My Journey

I have been asked to share my story of Palette Cancer. After being diagnosed, I couldn’t find much information about what life would be like after surgery. How do I eat? How do I swallow? How do I speak? How do I drink? I had so many questions and since this cancer is pretty rare, nobody had answers for me. I have always been a person that if I didn’t like how things were done, I would try to find a more efficient or more acceptable way to do it. This journey is no different. I had to find easier, more efficient, and more acceptable ways of coping with the life changes that occurred after surgery. If this blog helps just one person on their journey with this type of life change, then it will all be worth the time and effort of sharing my experience.

This is my story…..
It all began in the Spring of 2015. I discovered a blister on the roof of my mouth, on the back left side. It didn’t hurt and it didn’t get bigger or go away. It was just there. I thought at first that I had burned my mouth on hot tea, but realized there was no pain involved. When I went to my dentist, Dr. Nick Gardner, I told him about it and he checked it out

and said I should have it biopsied. I asked him if we could wait, since it didn't hurt, and just to watch it. I really didn't think it was a big deal. He respected my thought and we waited. You see, I had had a biopsy on a left parotid gland (salivary gland) benign tumor 15 years prior, so I knew what to expect to have a biopsy. I really didn't want one if it was nothing. Three months later, at my next dental appointment, Dr. Nick said that it was slightly larger and he firmly suggested that I get that biopsy. So he made the appointment and I went to the Oral Surgeon. After the biopsy, the Oral Surgeon wanted to know who did my previous surgery and he sent me to the Ear, Nose and Throat group at the University Medical Center of Vermont. Dr. Silverman is the doctor that I was introduced to. He is a kind, soft spoken man, that is very easy to talk to and who truly cares about his patients. He did another biopsy in his office to have it tested on what kind of lesion that he was dealing with. He also wanted to find out if it was a surface lesion or if the palette had been compromised. After a CT scan and the result of the biopsy, we found out that the palette had been compromised and that the tumor was sitting above the palette, under my nose and had worked a hole to create the lesion in the mouth. If you can find blessings along the way, this was mine. If the tumor

hadn't made its way through to my mouth, I still wouldn't know that I had a tumor.
Surgery was scheduled for November 10, 2015. Dr. Silverman met with us to discuss what was involved with the surgery. He explained that he was hoping not to have to extract more than was necessary. The worse case scenario would be a left inferior maxillectomy. That would entail removing the maxillary bone (top jaw bone), the three teeth in the back left side, and one third of the hard palette (roof of mouth) on the left side of my mouth. After hearing how extensive the surgery was going to be, all of that information was pretty difficult to absorb. My life as I've known it, was going to change forever. I accepted whatever was going to happen, but it occurred to me that I may never sing again. I have been a vocalist my whole life and that part of me was what I felt defined a part of who I am. So that might have been the most difficult part of acceptance for me. Life changing events, but now I am very happy to report that I can still sing.

I decided that my husband and I needed to take a vacation before all of this change would happen. Dr. Silverman was all in favor of the decision, so off we went to Myrtle Beach for a week of relaxation, meditation, beach walking, swimming and praying.

November 10, 2015

Surgery…..Dr. Silverman told us that he was going to go very slowly, taking only the tissue that he absolutely had to take. He figured the surgery would take about 3 hours. As he was doing the surgery, he was sending live tissue samples to the Lab for testing. When the Dr. got to the point of no return, he went ahead and performed the Left Inferior Matxillectomy. He took the top left jawbone, 3 teeth, and 1/3 of the hard palette on the left. When Dr. Silverman finished, the Prosthodontist came in and they packed the sinus cavity, inserted the Obturator (prosthesis) in my mouth, wired and screwed it in on both sides and packed in with wax to seal it all around. This procedure helped me be able to leave the hospital sooner.

The doctor had previously told us that I would have to learn to swallow, talk, drink and eat all over again, so I was somewhat prepared for that. I found that by packing the sinus cavity, it was all pretty much the same as before the surgery, except that when you plug the nose, you have no sense of smell or taste. So I found at that point that the only difference between my Cream of Wheat cereal in the morning and my pureed homemade chicken rice soup, was that the cereal was sweet and the soup was not. That was ok, because getting the nourishment in that form was going to make me heal faster and better. I drank many different smoothies and a liquid diet for the first 10 days until the sinus cavity was unpacked. After it was unpacked, it was very different. When I didn't put my obturator in, my speech was garbled and it was difficult for my family to understand me. The odd thing was, was that in my head when I spoke, my speech sounded better to me than with the obturator in. Our brain's memory is an amazing thing. The first morning, I decided to drink my smoothie without my obturator in, and when I took a drink, it came out my nose and right down the front of me! I found that to be unacceptable, so I decided to figure out a way to make it work. I went over to a drawer and took out a clothes pin and put it on my nose. I then took a swallow of liquid and sure enough, it worked perfectly. I realized that wearing a clothes pin in public probably wouldn't look very good, so my husband and I decided that a swimmer's nose clip would not be as noticeable and serve the purpose just fine. Problem solved!

The obturator works very well, but I find it to be an annoyance. The Prosthodontist couldn’t fit the wire between my teeth on the right side, so it laid on my teeth. It prevented me from being able to chew anything very hard. I had to stay on the liquid or soft diet for many weeks. I also found out at one of my appointments, that I would have to have two wisdom teeth and a cracked tooth pulled before I could go for radiation therapy. Three days before Christmas, I went to the Oral Surgeon that had performed the biopsy, and had three more teeth pulled.

When we went back for my follow-up appointment with the surgeon, he told me that I would need to have radiation therapy in a few weeks. The tumor had been removed completely, but the cancer had somehow followed a nerve path. The radiation therapy would significantly diminish the chance of a reoccurrence. I then went to the Oncologist for a consultation. The Oncologist explained that it was good that the teeth had been extracted because the radiation would deteriorate the teeth and jawbone. They said that you can not have any bad teeth when going to radiation. I had to wait a few more weeks before beginning radiation because everything had to heal first. The Oncologist told me that if you aren’t healed when going to radiation therapy, the tissues won't heal. The waiting was so hard. I was anxious to get everything done in a timely manner, but had to be very patient because it seemed that it was a hurry up and wait game.

RADIATION THERAPY

I was extremely fortunate that the Winter's Cancer Center is fairly close to my home. It made the daily visit much easier. I went there 5 days a week for 4 1/2 weeks, 23 sessions total. Radiation therapy itself is not painful or time consuming. It took me 25-30 minutes to drive to the Center and the session took a total of 10 minutes. The technician made a specialized mask that fit very tightly over my face and they snapped it to the table. You cannot move at all. A CT scan is done first and then the machine administers the radiation dose. I am not claustrophobic at all, but it is pretty unnerving if you let it get to you. The ten minute procedure can seem a lot longer when you are that immobile. Deep breathing and prayer can help a lot.

I found that cancer takes away your control. I like to be in control, so I tried to find ways that I could feel in control of the situation. Everyday I got up and got ready as if I were going to work. I put on my makeup, did my hair and put on my nice work clothes. For me, putting on my makeup was putting on my happy face or game face even when I didn’t feel happy. It really helped me to cope. I also found that when I went to the Center, I hoped it would help someone there that might be struggling, to see someone who was like them but had a smile every day. A smile and a kind word for someone without a support system is huge.

I lost my sense of taste at the end of the first week of treatment. The oncologist said that I shouldn’t have lost it so soon, but come to find out, at the beginning of the second week, I had a very bad mouth infection called Thrush. I guess it is a pretty common occurrence with radiation, but it is extremely painful. I was given a steroid and anti fungal medication to heal my mouth and alleviate the swelling. There were many days of treatment where I couldn’t wear my obturator because my mouth was so sore. Everyone at the Center were so kind and understanding. They were very patient with my speech not being very easy to understand, but I am sure they have seen worse cases than mine.

Each day of radiation gave me a purpose and made me get up, get dressed and move forward. During the fourth week of treatment, I found out that I was only going to have to complete twenty three sessions of radiation instead of 30. I was ecstatic!

On the last day of radiation I was given the mask that I wore every day and a Certificate of Completion. That was the day that I understood why cancer patients are called Warriors. The tumor was gone and the radiation was finished and I am hopeful that I will never have to do this again. There are no guarantees.

After I finished the therapy, I decided that I needed to get away. I have been in my house for months and I needed my freedom back, so my husband and I took a trip south to visit our siblings that happen to live in other states in the South. We were gone for about two and a half weeks of warm Spring weather. The flowers and trees were in bloom and I could feel myself feeling so much better. I slept when I was tired and took it slow. I didn't have much energy or stamina but it was so healing for me. We went to Pennsylvania, Kentucky, Tennessee, Florida, Virginia, Maryland, Pennsylvania, and home to upstate New York. When we were in Virginia, I realized that the Thrush was back and I didn't have any medication to help it, so we cut our trip short to get back home where I could get the medication. I was prescribed an anti-fungal mouthwash that works really well. Radiation, so they tell me, can stay in your system for 6 months or more. I still can tell it is in my system and it has been months since therapy.

I have good days of energy and stamina, walking up to 3 miles on the good days and only being able to complete 1-2 miles on the bad days.

After returning home from vacation, I rested and relaxed to try to build my immune system. It was really compromised because I found that if anyone had a virus, such as a cold, I would pick it up pretty quickly. I found that the cold didn’t last very long, because when you have to clean your mouth 3-4 times every day, and that includes the sinuses and nose, it flushes any virus and bacteria out. Who would have thought that by having a hole in the roof of your mouth, the flushing and cleaning would be a bonus!

After being out of work 6 months, I felt that I was strong enough to return to work. I felt happy to be able to return, but anxious about being around germs and a lot of people. I started out with reduced hours and gradually increased my hours over a period of weeks. I found it very empowering and liberating to get back to a normal routine again.

Prosthedonics

I have had to travel to Burlington, Vermont every month since November to have the Prosthodontist readjust the prosthesis. The obturator that they inserted during surgery, was only a temporary device to help me to leave the hospital sooner and to learn to eat, drink, and speak. The doctors adjusted the wires on the device each time to make it as tight as possible. They also used an epoxy to close the gaps to try to seal out excess airflow. When I drink liquids, I have to hold my nose so that the liquid didn't go over the top of the obturator and run down the back of my throat and choke me and food as well. Over the months, there was only one month that it fit really well. I found that it was better than not having one because without it my speech is very difficult to understand. Many times my family members read my lips to understand me. We have all had to adapt to the changes. Amazingly enough, I learned to eat and drink without putting the obturator in my mouth. It just felt much more natural first thing in the morning to eat my breakfast without it. The Prosthodontist had a difficult time understanding how I was able to do that.

It has been eight months now and I just received my new permanent obturator. It is made of metal and acrylic material. It fits in the hole very tightly and the metal hugs my teeth very well. It now feels much more natural in my mouth. It is heavier that the temporary one and is very much like a partial plate. There were times when the temporary obturator felt like I had a truck parked in my mouth. It seemed so large for my mouth and very unnatural. Now with the new one, I am able to enunciate better and I am able to have volume with my voice. People that don't know what I have been through, have no idea that anything is any different than before the surgery. My voice doesn't have a nasal quality and with the hole being closed tightly, has given me my life back the way it was previously. I am so happy and grateful for all of the hard work that they have done to let me be me again. I am blessed.