SEARCH

Winter 2003, Issue No. 54

NBTF
NATIONAL
BRAIN TUMOR
FOUNDATION
giving help,
giving hope®

Together in Hope

Brain Tumor Conference

March 14-15, 2003
Houston, Texas

Details on page 7

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FREE Teleconference on Radiation Treatments

April 2, 2003

See page 4

INSIDE

Silverlon and Surgery:

Our Search for Healing

BY JULIA E. SCHOPICK

For ten years, we were lucky and we knew it. My husband Tim was one of the fortunate long-term brain tumor survivors. Although he seemed to suffer all the complications and side effects from his first surgery and subsequent radiation treatment in 1990, he was able to maintain the most important thing: his Self. And we maintained our wonderful marriage in every sense, a full 100% partnership.


Julia Schopick and Tim Fisher.

One of the best things about Tim's level of survivorship was that, although he was able to work less and less, he could still fully enjoy his two great passions (besides me, of course!): music and reading. In fact, his tumor-forced semi-retirement gave him the opportunity to indulge these passions with no guilt and all pleasure. "Someday," he'd tell me, "I may not be able to enjoy my passions – so I'll enjoy them now." I happily agreed and became the primary breadwinner, working out of our large apartment and taking numerous breaks throughout the day to talk, cuddle with him and listen to his dissertations about music.

Like all brain tumor families, we knew our time together might be shortened, so we learned to live in the present. At times, we talked about what might happen in the future. We bargained on possible tumor recurrence, or brain damage as the side effects from his course of whole brain radiation became more and more debilitating. We didn't know that it would be his irradiated skin that would be the problem, and that when the shoe finally dropped, it would nearly topple us.

What happened to Tim can happen easily to so many brain tumor survivors who undergo radiation treatment. I now hope to pass on what I have learned to other brain tumor survivors in hopes that long-term survivors will not be toppled by the complications and side effects and will turn into permanent survivors, with a great quality of life.

But first, our story:

In October 1990, 41-year-old Tim underwent surgery to remove a huge, grade 3 astrocytoma from his left frontal lobe. About a month later, he underwent whole brain radiation. For the first four years after that, he seemed to suffer from every possible side effect and complication of both the surgery and the radiation. These complications caused him to require some eight or nine additional surgeries

CONTINUED ON PAGE 2

over the next four years. From 1990 to the present, there were also several adjustments in his medications, as well as a stroke (another "side effect" of the radiation), infrequent seizures and numerous trips to the hospital. But finally, we thought we had come out on the other side.

Then, in January 2000, he started having grand mal seizures that wouldn't quit. He was hospitalized for nearly a month in our local community hospital. Although the MRI at the local hospital turned up "nothing unusual," we were understandably tense as we waited for the results of a second MRI in April of 2000.

Our neurosurgeon, who had performed the 1990 surgery, said there was "something" on the scan. He advised having surgery as soon as possible. But, having lived through all the complications and side effects from the first surgery, we weren't too keen on the prospect of another. We decided to wait.

After 14 months, the doctor was adamant about surgery. The tumor was getting dangerously close to Tim's motor strip. In the weeks that followed, I talked back and forth with his nurse, who seemed confident that all the necessary pieces were in place – including having a plastic surgeon close Tim up because, years ago, Tim's skin had had trouble healing.

The surgery was performed on June 26, 2001. The surgeon (our primary neurosurgeon's partner) greeted us confidently at 7:30 AM – and in Tim went. He came out hours later in almost perfect shape. A miracle! I applauded myself for all the organic food and supplements I'd poured into him over the past five years. Tim was released from the hospital after four days – highly unusual for someone with his history.

For one month, everything was perfect. No changes at all, neurological or physical. We took long walks, went to the movies and out to dinner. Friends came over and Tim would hold court, playing his beloved classical music for them and interpreting it for his various "audiences."

I was astounded and grateful. We were surely blessed.

Then, it happened. The first shoe dropped. We had been trying not to notice a small "spot" on the suture line that seemed slow to heal. The visiting nurses didn't seem to be overly worried either, so we remained calm. But suddenly, Tim became confused and incontinent – and soon, I knew we were in deep trouble.

A trip to the Emergency Room where he'd had surgery a month earlier revealed that air had flooded Tim's brain. After 10 hours in the ER, they finally sewed up the tiny holes they found in the suture line and put him on several IV antibiotics at once. When there's air in the brain, we were told, infection can be assumed. We all hoped the wound would heal, and that we'd be "lucky." We weren't. Again, about three weeks later, air flooded his brain. They operated again, this time removing his plastic plate and shunt, and put him on yet more antibiotics. After three months he came home.

~

> ***"I don't think it was a fluke, and it certainly is a wonderful 'anecdote,' which I hope will be repeated many times over for other brain tumor patients in the years to come."***

~

Tim did extremely well for two months and began to walk again with a walker. We even went out for our 16th wedding anniversary, with Tim's caregiver sitting a few feet away. We were blessed, we thought again.

Then, the other shoe dropped. He again became disoriented, and this time he had a fever. Since we had been dissatisfied with the treatment he received in the first hospital, we had found another hospital – and another neurosurgeon. I took Tim to this hospital for another three-plus months of surgeries to try to fix the darned suture line. By now, they were putting in external drains on a regular basis, but nothing worked.

Tim's new neurosurgeon was puzzled and "distraught" about Tim's situation. Now the dura (the covering of the brain) was leaking. Meanwhile, I was spending hours and hours online, looking for out-of-the-box treatments that the doctors might not have thought of. I prepared a 200-page report on my findings for the doctors to read. I tried to get Tim approved for hyperbaric oxygen, which has been known to do wonders for both radiation necrosis and nonhealing wounds. But the doctor who ran the chamber at this hospital refused. He was afraid Tim was too fragile. I, too, was afraid, because I just *knew* Tim was dying.

And he would have, I think, if I hadn't been blessed to be interviewing a local internist on behalf of one of my clients. We chatted about personal matters and he asked, "How's your husband?" I told him. He asked me if I had ever heard of Silverlon. "Silver what?" I inquired. He explained that Silverlon was a healing system comprised of pieces of material made with silver ions which, when wet, caused many of the worst nonhealing wounds to heal. He had used it successfully on several patients with nonhealing diabetic wounds. And it was FDA approved, which meant it had passed all tests for safety.

I immediately contacted Bart Flick, MD, the physician who invented the product. I faxed Dr. Flick Tim's medical history and called him an hour later. Dr. Flick was wonderful, agreeing to talk with Tim's doctor.

I called Tim's neurosurgeon, only to find out that Tim was leaking yet again.

CONTINUED ON PAGE 6

An Urgent Message from the President

Dear Friend,

JANIS L. McCORMACK

Please allow me to share a story with you about a family member of a brain tumor survivor. His name is Tom, and his oldest daughter, Carla, was diagnosed with a meningioma in 1986 – just months before her 40th birthday.

Tom, Carla, and the entire family began the complicated journey that you are probably familiar with, and one of their constant champions during this 17-year battle has been the National Brain Tumor Foundation. They received so much help over the years from the Foundation, such as: comprehensive patient conferences, issues of this quarterly newsletter, access to a medical advice nurse, informational brochures, referral to a medical center of excellence for treatment, advice about enrolling in a clinical trial, support groups, a regularly updated web site, and much more.

Tom, who is retired, writes a donation check to the Foundation on the first of every month. He feels good that his monthly gift helps other families like his, who are searching for answers, help, and hope. He is hopeful the yearly grants awarded by the Foundation to brain tumor researchers will lead to a cure.

I ask you now to partner with Tom and the many donors like him who support the National Brain Tumor Foundation – providing help to anyone who needs it. The Foundation receives no government funding to provide our many services free-of-charge to patients and families.

Please join Tom in making a commitment to donate a comfortable amount each month to the National Brain Tumor Foundation, or put a donation of any amount in the envelope provided in this newsletter. You can also donate online by visiting www.braintumor.org and following the “Contribute to NBTF” prompts. Feel good about saying YES to those who need the Foundation’s help at a critical time in their lives.

Many supporters have also come up with unique and interesting ways of raising funds for the Foundation:

- writing letters to friends and relatives asking for contributions
- organizing bowl-a-thons and golf tournaments
- joining or organizing a community Angel Adventure® (a non-competitive walk)
- allocating your United Way contribution to the NBTF
- selling items on an on-line auction
- helping your family and friends to hold a special event.

Please contact the Foundation office at (510) 839-9777 for ideas to organize your own fundraising event.

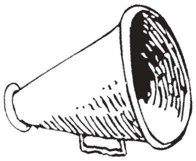
Thank you from the bottom of my heart for your loving support of the Foundation.

With warm regards to you and your family,

Janis L. McCormack

Janis L. McCormack
President, Board of Directors

P.S. The story in this letter is true – Tom is my father, and Carla is my sister. I have placed this direct appeal in the SEARCH newsletter to share my family’s story, and to save the cost of another mailing in these challenging economic times.



Announcements

Free Teleconference on Radiation Treatments

Want to understand more about radiation treatments? Then join NBTF for a free teleconference with Dr. Paul Sperduto, which will explain radiation therapy as well as advances in radiation treatment. Dr. Paul Sperduto has worked at the National Cancer Institute and served as Director of Oncology Research and Director of Stereotactic Radiosurgery for Methodist Hospital HealthSystem Minnesota.

A teleconference is like a giant conference call where participants can listen in to a presentation made by a health care professional. All you need is a phone and you are set!

The teleconference will take place on

Wednesday, April 2, 2003,
from 10:00 a.m. – 11:00 a.m.
Pacific Time
(1:00 p.m. – 2:00 p.m. Eastern Time).

The teleconference is free, but you must pre-register by e-mailing your name, address, and telephone number to teleconference@hotmail.com. Make sure to include all the necessary information and to put “Radiation Teleconference” in the subject line. Once you are registered you will receive instructions for participating. If you do not have access to e-mail, you may register by fax. Please fax your name, address and telephone number to 510.839.9779 (and remember to print clearly!). The deadline for registration is March 26.

MEDLINE disponible en español

(MEDLINE Available in Spanish)

MEDLINE está ahora disponible para pacientes que hablan español. Este website tiene información excelente sobre tumores cerebrales y tratamiento. Para más información visita http://www.medlineplus.gov/esp

Attending the 2003 American Association of Neuroscience Nurses’ (AANN) Conference in Atlanta, Georgia in April?

Stop by our table for information about NBTF and our National Angel Adventure® program.

Honoring Social Work

Do you know an oncology social worker who works with brain tumor patients and provides innovative and compassionate services? The Association of Oncology Social Work (AOSW) and the National Brain Tumor Foundation are now accepting applications for the 2003 Neuro-Oncology Social Worker of the Year. The recipient of this award will receive funding to attend the AOSW National Conference in Salt Lake City, Utah on April 9, 2003, as well as a special award.

To nominate a social worker, visit the NBTF website at www.braintumor.org and click on “What’s New” for an application and information. **Deadline is March 15, 2003.**

Presentations from NBTF 2002 Conference Now Available Online

In September 2002, the National Brain Tumor Foundation presented the first interactive video-broadcast brain tumor conference.

Summaries of the presentations from the general morning session are now available on our website. To see the slides and read the text, visit our website at www.braintumor.org and click on “What’s New.”

NBTF ART CONTEST!

The National Brain Tumor Foundation is sponsoring an art contest! Winners will find their art on greeting cards that will be sold to help raise funds for patient services and research. For more information, please e-mail nbtf@braintumor.org or call 800.934.2873 and ask for Jaime. ***Deadline is March 15.***

Caregiver Survey

In order to understand the needs and feelings of people who care for persons with a brain tumor, Paula Riess, RN, MSN, CNRN, is conducting a one time, 45-minute telephone interview with caregivers. The interview can be split up into two 20-minute segments, as long as the entire interview is completed within four days.

All information is confidential and there is no financial cost to you.

Please call our project toll-free at 1-866-855-0941 or e-mail us at paula.riess@ht.msu.edu

SURVIVOR'S
STORY

Life is a Journey, Not a Destination

By Jenelle Rose

My name is Jenelle Rose. I am 19 years old. I suffered from horrible headaches and migranes for a year prior to finding out about my tumor. It wasn't until June 3, 2002 at about 3:30 in the morning that I finally realized something was terribly wrong with me. I was driving home from a friend's house and I was by myself. I live in the country so I was taking back roads to get home. I still don't know why, but as I was driving, I couldn't really control my right arm anymore. My right hand kept reaching down to the shifter and trying to push it up until my car was in park. It was the strangest thing because I had absolutely no control of my arm. Now I know it was a sign to stop the car because not even five minutes later I blacked out. Thank goodness I was only driving about 35 mph! I woke up about half an hour later in the middle of a field. I was very sweaty and nauseous. I had no idea where I was. I was so scared I just drove right out of the field hoping I was going the right way. When I got home I woke up my mom and told her what happened while I was being sick in the toilet. I threw up for about 20 minutes. She didn't know what to tell me.

"I'M SO HAPPY I CAME OUT OF THIS WITH FLYING COLORS."

Two days later I went to the doctor. At first he thought I was pregnant, then he thought I had hypoglycemia. Then I got sick in his trashcan. He told us to go get a CAT scan at the hospital. After the results came back, we went back to the doctor and he gave my mom, dad and me the bad news: I had a brain tumor the size of a baseball in my head. I think seeing your father cry has got to be the worst thing in the world. The doctor referred us to a neurosurgeon. I really didn't know what to think at that point. I was definitely in a state of confusion. I didn't think someone as young as I was could have a tumor, let alone that big, in her brain.

Three days after that I was in the hospital getting prepped for surgery. My neurosurgeon told us that it was a benign meningioma tumor. After six hours of surgery, it was all removed. I started recovering very quickly after that. All I wanted to do was go home. My surgery was on Monday and by that Friday they said I could go home. But I got too big for my britches that day. I decided to take a shower in my own room and stand up while I was doing it. Well, I guess that was way too much for me, because I ended up passing out. When I came to, I had about half a dozen nurses standing over me, asking if I was okay. My release from the hospital was postponed, but by that Tuesday I was free to go.

The first couple of weeks at home were hard because I couldn't concentrate on anything, I couldn't read, I couldn't bathe myself, I couldn't go up and down stairs and I felt very frustrated with myself all the time. I became very depressed because I felt like I had changed and I really didn't like myself anymore. I felt like I would never get back to normal. But that all changed pretty quickly. Every day it got easier and easier for me to do things for myself and I became a lot happier. I also had lots of friends and family that kept me company.

I have checkups about once a month and I'll have to get annual MRIs for the rest of my life. That doesn't really bother me though because at least I am okay. It's about two months after my surgery now and I am almost back to normal. But I guess I will never actually be "normal" again because I am the only person I know who had a brain tumor. I'm so happy I came out of this with flying colors. I know I couldn't have done it without help from my friends and family. Now I know that they are the most important things in my life. And life is definitely a journey, not a destination.

Jenelle Rose is now back at work as a full-time nursing assistant in Sidney, Ohio. Helping people is her favorite thing to do.

Silverlon and Surgery

CONTINUED FROM PAGE 2

"I don't really want to do any more surgery," he said, sounding almost sick. "Tim's been through much too much already."

"Would you consider trying something a bit different?" I asked. "Yes," he said. So I had him hold, while I dialed Dr. Flick's number, hoping to place an instant three-way call. Thank goodness, Dr. Flick was there – and available. I patched the conference call together and the two doctors spoke, with me quietly crossing all fingers and toes. I heard Dr. Flick offer to supply all the Silverlon dressings for Tim free of charge. That night the samples were on Tim's head.

That was the last day he leaked.

> ***"I hope to pass on what I have learned to other brain tumor survivors."***

When I told the neurosurgeons I initially interviewed for this article about Silverlon, they all warned me that Tim's success might well have been a fluke. In any case, it was, they advised me, "anecdotal." But I don't think it was a fluke, and it certainly is a wonderful "anecdote," which I hope will be repeated many times over for other brain tumor patients in the months and years to come. I am therefore delighted to report that study protocols at various medical institutions nationwide are currently being developed for neurosurgical procedures.

After many talks with Dr. Flick, I now understand why Silverlon works – as well as why some doctors are so skeptical. You see, the principle of Silverlon is very different from what doctors learn in medical school about how skin heals. Dr. Flick told me he thinks Silverlon helped to heal Tim's head by changing the electrical environment, or electrostatic field, on the surface of the body (i.e., on the skin). He hypothesizes that this, in turn, affected the electrical characteristics of the dura, allowing it to heal. Dr. Flick has found, from his 20 years of research, that skin has a definite electrical potential. When there is a wound, the electrical potential of the affected area becomes abnormal. But if you can pull electrical potential from the surrounding, healthier skin, you can reestablish the normal electrical potential at the wound's site. This causes the affected skin to heal more quickly. This is the power of conductive fabrics made from silver. So Silverlon cannot just be placed over the affected area of the skin. In order to harness the electrical potential of healthy skin, the material must be placed wet over the affected area – and it must also touch 2 cm beyond the affected area on all sides. Fascinating. And by the way, silver foils were routinely used as surgical dressings at the prestigious Johns Hopkins University Hospital before antibiotics were invented.

I am now convinced that if we had known about Silverlon, it would have given Tim a much better chance of healing from the June 2001 surgery. In fact, had we found Silverlon earlier, I doubt Tim would have the cognitive deficits he now has. So I am writing this article for Tim, and for all the other brain tumor patients with irradiated skin who run the risk of leaking and getting infections from second, third, fourth, and more surgeries in the years to come.

Julia Schopick is the wife of Tim Fisher, a 12-year brain tumor survivor. Julia has become adept at what she refers to as "intuitive online research," helping people to find out-of-the-box solutions to serious health problems. She enjoys teaching people how to do their own online research. Julia can be reached at angiojs@aol.com. To read more about Silverlon, visit www.silverlon.com.

Searching For Information, Education and Support On the Internet

Questions to ask when looking for and evaluating information on the Internet:

- What is the purpose of the website?
- Are the mission and goals of the website clearly stated?
- How comprehensive is the website?
- What information does it contain?
- Where does the information come from?
- Is the information accurate and objective?
- Does the site provide timely and medically sound information or education?
- Are the website content and links provided relevant and appropriate?
- When was the site created and updated?
- Are the website's contact information, privacy statement, disclaimers, linking policy, advertising policy, sponsors and affiliations easily found and clearly stated?

This information was prepared by Katherine Walsh-Burke, PhD, MSW, Springfield College School of Social Work and Yvette Colón, MSW, American Pain Foundation.

The National Brain Tumor Foundation is an independent non-profit 501(c)(3) agency. We are not affiliated with any company, medical institution, hospital or physician. We do not receive any government funding to provide our services. Our services and publications are provided free of charge to brain tumor patients and their families.

The University of Texas
M. D. Anderson Cancer Center and the
National Brain Tumor Foundation present:

TOGETHER IN HOPE

A Conference for Brain Tumor Patients and Their Families

Take part in an exciting exploration of new therapies and sharing of common experiences. The University of Texas M. D. Anderson Cancer Center and the National Brain Tumor Foundation have teamed up to bring you a conference designed to answer your questions about the newest research on the causes and treatment of brain tumors, and strategies for dealing with issues faced by brain tumor patients and their loved ones.

March 14-15, 2003
Omni Hotel – Westside
Houston, Texas

CONFERENCE HIGHLIGHTS

General Sessions will highlight information on pathology, surgery, the newest treatment strategies, as well as complementary therapies, and what laboratory advances can mean for future therapies. **Workshop Sessions** organized into four tracks will allow you to tailor your educational experience to your specific needs. Experienced health professionals staff the **Consulting Room** for one-on-one sessions to answer your questions. Refresh and refocus in **Support Groups**, and stop by the **Wellness Room** to experience guided imagery, massage therapy and other therapies. Join us on Friday evening for dinner and entertainment for a small fee of $25. Saturday evening a buffet dinner will be served followed by a performance by David Bailey. The buffet is inclusive in your registration fee.

For a complete program posting, call 713.792.2222 or visit www.mdanderson.org/conference

NBTF Grants Award at SNO Conference

Dr. Paul Sperduto of Methodist Hospital HealthSystem Minnesota was recently awarded the NBTF Award for Excellence in Clinical Research for his research on metastatic brain tumors. The award was presented at the Society of Neuro-Oncology (SNO) Annual Meeting in November 2002.

Dr. Sperduto has been working on a Phase III Radiation Therapy Oncology Group clinical trial for patients with brain metastases. Patients who had a solitary metastasis, were in RPA Class I, younger than age 50 and had non-small cell lung cancer or squamous cell carcinoma were most likely to benefit from the addition of stereotactic radiosurgery after whole brain radiation. But improved survival was not the only outcome Dr. Sperduto observed.

Dr. Paul Sperduto with daughter, Maria, age 11, and NBTF executive director Janis Brewer.

"At least as important, if not more important, was the significant benefit in performance status, local control of brain metastases and reduced dependence on steroids in patients who were treated with stereotactic radiosurgery," commented Dr. Sperduto. "These quality of life issues are usually very important to patients and families."

NBTF executive director Janis Brewer, who attended the SNO Conference, remarked that "NBTF is proud to honor Dr. Sperduto and all the researchers conducting work that impacts directly on patients' lives."

SAVE THE DATES!

Upcoming Angel Adventures

Atlanta, Georgia
Saturday, April 26, 2003

NEW DATE!!
Denver, Colorado
Saturday, May 3, 2003

Bay Area, California
Saturday, June 21, 2003

NEW EVENT!!
Amarillo, Texas
Saturday, June 28, 2003

Fox Valley, Wisconsin
Saturday, September 6, 2003

Orange County, California
Fall 2003

NEW DATE!!
San Diego, California
Fall 2003

For more information about upcoming Angel Adventures, call the toll-free Angel Adventure® line at 866.455.3214.

WANTED –

Angel Adventure® Volunteers

The National Angel Adventure® Program is a series of non-competitive fundraising walks held in communities throughout the country and organized by volunteers with some support from the national staff.

Volunteers are needed to chair various committees to secure appropriate event sites, organize day of event activities, obtain corporate sponsorships, and encourage walkers to raise funds for the National Brain Tumor Foundation.

Volunteers should:

- Possess strong leadership and organizational skills
- Attend regularly scheduled meetings
- Commit ample time to achieve the assigned goals
- Exhibit a working knowledge of your community
- Communicate Angel Adventure® goals to the public in your areas
- Thrive on a challenge

Angel Adventure® chairpersons and/or committee members are needed in the following metropolitan areas: Atlanta, Georgia; Washington, D.C.; Portland, Oregon; and Phoenix, Arizona.

For more information call toll-free 866.455.3214.

The Sun Shines on Orange County Angel Adventure®

Although the day started out with overcast skies, spirits were high at the 1st Annual Orange County Angel Adventure®. Nearly 200 participants joined in the festivities held at Huntington Central Park in Huntington Beach, California. Emcee Mary Holms, an entertainer and cancer patient advocate, lent a note of humor as well as compassion as she encouraged people to come forward and share their personal stories during the opening ceremonies.

Co-Chairs Sue Gerow and Wendy Fuld led the 3-mile walk through the tree-shaded park. Many participants formed teams to honor or remember a loved one. Team names such as “Funky Monkey,” “Team Grrr” and “Let’s Get a Party Started” all had special meaning for the team members. Committee member Dana Bloom shared how her team name originated. The first grandchild of the family mispronounced her grandfather’s nickname: Gramps. She could only say “Grrr” and the name held. Seventeen family members and friends walked in memory of Grrr.

Held to support NBTF’s patient services programs and to fund research grants, the Orange County Angel Adventure® raised over $54,000! The committee is ready to plan an even bigger event for 2003. Congratulations to the Orange County Angel Adventure® volunteer committee!

Corporate Sponsors for
Orange County Angel Adventure®

Regional Sponsors:
  Schering Oncology
  Tanimura & Antle

Silver Sponsors:
  California Ancillary Network
  Farmers Y Merchants Bank
  Phillip’s Steel Company

Bronze Sponsors:
  Berro Property Management
  Cadworks Design Service
  JSL Construction and Landscaping, Inc.
  Longs Drug Stores California, Inc.
  Parker Hannifin Foundation
  Pierside and Art Center Gallery, Inc.
  San Diego Gamma Knife Center
  Staples

Matching Gift Programs

Many companies offer matching gift programs, allowing donors to double or even triple contributions without putting a strain on their pocketbooks. Each program has different restrictions and benefits, but most will match dollar for dollar (or more) any donation an employee makes to a charitable organization. Matching gift forms can be submitted to NBTF in combination with any donation, regardless of amount or purpose. Below is a short list of companies that currently match donations to charitable organizations. Check to see if your company has a matching gift program.

Bank of America
Black and Decker
Boeing
Champion
The Charles Schawb Corporation
The Gap
Genentech, Inc.
Hambrecht & Quist
Honeywell, Inc.
IBM Corp.
John Hancock
Johnson & Johnson
LexisNexis
Microsoft
PepsiCo
Pfizer
Pitney Bowes
Prudential
Sara Lee
The Times Mirror Foundation
Verizon
The Washington Post

SEARCHing for the Memorial Honor Roll?

Due to space constraints and the increasing generosity of donors like you, the Memorial Honor Roll has been moved. Please visit us online at www.braintumor.org

Oligo Brain Tumor Fund

Remember, contributions of any amount up to $10,000 to the Oligo Brain Tumor Fund are automatically doubled. Contact the Development Office at (510) 839-9777 for details.

CHAMPIONS OF RESEARCH

The NATIONAL BRAIN TUMOR FOUNDATION thanks Andrew's Warriors and acknowledges them as Champions of Research for their support of research through the establishment of:

The Andrew Christian Bryce Pediatric Research Grant for Medulloblastoma/PNET

A Special Thank You to Mrs. Kyle Bryce for her significant support of research by creating Andrew's Warriors and working tirelessly to raise funds for research.

Individuals support NBTF in unique ways

Morsels & Memories: A Tribute From Daughters to Their Mother

Brenda Albrecht, Karen Skarda, Sarah Wyss, and Barbara Wilson have created a family cookbook entitled *Morsels & Memories* as a tribute to their mother, Arlene Wilson. Two years ago at the age of 57, Mrs. Wilson was diagnosed with two brain tumors. After her passing, Arlene's daughters collected the recipes of their favorite dishes; the ones she had made for them while they were growing up.

Family and friends who had shared meals during Arlene's illness added recipes. Fond memories are also included. Some appear on specially designed divider pages; others as anecdotes throughout the book.

The Wilson family has published this treasured keepsake in memory of Arlene Wilson. Copies are available for $15.00 each, with the proceeds being graciously donated to NBTF. By supporting NBTF, Arlene's daughters are helping others who face the challenges of a brain tumor. If you are interested in purchasing a cookbook you can e-mail Brenda at jbalbcht@mhtc.net.

Running a Marathon

Raziuddin Ali from Norfolk, Virginia, successfully completed the Chesapeake Bay Bridge Tunnel Marathon on October 21, 2002 in 4 hours and 9 minutes. Razi ran not only to honor a close friend, Natchiket Patel, but also to support NBTF. Pledges from friends and family helped him raise over $1,000! Congratulations!

Celebrating Her Coming of Age

Sara Lederman of Golden Valley, Minnesota, is celebrating her Bat Mitzvah in a very special way:

> *As I prepare to become a Bat Mitzvah, I feel fortunate to have so many reasons to celebrate. I have realized that one of the most important things that many people take for granted is good health. Some people are not so lucky. As most of you know, my father, Russell, lived with a brain tumor for almost two years. Unfortunately, there is not yet a cure for this horrible disease, so many families continue to struggle as we did a few years ago.*
>
> *There is a group of people working to serve those whose lives are affected by brain tumors. The National Brain Tumor Foundation is dedicated to promoting a cure for brain tumors, improving the quality of life and giving hope to the brain tumor community. Instead of a personal gift, please consider supporting NBTF in honor of my Bat Mitzvah. I chose this foundation because I feel connected to it due to my family's situation.*

We salute Sara's accomplishment and dedication to NBTF's ongoing mission. *Mazel tov!*

This issue's Caregiver's Corner is a memorial piece written to validate the feelings of caregivers and family members whose loved ones have passed on. The author hopes her article "will give a perspective on how valuable it is to spend time together with loved ones while we have the chance." She focuses on what her family gained from the experience.

"My Good Old Days"

BY SADHANA KUMBHANI

It was the worst day of our lives when Rohit was diagnosed with a malignant brain tumor. He was a happy, healthy, slim, non-smoker who never even caught a cold, but now had the deadliest kind of disease. The tumor was a glioblastoma multiforme grade IV, which meant that it was the most malignant kind for which there is no known cure. It felt like someone had clipped our wings in mid-flight, and yes, we were flying. Flying high with two professional jobs, the stock market skyrocketing, and three bright, wonderful children who were all doing exceptionally well in school. To top it all off, Rohit and I were the best of friends. We were past the thick and thin of marriage and had reached a point where only the thick remained. Our lives had never been better. We had always talked about how we would travel the world and spend more time together when our last child left the nest in a year. When Rohit heard about his tumor, the first words from his mouth after the doctor left the room were, "I am going to beat this, you'll see. I'll do what it takes. I still have lots of things to do and miles to go." Little did we know what struggles and difficulties lay ahead of us.

The next two years went quickly with multiple surgeries, radiation, chemo, and many hospital stays. The "living" part of life dwindled quickly. But through it all, Rohit was a brave soldier who put up a good front. He never complained. He was always hopeful and always cheerful!

In retrospect, the last two years were the hardest time for our family but in more ways than one, it was the best time for us. We grew closer than ever, we became even better friends, and the kids matured overnight. They became responsible adults almost immediately. Rohit and I had the chance to shed tears together, and we got an opportunity to take care of each other. We went for long walks, spent many nights lying awake in bed just staring at each other and talking about silly things. At the time, it never occurred to me that these were going to be "my good old days." Although both of us knew in our hearts that we were going to be physically separated forever, we never gave up hope. We fought hard. Thank goodness for the Internet; it served as our right arm, keeping us up to date on all the latest research and clinical trials. We consulted brain tumor specialists around the country to make sure that he was getting the best available treatment. We consulted a nutritionist to keep him well through chemotherapy. We even tried homeopathic medicine and acupuncture. After two grueling years of treatment, he passed on.

Life has been tough since his passing. I have lost my best friend, my soul mate, and my kids have lost the best dad. But after a year of nothing but sorrow, I learned to put things in perspective. There are so many positives that I can't help but count my blessings every day. I had 30 years of a good marriage and memories that I wouldn't trade for anything. Three wonderful children are his living legacy. There are reminders of him in each of them, in their little smirks, in their laughter, and in all of the subtle behaviors that resemble him. After all, that is what life is all about: how we live and what we leave behind. We are all time travelers, we are here one day and the next day we are gone. Most of us will be separated from our spouses sometime in our lives, but it is the time we spend together that lasts forever. My only regret is that, had I believed that those two years were going to be my "good old days," I would have enjoyed them more. I thank God for the two years that served as a warning, which allowed us to grow closer than ever as a family.


From left to right: Rohit (inset), Sheba, Sadhana, Shilpa, and Meera Kumbhani.

> ***"Most of us will be separated from our spouses sometime in our lives, but the time we spend together lasts forever."***

Remembering the times we had together gives us the strength to go on. Rohit will always live in our hearts. His memories bring tears along with a smile, and that is what makes it all worth it.

Sadhana Kumbhani is a software engineer by profession. She can be reached at skumbhani@brocade.com.

If you need help coping with a loss, contact these toll-free resources:

Cancer Care, Inc., 1-800-813-HOPE (4673), www.cancercare.org
Candlelighters Childhood Cancer Foundation, 1-800-366-2223, www.candlelighters.org
Hospice Foundation of America, 1-800-854-3402, www.hospicefoundation.org
Wellness Community, 1-888-793-WELL (9355), www.wellness-community.org
Well Spouse Foundation, 1-800-838-0879, www.wellspouse.org

ASK THE HEALTH PROFESSIONAL

By Mary Lovely, RN, PhD

Question:

I had an acoustic neuroma removed six months ago and I'm feeling quite confused. I am having problems focusing when there is more than one person talking or if there is any type of commotion. I can't take babies crying. I have problems shopping if it's too noisy; I get really confused and disoriented. Do other people feel this way? Do you have any suggestions on how to manage this problem?

Answer:

Overstimulation due to noise is an important issue. It causes disorientation and may lead to feeling fatigued. You are not alone. Many people who have had brain surgery for any reason or brain injury have trouble managing several noises at once. Normally, we have the capacity to be able to block out background noises and selectively hear what we would like to hear, but that capacity may diminish with brain injury.

Here are some suggestions on how to manage noise overstimulation. First, take an inventory of what kinds of noises or situations cause you the most problems so you can understand what makes you confused. Second, reduce the amount of noise, if possible. For example, shop when there are less people in the stores. Third, let your friends know that overstimulation may cause confusion so they know you may become overwhelmed with too many noises. Ask them to turn off background noise like the television or radio when you visit or talk to them on the phone. You may want to excuse yourself for a little while to compose yourself. One man told me that after a long day's work, he would come home and just sit in his room for a bit before having dinner with his family. He needed time to calm down before being confronted with the family hustle and bustle.

You may find more help for noise overstimulation in a head injury rehabilitation setting. If you have one in your area, talk to a cognitive therapist or a neuropsychologist for some more suggestions.

Mary Lovely, RN, PhD, Medical Advice Nurse (made possible with financial support from the Tim & Tom Gullikson Foundation), is available to answer your questions concerning brain tumors. Please contact her by visiting the Ask The Health Professional *section at* **www.braintumor.org** *or by calling 800.934.2873*

The general medical information provided in this column is not a substitute for your doctor's medical advice. Consult your physician about your individual medical treatment.

Ask the Technology Experts

Portable Note-Taking Solutions

QUESTION:

My son needs help maintaining written notes in his college classes. He experiences fatigue after writing by hand for only a short length of time. I know a laptop computer is one solution. Are there others?

ANSWER:

You may want to consider the AlphaSmart 3000. This is a 4-line LCD display portable note-taking device. It is a lightweight and rugged unit that allows users to capture up to 100 pages of single-spaced text. It runs on three "AA" batteries for nearly 700 hours. Transferring text to your PC or MAC application is as simple as hooking up a cable to your keyboard port. This device weighs less than 2 pounds, is smaller than your standard keyboard, and costs less than $250.00 with cables and basic software upgrades. For more information, check out www.alphasmart.com.

Another option would be to use a Palm or other personal digital assistant (PDA) with an expandable keyboard attachment. If you already own a PDA, keyboards generally cost less than $100.00. One advantage of this setup is the synchronization (data sharing) that can generally occur between PDAs and your computer e-mail and contact management software.

Both solutions are portable, relatively low cost (when compared to a laptop) and require some ability to type. Remember, typing for personal note taking is an inexact science that can support and foster your own imaginative style. So, don't be afraid to DV8 (deviate) from the well-worn path.

For more information, visit ***www.thesierragroup.com*** *or contact Michael Fiore, Rehabilitation Engineer at 610.992.0288 or* ***michaelfiore@thesierragroup.com***

Welcome
NEW SUPPORT GROUPS

Tucson, Arizona
Arizona Cancer Center/University Medical Center
Brain Tumor Support Group

Location: Arizona Cancer Center
1515 N. Campbell Avenue
Room 4968

Time: First Tuesday of each month
10:30 AM - 12:00 PM

Contact: Linda Jones, MSW, 520.694.4786
or Marsha Drozdoff, ACSW, CISW, 520.694.4605

Watertown, Massachusetts
"Coffee on Saturdays" Brain Tumor Support Group

Location: Watertown, Massachusetts

Time: One Saturday each month
Call for times and locations

Contact: Bonnie Tamarin, LCSW,
617.924.9997 ext. 16

Las Vegas, Nevada
Southern Nevada "Gray Matters"

Location: Valley Hospital Medical Center
620 Shadow Lane, 3 Tower Day Room

Time: Third Monday of each month
5:30 – 7:00 PM

Contact: Janet Leinen, RN, 702.388.8462
or Kim Reuse, RN, CNS, 702.737.1948

For a complete listing of brain tumor support groups throughout North America, visit the Connecting & Coping *section at* ***www.braintumor.org***.

SEARCH*ing* for SUPPORT

To share information and experiences with other readers, email or mail your name, address and phone number along with a one-sentence description of your request to: Searching for Support, NBTF, 414 Thirteenth St., Suite 700, Oakland, CA 94612, or email ***nbtf@braintumor.org****. Please* ***type*** *or* ***print*** *all information and be sure to note if you want to include a phone number in the published item. Because several months elapse between issues, readers are also invited to contact the Support Network by calling NBTF at 800.934.2873 or use the NBTF Message Boards on our web site.*

SEARCHING for other meningioma brain surgery survivors to talk with. Please call 928.535.4700 or write to Debby Fisher, P.O. Box 2616, Overgaard, Arizona 85933

SEARCHING for someone with an intraventricular neurocytoma or something similar. Darren Hofferber, 649 K Street, Rio Linda, California 98673 or call 916.992.9902.

SEARCHING for anyone with an anaplastic astrocytoma II, who has undergone Gamma Knife procedure and is currently taking Temodar. I would greatly like to hear anyone's experience, side effects, and results with this relatively new chemotherapy drug. E-mail sarafraser@cox.net or call 619.206.0601 (cell phone)

Attention SEARCH Readers:

The information in this newsletter is subject to change. The reader is advised that information obtained from a physician should be considered more up-to-date and accurate than the information in the newsletter and that this newsletter does not and cannot purport to address facts and circumstances particular to any patient. This is something that can only be done by the patient's physician. Sponsorship of this newsletter does not imply the National Brain Tumor Foundation's endorsement or recommendation of any particular form or forms of therapy, regimen or behavior.

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