

The Fox Valley Brain Tumor Coalition was founded in 2001. As a non profit organization its purpose is to offer educational, emotional, and financial support to those affected with brain tumors.

All monies received from donations and fundraisers go entirely toward assisting brain tumor patients with the costs of treatment and supporting the efforts of new therapies.

The Fox Valley Brain Tumor Support Group meets the third Thursday of each month and is open to brain tumor patients and their families.

For more information, Contact David Bond, APNP, CNRN (920) 882-0818 or 1-888-231-5236

*This newsletter was created for informational use only. The opinions contained are those of the authors. You should always consult with your doctor.*

## Meeting Notice

Date:  
Thursday, June 17<sup>th</sup>, 2010

Time:  
6:00 to 8:00 p.m.

Place:  
NeuroSpine Center of Wisconsin  
5320 Michaels Drive Appleton

# Synapse

ISSUE 53

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## THE SAME BRAIN TUMOR TISSUE THAT TAKES LIVES, CAN BE USED TO SAVE THEM

Each day in the United States, 482 people are diagnosed with a brain tumor. For these 482 people, not many treatments exist. With the current treatments available, only 5% of those diagnosed with a Glioblastoma Multiform will survive more than 5 years. Only four new treatments have been approved by the FDA in the past two decades. Hope is on the horizon: there are a few promising treatments that exist in the clinical trial stages. However, some of the treatments are personalized, and require the actual tissue from the patient's brain tumor to be properly stored and preserved, so that it can be used to make those personalized treatments.

Robert Gibbs knows firsthand: he has survived almost 6 years since his brain tumor diagnosis in 2004, thanks to cutting edge treatments and an experimental brain cancer vaccine he received. "Most people are unaware of the magnitude of this disease and that some very promising clinical trials exist. It is shocking the number of patients and physicians that have no idea that this cutting edge brain tumor vaccine exists. I owe my life to this vaccine. Some of the new treatments in current clinical trials, such as the personalized DC Vax-Brain® vaccine that I received, are processed using the patient's own tumor tissue", stated Gibbs.

While the patient's brain tumor tissue can be used for personalized treatments, that is just the beginning. Once preserved in the appropriate manner, the tumor tissue can actually be tested to see how it responds to different chemotherapy agents. This testing prevents the patient from having to go through a guesswork process to determine how their brain tumor responds to different types of chemotherapy, and can help the patient's chemotherapy be tailored for their tumor. Genetic profiling of the brain tumor tissue is also available to help determine current and future treatment protocols. A test even exists that will determine how likely a brain tumor is to return, solely based on the testing of this stored brain tumor tissue.

"All of this is only possible if the brain tumor tissue is saved and stored properly", said Gibbs. Gibbs is the co-founder of Miles For Hope, a national organization who focuses on raising awareness of brain tumors and on funding cutting edge brain tumor research. "Many people contact us wanting to enroll

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## *From the Editor* Brian Burns

The Synapse was created to share our questions, experiences, and services with other members as we learn and grow together. Please contact me if you have a contribution or have a particular subject you would like to have addressed.

Submissions must be received no later than 10 days prior to the support group meeting to be included in that month's Synapse. Please include a phone number where I can reach you. You may remain anonymous.

You may contact me via the Fox Valley Brain Tumor Coalition website  
[www.fvbtc.org/contact/](http://www.fvbtc.org/contact/)

Or via conventional mail

Synapse Editor  
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in a vaccine clinical trial only after they already had their tumor removed. It is hard for us to tell them that they don't qualify for these new treatments since the tumor tissue was either disposed of, or not stored properly for further use. Most hospitals will store a small sample of the patient's brain tumor tissue in their pathology departments, but they typically use the tumor sample for their own research and will not give patients access to this tumor tissue once it's removed and stored, treating the sample as the property of the hospital or facility where it was removed.

In order to give other patients access to the same type of personalized treatments and technology that saved my life, Miles for Hope reached out to HealthBank to find a solution. HealthBank is an independent bio bank, specializing in storing various kinds of cells, including tumor cells, immune cells, adult stem cells, and others.

HealthBank is dedicated to providing this bio banking for patients who wish to store their own cells so that they can make their own decisions and can choose whether to have personalized treatments made and/or to have genetic profiling of their cells or testing of various chemotherapies on their tumor cells.

Prior to the tumor being removed, a representative of HealthBank will discuss the necessary and steps with the doctor who will be performing the surgery. HealthBank will then send a collection kit directly to the doctor with proper collection and shipping instructions. After the tumor is removed and sent to HealthBank, the tissue will then be cryogenically frozen, similar to the process of saving umbilical cord blood. This will preserve the tumor in such a way that the tumor can be used for either a vaccine or specialized testing. The cost for the process is similar to that of cord blood.

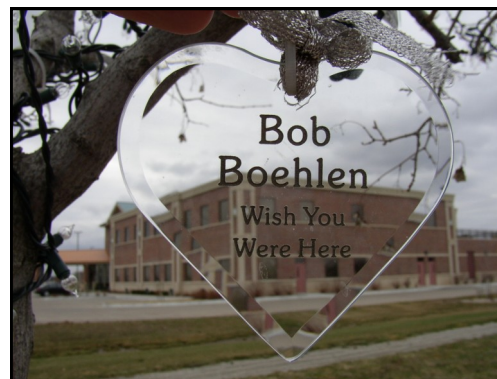
# Member Services

## Handmade "Caring Cards"

Contact Jolene for a special member greeting from the Fox Valley Support Group

Jolene Smaney  
7984 Prausa Ln.  
Oconto Falls, WI 54154  
[jjasmaney@centurytel.net](mailto:jjasmaney@centurytel.net)  
Subject Re:CCC

## Engraved glass ornaments for the Tree of Life are available through Appleton Trophy



"I would encourage all patients diagnosed with a brain tumor to discuss this option with their physician. Many life-saving treatments and testing technologies continue to evolve, but without collecting and properly preserving the tumor tissue, there is no way that these tests and treatments can happen", said Gibbs. If you would like more information on the tumor banking process, doctors and patients are encouraged to contact Miles for Hope by calling (727) 781-HOPE (4673) or by visiting their website at

<http://www.MilesForHope.org>