



CULLATHER BRAIN TUMOR QUALITY OF LIFE CENTER



5875 Breemo Road, St. Mary's Hospital, Medical Office Building South, Suite 108 Richmond, VA 23226
(804)287-7809 www.braintumorqol.org

A Year of Success: A Year of Advocacy

By: Dr. Sherry Fox

It is unbelievable that a year has passed since the opening of the Cullather Brain Tumor Quality of Life Center on September 24, 2006. And what a year it has been! As of this writing, we have served over 100 patients and families living with a brain tumor, established a beginning volunteer network and promoted two fundraising events! We have much to be grateful for and proud of in our first year of operation.

Our most poignant success has been fulfilling the dream of Jack and Jean Cullather to establish this center. We owe them a debt of gratitude for their vision for this center and for Mr. Cullather's unwavering commitment to make it happen. In addition, we owe our thanks to Jack and Jean's daughters and their husbands, Maureen and Mark Stepanian and Maribeth and Tom Carr for their enthusiastic support of Jack and Jean's vision for brain tumor patients in Richmond.

Fulfilling the dream of Jack and Jean for the establishment of the center has led to beginning efforts to advocate on behalf of individuals as well as the collective group of brain tumor patients and their families. We have made great strides in our first year in "telling the story" of individual patients so that they could obtain needed services that promoted their quality of life. One of our most powerful examples is how we helped a patient obtain living space in an assisted living facility versus a locked dementia unit simply by telling the patient's story and by educating the staff about the special needs and characteristics of this brain tumor patient. It is somewhat difficult to convey the impact of this story without breaching confidentiality but suffice it to say that this person continues to his highest level of quality of life possible and his family is happy

that they have left no stone unturned in promoting that quality.

In addition to advocating for individual patients, we have also been busy advocating for brain tumor patients as a group. Early in the year, Dr. John O'Bannon sponsored HB 2156 in the General Assembly to mandate that Virginia insurance companies pay for second opinions at Comprehensive Cancer Centers, thus giving patients access to greater knowledge about clinical trials and innovative research. These efforts were supported by volunteer, Karen Gregory Miller. Stay tuned this fall for more information on the progress of this bill. Also this year, the center staff, assisted by Archer Ticer, PT (volunteer and advisory board member), began work to develop strategies to assist brain tumor patients in applying for and obtaining social security disability on their first application. Many individuals with brain tumors are unsuccessful in their first attempts to obtain disability. Look for developments as this advocacy project unfolds in the coming months. Finally, in this later part of our first year, Mr. Cullather and I provided testimony on behalf of St. Mary's Hospital for their certificate of need application for an intraoperative MRI (IMRI) before the State Corporation Commission. This surgical tool can promote a more precise surgical resection of tumor, improving the odds of a longer survival and better functional outcome for brain tumor patients. No other hospital in the Richmond area currently has this technology.

Indeed, it has been an incredible year for the Cullather Brain Tumor Quality of Life Center. So much of a success that the word is beginning to spread across the country about our efforts on behalf of brain tumor patients. Just in time for our first anniversary, I will be traveling to University of California, San Francisco to deliver an inaugural address to the Neurosurgeons and staff on the quality of life issues facing patients. (next page)

with brain tumors and how the Cullather Center addresses those issues. On the same trip, I will by invitation also be “telling the story” of the Cullather Center to the patient services staff of the National Brain Tumor Foundation. These upcoming events put the Center in the national spotlight and create greater opportunities for advocacy on behalf of patients and families. Celebrate our success in our first year and join us in our second year of advocacy on behalf of brain tumor patients and their families.

Spotlight: Cathy Willis, Patient Advocate

In each issue, we are going to share a special patient advocate with you so we can learn more about wonderful individuals who give their time and their talents to bettering the lives of brain tumor patients. This month we are highlighting the Cullather Center's Cathy Willis.

When you call the Cullather Center, the one you immediately reach is Cathy Willis, our Patient Advocate. We are thrilled to share her story with you!

How did you become involved with the Cullather Center? “When I heard that Bon Secours had opened the center I was immediately drawn to it because of the role it plays in helping patients thru a very frightening time in their life. I wanted to be a part of that team because I felt I could help since I have had experience in coordinating care and services for patients thru my work in a physician’s office for 15 years and as a patient advocate for a hospital. Also, I found during my husband’s illness that it meant so much to talk with people that were going thru the same thing we were that I wanted to give that help to others. The Cullather Center is the perfect place to do that.”

What is your role when a patient first comes to the Cullather Center? “I explain to patients what the Center is about, that we are here for them in any capacity that they may need us whether it is for more information about their illness, insurance issues, financial issues, coordination of care, gathering their medical

records, assisting with scheduling second opinions etc... One of the most important things I do is listen. I show them around the facility and explain what we have to offer. Many times patients are so overwhelmed with their diagnosis that they don’t know which way to turn. We help them figure out what their needs are and walk them thru the process. I keep in contact with the patients thru email or phone calls and continually evaluate their needs and refer them as needed to the services we think will best serve their needs. To sum it up, I am an advocate for patients and families living with a brain tumor.”

What do you find is the patient’ or caregivers’ greatest reward/need with the Cullather Center? “I think that the greatest reward that the Center gives patients is the feeling that they are not alone. We give them emotional support and we are here for them no matter what comes up during or after their treatment. Sherry has so much knowledge about brain tumors and its effects on the patients and families. That is a comfort to them to know they have an expert only a phone call away. Because of my personal experience with cancer with my husband, patients know they have someone to talk to that has been there. “

What makes you most proud about your work with the Cullather Center? Being given a diagnosis of cancer is devastating; I like and hope to think I have made their walk a little easier. It touches my heart when patients are so appreciative of the little things we do for them. Just a phone call can mean so much to them.

What are your hobbies and interests? I like to mountain bike, motorcycle ride, spend time in the mountains and on the beach. I love to float the river and fish, spend time with my family and friends.

What would our readers find surprising about you? When my husband and I first got married we decided we wanted to do something different so we lived in a tent for 2 years. It was a large wall tent-18X20 feet. It was in the country on a pond. We built a plywood base and put in on that so it wouldn’t be on the (next page)

ground. We had carpet in it, furnished it with a table, chairs, a dry sink that my father-in-law made us, sofa bed, a wood stove and a couple of dressers. The first year we moved in our wood stove was not too good and the fire would go out at night. We would wake up in the morning with frozen spots on the blankets where our breath had frozen! It was quite an experience! We loved it!

What is your favorite inspirational quote? “God didn’t promise days without pain, laughter without sorrow, sun without rain, but he did promise strength for the day, comfort for the tears, and light for the way” I have that taped to my computer and read it everyday. It gives me comfort to know that no matter what “punch” life has given us, that God is there and we are in His hands no matter what happens.

Tell us about your family “I was married for 27 years to the love of my life who lost his battle with cancer in 2004. I live in a log cabin in the county that my husband built. We have two children. My daughter, Annie is 25 and married to wonderful guy, Wes. They have blessed me with my first grandchild who is now 4 month old. I absolutely love being a grandma! My son, Michael is 22 and lives beside me. He works in construction. He keeps a close eye on his Moma, which I appreciate.



The Origin of the Brain Tumor Support Group

“A support group is created when two or more individuals come together on a regular basis to provide mutual support, information, education, and assistance to one another.”

The Richmond Brain Tumor Support Group (BTSG) originated in 1989 as a result of a class project. Donna Gammon had graduated from a Diploma School of Nursing and was working as an RN for the Division of Neurosurgery at VCU/MCV. She was enrolled in the RN to Bachelor of Science Degree program at VCU/MCV. Her project was to research the area of support groups, and actually started the group as a result of the class.

The first few meetings of the BTSG were held in the Massey Cancer Center. The format of the group was a 12 noon brown bag lunch. After several meetings, it was suggested the group meet at night to increase participation and afford working patients/families the opportunity to join. The vast majority of the group did not want to travel to “downtown” Richmond at night! The Weiners of Saxon Shoes were gracious and offered the group a meeting room in their new West End location. It worked out great for Donna (she got her shoe fix!) and most people were inquisitive about the meeting location - Why did the group meet in a shoe store? The group soon outgrew this exciting location and moved the meetings to St. Mary’s Hospital, where meetings are still being held. They felt like this was a central meeting place for all and included a well-lit, safe parking environment.

Currently, the group is facilitated by Carol Roberts, RN and Nancy Hsu, PhD. We meet on the second Tuesday of each month from 7 to 9 pm in the Education Center at St. Mary’s Hospital. You may contact our message line: 877-284-3905 or e-mail: curebt@hotmail.com

Legal Information Network for Cancer Patients (LINC)

On November the 13th at 7:p.m. the Richmond Brain Tumor Support Group guest speaker will be a representative from LINC speaking to the group on financial planning. There will be an opportunity to sign up for individual counseling sessions at a future date in the Cullather Center. The meeting will be at St. Mary's Hospital in the education center, which is located down the hall from the cafeteria. The room number will be posted at the entrance to the education center. For more information visit the website at www.curebraintumor.org or call (877)-284-3905.

A very special donation

A very special young man and his family came to visit the Cullather Center in August. His name is Mitch Calhoun. His Mom, Kathy and two brothers Abe and Quinn came to the center to deliver several bags of art supplies that they had collected. What makes this donation different and extra special is that Mitch decided that for his 8th birthday instead of receiving gifts for himself he wanted everyone to give him art supplies to be donated to a place that helps the sick. What a wonderful example of selflessness this young man displayed!! Kudos to Mitch and his family!!!



How Can I Get Involved and Help?

There are so many ways to make a difference and help the Center! Here are a few:

Join Us!

Attend our Volunteer Training sessions to see how you can jump in and help. They will be held Sept 20th from 6-8 p.m. and Sept 25th from 11-1 p.m. RSVP by the 14th to Cathy at 287-7809.

Support our Fundraisers:

- **"Indomitable Spirit"**. Purchase a beautiful P. Buckely Moss hummingbird print, "Indomitable Spirit", created especially for the Center. The print is \$100 and all proceeds go directly to helping our patients. It's never too early to begin your holiday shopping!
- **Use "www.GoodSearch.com as your search engine"**. It doesn't cost you a penny but sends many our way! Go to www.GoodSearch.com and enter Bon Secours Cullather Quality of Life Center. A penny is donated every time you make a search.
- **Make a donation in Honor or Memory of a loved one**: Your donation will support the Center's work so that we can continue to provide quality guidance and care to our patients. All donations are tax deductible and are wonderful tribute to a loved one.

Donations may be sent to:
Cullather Brain Tumor Quality of Life
Center
5875 Bremono Road, St. Mary's Hospital
MOB South, Suite 108
Richmond, VA 23226
Please call 287-8700 for credit card
donations

**Our website is up and running!!
Take a look!**

www.braintumorqol.org

