



“510 DAYS”

**A journal sharing the story of one family’s battle against
Glioblastoma Multiforme Brain Cancer**

A Tribute to Shawn Travis Simon; He fought to the very end



Shawn and Kelli – Our Journey through GBM Brain Cancer

March 2008. Shawn and Kelli meet each other through an online dating site. The first time they ever met, it was obvious that theirs would be a relationship full of fireworks and challenges. Neither one had no idea how short lived their bliss would be.

Fast forward to March 7, 2012. Shawn comes home from work and is talking to Kelli on the patio, and his left arm begins floating in mid-air. Kelli is confused by the gesture and asks what's up with his arm. "What are you talking about?" he asks. He blows it off but as he continues to talk, his arm floats again. Kelli points it out, and Shawn once again laughs it off.

Kelli knows something is "off". Later, as Shawn lays in bed prior to sleep, Kelli leans over him and looks into his eyes. "Are you sure everything is OK?"

Laughingly he replies, "Yes".

Kelli is afraid for him to fall asleep. She knows something is not right, though she can't say what.

March 8, 2012. Shawn is at work and with the events from the night still weighing on her mind, Kelli phones Shawn to ask him how he is doing. He answers irritably that he is fine. Knowing him as she does, she then calls his boss (who is also his best friend) and inquires about Shawn's state.

"Kelli, you need to come and pick up Shawn and take him to the ER."

"What is going on?"

"I think Shawn had a stroke! He couldn't remember how to make a pot of coffee this morning and then he started making basic mistakes on his machine and he could hurt himself. I pulled him off the machine, brought him into the office, and gave him baby aspirin."

Kelli drives down to the machine shop and picks up Shawn. He looks normal and is understandably irritable. She drives him to the "Doc in the Box" clinic and they get checked in. The doctor comes into the room and listens to the answers to his triage questions. He suddenly stands up and says, "I am sending you back to my receptionist and she is going to refund your money. You need to get to the ER as soon as possible."

Kelli drives Shawn to the ER and again, as before, as soon as the triage nurse hears Shawn's symptoms, she immediately takes him to the back and prepares him for both an MRI and a CAT scan. Afterward, the nurses begin approaching Kelli to ask if there's anything she needs, is there anyone they can call. Obviously something is up. There is ER customer service and then there is THIS ER customer service. The nurses even wish them "the best of luck".

While at the ER, Shawn is told he has a “bleeding tumor” in his brain and is going to be transported by ambulance immediately to the bigger hospital in the neighboring city. A hospital equipped to handle brain tumors. Kelli stays with Shawn throughout each of the next endless days, going home only after he has gone to sleep and returning to be with him as soon as he wakes up.

March 12, 2012. Neurosurgeon Gregory Helbig performs a brain resection on Shawn. Thinking the surgery would be lengthy, Kelli goes to the cafe, only to miss the family update from Dr. Helbig when the surgery is complete after only an hour. All Shawn’s dad can recall from the name of the tumor is that the word “Blast” is in it. Kelli says she’ll Google brain, “blast”, and “tumor” after she gets home that evening. Extreme exhaustion overwhelms her good intentions.

She is pulling into the hospital parking garage the next morning when her girlfriend, Hillary, calls her.

“Did you do any research last night?”

“No. Did you?”

“Yes.”

“What does it say? Is it bad?”

“I don’t want to tell you. You need to read it yourself.”

“Hillary, you just answered my question. Tell me what the internet says.”

Hillary proceeds to read the Wiki page on Glioblastoma Multiforme Brain Cancer. Sitting in her Escape in a parking space at the hospital, Kelli begins to weep as she listens to Hillary use the words, “terminal”, “incurable”, “most aggressive malignant”, and “median survival time”. At that moment, Kelli knows her life has irrevocably changed.

After a week’s stay, Shawn is released from the hospital. The pathology report comes back with the expected diagnosis, GBM. Dr. Helbig didn’t sugar coat anything so both Shawn and Kelli leave the hospital knowing they have a hard fight ahead, but determined to fight for as long as possible.

Shawn is uninsured, and so begins the complicated process of applying for everything, wading through mounds of government red tape, trying to find some way, any way, to pay for the treatment he needs. Blessedly, his father reminds them that because of Shawn’s seven years’ service in the Air Force, he should have VA medical benefits.

Kelli is now in a full-out quest for information about Glioblastoma, its treatment, its prognosis, and anything else she can learn. The primary thing she learns is that there is next to nothing available in the way of either information or support for those reeling from this diagnosis, or for their loved ones. She can't help but compare the plethora of publicity given to fighting other kinds of cancer, with the silence surrounding brain cancer in general, and GBM specifically.

April 2012 begins the process of driving 84 miles one way to go to Oncology appointments at the Palo Alto VAMC and Stanford Cancer Center. By June, Shawn is undergoing 31 treatments of radiation combined with chemo 5 days a week for 7 weeks straight.



In August, Shawn is recovered enough from the combined treatment to go on his greatly anticipated "Bucket List" fishing trip to Alaska. At the Laughing Raven Lodge in Port Alexander, Alaska, Shawn forgets all about his cancer. His favorite catch is a 180 pound halibut. He never gets nauseous and comes home with 100 pounds of fish for the freezer.

Speaking of his "Bucket List" items, marrying Kelli is also on his list.

Saturday, September 8, 2012. Elopement in Reno, NV Shawn is so incredibly happy this weekend.

With his skills as a machinist, Kelli had asked him to create matching wedding bands and an engagement ring. "How many women can say their husband made their wedding bands?!" she said.

They are beautiful steel bands with "Till Death Us Do Part" inscribed inside. They are worth more to Kelli than any diamond wedding set.

Shawn's last "Bucket List" request is fulfilled later in September when his best friend's black lab, Sierra, had puppies, and Shawn is given first pick on the female pups. Sophie is the one who chose him to be her daddy.



October 2012 Shawn's tumor has begun to grow again. His personality changes and Kelli begins to not recognize the man she just married.

December 2012. Shawn experiences a seizure. The ER doctors prescribe strong steroids, without any caution concerning side effects. Two days later, Shawn experiences a 12 hour psychotic break which involved him holding a knife to his throat and then to Kelli's while threatening to kill her if she didn't answer his questions by the count of 3.

This is when Kelli begins to understand why they had been told back at the first Oncology meeting at the VAMC that wives leave their husbands quite frequently after a GBM diagnosis. In addition to her passion for creating awareness about brain cancer, she is realizing the immense need for support to those who love those who are fighting the illness.

January 3, 2013. Shawn chooses to undergo his second brain resection at the Palo Alto VAMC in hopes of regaining some of what the tumor has taken from him. He spends the entire month in Rehab on campus, so Kelli is given some respite to tend to her own well-being, and gather strength for whatever lies ahead. She drives up and visits Shawn on the weekends. He makes great progress in all areas of rehab.

Shawn comes home at the end of January. By mid-February, it becomes apparent that his right arm and hand are not fully functional. This is incredibly frustrating to Shawn and he works extra hard in Physical Therapy. Unfortunately, by the end of the month, he has lost all use of his right arm and hand.

March 21, 2013 is Shawn's first infusion chemo treatment with Avastin. His previous MRI, done earlier in March, showed "suspicious" cells on the walls of the second resection hole. The radiologist did read the MRI as the "suspicious" cells being aggressive tumor regrowth. Typical behavior for GBM.

Kelli launches a Facebook page to provide support and what information she can find for the caregivers of those she calls "GBM Warriors".

<https://www.facebook.com/GlioblastomaBrainTraumaCaregivers>

She is amazed at how quickly other caregivers find her page, and how openly they share their heartbreaking stories. A common thread is the loss of the patient's typical personality as the cancer progresses. The caregivers lose the loved one long before death occurs.

April 2013. Shawn's Oncology team tells Kelli they have reached a "day by day" basis with Shawn. She is also finally told that the oncology team was in shock at how fast the tumor re-grew in the 10 months between the two surgeries. Less than 3 months after the 2nd resection it is growing back again. The aggressive growth shocks the team and they are helpless to stop it.

May 2013. Shawn and Kelli relocate to Texas to ensure stronger support for Kelli as his condition declines.

May 6, 2013. This is the first appointment at the Overton Brooks VAMC in Shreveport, LA. Shawn is taken to the OT Department and they fit him with a Shoulder Immobilizer Sling and a Compression Glove. The dead weight of his arm/hand has been causing him intense shoulder pain thus the immobilizer to alleviate it. The compression glove is to reduce swelling in his hand, and he experiences immediate relief. Over all, Shawn is happy with the first visit results. Based upon their own testing and findings, the Overton Brooks VAMC has chosen to follow the lead of Palo Alto VAMC and also treat with Avastin.

May 16 and May 30 Avastin treatment days.

June 13, 2013. Another Avastin treatment. A wheelchair ramp is installed at the house and Shawn is given a wheelchair compliments of the VAMC. His right leg is 90% useless. At this time, he can still put weight on it for a very short time, so his walking consists of pulling the right foot up and letting it thump down hard on the floor, moving his left foot into position and then dragging his right foot up to his left. His toes are curling underneath his foot and are becoming very battered. He is using his rolling walker most of the time and the wheelchair if there is a lot of walking required.

June 27, 2013. They receive the results from the latest MRI. Avastin is not working and the tumor has now more than doubled in growth. There is nothing else the Oncology team can do and treatment is suspended. Hospice arrangements are made.

July 1, 2013. “Hearts Way Hospice” of Northeast Texas begins caring for Shawn at home

July 2, 2013. Shawn is able to go fishing out on Gilmer Lake with his brother-in-law on the boat.

July 4, 2013. Shawn and Kelli watch the City of Longview fireworks

July 5, 2013. Firemen came to pick him up after a fall.

July 7, 2013. Firemen came to pick him up after another fall.

July 12, 2013. Shawn's younger brother from NC, Frank, drives 13 hours to be with him.

July 13, 2013. Shawn sits on the deck outside with Frank and asks Jesus to come into his heart.

July 15, 2013. The hospital bed and his Power Chair arrive. He is quite delighted with the regained independence the chair provides him, and insists that it be placed beside his bed while he is sleeping.

July 17, 2013. A Foley catheter is put in, Ritalin begins to help calm him and his 2 daughters arrive at the DFW airport at 8:55 pm. Shawn stays awake until 4 am visiting with them.

July 21, 2013. Defying Hospice recommendations, Shawn rides along on the trip to take the girls to DFW to catch a plane back to CA. He is extremely uncomfortable and in pain.

July 22, 2013. Shawn has a 30 minute window of clarity during a conversation with Kelli in which he says all that he needs to say without the hindrance of his tumor. Kelli treasures the gift of those 30 minutes. His dinner tonight would be the last meal he eats.

July 23, 2013. Shawn has chosen to remain in bed. This represents a huge change in routine, as up to this point, his need for cigarettes has driven him out of bed, multiple times, at any time of day and night.

Not only has Shawn stopped eating, but his lungs have begun filling with fluid to the point that he can no longer drink because the fluid goes straight into his lungs. The fluid retention is also causing constant coughing. His pain levels are increasing noticeably, necessitating morphine. However, he is unable to ingest any other medications, so his high fevers must be brought down quickly to keep him from experiencing seizures. He is still being given bed baths, which only increase his pain levels due to the moving of his body. The longer he lays in bed, the more he develops bedsores and continues to lose weight until he is intolerably frail looking and bony. His communication becomes increasingly limited. Mucus builds up in the back of his throat, which must be swabbed out often, in spite of his efforts to bite down on the sponge in his desperate thirst. He fights death with every cell of his being until his body simply refuses to function any longer. He didn't give up on a single thing in his entire life, and dying is no exception.

July 31, 2013. 8:50 am. After 510 days, Shawn takes his last breath. He is 47 years old.



Our story continues below...



From my heart ~

Our wonderful hospice LVN was with us and called the time of death. I thought my heart was going to burst out of my body when she lifted the stethoscope off his chest and said, "8:50 am." I learned the hard way that even if you have been to hell and back, and you think you are prepared, nothing prepares you for THAT moment. I was a widow. My life at 44 was going to be starting over from scratch. All the plans Shawn and I had ceased to exist at that moment.

I traveled to CA in November 2014 and his daughters and I held a "Celebration of Life" gathering and we divided up his cremains. Each of us chose our own special "urns" to contain them. Certainly a surreal moment in time that still seems such an unfair thing even after the passing of time.

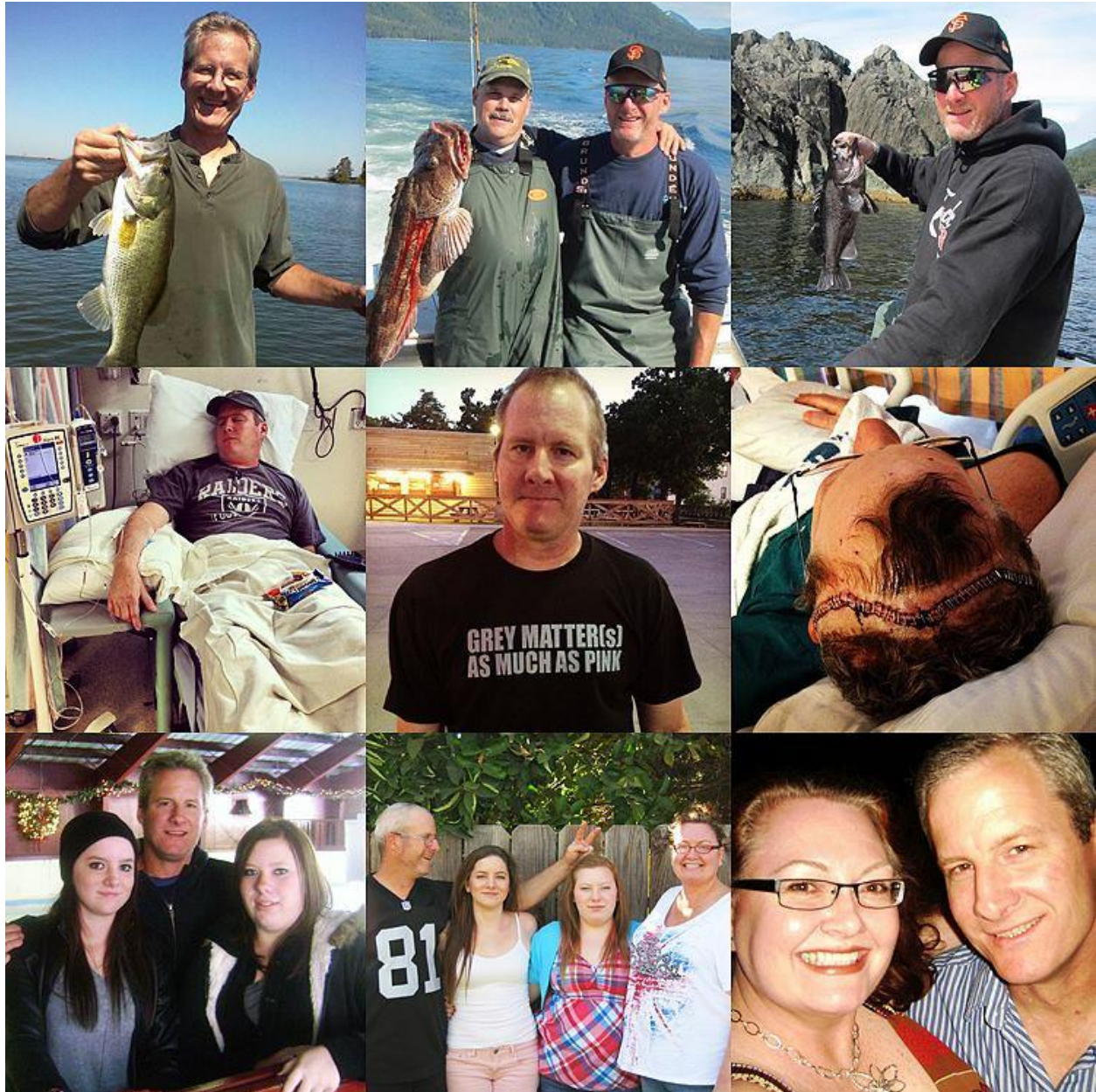
This has been a journey I would not wish upon anyone. This cancer robbed Shawn of everything that made him feel like a man, and that made him who he was, and it was horrible to witness. I know that Shawn is no longer suffering and that knowledge makes me not so sad that he is gone.

I miss him every day. Kelli



The photos below are some of my favorites...

The many facets of Shawn: avid fisherman, loyal Oakland Raider fan, father to two daughters, Stephanie and Jordan, step-father to two step-sons, Andrew and Colin, son, brother to Frank, husband to Kelli, “Alpha Dog” to Sophie, his black lab, friend, and brain cancer fighter. The black rock in the background of the upper far right photo is where his remains will be scattered in Alaska. His favorite fishing rock.



This collage was created by Shawn’s daughter, Stephanie

“I was waiting for the longest time, he said. I thought you forgot.

It is hard to forget, I said, when there is such an empty space when you are gone.”

“Death leaves an ache no one can heal, love leaves a memory no one can steal.”

Those we love don't go away, they walk beside us every day.

Unseen, unheard, but always near; still loved, still missed and very dear.

- Anonymous

