

What!?...AGAIN?

by George S. Plym



It all started in 1967. I like to think that I was a typical boy. I enjoyed fishing, hiking, and hunting. But my favorite of all, was baseball. As a matter of fact, it was on a baseball field when my journey started. A journey that took me to a place that no one should go on.

I remember it was a hot, muggy, typical Midwest summer evening, and I was playing baseball for the Spring Valley Little League All-Star team. Early in the game, a routine pop-up fly ball came to me. I was somewhat startled. As I looked up into the soft, fading light, there were two balls coming down to me! I missed the ball. In the next inning, a ground ball game to me, and again, I saw two balls coming to me on the ground. Again, I missed the ball. Something was drastically wrong. The double vision that had appeared that night was just the beginning of a lifetime nightmare. The next day, I was taken to the doctor. It didn't take him too long to figure out that the double vision was caused by pressure building up in the optic nerve. The tremendous headaches and nausea were a clue also. The doctor went out in the hall to speak to my parents. Even though I was having vision problems, there was nothing wrong with my ears. I heard the doctor tell my parents, "I'm sorry, but your son has a brain tumor." Those words are devastating words to a parent and a 12 year old boy. Those words still haunt me and my parents today.

The tumor was removed through the skilled hands of Dr. Elwood. (Methodist Medical Center, Peoria, Ill) To kill any stray cells from the tumor, cobalt beam radiation bombarded my brain. The pathologist said that the tumor was an astrocytoma the size of an orange. It was then when we were told that I had a year, maybe two years to live. That was over 36 years ago! I'll call it number one, and that was in 1967.

Number seven (2000) just about killed me. After years of conventional surgery, the Gamma Knife Surgery was used at Wake Forest Medical Center in Winston-Salem. While traditional surgery may deliver more immediate results, the Gamma Knife's long-term prognosis is often comparable or better. In most cases, gamma knife radiosurgery immediately stops the growth of tumors, which shrink or disappear over a period of time.

"Gamma knife surgery offers some patients the ability to maintain or improve quality of life," says neurosurgeon Charles Branch, M.D. "People with lesions that were considered inoperable or with health issues that made them poor candidates for open surgery are good candidates for this procedure. It is especially useful when conventional surgical techniques would pose a high risk, such as in the presence of other illnesses or when a patient's age prohibits standard surgery." (Wake Forest Medical Center in Winston-Salem)

So I was excited about the chance of removing this tumor without actually being cut on. You see, the Gamma Knife is not really a knife, but uses radiation with pinpoint accuracy to destroy tumors.

I went through the procedure in the first week of the new century, Jan. 4, 2000. I was somewhat excited because I knew that given enough time, eventually, there would be a procedure that would eliminate the need for open surgery. That time had finally arrived. Everything went well, and I was able to go home the same day that I had the Gamma Knife procedure. I didn't feel any different, but I thought that all of my troubles were finally over. Well...

Three days later, I had a major seizure requiring hospitalization. The doctors felt that it was caused from swelling in the brain. I was put on steroids to alleviate the swelling. I was still having problems with seizures and I was in a lot of pain. The tumor was dying inside my head, but the dying tissue could not be absorbed by my body fast, enough causing pain, pressure on the brain, and seizures. The doctors tried several spinal taps to remove the pressure in my brain. A spinal drain was put in. The screams could be heard down the hall. I couldn't help it. That hurt more than the spinal taps, and they were no picnic either! Anyway, it caused more seizures.

Then a lower lumbar shunt was implanted. A lumbar shunt is placed in the lower back, and is threaded into the abdominal cavity. The lumbar shunt is safer if the surgeon feels that infection is a risk, and I was at risk for infection. I felt fair, and I went home.

Two weeks later, I started to feel bad again. By this time, I was very weak and very sick. And now, I was beginning to throw up and the seizures were more frequent. My wife, Diane, called Dr. Shaw, and he said to come the hospital, now! We drove (Diane did) to Winston-Salem from Asheville, a two and a half hour drive. I was in the back seat eating Vicodin and puking in a bucket!

A new MRI showed that I had now chemical meningitis. Dr. Branch didn't want to operate. He felt that he had "pushed the envelope" and was concerned about infection. Every time you get cut on, your lose your ability to fight infection in that area. Infection in the brain is worse than the tumor itself is. But he had no choice but to operate to remove all the "junk" in my brain that had accumulated in my brain cavity. (Wake Forest Medical Center in Winston-Salem)

I made it through the surgery. When I was in the recovery room, I remember waking and talking to the nurse like nothing had happened. But when I was in ICU, the pain became unbearable. I screamed at the nurse to give me something for the pain. He said that I was maxed out on morphine, and could not have anymore. I have never, ever been in so much pain my life. I prayed to God, "Lord, You said that You would not give me more than I could handle. Well, I can't handle this pain. Please, make the pain tolerable, or let

me die". In less than three minutes, the pain subsided and I was resting comfortably. Praise the Lord!

Two and a half weeks later I went home. I was weak and still nauseated. But it wasn't over...yet. The shunt was working well and I felt very alert with no pain in my head. For the first time in 30 plus years, I didn't have major headaches everyday, my head was clear, and the seizures had ceased! But the shunt, located on my right side, was killing me! Every step, every move, every breath hurt like I was being stabbed in the side with a dagger. The only way I could eliminate the pain in my side was to curl up in a fetal position and stay there. I kept thinking that if I didn't move, it would heal up and I would be O.K.... Wrong!!

One morning I got up to use the bathroom. As I got up, my legs would not hold me. I thought that maybe I over did it the day before (I was starting to walk to the living room from the bedroom) so I laid back down and used the urinal that I kept from the hospital. The next day it was the same or worse. I hobbled with my cane and sat in my easy chair, watching the birds. I had on the usual clothes, T-shirt and jogging shorts. That's when I noticed my right leg was swollen. Not just a little, but double in size. I was scared! I had remembered that the doctor said that if I had a loss of breath, or got swelling in the legs, go to the emergency room. My wife was at work and I could not drive myself, so I called 911.

The ambulance came and took me to the E.R. where they did an ultra-sound. They found a D.V.T. (deep venous thrombosis), or blood clot. The swelling was so bad that skin on my right foot broke and was bleeding. My upper thigh was so swollen, it pushed on parts of my body that should not been pushed on! (ouch)!

It felt like I was kicked, but the pain was constant. I was on I.V.'s to devolve the clot, and then I was put on blood thinners (Coumadin). After more testing, Dr. Pekal (Cancer Care of WNC) found that I had a rare blood disorder called "factor 5 Leiden mutation". It is a blood disorder in which the blood clots at a rate 60% faster than the normal person. Thus, I am much, much more prone to thrombosis. After eleven days, I was released, although the swelling had not subsided much. It took six months before the leg was back to normal, or close to it, and will be on blood thinners for the rest of my life. So now instead of worrying about a brain tumor or a blood clot, I have to worry about bleeding to death if I have a cut!

I was still having a lot of pain on my side from the shunt. I was in a no-win situation. If I moved or walked, my side hurt. If I didn't move around, there was a chance I could get another blood clot...but my head felt great! I went back to Dr. Branch to talk about the shunt. He said that sometimes a shunt needs to be revised, or repositioned. We decided to just take it out. It did its job, and there was no need to have it if it was causing problems. So after the surgery for the shunt removal, I started to feel better immediately, although with the shunt gone, the headaches returned. I can put up with a headache, but I could not put up with the pain the shunt was causing! So after a slow, painful recovery, I felt well enough to "carry on" and function fairly well in society.

I thanked God for giving me another chance, and I wanted to use my brain tumor as a tool to reach other brain tumor survivors. It was then that I started the Asheville Brain Tumor Support Group (now WNC Brain Tumor Support). I knew that I was not alone. There had to be other people that were going through the same things that I have been

going through. I did some research and found out that 180,000 people will be diagnosed with a brain tumor this year! (American Brain Tumor Association)

It was at that time that I got the idea of starting a brain tumor support group. In March of 2001, I started laying the groundwork by getting in contact with the local county health center to find out how many people in the county had a brain tumor, but it was only up-to-date to 1998. I then went to the American Cancer Society to get information. I also talked to other support group leaders for advice. After talking to 15 to 20 local health businesses, I contacted some of the national brain tumor organizations. The American Brain Tumor Association, The Brain Tumor Society, and The National Brain Tumor Foundation were all very receptive. It was through the national foundations that I was able to obtain literature and information. And of course, the doctors and staff at Wake Forest Medical Center were outstanding. They called, e-mailed, and sent a lot of informative brochures. The Duke medical team was also very receptive. By September, I was ready for our first group meeting.

Even though people with brain tumors function fairly normal, there are thousands who have major deficits. The thought of a recurrence has become a reality for me. I was diagnosed with a brain tumor for the eighth time. (2002) Again, the Gamma Knife surgery was in order. This time, everything has worked out so far.

Oh Oh. I spoke too soon. Your not going to believe this...I need to write another chapter. Yes, its back. On November 11, 03, another tumor was spotted on during my six month MRI. Again, its GK time(gamma knife). On December 2, 03 I had another MRI in conjunction with the GK. More tumors. All of those areas were nuked with the GK. I will under go chemo in the middle of January.

You know, as we read this article, I wonder, are there stray tumor cells in my brain still multiplying?... or at rest?...or dying? Those are questions that are asked by all brain tumor survivors. Our brain tumors always are on our minds. We can never rid the thought that we have a brain tumor (or had), and we get a real tense feeling when we get close to our MRI appointments.

Researchers are in the last phase in some very promising trials. We keep coming closer and closer. Doctors like Branch, Elwood, Shaw, Tatter, Friedman's, Hamilton, and a host of many, many others, are finding new ways to stretch out our lifetime despite having a brain tumor. It may be soon, or it may be later. But it's going to happen. There will be a cure for brain tumors!

It may not sound like it, but I have had a great life! I have a terrific Mom and Dad. I have best sister in the world, Nancy, and a very supportive wife, Diane. I also have been privileged to have a wonderful step-daughter, Laura, and a son-in-law, Eric, whom have blessed us with two granddaughter, Elizabeth and Anna. They are sooo special! I love them all.

This is not a fare-well send off, by any means! I have a few goal to achieve yet. Some of them are to see Elizabeth in her prom dress, to be brain tumor free, and to die of old age!

I don't know what the future holds, none of us do. David M. Bailey sums it up in his song, "Live Forever" where he writes, " If there's 1 chance in 500, someone's gotta be the

one." Well, I am one of the "1," and as sure as the sun comes up, I will continue to fight until this beast called, "brain tumor" is no longer!

Update 7/04

In the last update, I had reported that I had a recurrence and had Gamma Knife surgery. What I did not write at that time, was that when I was dx in November of 03, I told my doctor something that I never thought I would ever say. I told Dr. Shaw, "OK. It wins. The tumor wins. I am tired of fighting. Keep me comfortable and let me die." I couldn't believe what I was saying. But that is how I felt. Thankfully, my brain tumor group friends picked me up and got me ready to fight...again.

It has been six months since my update. Great things are happening! The tumor that appeared last November is slowly dissipating. The most recent MRI last week (7/04) shows that the Gamma Knife surgery in last December has killed the tumor. The outline of the tumor is still visible, but has taken a different look in color. A dark shade of gray much different than the contrast that eerily glowed as we viewed it six months ago. And just in case that there are some unseen abnormal cells that may cause a recurrence, Dr. Lesser and Dr. Shaw at Wake Forest Comprehensive Cancer Center in Winston-Salem has started chemo. Temodar 440mg a day for five days, blood work two weeks after, and start all over in two more weeks. It is a real roller coaster ride! But if it works, I am all for it.

People ask me what can they expect on Temodar. I can't answer that. But I can say how it has affected me. The first night I took it, I was nervous. I didn't know to expect. The next morning, I thought I would be sick. I wasn't. Nor did I the second day. A little queasy the third and fourth days, and a lot queasy on the fifth and sixth days! The anti-emetic, Zofran really helps. The Zofran had an unpleasant side effect for me though. Constipation! Stool softener helped. I also have noticed that pills don't go down as easily as they use to. It is like my throat says, "What are you trying to put down into my stomach? This stuff is toxic!" So I talk to my throat and stomach and tell them, "Open up! Got some good vitamins for you. Mmm...this is sooo good for you." Mind games with my throat and stomach. Hey...what ever takes! I haven't gotten this far in life with out bending some of the rules!

I pray that all of you brain tumor survivors and caregivers to muster all of the strength and courage needed to fight the fight and win the battle. "The only time you lose, is when you quit trying." (Ditka)

Update 3/05

Time for a new update! It has been six months since my last update. Obviously, I'm still kicking, but not quite as high! I have good news and bad news. The good news is that the tumor that was found about 14 months ago... is dead! There is no doubt that the gamma knife surgery has again saved my life. The Leksell gamma knife at Wake Forest University Baptist Medical Center has stopped three tumors dead in its tracks, allowing me to enjoy life which I so cherish. I am also very thankful for the Temodar which seems to stop any renegade cells that may have been lurking outside of the perimeter of the gamma knife target area. I still have two more chemo cycles left. Part of me says "I sure will be glad when this chemo is over," but another part of me says, "I am afraid that stopping the chemo will invite a recurrence." That is when I remind myself that I have

turned these brain tumors to the Lord a long time ago, and that I need to continue trusting Him.

Now for the bad news...Although the area of the original site and subsequent tumors have been cut, radiated, nuked, chemically altered, prayed on (and cursed as well), a new tumor has appeared in a new location. It is not an oligo-astrocytoma as the original tumor. This time, it is a meningioma. It seems that the radiation that was so effective so long ago, has caused this new tumor. Damn...I can't catch a break! OK, I will not get upset about things that I cannot control. I learned that a long time ago. I preach it at my brain tumor support group, WNC Brain Tumor Support here in Asheville, NC. I guess if I am going to have another brain tumor, I think that it is better to have a meningioma, because it is a slower growing tumor than the oligodendroglioma or an astrocytoma. But none the less, it is a growing tumor and must be taken care of. As soon as I finish my chemotherapy in April, I will again go to Wake Forest University Baptist Hospital in Winston-Salem, North Carolina for yet another gamma knife surgery. I am absolutely blessed to have the opportunity to be treated non-invasively. This is my only option, and it is a great option! Because the Leksell gamma knife is a non-invasive procedure, I have all of the confidence in the world that I will continue to live a fairly normal life without major deficits. I would bet my life on it....Again...And again... And again...

Update 7/27/05

Quite a few of you have been e-mailing wanting to know how I am doing. As you remember, I had gamma knife surgery on April 14th and also had a biopsy for a lesion on a left side of my scalp. It came back positive for cancer... Not brain cancer, but it was called, "adenoma carcinoma" and was believed to be a secondary cancer. Now after all of the testing, including MRI, x-rays, PET scan, CT scans, colonoscopy, thyroid testing and testing of the sinus, the doctors and technicians have not been able to find the primary cancer. That does not mean that I don't have a cancer, it is just not visible using all of the testing. It is now though that even though the biopsy shows an adenoma carcinoma, Dr. Shaw feels that the cancer is more likely to be a skin cancer from old radiation 38 years later. He called it "radiation induced cancer." The treatment 38 years ago is now causing cancer now. Most of the time, I have been told the brain patient dies before all of the radiation affects finally hits you. So I guess my reward for being a longtime survivor is... Cancer?

Yes, I am bummed out, but I am not going to lay down! My life has been nothing but a struggle to survive. I have almost gotten to the point that I am looking for another challenge. I said almost! The plan now is to go through radiation again and see what happens. I know you are probably thinking, "more radiation?" That's what I thought too. The radiation kills or slows down the cancer and then later down the road, it causes cancer... And now will be treated with... RADIATION? Go figure!

Also, I have had some major problems with the head also. The area were all of the surgery has been performed has caused a major battle. It has started to swell (the brain) and caused unbelievable pain in my head. For the first time in five years I really needed to use narcotics to ease the pain. The cause is still unknown, but it seems that and infection has causing the problem. I have started antibiotics and it seems that the swelling is going down. It has been the most excruciating pain since 2000. I have not been able to pick up thing heavier than a cup of coffee and even that hurts! The infection may have been from the Gamma Knife surgery, but maybe not. The final diagnosis was

chemical meningitis. The dead tissue from the gamma knife surgery could not get out of the brain causing swelling and the pain. I was in the hospital for five days, but the effects are still lingering to this day.

I forgot to mention that I had my thyroid removed on June. Blame it that on the radiation too. It is common for thyroid not to work properly after whole brain radiation. I was told that the mass in my neck/throat was the size of a fist and a part of it was malignant. It was causing pressure on the sternum and swelling in the throat as well. The surgery went well and hardly any pain.

Then about less than two weeks after that, I started the radiation. Not for the thyroid, but for the adenoma carcinoma/cancer they found with the biopsy in mid-April. (It is now mid July!) Last week, two more "spots" of cancer were found in the same area where all of the original area was irradiated. So, what do you think the fix is? Of course...**MORE RADIATION AND A BIGGER DOSE!!**

I haven't gotten this far without God's big shoulders around mine, leading and guiding the way. I will continue to trust. Please pray for me to have a bit of a break before I start another challenge! Thank you all of your support and emails!