



CULLATHER BRAIN TUMOR QUALITY OF LIFE CENTER



5875 Breemo Road, St. Mary's Hospital, Medical Office Building South, Suite 108 Richmond, VA 23226
(804)287-7329

Telling the Story!

By: Dr. Sherry Fox

Over the many years that I have worked with people with brain tumors, I have frequently been asked, "Why do you do this type of work?" "Isn't it difficult?" or "Isn't it too depressing?" I would respond with, "Well I just enjoy it" or "I don't know I just like it" and continued on with the work. With the opening and evolution of the Cullather Brain Tumor Quality of Center, I have come to realize that I keep doing this work for much more important reasons. I do it to "tell the story" of living with a brain tumor because in telling these(your) inspiring stories we collectively increase awareness of the plight of those with this often hidden disease. This newsletter is just one way in which the Cullather Center staff and volunteers want to "tell the story" to the community at large. We hope you will join us in our efforts to increase awareness about brain tumors by reading the newsletter, telling others about us, and most importantly by sharing your stories of living with, caring for, or volunteering on behalf of those with brain tumors.

The unfolding story of the Cullather center, after just 8 months of operation, is one of success! The center staff have helped 78 patients and their families. There have also been 300 visitors to the center. In our quest to help brain tumor patients and their caregivers "live the new normal" we provided extensive education on brain tumors and have made numerous referrals for important services such nutrition consultations, neuropsychological evaluations, home care, health care assistants, and legal and financial services. If you or someone you know needs these type of services be sure to give us a call!

Volunteers play a critical role in the story of the Cullather Brain Tumor Quality of Life Center. In celebration of May as Brain Tumor Awareness Month volunteers created and mailed our first newsletter, and supported a successful fundraiser hosted by Flemings Steakhouse Charity "Wine on Wednesday's" that raised approximately \$1500.00. We are grateful to our many volunteers who make these activities a success and help us tell the story!

Part of the story of living with a brain tumor and one that often goes unacknowledged is the financial impact of having a brain tumor. One of the critical roles of the center and this newsletter is to bring such stories and issues to light for those we serve. The National Brain Tumor Foundation has just published a report on the financial crisis experienced by many who have had a brain tumor. Although the findings of the report are no surprise, the report is critical because of its public acknowledgement of this often hidden issue. As a result of the report the NBTF has initiated the Patient Help Fund to help patients with treatment related expenses. For more information or for a copy of this study contact the NBTF at 1-800-934-2873 or go to their website at www.brainumor.org

Well my story for this issue needs to come to an end so you can read other important information in this second edition. Let us know how we are doing at "telling the story".



P. Buckley Moss "Indomitable Spirit" print - see next page

The Hummingbird Story

By: Mrs. Daniel Gregory

My husband Daniel Gregory was dying from multiplying brain tumors in the spring of 2006. Each day, although he was quickly becoming paralyzed, Daniel insisted on being pushed outside in his wheelchair, so he could sit on our back porch and feed the birds, squirrels, moles, skunks, raccoons, and anything else that would come out and play. Everyone that knew Daniel knew how much he loved to do this, even when our Hospice nurse would come, we would have our "meetings" out on the back porch! Daniel didn't want to miss a second of God's beautiful creation. It was Daniel's view of Heaven from earth as he was quickly fading away from us. Some days, people would call before coming to visit and ask what we needed, instead of saying he needed some medicine from the pharmacy, or he needed them to bring one of his favorite foods from Applebee's, Daniel would say, "can you get me some bird seed or some peanuts for the squirrels?" The smile that he got on his tired, weary face when he was sitting out in the sun with the animals was a gift to me straight from heaven above.

One of the ladies from the Infusion Center at the hospital where Daniel had been getting his treatments brought Daniel a hummingbird feeder. He was so excited! He would tell me stories about the hummingbirds that used to come to his Granny's house when he was little. So, I went out and bought some hummingbird "nectar" and we hung the feeder out back. We would sit out there and be talking and as quick as lightning a hummingbird would fly up. Daniel would stop talking, and he would say "Look Karen, do you see it?" He would educate me on all the things hummingbirds do and why they do it, although this devastating illness was attacking his body, his wits were still so amazing, I loved to sit and listen to him talk about everything that was on his mind each day.

One day, Daniel and I were sitting quietly on the back porch by ourselves. Daniel looked up and said to me, "Karen, I want you to know my prayers. Recently I prayed and I asked the Lord to send me a white hummingbird". I was surprised by this and I said in reply, "What do

you mean, you prayed for a white hummingbird"? Daniel said, "I prayed that if God sends a white hummingbird, that will be a sign from God telling us that everything is going to be OK". I remember chuckling a little and asking Daniel if there was even such a thing as a white hummingbird. I asked him, "Have you ever seen a white hummingbird, Daniel?" In a very Daniel sort of way, he responded with a quick "Nope." I laughed and said, "Daniel, don't you think that takes a large amount of faith to pray for something that may not even exist?" He responded, "God will send it, Karen. To let us know that everything is going to be OK. I just want you to be ready for when He does."

About 2 weeks later, while Daniel was sleeping, he went home to be with Jesus. To be honest, I never thought about the white hummingbird conversation again at all during those last two weeks of his life or for many weeks after he was gone. Then, one day, about 2 months after Daniel was gone, during a very emotionally hard week for me, I came home from work and did my evening routine of getting the mail and feeding my cats, etc. As I sat down on the couch to open the mail, I saw a small envelope that looked like it was containing a card. Most of the "Thinking about you" or "In Sympathy" cards had stopped arriving by this point, so I wasn't sure exactly what it was. I opened the envelope, and inside there was a card inviting me to the Blessing and Grand Opening of the Cullather Brain Tumor Center at St. Mary's Hospital (something Daniel wished he could have witnessed the opening of). But what I was most surprised to see, was the picture that I saw upon opening the envelope. It was a picture of a white hummingbird fluttering over a flower. I lost my breath for a second when I saw it and started crying as I looked closer at the picture. It was as if God was sending me a note from Heaven, to tell me "Karen, everything is going to be OK."

"INDOMITABLE SPIRIT"

P. Buckley Moss created her second hummingbird print, "Indomitable Spirit", (shown on front page) especially for our Center. We introduced it at the Flemings fundraiser and several prints were purchased. If you would like to view and/or purchase a print, please visit the Center. The prints are \$100 and all proceeds go directly to the Cullather Brain Tumor Quality of Life Center.

How you can help...

Volunteer

Attend our next volunteer training sessions, September 18th from 11 - 1 and September 20th from 6-8 at the center. RSVP to Cathy Willis at 287-7809. Our clients need support in so many ways, everyone can help.

Goodsearch

Go to www.GoodSearch.com and enter Bon Secours Cullather Brain Tumor Quality of Life. GoodSearch will donate a penny to our cause for each online search you make. Pennies from many equals more resources to help our clients. Please spread the word on this.

Fundraisers

Our St. Patty's Day in the Park and Flemings Wine on Wednesday events were both lot's of fun and generated over \$9,000 to our cause. Additional events are in the planning stage and will be announced in our September newsletter.

"Indomitable Spirit"

This beautiful P.Buckley Moss hummingbird print was created especially for our Center. If you would like to view and purchase a print please stop by the center. The print is \$100 and all proceeds go directly to the Cullather Brain Tumor Quality of Life Center.

Donations & Gifts

Help enable us to continue our service to the community through your tax-deductible gift. Make a donation in memory or in honor of someone. We will send a card to your designate. Make a general donation to support our quality care, patient services and outreach programs.

Looking for Caregivers:

Please call the center if you are aware of people who provide care-giving services in people's homes.

Your donations may be sent to:

Cullather Brain Tumor Quality of Life Center
5875 Bremono Road
St. Mary's Hospital
Medical Office Building South, Suite 108
Richmond, VA 23226
Phone: (804)287-7329
Fax: (804)287-7556

Credit cards donations are accepted. Donors may call **287-7700** and tell the person answering that they wish to make a credit card donation to the Center.

All donations are tax deductible.

LINC

Legal information Network for Cancer

Need help with the business side of cancer? Financial/Legal concerns? LINC (legal information network for cancer) can help. Don't wait until you have a crisis, this is a very valuable resource and can help you plan for the future. The CBTQLC has partnered with LINC to come to the center and provide free one on one consultation/assistance for our patients. We will be holding this session in August. If you would like to sign up for a consultation, please contact the center at 804-287-7809 for details and to reserve a time slot. Spaces are limited so call early.



Brain Tumor Resource and Information Network



In 2005, as a brain tumor survivor, I established B.R.A.I.N. Brain Tumor Resource and Information Network is a 501 (C) 3 non-profit charity, volunteer organization dedicated to improving the quality of life of brain tumor survivors, increasing public awareness, and raising funds to aid in the research to eliminate the disease. Many members of the organization have brain tumors, have a child with a brain tumor, or have lost someone very dear to a brain tumor.

We established the network to provide care and HOPE to those diagnosed with the illness. We understand that brain tumors are still considered an orphan disease. Because of its orphan status, there is a great need for more research dollars to support brain tumor research and clinical trials. There is no known cause and no cure for most brain tumors.

We provide information packages about the disease to 4 main hospitals in the Richmond, as well as two neurosurgery offices, that are provided to newly diagnosed brain tumor patients. This information is critical to the patient and the caregiver to help them better understand the disease and make decisions about treatment options.

Each fall we have a fund raising event called **Celebration of Hope**. October 28th, 2007 will be our third event. The event will include a 5k run and fundraising walk. Susan Greenbaum will perform. To date we have raised more than \$75,000 in research funds. This has enabled us to provide grant money to VCU Health Systems Pediatric Brain Tumor Research, Preston Robert Tisch Brain Tumor Center at Duke, and California University San Francisco Brain Tumor Research.

Another initiative is our partnership Dale Thomas who was diagnosed with a GBM last year. He initiated working with the Department of Motor

Vehicles in Virginia to gather 350 **Brain Tumor Awareness License Plate** applications. We have a sponsor who is donating \$3,500 for the first 350 applicants, so the license applications are free. Once we have gathered the 350 applications we will approach Virginia legislation for approval. Our objective is to have 350 plates by the end of 2007, with approval in 2008. See an example of the license plate above. It is another way to create awareness about the disease. **We would be the first state to have a BRAIN TUMOR AWARENESS PLATE.** Visit our website for a license application, www.brainsite.org or stop at the Cullather Quality of Life Center to pick up an application.

Our organization meets on the first Saturday morning of each month year round, and additionally in June through October, the 3rd Thursday evening of each month. If you are interested in volunteering please check out our website or call our toll free number for more information, 1 (800) 900 6195 access code 48. We are also a member of the **International Brain Tumor Alliance**, an organization established in 2005 that recognizes brain tumors as a major disease for the world to be concerned about. Please see www.theibta.org for more information.

Our organization is **passionate** about making a difference. We support each other, care for each other, give each other strength and hope. Each one of us makes a difference. **Our toll free number can be called at any time, day or night, if a survivor or caregiver needs help.** If we are out we check our messages frequently.

With love, prayers, and hope,

Marguerite Sciuk
President and Survivor
PO Box 4316 Glen Allen, VA 23058

