



Spring 2011
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5875 Breemo Road, St. Mary's Hospital, Medical Office Building South, Suite 108 Richmond, VA 23226
(804)287-7809 www.brainumorqol.org

May is National Brain Tumor Awareness Month

Brain Tumor Awareness and the Power of the Grapevine *by Sherry Fox*



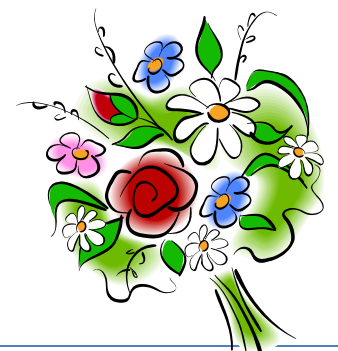
If I were a betting woman, I would bet that almost everyone reading this newsletter knows numerous folks who have had cancer. But until your life is touched by someone with a brain tumor, you likely haven't heard much about them. In my 33 years

of caring for persons with brain tumors, one of the comments I frequently hear is, "I have never known anyone with a brain tumor and now that I have one, they seem to be everywhere".

One reason that you don't hear as much about brain tumors is that they comprise only 2% of all cancers making them rare compared to other cancers such as breast, lung and prostate. With their rarity there are often not a lot of resources or experts in communities to assist patients. Even when there are resources they are often not promoted by the patient's health care team. As testament to this, in an International Brain Tumor Association world-wide survey about experiences of brain tumor patients with medical staff, a majority of patients and caregivers were generally satisfied with their experiences, except for one notable exception: only 28% of respondents were given information about support groups, brain tumor charities, or non-profit support organizations.

Of course, such groups might not exist in their local area but the result indicates the need for greater attention to this issue, particularly where groups do exist and patients are not being told about them. Unfortunately, this is the case in Richmond. The largest source of referral to the Cullather Center is "by word of mouth" from families who have benefited from our services. While this is wonderful, we still have much work to do to educate the health care community and the community at large.

As we enter May and Brain Tumor Awareness Month, it makes me sad to know that there are persons out there who are not informed about our specialized services. In this situation the power of the grapevine or "word of mouth" is the best way we can reach out to people experiencing this catastrophic illness. My special request of you in the coming year is that you will provide hope to those who may be experiencing a brain tumor and use the power of the grapevine to tell them about the Cullather Brain Tumor Quality of Life Center and all we can do to help them! Remember, "Be the Hope."



Cancer Survivor's Day

Saturday, June 4, 2011 4-6 p.m.

St. Mary's Hospital Auditorium

5801 Bremono Road

Entertainment provided by harpist Charles Overton.
visit his website at www.harpmanmusic.com

*Food, gifts and enjoyment
for the whole family!*

■ Music ■ Chair massages ■ *And much more!*

This free event is held to honor anyone who has ever been touched by a cancer diagnosis. Whether it be you, a family member, a friend, a patient, or to honor a loved one who has endured — we hope you will join us!



BON SECOURS CANCER INSTITUTE
Bon Secours Richmond Health System



Good Help to Those In Need®

Ask Lee...

There are many behaviors that are a result of brain tumors that are difficult to deal with. Some of the most difficult behaviors are changes in personality or mood. In this issue, we will look at paranoia.

Paranoia is not found in all patients, but depending on where the tumor is located, paranoia may be seen. Some signs of paranoia include having fears, such as being watched, harmed or poisoned. They may feel that others (including those closest to them) are no longer trustworthy. They may feel that you, the doctor, or others in their life are “out to get” them. A person who is paranoid has a hard time not being suspicious of everyday occurrences. For example, they may hear you on the telephone talking to a friend and make the assumption you are talking about them. They may go out of their way to prove their suspicions, even though there is not concrete evidence to prove what they are thinking and feeling. It is very easy to become overwhelmed and not know what to do.

If possible, see a neuropsychiatric specialist or general psychiatrist for proper medication management. There are several medications that may be effective in lessening the symptoms of paranoia. Often, it is difficult to get an appointment with a psychiatrist, so call as soon as you notice changes. Many doctors who treat patients for brain tumors will not be comfortable prescribing a medication to address these symptoms, but it doesn't mean you cannot ask them. However, sometimes the doctor may be able to make a referral to a colleague who is a specialist in symptoms such as paranoia. If the

referral comes directly from your own MD, you may get an appointment sooner than if you called on your own.

Another thing you can do is simply try to be supportive. Paranoia requires patience, understanding, love and encouragement from the loved ones. If possible, try not to “challenge” them to make them understand that what they think and feel is not true. Encourage them to maintain a positive attitude and to not feel helpless. Try to convince them that no one is out to get them, and do what you can to help them feel safe.

For the caregiver, give yourself permission to take “time off” and focus on yourself. You hear me say constantly that the caregiver needs to pay special attention to his/her own needs, in addition to making sure the loved one with a brain tumor gets the help needed. Don't forget our online support group for caregivers (www.brainumorqol.org). You can reach out to others who may be experiencing similar issues. Often, your peers will offer you the best support, suggestions and guidance. No one completely understands a situation until it personally affects them. So, if you can find others who are in similar situations, try to reach out. Also, don't forget the Brain Tumor Support Group here at St. Mary's Hospital on the second Tuesday of the month. That is another great place to receive support and guidance from your peers.



Lee received her Master's Degree in Clinical Social Work because she is interested in the Biopsychosocial model instead of just looking at the psychological needs. Biopsychosocial basically means looking at the whole person in their environment. She has experience in the oncology field, as well as a strong mental health background. The services of the Cullather Center fit both of her fields of expertise. Feel free to call her or email her questions: Lee_Carter@bshsi.org. We may print your question, anonymously if requested, in the next newsletter.

Cancer Survivor's Day

Sunday, June 5, 2011 4-6 p.m.

Bon Secours Cancer Institute

14051 St. Francis Boulevard

Midlothian, Virginia 23114



Brought to you by the Bon Secours Cancer Institute at St. Francis

An afternoon of fun for the entire family!

- Food
- Prizes
- Music
- Massages
- And much more!

good help brings *hope*

This free event is held to honor anyone who has ever been touched by a cancer diagnosis. Whether it be you, a family member, a friend, a patient, or to honor a loved one who has endured — we hope you will join us!



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Brain Tumor Awareness:

Experience with a Vaccine Trial

There is much in the news about vaccine trials, so in order to continue to educate people about brain tumors and their treatments, we invited one of our clients to answer some interview questions regarding a vaccine trial in which he is enrolled. Remember, the trial has to be specific to your type tumor so no one trial fits all. More info can be obtained about specific vaccine trials at the link below or by talking with your medical oncologist.

How did you learn about the vaccine trial in which you are entered?

I learned of it through an email blast from www.virtualtrials.com.

Why did you decide to enter a clinical trial for vaccines? What appealed to you about a vaccine trial?

After having 2 biopsies, a craniotomy, and 18 months of Temodar; the residual tumor was still in my head and beginning to grow slowly. I was interested in vaccines due to the lack of side effects versus other options such as radiation or further chemotherapy.

What concerns did you have about the vaccine trial?

I had 3 concerns: 1) Exclusion from other types of future treatments if I enrolled in the vaccine. However, after discussing this with my neuro-oncologist, he reassured me that this typically is not the case. 2) Meeting the stringent eligibility requirements because they required the presence of specific blood cell markers that exist in 1 in 2 people. 3) Insurance coverage since it was a Phase I/II trial.

What has been your experience thus far?

Experience overall has been really positive. The main side effects for me are arm soreness, redness at the injection site, and tiredness. However, these side effects are only present for 24 hours. The side effects are certainly better than many of my other options.

What advice do you have for others looking at a vaccine trial?

Take vaccines into serious consideration when you are exploring treatments. They seem to be the cutting edge treatment for brain cancer. The only constraints for me have been time out of work and money to travel to Pittsburgh. However, these are both small prices to pay for a treatment that can potentially save my life.

What else would you like to share with the readers that I may not have asked you?

Have an open mind and explore all your treatment options before you jump into anything!

May is National Brain Tumor Awareness Month

What would we do without our wonderful supporters and volunteers?

In the past two months, the Cullather Center has had “cheerleaders” out in the community raising awareness of the Center and our mission...”to assist those individuals and their families living with a brain tumor to live a new normal”. We are grateful to these individuals for their support and for sharing the message!

In February, the owners of **Pescados China Street** generously donated 15% of the lunch and dinner sales to the Cullather Center. With the largest Monday crowd they have ever seen, Cullather Center supporters treated themselves to delicious Caribbean and Latin cuisine! Thank you to Pescados and our wonderful supporters! The funds we raised from this one day will greatly help our patients in need.



Also, the Cullather Center provided a “volunteer army” to help with the Kids Zone at the **Church Hill Irish Festival**.

A big thank-you goes to the following people:

Louise Leary, Bill Funk, Judy Hoffman, Hannah Pike, Gordon Grappone, Tony Grappone, Matthew Puerto, Linda Stepanian, Sherry Price, Patti Connolly, Jamie Wigginton, Chip Wigginton, Noelle Loving, Lynne Garrett, Nancy Ring, Dennis O’Keeffe, Roy Woolwine, Lisa Avram, Ellen O’Leary, Steve Meadows, Suzanne Newell, Cary Cronemeyer, Margaret Waldrop, Bobby Waldrop, Marsha Brady, Kevin Sciuk, Whitney Rayner, Julia Sroba, Caroline Carr, and Emily Baish.

Do you have a business that would like to support the Cullather Quality of Life Center by offering a fundraiser to our supporters? If so, please contact Cathy Willis at 287-7809. We are incredibly grateful to the community for their continued support.

“Most of all the other beautiful things in life come by twos and threes, by dozens and hundreds. Plenty of roses, stars, sunsets, rainbows, brothers and sisters, aunts and cousins, comrades and friends - but only one mother in the whole world.”

—Kate Douglas Wiggin

In honor of the upcoming Mother’s Day holiday, why not make a tribute to a special “Mother” in your life. Every penny donated goes directly to helping our patients receive the quality care, guidance and assistance they especially need at this time. What Mother wouldn’t be proud to know your generosity was directly helping others?

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 (804)287-7700 for credit card donations.

- ALL DONATIONS ARE TAX DEDUCTIBLE -



Spring Time Wellness Habits

Yay, spring is here! Spring is a time for rejuvenation both for the earth and for us. This spring think about what you can do to help yourself; whether you

need more energy or something to lift your mood. Some examples would be to get outside and soak up a little bit of sun and get some much needed vitamin D which is not only good for your bones, but is essential for healthy functioning of the brain and the body. I don't know about you, but I feel more energetic when the weather is warm and the sun is shining. Don't forget to pay attention to your diet; your diet can play a key role in your energy level. Some foods that provide an energy kick are oatmeal, lean beef or chicken, black beans, almonds, and seaweed to name a few. Also, don't underestimate the wellness benefits of exercise. Just a 10 minute walk a day can do wonders, or a yoga class once a week, or treat yourself to a massage to help melt away the stress. Remember we offer free massage for our patients and caregivers!

Here is a common recipe for an energy boosting smoothie:

- One banana
- One cup strawberries
- One fourth cup orange juice
- One egg white
- One cup of yogurt
- Ice cubes



Blend all together and *enjoy the spring!*

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