

# Brain and Spine Tumor News

Making Cancer History®

THE UNIVERSITY OF TEXAS  
**MDAnderson**  
**Cancer Center**

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

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## Events

### 14th Annual Run for the Rose 5K/1K

*Benefiting brain tumor research at MD Anderson*

Sunday, April 10 — 8 a.m.  
NRG Park  
[Details](#)

### 2016 Stand-Up for Brain Cancer Gala

*Benefiting brain tumor research at MD Anderson through the lab of Frederick Lang, M.D.*

Wednesday, April 20  
River Oaks Country Club  
[Details](#)



Dawn Standera

**February 2016**

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## Life after spine tumor surgery: the gift of hope

*By: Dawn Standera*

Last September I spoke at MD Anderson's [6th Annual Spine Tumor Patient Education Conference](#). The topic was: "When is Surgery Right for Me?" The day after the conference I met with Dr. Rhines and made the decision to proceed with surgery.

If you watched the [video of the presentation](#) you will know I lived with the diagnosis of an intramedullary spinal cord lesion at C1-C2 for four years and ten months before having surgery. You will have heard the challenges I had in living with the tumor and making a wise decision about when to risk the surgery.

On Dec. 8, 2015 I became tumor-free. The tumor was a grade II ependymoma, which basically meant no need for radiation. In short, I consider myself cured.

After surgery, I spent 23 days in the hospital where I received excellent care. By the way, I'm a tough critic and do not falsely praise so believe me when I say the care was excellent. I am home now and continue therapy on an outpatient basis. I have physical therapy three times a week and we have hard data that shows my endurance, balance and coordination are improving. I can safely manage a 3/4 mile walk with my dogs in the snowy woods. I am just starting to drive short distances. I ditched the cane already and my stride is smoother. For all of these things I am grateful.

I also have occupational therapy twice a week to work on improving fine motor skills in my right hand, which sustained damage from the surgery. It is improving. I can read my handwriting now and typing is better, although both tasks cause surprising fatigue.

*... Continued on page 3*

## Clinical Trials

[Search all open and enrolling clinical trials.](#)

We have many clinical trials available. A few open trials are listed below. Click on the link above for details and enrollment information.

**Study No. 2013-0765**  
Phase I Study of Fourth Ventricle Infusions of Autologous ex vivo-expanded NK Cells in children with recurrent/refractory malignant posterior fossa tumors of the central nervous system. NOAH's (New Opportunity, Advancing Hope) Protocol

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**Study No. 2013-0632**  
A Phase Ib/II, open-label, multicenter study of INC280 in combination with buparlisib in adult patients with recurrent glioblastoma

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**Study No. 2014-0817**  
A Phase 1 Study Evaluating the Safety and Pharmacokinetics of ABT-414 for Subjects with Glioblastoma Multiforme

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**Study No. 2015-0013**  
Couple-based Yoga Program for Glioma Patients and their Partners

## Intraoperative CT suite opening soon

This spring, our spine surgeons will be busy in our new intraoperative CT (IOCT) suite. It's one of six new operating rooms on the fifth floor of The Pavilion.

The IOCT suite is a project eight years in the making and was designed specifically with spinal surgeries in mind. The advanced equipment and technology in this room will do for spine surgery what the BrainSuite® did for brain surgery.



*Rhines gave a tour of the suite to internal leaders in January.*

Our spine surgeons have been using intraoperative navigation in many spine cases for years. However, the navigation is currently based on the preoperative CT scan, which is taken with the patient laying on his or her back. For spine surgery, the patient is positioned facedown, which means the preoperative CT scan isn't 100% accurate in the operating room.

The IOCT suite features a large CT scanner on automated rails. With the flip of a switch, the surgeon can bring the scanner forward and over the operating table to get a 100% accurate, real-time CT scan. The operating table itself was custom designed to comfortably accommodate spine procedures and the intraoperative CT scanner.

"The technology in this room will give us even greater accuracy for complex spine surgeries," said Laurence Rhines, M.D., director of the Spine Tumor Program.

It will be especially helpful for procedures that require removal of the tumor in one piece, just millimeters away from the spinal cord, blood vessels and other critical structures.

The IOCT suite will officially open this spring, after OneConnect, our new electronic health record, launches (see page 4).



### Welcome, Dr. Kamiya Matsuoka!

Carlos Kamiya Matsuoka, M.D., is the newest addition to our team in the Brain and Spine Center. After finishing his neurology residency at The University of Texas Medical Branch in Galveston, he completed his fellowship training at MD Anderson and is now an assistant professor of Neuro-Oncology.

His areas of expertise include primary brain tumors and cancer neurology. [Learn more.](#)

# Patient Support Groups

## Spine Tumor Patient Support Group



Join Gisela Sanchez-Williams, advanced practice registered nurse for the Spine Tumor Program to discuss issues of interest to spine tumor patients. Open to primary and metastatic spine tumor patients and caregivers. Walk-ins are welcome.

**First Wednesdays — 5 to 7 p.m.**

Mays Clinic, Floor 2, Elevator T, Integrative Medicine Center (ACB2.1005)

## MD Anderson BEST

*Brain tumor Education and Support Together*



Join other brain tumor patients and caregivers as Julie Walker, advanced practice registered nurse from Neuro-Oncology, presents on seizures and GI side effects. Discussion/support group will follow. Lunch and valet parking validation provided. Pre-registration is appreciated, but walk-ins are welcome. To register, contact Amy Sheehy at 713-563-7728.

**Thursday, March 10 — 12 to 1 p.m.**

Main Building, Floor 4, Elevator D, Conference Room (B4.4351)

## Life after spine tumor surgery *Continued from page 1*

We also work on sensory retraining because I do not feel anything with my right hand unless I can see it. It's a strange thing and it makes me grateful for my eyesight and my body's ability to compensate. The degree of recovery is both unknown and limitless. I will just have to wait and see.

I do have many changes in my body, as would anyone who goes through a spinal cord surgery. I think the best way to describe it is that there is a constant effort to reconcile the differences between the reality of my body and what I experience in my body.

I woke up from surgery numb from my collarbone to my toes. Currently I am numb on the left side from my knee to toes. I am still numb on the right side from my chest to toes but much less so and patches of the right side are no longer numb at all. It changes every day.

Life is very slow as I recover. My days consist of activity balanced with rest. Showering and dressing tire me more than anything. The fatigue after activity is real and I honor it. There is also fatigue related to the constant effort it takes to reconcile reality versus perception in my body. I have learned that sleep is the way my body adjusts to neurologic healing. Naps! Naps! Naps is my warrior cry!

As I write this, I am two months tumor-free. The best news is that the head pain I had for three and a half years left with the tumor. This is happy, happy news. The stress of whether or not to have surgery is gone. My leg pain is gone. My dizziness is gone. That little tumor was the cause of so many problems, all of which left with the tumor. I am grateful for these things.

I know that I am having a miraculous recovery and am happy with my decision to proceed with surgery. I spend time every day intentionally thanking my body for its ability to recover from the trauma of a surgical intervention in the spinal cord. The body knows how to heal and my job is to humbly stay out of its way. Arrogance has no place in this journey. I am compliant with my therapy and physician recommendations and do my part to help my body heal. But it is the body doing the job. Again, for that I am grateful.

One of the greatest gifts of the surgery is the gift of hope. Before surgery it felt like the tumor was taking away bits and pieces of my life. The effects of the tumor were controlling my ability to make plans. Being tumor-free has given me a hopeful future. My husband and I are planning adventures again. I love adventures.



# This. Is. Huge.

## New electronic health record coming March 4

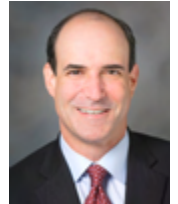
MD Anderson will soon launch OneConnect, a new electronic health record (EHR) that will connect our people and patients like never before. When the integrated system officially launches on March 4, it will be a major milestone in the largest initiative ever at MD Anderson.

Barbara O'Brien, M.D., assistant professor of Neuro-Oncology, and Jeffrey Weinberg, M.D., professor of Neurosurgery are two of the more than 1,300 "super users" working with the EHR OneConnect team to help employees transition to the new system.

In this Q&A, they share how the EHR will affect patients in the Brain and Spine Center.



O'Brien



Weinberg



### Why is MD Anderson doing this?

**Weinberg:** Implementing a fully integrated EHR is absolutely necessary to continue improving our patient care and research efforts. OneConnect will replace dozens of different computer systems that currently house patient data and provide one place to manage all aspects of patient care.

### How will the EHR benefit patients?

**O'Brien:** The new system will display real-time information across centers, so you won't have to answer the same questions or fill out the same forms multiple times. It will standardize processes across the institution, creating safer, more efficient patient care. It will also allow us to share information quickly with you and your outside doctor.

### What should I expect in if I have an appointment in March?

**Weinberg:** Expect to receive the same world-class, compassionate care for which MD Anderson is known. Also expect to bring a little extra patience, as you may experience longer wait times during check-in and appointments. We're working hard to learn the new system, but it will take time before we're fully up to speed with it.

### What should I do to prepare for the new system?

**O'Brien:** To avoid delays with your medication, we recommend picking up any requested prescriptions from our retail pharmacies before Thursday, March 3. Also, if you do not already have a myMDAnderson account, we recommend that you register for one at [my.mdanderson.org](http://my.mdanderson.org). You can complete certain forms and paperwork in your account online before your appointment.

### How will this affect myMDAnderson?

**Weinberg:** The myMDAnderson portal will be updated with a new look, similar to our new website. You will be able to enter scheduling and communication preferences within your account. You will also have quicker, easier access to your test results, records and care team within myMDAnderson.

### How will this help research efforts?

**O'Brien:** The new system will collect data in one secure data warehouse. This will allow us to effectively mine data and analyze it for research, trends, improvement opportunities and quality reporting requirements.

### Find us online:

Digital Newsletter: [www.mdanderson.org/spinetumornews](http://www.mdanderson.org/spinetumornews)



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