

Spine Tumor News

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THE UNIVERSITY OF TEXAS
MD Anderson
~~Cancer~~ Center

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Spine Tumor Conference 2013

By Gisela Sanchez-Williams, RN, MSN, ANP-C

"It gets better and better every year", "Keep doing this, I learned a lot and enjoyed meeting fellow spine patients", "This was a wonderful day", "This was a great morale booster and educational experience". These were just a few of the comments from patients those who attended the 4th Annual Spine Tumor Patient Education Conference. Patients and their caregivers who attended came from places as close as Louisiana and as far as Colombia. First time attendees had an opportunity to visit with others who have also had rare diagnoses and complex surgeries. The roundtable sessions offered patients and their families strategies on how to deal with stress, as well as insight on how to cope with personal trauma and change.

This years' presentations addressed spinal tumor surgery from a different

perspective; not only allowing the patient to better understand the disease and how the surgeon determines whether or not surgery is the treatment of choice, but also focusing on weighing the risk and benefits of spinal tumor surgery and how the treatments ultimately impact the disease and functional outcomes.

Spinal tumor survivors also learned about cutting – edge research in the management of neuropathic pain. A symptom which has limited treatment options, and is often difficult to control. One participant stated, "I thought this was interesting since I am interested in non – medicinal approaches to pain control". These and other areas focused on what is vital to all cancer patients, their quality of life.

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Our mission is to provide support and education to patients, families, caregivers and friends of individuals with spine tumors.

EVENTS

PLEASE NOTE CHANGE IN FREQUENCY OF MEETINGS:

First Wednesday Quarterly Starting in November 5 p.m. - 7 p.m.

Spine Tumor Support Group
Place of Wellness
Mays Clinic ACB
Room 2.1041

Future Meetings:

February
May
August
November

More events:
www.mdanderson.org/neurosurgery/events

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From the topic presentations to the exhibitors' hall, the emphasis was on learning about spinal tumors, options for treatment, and how to adjust to "your new normal".

Participants also had the opportunity to learn about the field of radiation, and which medical scenarios allowed for the delivery of radiation to a site that had been previously radiated.

Our patient testimonial was delivered by John Berlin, a metastatic kidney cancer survivor. Mr. Berlin shared personal experiences of his childhood, and how specific life events helped him to ride "the rollercoaster" of a cancer diagnosis, and how to confront, and accept a cancer diagnosis. Mr. Berlin offered hope to others by explaining how the concepts of teamwork and being goal-oriented have given him

the will to never give up. He shared his MD Anderson experience and his hopes for the day when metastatic cancer will be eliminated. Mr. Berlin gave a truly profound testimonial, touching on all the aspects of the cancer journey. (If you missed his full story at the conference, you can enjoy a recap in the article following titled, *The Last Patient*, on page 3).

The conference offered an exchange of hope, joy, humor, and encouragement amongst patients, caregivers, and healthcare professionals alike. As a healthcare provider, I can say that it was an experience that touched the heart and regenerated the soul. One that puts us all on the same playing field or better said, on the same team in this fight against cancer. I hope to see you next year; you would not want to miss it!

~ Gisela

Conference Photos



The Last Patient

The Story of John Berlin



Background: John Berlin was born and raised in Alexandria, Louisiana. He is a mechanical engineer by trade and an avid outdoorsman. He was diagnosed with kidney cancer with metastatic disease that spread to his spine. Since then he has spent over 30 hours in the operating room between four surgeries and two resections of his spine.

John Berlin shared his patient story at the 4th Annual Spinal Tumor Conference. It's a story of his journey through fighting cancer and finally his defeat of what he calls "the cancer roller coaster". John began his story by recalling a few things from his childhood that helped him fight cancer. First was football. Football taught him to be strong-minded, never quit, to always get back up and do better. The second was Boy Scouts, which taught him to be goal-oriented and never stop. These were helpful to him through his journey because as a cancer patient, you have to be just as much a part of your treatment team as the physicians and nurses.

The Shock: Although John had spent much of his life dealing with back pain, he recalled how a family trip and a simple accident changed his life forever. One day on his trip he was just reaching for a glass and dropped it on the counter. While trying to catch the glass he cut his hand and decided he needed stitches, so not thinking much of it, he went to the doctor. He noticed during that time that his back pain was hurting in a different way than he had ever experienced, so he told the doctor when he was getting his stitches removed. The doctor took a look at his back and saw a large knot to the left of his spine. A few days after his visit the doctor called and asked if he could come back to his office immediately. John thought nothing of it until he arrived at the office. Instead of sitting and waiting, this time he was called back immediately. He passed by the normal exam rooms and went to an office he had never seen before. He reflected that at this point "it felt like someone had turned on the heater" and he knew this could not be good.

The doctor entered the office white as a ghost. There was really no good way to tell John the news he was going to hear. The doctor explained that he had a compression fracture of his T8 vertebrae and there was a mass associated with it. This mass was most likely cancer and the cancer probably originated from somewhere else. All of the sudden everything changed for John. He was in shock. After he left the doctor's office his first reaction was to pull out his small green Bible from his jacket that he carried with him since his childhood and begin to read. Even when he felt he had strayed from the flock, he always returned here during his time of need.

The next day he and his family went to see an oncologist. He and another physician felt that the tumor was benign because his blood tests showed no signs of cancer. Just to be safe, the oncologist ordered a PET scan. When John returned for the results the doctor said, "I'm sorry, but I don't have any good news for you today." He brought him into a dark room where he could see the results of his tests. Glowing bright orange in the center of his back was a large tumor, which indicated cancer. At that point denial for John and his family was all over. The doctor then showed John where another large orange spot glowed on his left kidney. John knew this was where his cancer originated from. It was called metastatic renal cell carcinoma, or kidney cancer.

John was told he didn't have a lot of time and needed to be treated soon. Over the next few weeks doctors gathered to make his treatment plans. While he waited, John spent a lot of time reading on the internet, which did nothing but convince him he had all but a death wish. He began to lose his motivation and hope, but he still

The Last Patient

The Story of John Berlin continued from page 3

went ahead with his doctors' treatment plan.

On the day of his first surgery he looked back at his brother and sister as if it were his last time. After an extensive fourteen hour surgery that included the removal of his left kidney, a rib and his T8 vertebrae, wiring of his ribs together to close the gap, and fusion of his spine with rods and screws, he woke up. It would be two more months of healing before John would be able to visit MD Anderson to begin further treatment. When he arrived at MD Anderson he met with Dr. Tannir, who explained to him that there was regeneration of the tumor on the T8 vertebrae and that it was on his spinal cord. He was then referred to a neurosurgeon for yet another spine surgery.

Following his surgery at MD Anderson, John looked at his doctor and asked, "Do you really think I have a chance?" His neurosurgeon replied, "You need to stop reading the internet. You came to MD Anderson where we treat cancer aggressively. The only thing that matters is you, your faith, your treatment team, and your family and friends. You get all that straight and you will do just fine." It was at that point

where John changed how he faced cancer and how he coped with having a cancer diagnosis.

The ending words to his story, but certainly not the end of his fight were, "My biggest fear is that after all the radiation, surgeries, targeted medications and sickness, that I will die just one month, one week, one day before the day it is announced that metastatic disease is cured, or at least manageable. I have a dream where all of the metastatic patients and I are the last patients with metastatic cancer. I want to see that day because of all of the things I have done and been through. I at least deserve to see that. All metastatic patients do. I will never give up, not even after my last breath. I've got cancer, but it hasn't got my life. Whatever I have, I will accept it. Be thankful and never give up, because what MD Anderson learns from me and you might make the difference."



Thank you, John, for sharing your journey of courage, hope and faith. Your story is truly one of hope and inspiration.



Conference Photos



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