

# Spine Tumor News

Making Cancer History®

THE UNIVERSITY OF TEXAS

MDAnderson  
Cancer Center

February 2013

this issue

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

## EVENTS

**First Wednesday of Every Month, 5 p.m. - 7 p.m**  
Spine Tumor Support Group  
Place of Wellness, Mays  
Clinic ACB Room 2.1041

**September 20, 2013**  
4th Annual Spine Tumor  
Patient Education  
Conference  
MD Anderson  
Houston, TX

More events:  
[www.mdanderson.org/  
neurosurgery/events](http://www.mdanderson.org/neurosurgery/events)

## RESOURCES

Spinal Cord Tumor  
Association ([SCTA](#))

National Institute of Neuro-  
logical Disorders and Stroke  
[Brain and Spinal Tumor  
Information Page](#)

MD Anderson  
[Spinal Tumor Disease Page](#)

## Paying it Forward

*By Wiley Shaw*

**In this edition, we place emphasis on support groups – individuals joining together to provide help and guidance to each other. Support groups are a valuable resource for patients and caregivers that are often under appreciated and intimidating for new patients.**

**Wiley Shaw is a chordoma patient at MD Anderson who quickly learned that if he was going to survive his disease, he needed support. The chordoma network became his salvation. Now, he mentors others.**

. . .

Nothing puts your life in to perspective like cancer.

The unknown factors, the fear and the hardships can all be disabling. To get through you need family, friends, a skilled medical team and a support group – strangers with the same disease who soon become friends sharing experiences and words of comfort.

Within the spine tumor support group, I learned about a phenomenon called paying it forward. It has helped me through my disease and ultimately, live a positive, normal life.

### The beginning

Just about everyone's journey prior to surgery is remarkably similar. After years of managing pain and discomfort, the decision is finally made to determine the cause and seek treatment. This is followed by a flurry of appointments with different care centers and doctors, who perform an array of tests without, in my case, finding many answers.

X-rays showed nothing. In September 2009, a pelvis CT scan revealed a tumor and bone destruction of the lower sacrum. Doctors suspected it was chordoma or chondrosarcoma, but had no experience with either disease.

It was a gut wrenching time for me. One doctor told me, after my spine tumor was discovered, "There are only two surgeons in the state of New Mexico that could perform this surgery. I am one of those surgeons and I will not do the surgery."

My life was crashing down around me. I had a family to care for, a job and so many other obligations, which I was afraid I would not be able to fulfill. It's bad enough to be told you have cancer, but to be told it's a rare spine cancer – one-in-a million chance of contracting – is devastating. I felt isolated and helpless.

*Continued on page 2*

**Finding support at MD Anderson**

After a lot of research, I decided MD Anderson Cancer Center was the best facility to handle my cancer. From my first meeting with Laurence Rhines, M.D., director of the spine tumor program, and advanced practice nurse Gisela Sanchez-Williams, I was given hope. A biopsy confirmed that I had a chordoma, so Dr. Rhines and his team determined a treatment plan and gave me the confidence that the plan would work. Finally, I saw light at the end of the tunnel.

***“Talking to him eased my anxiety and I started to believe I could gain back my independence.”***

While awaiting surgery, my wife, Sharon, and I attended a spine tumor support group meeting. We heard a panel of four spine cancer survivors talk about their journeys and post-surgery “new normal”. Their stories were inspirational – they were regular people who got past a crippling illness and were now living normal lives.

At the meeting we met Neal Ayme, who had the same surgery I was facing. We talked for hours after the meeting. He told us his story, shared the good and the bad, and answered question after question, even questions we were afraid to ask. This deep sharing, we learned, is called paying it forward.

For the first time we did not feel alone. The light at the end of the tunnel was getting brighter and brighter. For me and many others, Mr. Ayme is our rock and mentor.

**The road to recovery**

My 10-hour surgery was pretty much text book for MD Anderson. The next step was getting well and returning to my normal life. It wasn’t easy, but because of Mr. Ayme, I at least knew what to expect.

I started down the road to recovery with a great support crew – doctors, nurses, and my family of caregivers. Every couple of days Mr. Ayme took the time to call to cheer me on. Talking with him eased my anxiety and I started to believe I could gain back my independence. I worked hard, earning the nickname “Rocky” among some of the physical and occupational therapists.

I was not going to disappoint the people who believed in me. Somewhere along the way I remember telling myself that when I get past all this, I want to give back and help other chordoma patients.

Leaving MD Anderson was a huge milestone. Life was so safe, secure and organized there that when the time came for me to go home I didn’t feel ready. What if I couldn’t do this on my own? My wife and I decided to stay a couple of extra days in a Houston hotel to practice what I learned during my hospital stay and develop a daily routine.

The first couple of weeks at home were a big adjustment. I was facing new challenges and had new questions for my mentor, Mr. Ayme. We talked on a regular basis and the exchange of information between us was invaluable.

I started physical therapy and began to gain more confidence. I was getting stronger physically and mentally. Over time, and

through trial and error, I was getting my life back. Eventually, I went back to work full-time.

However, I was also discovering a new normal and still didn’t feel whole.

**It all comes full circle**

In my follow-up appointments to MD Anderson, I met new chordoma patients and their families. I watched them go through what I had just gone through. We talked, I listened and shared, and soon, I became the mentor.

In one instance, I was able to sit with a family whose husband and father was in surgery. The daughter cried with relief when she saw me walk into the surgery waiting room. After researching her dad’s disease on the Internet, she was convinced he would never walk again. It calmed the family to just see me, someone who had recovered from the same surgery and was back to living his life.

It wasn’t until later that I realized how good it felt to be a mentor. It was helping me with my emotional and mental recovery. I no longer question why this has happened to me. I have something to offer other chordoma patients: personal experience. I have come full circle.

It’s been a little over three years since my surgery and I have a very positive outlook on life. With a little extra planning, I am now able to travel with my wife, go deep sea salmon fishing with the guys, take care of the yard and even chop firewood. Living a “new normal” life has a few challenges, but for the most part I live a full, independent life.

**The chordoma network**

So far, I have had the honor of mentoring five chordoma patients and their caregivers. If hearing about my experience eases their anxiety, gives someone hope or speeds up his or her recovery, then I have paid it forward.

The network of chordoma survivors continues to grow. We all share and learn from each other and have become each other’s support group.

*If you are interested in joining the chordoma network, please e-mail: [spinetumornews@mdanderson.org](mailto:spinetumornews@mdanderson.org)*





# What's Happening?

News from the Brain and Spine Center



## Save the Date

The 4th Annual Spine Tumor Patient Education Conference will be on September 20, 2013 at MD Anderson. The conference addresses the needs of spine tumor patients.



## Improving Patient Care

MD Anderson is restructuring and streamlining its process to improve the management of patients who present to the emergency room with spinal cord compression.



## Ependymoma Awareness Day

The CERN Foundation is raising awareness for ependymoma, a rare type of primary brain or spinal tumor, with a butterfly release on April 18, 2013 in Memphis. Get involved!

**Sign-up!** Receive the electronic version of this newsletter, directly to your e-mail inbox, by signing up online, [www.mdanderson.org/spinetumornews](http://www.mdanderson.org/spinetumornews). Spine Tumor News is a quarterly publication.

## Patient Corner

*Our patients talk, we listen. Here are some words of wisdom and encouragement from those who know best.*

*"I made the choice to fight to survive. I told my family I wasn't going anywhere, and I believed it." - Michelle Mahar-Kasten, osteosarcoma*

*"Dr. Rhines is a dedicated, preeminent spine surgeon with a wonderful demeanor and sense of humor. Ms. Sanchez-Williams' focus on patient care is legendary." - Christina Collier, spinal cord tumor*

*"Most important, embrace each moment of your life with outstretched arms. We owe it to ourselves and to life itself to not let each moment pass without laughter, love and friendship." - Anonymous, chordoma*

*"I no longer question why this has happened to me. I have something to offer other chordoma patients: personal experience." - Wiley Shaw, chordoma*

*"I'm grateful to be here today, more than I can say in words . . . It is phenomenal what type of surgeon Dr. Rhines is, but he is also a pretty dang good engineer." - Jeffrey Head, sacral chordoma*

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