as they asked the nurse to help them restrain me. I know how horrible that night was for me so I can just imagine how horrible it was for my loved ones.

The next morning, I was told that I had a primary brain tumor and that in 3 days after the swelling had gone down, I would have surgery to remove the tumor. OK. Sounds simple enough. My thinking was that alright, we'll have the surgery, recover and then life will go on and all will be fine.

So, preparing myself mentally for brain tumor surgery was challenging, but I HAD to do it. I had to be brave for my family. Heck, the sooner I get through surgery and recover, the sooner I could return to my wonderful life. Apparently, that wasn't what God had in mind for me.

When I woke up from surgery and recovery, Dellann, my mom and dad and my brother and sister were at my bedside. Wow! Was I glad to see them! I have to say that the scariest thing after waking up was looking in the mirror and seeing about 40 large staples in my head. I looked like Frankenstein! But, I was awake and I was going to be fine. Later in the day, Dellann and my neurosurgeon came in to visit together. He proceeded to tell me that the type of cancer that I have is a type called either an Astrocytoma or a Glioblastoma. Either one, it didn't matter because he told me that it would kill me sooner than later and was a very aggressive type of terminal cancer. There was no cure. An appointment was made for an oncologist

to come by to meet my family and me and to discuss a treatment plan. Well, what do you do with that kind of news! I couldn't believe I had just heard what I had heard. I looked at Dellann and I know she was so scared, but she just tried really hard to be strong for me and to let me know that if anyone could do it, that I could and that she would be with me through the entire battle. Shock is a wonderful thing because it allows you to handle just as much or as little as your brain can absorb at one time. I didn't think for a minute that I wouldn't be able to lick this type of brain cancer and that I would be the exception. That is how I got through the next 3 brain tumor surgeries, all the different types of chemo that I tried, all the sad times crying with my wife, radiation, one doctors appointment after another, being told that I would never get to go back to work again and going into the office to clean out my office, trying experimental drugs/protocols, trying to not be bored at home, feeling sick like I had the flu for 2 -3 weeks per month, facing my mortality, coping with the awesome sadness that comes with the fear of wondering if you will ever get to see your children grow up, making a deal with God so that I could see my children graduate from high school, fearing the unknown..... January's MRI revealed that the tumor had come back. Surgery was scheduled and performed by Dr. Daniel Silvergild at the University of WA. Once again, the surgery was considered successful and all of the tumor that could be seen was removed. My oncologist was Dr. Alex Spence and I started the recently approved drug for brain cancer, Temodar. My spirits were high as I'd seen the research on Temodar. It was the first newly approved drug for brain cancer in 20 years! It worked for me for about 4 ½ months. When my tumor came back for the second time in early July, I was told by my doctors in WA state that due to the location of the new tumor, there was nothing that could be done and if I was lucky, I had maybe 3 more months to live. Of course, we needed to consult with a brain tumor center based on this news. It is unfortunate, but where I live in Washington state, there is not a nationally recognized brain tumor center for adults. So, we consulted with UCSF. I nearly gave up hope when they also said that based on the scans and location of the tumor, surgery was not an option. Well, it wasn't to be like that. You see, my wife did not accept the words "there is noth-

ing more to be done", and had been anticipating this day. Research is power against brain cancer. She had started researching clinical trials, surgeons, drugs, etc. about a month after my first diagnosis so that we would be prepared with the next step when we were told there was nothing else left to do. She had been consulting for months with a research scientist/oncology doctor at the Dana Farber Cancer Institute who researches and treats only patients with Glioblastoma. The Dana Farber Cancer Institute is a national recognized brain tumor center. This doctor gave her the respect she deserved as the wife of a man with a terminal illness who was seeking answers. That doctor's name is Dr. Elizabeth Maher, M.D., Ph.D. Dellann also sought opinions from Dr. Henry Friedman from Duke, another major brain tumor center just to make sure we were doing the right protocols and to make sure that there wasn't something else experimental on the horizon that we should be doing instead. Dellann asked me if I wanted to pursue what the Dana Farber Cancer Institute was proposing. They were proposing that we fly out for 10 days, have the world renown Dr. Peter Black perform surgery, recover and then fly back and then have our doctors here in WA state follow Dr. Maher's protocol. I never thought twice about going someplace that offered me a longer chance of living a quality life. Of course, we went to Boston two days after celebrating our 10th wedding anniversary. The lengthy surgery was a success. However, after surgery and recovery, I discovered that I had lost the use of my right arm and the ability to walk. That was scary! Traveling is really challenging when you can't walk! However, after several days of recovery and a week in an in-house rehabilitation center and hours of physical and occupational therapy, the only thing that was different or remained from my surgery was a slight limp and of course, I was minus one brain tumor. All was well. I played a lot of golf, played and enjoyed my children so much, appreciated my wife and life more than I had ever before, made many more happy memories with my family and started the experimental drug therapy, Gleevec. I also added the drug Thalidomide to try to stop any additional microscopic tumor that we couldn't see from drawing a blood supply to it so that it could grow. Both Dellann and I tried very hard to have a normal life. We felt that brain cancer had come to visit our home, but that we didn't want our

lives or our children's lives to be all about cancer. We felt that if we didn't keep it normal, the CANCER would have already won. When I felt good, I felt good and played hard. But then, I started to have problems with my eye sight and eventually, had to hang up my drivers license. THAT was a sad day for me because in a way, it was having to acknowledge that the cancer had just won a victory. My MRI's were clear and we got the feeling that the experimental drug, Gleevec, was working, however, my balance was off and I needed to start walking with a cane. Dellann, the kids and I spent another great week in Maui relaxing, playing and enjoying the place that we were fortunate enough to call our second home. It is likely that we would have retired there at some point. We showed the kids all of our special spots, took tons of pictures and really took in those beautiful sunsets. When one is suffering from a brain tumor, it is so tragic because it takes away one's independence. I knew that my balance was off and of course, Dellann knew it too. She would offer to go and get me things or do things for me, but I didn't want to give in to the brain tumor, so I insisted that I do things myself. Well, I had a bad fall while we were there. I had walked up from the beach to the condo by myself and fell on a 2-ft. wall made out of lava rock. I cut my leg so badly that I kind of crawled back to where Dellann was and she took one look at me and took me to an emergency room. This incident really shook me up, but I couldn't understand the problem because my last MRI didn't show growth of any kind. I really was losing control of my body. For all the good memories that trip provided, it also was a sad trip for me and my family. My body was not in my control anymore. It was no surprise that in late April, another tumor was spotted. We made plans to go to Boston for yet another surgery – my 4th. Although I have never looked forward to surgery, I felt like if this is what it is going to take until the magic drug is discovered, I would wait it out and have as many surgeries as necessary. I badly wanted my life back!!! This time, traveling to Boston was difficult! It was extremely exhausting and challenging. I was frustrated at my body. It was hard to travel because I didn't have control of my balance. I should have been in a wheel chair, but I wasn't ready for that. So, I just leaned on Dellann and we struggled with a plane change and delay, but finally, we made it to Boston. I

remember being anxious and edgy about everything and I know I was hard to get along with. It was really a difficult time. I think I knew or maybe my subconscious knew that I might be coming to the end of my journey. Things just didn't make sense to me. I was exhausted.

I was all checked into the hospital, the paperwork was done, the pre-surgery MRI was done and tomorrow I had nothing scheduled but brain surgery.

It was early in the morning on May 18th and I was awake visiting with Dellann and Dr. Maher waiting for my consult with my surgeon, Dr. Peter Black. He came into the room and said "We aren't going to be doing a surgery today". "What?" I heard the words "you have a new brain tumor that is inoperable in your brainstem" echo in the hospital room. A part of me was shocked but another part of me wasn't surprised. Glioblastoma is terminal and I had beaten the odds and lived about 10 more months than I was told I would. He told me that he could do surgery instead to put in a shunt to help relieve some of the fluid and pressure in my brain and that this procedure might buy me two more months of life. I of course, said "YES".

For those of you who know me, you know that if there was a possibility for anyone to beat the odds, I would have been that person. When one describes me and my personality, they capture me by simply saying that I was dedicated, devoted, did my best at whatever I was doing and therefore, usually excelled. The one word that best describes me is "**PERSISTENT**". There is just something inside me that drives me to be the BEST at whatever it is that I do. I am blessed that way and it has been a wonderful way to live. Although I will be only 41 when I leave this earth, I have lived a full, wonderful life with many blessings. I KNOW I had it good. Thank you God.

So, when Dr. Maher essentially said that "there was nothing more that I could do to beat brain cancer", I knew that my journey on this earth was coming to an end. All three of us cried in the hospital room for what was now the lack of hope.

I remember about an hour after getting this devastating news, that I asked Dellann to go get me paper and a pen. I was thinking very clearly and wanted to make a list of "Chris' To Do's Before I Died". I remember how hard this was to do and how hard it was to write through my tears and then I went into surgery to have a shunt put in to help relieve the

pressure on my brain from all the fluid surrounding my brain. It was at this time that I was also confined to a wheel chair as my balance was way off and I just couldn't hold up my body any more.

The next day, I had a very candid conversation with Dr. Maher. I still didn't understand why there was NOT a cure. I had fought the good fight and now I wanted to do more. Dellann, Dr. Maher and I began discussing the possibility of setting up a research fund for Glioblastoma Brain Cancer Research, hence, the Christopher S. Elliott Memorial Glioblastoma Brain Cancer Research Fund/CEF was born. It was a way to turn my tragedy into a positive and I believe that one day, there will be a cure for Glioblastoma. I am proud to have helped find that cure.

A few days after surgery, I decided that I would give it one last effort. YOU NEVER KNOW, I STILL MIGHT BEAT BRAIN CANCER. So, I went ahead and had chemo at the Dana Farber Cancer Institute the morning before I got on a plane home to Seattle. Before my chemo transfusion though, I had the pleasure of thanking Drs. Maher and DePinho for their excellent care, their knowledge and their belief that the treatment for brain cancer will soon be discovered. I thanked them for including me in their studies, for their compassion, for not allowing me to be just another statistic and for giving me the hope and dignity to fight a good fight. There were plenty of tears and hugs to go around.

So, Dellann and I came home to Seattle believing that if I were lucky, I would live another two months. So, I came home to spend time with Riley and Hunter and tried to complete projects that needed to be done so that I could rest and know that my family would be taken care of. I also continued with physical and occupational therapy at home, although, I was getting more and more tired each day and spending more and more time in bed.

My mom, brother and sister came to live with us for the last two weeks of my life to help care for me and to say good bye. That was truly a gift. I will never be able to thank them enough for helping Dellann during such a difficult time in our lives. Eventually, I slept most of the day and needed more medication for the pain. We made the decision to call in Hospice and discuss how I wanted to die at home and made arrangements for that. I slowly slipped into a coma, although, I was aware of the many friends who did come by to tell me that they loved me and to say goodbye. I

could hear each and every one of you. THANK YOU for your love and kindness.

It was a beautiful, sunny afternoon on June 13th, 2002 when God decided to bring me home and give me peace. It was 5:40pm. I was in the family room, the windows were open and I could hear my kids in the backyard playing, although I was in a coma induced sleep. My mom and sister were beside me and Dellann was outside on the porch talking to the kids' grief counselor when I took my last breath.

Hunter had gotten up very early that morning to come down and sit beside me while it was quiet. He slipped his special "crystal" rock into my hands and put his baseball cap down beside me on the bed. I heard him whisper "I love you". It was his way of saying "goodbye". Riley also was able to tell me "goodbye" that day. She wanted to stay home from school and just cuddle with me. I remember that she gave me the Father's Day present that she had made for me, read me stories and then continued to sit by my bed and write in her journal until she went outside to play that afternoon. My children are such beautiful gifts!!! Dellann was able to spend some time with me the day the I died too, although, she had already taken her opportunity to say "goodbye" and to tell me that "it was alright to go now, that she loved me, thanked me for loving her and that she would FOREVER miss me". She took the opportunity to tell me this several times after we returned from Boston and while I was still awake.

The strength, love and courage demonstrated by my family and friends during my illness were such a beautiful gift to me. Thank you to each of you for that gift. It's a gift that keeps on living through your memories.

So, when you think of me, Christopher Stewart Elliott, please smile and know that I have been blessed and that I continue to watch over you and live on. I pray for a cure for Glioblastoma and I thank all of you who continue to donate and participate in CEF events and especially, the annual golf tournament that honors me. YOU KNOW HOW I LOVED TO GOLF! See, I still live on. It's a **WONDERFUL LIFE**, so above any thing else, live it to your fullest potential and enjoy your loved ones and those around you while you can. I'll see you in heaven when your work on earth has been done. Blessings.

Christopher Stewart Elliott

November 6, 1960 – June 13, 2002