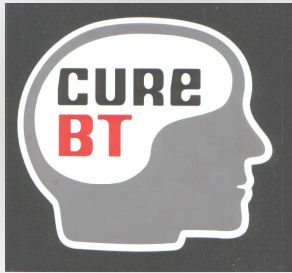


# The Newsletter of the Richmond Brain Tumor Support Group



## Cure BT Buzz

Summer  
2009

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### New Online Physician-Moderated Support Group

News has come to your local support group inbox recently regarding a new brain tumor resource, an online support group from an organization called Physicians for Patients. Physicians for Patients has established this online version of a social support group for those living with brain tumors, their families, and their supporters. One thing that makes this new resource unique is that the forum is *physician moderated*, allowing users to interact with each other; as well as, with a physician specialist, at no cost.

The Physicians for Patients moderator is Dr. Prakash Chinnaiyan, MD, a graduate of The University of Michigan, who is completing his specialty training in Neuro-Radiation Oncology at Wayne State University. Dr. Chinnaiyan is present on the forum to help answer questions and encourage discussion.

In addition to directly supporting those living with brain tumors, Physicians for Patients is interested in using the site to assist in lobbying efforts. The website is equipped with polling functions and surveys. The goal of offering these voluntary survey functions is to enable collaboration with the larger brain tumor organizations in determining which polls have the potential to support the passing of legislation for brain tumor related causes. The site will have the capacity to collect, compile, and share polling information to assist in legislative efforts.

Another priority for Physicians for Patients is to use the website to promote the development of new research and treatments for brain tumors. Data suggests that potential new treatments can be recognized through identifying trends in complex data sets of

anonymous pooled information. Physicians for Patients anticipates that survey results will reveal important relationships that may appear to be anecdotal on a case to case basis; but clearly become significant when occurring with some frequency in a large population. They are committed to work with research organizations, non-profit companies, and pharmaceutical companies in order to achieve these goals.

Physicians for Patients is looking for input and feedback on their new site. In order to take advantage of this new physician moderated online support group, go to:

<http://braintumors.physiciansforpatients.com/>.

### Richmond Ride for Kids 2009

Virginia bikers came through once more, and broke all fundraising records for the 2009 Richmond Ride for Kids, rolling in with more than \$117,700.00, and proof that there are no economic downturns for caring and compassion. Ride for Kids events take place throughout the year, in locations all over these United States, and support the efforts of the Pediatric Brain Tumor Foundation (PBTf). What started as a single event in 1984, organized by one North Carolina couple and their biker friends, has grown and grown,

and has enabled the PBTf to become the **largest non-government source of funding for pediatric brain tumor research**. In 2008 alone, Ride for Kids helped the PBTf raise its medical research funding commitments by more than \$8 million. And in addition to those accomplishments, the PBTf has earned Charity Navigator's highest rating of 4 stars for five years running. For a blog on the 2009 Richmond Ride for Kids from a survivor's mom, go to <http://twinmuses.blogspot.com>.



Support Group Facilitator Carol Roberts helps bikers register for the big ride



Volunteers Bob and Jamie Flanagan show how much they enjoy Ride for Kids



Ride for Kids Star Denise Tomney, and her escort Butch—ready to roll!



All the Richmond Ride for Kids Stars pose with Miss Teen Virginia

For more information about Ride for Kids and the Pediatric Brain Tumor Foundation go to [www.pbtfus.org](http://www.pbtfus.org).



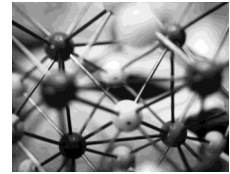
## New Research Into Childhood Brain Cancers

A recent online report posted by Insciences, a non-profit global networking site for science professionals, notes that a team of researchers from Virginia Commonwealth University is studying the underlying causes of brain tumors in children. Through the VCU Medical Center's Pediatric Brain Tumor Research Program, Timothy E. Van Meter, Ph.D., an assistant professor in the VCU Department of Neurosurgery, and Gary Tye, M.D., a pediatric neurosurgeon at the VCU Medical Center's Harold F. Young Neurosurgical Center, are looking at the genetic changes that take place in healthy cells and transform them into cancer.

The VCU team has been working in collaboration with investigators at the Labatt Brain Tumor Center at the Hospital for Sick Kids in Toronto, Canada, using a variety of molecular techniques to look at the tumor-specific changes that lead to transformation of normal brain cells into cancerous cells. As reported on Insciences, Van Meter said, "Ultimately, we hope to develop tests that will tell us, based on the patterns of gene alteration in a patient, which tailored treatment they will most benefit from and which treatment protocol will most effectively eradicate their tumor. Our large-scale studies are providing the information we need to do just that."

The Insciences report notes that, "in a study published online the week of March 9 in Nature Genetics, the international team reported the discovery of a molecular pathway that becomes genetically altered, resulting in the growth of a brain tumor called a medulloblastoma. The findings may one day help researchers develop a therapy to target the specific pathway and block the genetic changes from occurring, possibly preventing tumor growth. According to Van Meter, a medulloblastoma typically originates in the cerebellum and can be extremely aggressive. This area of the brain is responsible for the coordination of voluntary movement and helps maintain balance and muscle tone. Medulloblastomas can cause pressure in the brain and may block the flow of cerebrospinal fluid. Unfortunately, treatment options such as chemotherapy and radiotherapy can cause severe developmental and cognitive deficits in patients."

"Conducting research in pediatric brain tumors is challenging because statistically meaningful, clinically relevant studies require more patient samples than most centers have available to study," said Van Meter. "Therefore, scientists such as myself form large collaborative networks - like the one we formed for this study - pooling resources and patient materials."



In this study, the report continues, "the team examined approximately 200 medulloblastoma specimens and characterized alterations in DNA on chromosomes. The VCU team consulted and provided medulloblastoma clinical samples and data. Van Meter said that the team continues to examine this large cohort of patient material with other genomic technologies as well, to look at gene expression and other chemical and biological processes at play."

This work was supported by the American Brain Tumor Association Cherise Fleming Translational Research Grant Award from the Childhood Brain Tumor Foundation and the VCU School of Medicine Harold F. Young Neurosurgical Center. This research involves faculty from the VCU Department of Pathology in the Molecular Diagnostics Laboratory and the Department of Biostatistics



Cheryl Fare



Attentive Fans



Susan Greenbaum

## Benefit Concert—Fun and Successful!

from Support Group Co-Facilitator Nancy Hsu

To celebrate Brain Tumor Awareness Month, the Richmond Brain Tumor Support held its first annual Benefit Concert at Ashland Coffee & Tea on May 23rd. And, it was a success! We raised \$1,600! It was a perfect Saturday afternoon to be indoors enjoying music. The room was full of survivors, caregivers, family members, neighbors, and music lovers who came out to support the cause. Cheryl Fare and Susan Greenbaum generously donated their time to perform at the event. The first set of music featured laid back tunes with Cheryl's beautiful

voice backed by The Solid Band, and then the audience rocked on to the upbeat songs and powerful delivery of the Susan Greenbaum Band. In addition to the music, there was a 50/50 raffle to benefit a local Ashland family. The winner took home half of the money collected - not a bad deal! All in all, it was fun event that brought the community together to raise awareness. Thank you Cheryl for organizing this wonderful event! We also want to thank BRAIN for their generous donation. Hope to see you at the next year's event.



## Member Profile—Marguerite Sciuk

by Support Group Co-Facilitator Carol Roberts

Marguerite Sciuk is one determined brain tumor survivor. She is determined to do everything she can to help as many people as she can, for as long as she can, in their struggle with a brain tumor.

Marguerite and her husband, Kevin, began attending support group meetings six years ago after she was diagnosed with an oligoastrocytoma. Since then, she has established the Brain Tumor Resource and Information Network (B.R.A.I.N. - website: [www.brainsite.org](http://www.brainsite.org)), which has raised more than \$100,000 for brain tumor research and quality of life groups. BRAIN has supplied over 450 information packets for newly diagnosed brain tumor patients in the Richmond area. Some of their funds have been donated to the Richmond Brain Tumor Support Group (Thanks!!), the Cullather Quality of Life Center, and to fund research.

Family is very important to Marguerite and Kevin. She has 2 brothers and he has 4 sisters. They grew up in New Jersey, met, and married there and moved to Virginia in 1989. Initially, Marguerite thought she wanted to be a marine biologist, going for part of a

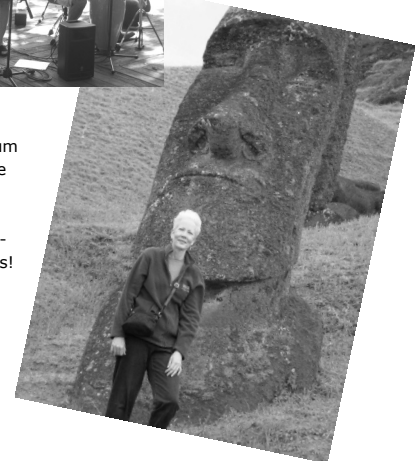
semester to ODU to study oceanography. Eventually, she changed her sights to business and has worked for ATT and Circuit City.

Both she and Kevin had dreamed of serving with the Peace Corps when they were younger, but were advised to get established, buy a home and acquire some stability first. When they did accomplish those things, Marguerite says, "we got a brain tumor." So, she has been working with the Zimbabwe Brain Tumor Association to bring medical and palliative care to brain tumor patients in Harare to fulfill part of her dreams of helping disadvantaged people overseas.

Marguerite and Kevin love to travel. She does not have **one** favorite locale, but loves wherever she goes. She would still like to visit Australia, one of the two continents she has not yet visited (Africa is the other). Marguerite and Kevin do not have children, but they cherish their time in their relationship. They have a home in Duck that Marguerite loves to escape to; it's a special place that feeds some of her spiritual needs.



Marguerite Sciuk, (pictured above with Susan Greenbaum and Chris Parker, thanks the participants of the 2008 Celebration of Hope event; (right) a photo from a treasured vacation to exotic lands!



## In Case You Missed It....

An Update on recent Support Group Meetings from Co-Facilitator Carol Roberts

Dr. Nicolas Roman was the featured speaker at our April meeting. Dr. Roman is a radiation oncology resident at the Massey Cancer Center on the MCV Campus of the VCU Medical Center. He reviewed the central nervous system with its role of coordinating activities in the body, the various cells, and types of primary brain tumors. He explained that malignant tumors anywhere in the body will invade any type of tissue, such as bone or blood, but benign tumors remain encapsulated and non-invasive. Benign tumors may push against other struc-

tures or put pressure on tissues, such as nerves.

Dr. Roman discussed the WHO System of grading astrocytomas and reminded us that tumors grow inside the tissue; they are not well circumscribed, but grow like a ribbon between cells. When a person has neurological symptoms, they will have an examination that includes a health history and physical, a neurologic examination, CT, MRI, and, possibly cerebral spinal fluid studies and/or a biopsy. Treatment options for primary brain tumors are surgery, chemotherapy and radiation ther-

apy or a combination of these modalities.

Radiation is energy, a wave, comprised of two parts: magnetic and photon. This radiation breaks down the DNA in cancer cells so these cells cannot repair themselves. The person receiving radiation treatment cannot feel the energy. These treatments are now very focused to the site of the tumor or in the case of most metastatic brain lesions are given to the whole brain. Radiation oncologists can give only so much radiation to a person or the treatment be-

comes toxic, damaging more than just the cancer cells.

Dr. Roman explained some of the various delivery systems - linear accelerator, stereotactic radiosurgery, IMRT radiation, brachytherapy or tomotherapy. Radiation therapy is just one aspect of treatment for primary or metastatic brain tumors. There may be acute and chronic side effects from the radiation treatment, but many developments have improved the delivery of radiation in the last several decades.

## Grief Resources for Children

As you may be aware, children grieve differently than adults. Children's grief and bereavement is often poorly understood by adults, and although adults want to be helpful, they often do not know how. Depending on the age of the child experiencing a loss, they will react differently based on many factors.

Fortunately, there are some resources located in the Richmond area to specifically help grieving children.

**Comfort Zone Camp** is the nation's largest nonprofit be-

reavement camp. They provide a fun and safe place for children between the ages of 7 -17 who have experienced the death of a parent, sibling, or primary caregiver. These camps are offered free of charge throughout the year. Contact information is: 4906 Cutshaw Avenue, 2<sup>nd</sup> floor, Richmond, VA 23230, Toll free: (866) 488-5679, Phone: (804) 377-3430, Fax: (804) 377-3433, E-mail:

[info@ComfortZoneCamp.org](mailto:info@ComfortZoneCamp.org)  
[www.ComfortZoneCamp.org](http://www.ComfortZoneCamp.org)

**The Full Circle Grief Center** is a non-profit organization that supports grieving children and their families as they move through the healing process. They offer hands-on healing groups, community outreach, education, remembrance programs, and individual counseling. Contact information is: Allyson England Drake, Founder/Chief Executive Officer, P.O. Box 29066, Richmond, VA 23242, (804) 357-5924, E-mail:

[allyson@fullcirclegriefcenter.org](mailto:allyson@fullcirclegriefcenter.org)

[www.fullcirclegriefcenter.org](http://www.fullcirclegriefcenter.org)



Our thanks go out to Dr. Randy Merchant, who provides support for this newsletter through the Sun Chlorella Fund of the MCV Foundation.

## Upcoming Events

**Tuesday, July 14, 7pm**—Monthly Support Group Meeting

**Tuesday, August 11, 7pm**— Monthly Support Group Meeting

**Tuesday, September 8, 7pm**—Monthly Support Group Meeting

**Tuesday, October 13, 7pm**—Monthly Support Group Meeting

### **Can't Make it out to the Meeting?**

You can participate by conference call!

Call the toll free number (888) 617-3400

And enter the pass code 187033



### **Richmond Brain Tumor Support Group**

P. O. Box 980631  
Richmond, VA 23298-0631

Phone: (877) 284-3905  
Email: [curebt@hotmail.com](mailto:curebt@hotmail.com)  
[www.curebraintumor.org](http://www.curebraintumor.org)

**Richmond Brain Tumor Support Group** is a 501-c3 non-profit organization dedicated to providing support for brain tumor survivors and their loved ones, promoting awareness for brain tumor issues, and advocating for brain tumor research in Central Virginia.

**Meetings** are open to all, and are held on the 2nd Tuesday of each month at 7:00pm, in the Education Center of St. Mary's Hospital, located at 5801 Bremono Road in Richmond. The room number for the meeting will be posted on the bulletin board in the hallway leading to the Education Center.

#### **Our Board of Directors:**

Medical Advisor—William C. Braoddu MD  
Facilitator— Carol J. Roberts CCRN  
Administration— Cheryl Fare Tormey

Visit us Online!  
[www.curebraintumor.org](http://www.curebraintumor.org)

