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Check Out Our Website!

<http://www.childhoodbraintumor.org>

Neurotoxicity: Changes in the Brains of Children with Tumors of the Central Nervous System

written by Dr. Kathy Warren

Neurotoxicity is a significant tumor-and treatment-related complication for a number of childhood cancer survivors. It is particularly relevant for children with brain tumors who require therapy specifically directed at the central nervous system. Despite its significance, relatively little is known about the etiology, diagnosis, prevention, or treatment of neurotoxicity. As more children with cancer are surviving longer, the importance of determining the long-term effects of treatment becomes paramount. Clinical studies to investigate these issues are becoming more prevalent.

Neurotoxicity is defined as a detrimental effect on the nervous system caused by a biological, chemical or physical agent. It can manifest in a variety of ways, which include headache, seizures, a decrease in IQ, new learning disabilities, difficulty with concentration and memory, and personality changes. The degree of neurological impairment varies from clinically undetectable to severe. Injury to the brain tissue may be due to the primary tumor itself, a neurological intervention, radiation therapy, systemic

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Becca's Run

Becca's Run was established in 1997 in memory of Rebecca Lilly, who lost her courageous battle to brain cancer in June 1997 after a six year battle. October 21, 2000 marked the fourth annual 5K run/walk event that was held on a beautiful, crisp autumn



Runners take off for a great race on a glorious Saturday morning.

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SUCCESSFUL CANCER TREATMENT BEGINS WITH AN ACCURATE PATHOLOGY DIAGNOSIS

by Dr. Barry Shmookler

The first crucial step in cancer management is to assure that the pathology diagnosis (the biopsy) is correct and accurate. What is the basis for this statement?

A pathologist is the only physician who can make the actual diagnosis of cancer. He/she is a medical doctor with a specialty training in the examination and diagnosis of cells and tissues under the microscope that have been removed from the body by various types of biopsy procedures. Based on detailed characteristics of the cells, the tumor is diagnosed as either benign or malignant.

Furthermore, the type (classification) and grade (aggressiveness) of the tumor must be accurately evaluated at this time. Based on these findings, the multidisciplinary team will determine the optimal therapy. An excellent

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Neurotoxicity: (continued from page 1)

chemotherapy or intrathecal (administered directly into the spinal fluid) chemotherapy. Neurotoxicity may occur immediately after a treatment, weeks, months after a treatment, or even years after treatment. Some effects may be partially or completely reversible, but for others, the extent of clinical impairment can worsen over time even after the treatment has been completed.(1) Research to identify patients who are at risk for neurotoxicity is ongoing. Young age, radiation to the whole brain, tumor location within the brain, and the rate of tumor growth are factors that appear to have a direct impact on the level of cognitive decline.(2)

Neurotoxicity can be classified functionally (behavioral, chemical or electrophysiologic) or structurally (anatomic location of the brain injury). There is uncertainty about how best to objectively classify functional information about brain function, but there are methodology problems associated with testing children while they are being treated on a clinical trial.(3) For example, different testing instruments are used depending on the patient's age. A child may receive one battery of tests at the beginning of the study, but may cross over to another test battery as they get older. Comparing scores among different tests that measure the same neurological function (e.g., I.Q.) over time may not be valid. Children may also demonstrate a "practice" effect with repeated testing. Furthermore, correlation of MRI changes with clinical symptoms and neurological testing has been inconsistent (4) and the clinical implications of abnormalities on MRI or CT scans are unclear. (5) We are still searching for early objective predictive tests of early neurotoxicity. At present, neurotoxicity is best classified as structural changes within the brain.

The medical terms for the structural changes that occur within the brain and that have been associated with neurotoxicity are 1) subacute leukoencephalopathy, 2) mineralizing microangiopathy, and 3) cortical atrophy. Subacute leukoencephalopathy is damage of the white matter (nerve fibers) of the brain and is manifested by loss of neuronal processes and the myelin sheaths that coat nerve fibers and enhance the transmission of signals through these fibers. This can occur in several discreet areas of the brain or be confluent throughout the brain and is commonly seen around the ventricles (fluid containing compartments within the brain). Patients may be asymptomatic, or exhibit a range of neurologic deficits. Mineralizing microangiopathy is degeneration of the wall and lining of the small blood vessels. (6) Although this results in permanent destructive changes to the surrounding brain, its effect on neuropsychologic functioning is not clearly defined.(6) Cortical atrophy is a gray matter (nerve cell) disorder with irregular loss of neurons. The exact relationship between

treatments and development of these structural lesions has been difficult to define.

New techniques in brain imaging may provide better, non-invasive tools for detecting and characterizing changes associated with the development of neurotoxicity. Proton Nuclear Magnetic Resonance Spectroscopy (¹H-NMRS) is a non-invasive imaging technique currently being studied at the National Cancer Institute. It is performed in a MRI scanner, at the same time that a standard MRI is obtained. Whereas the standard MRI gives a picture of a section of the brain, •¹H-NMRS provides a profile of chemical make-up within a section of brain tissue. The chemicals that are measured include: 1) N-Acetyl Aspartate (NAA), 2) Choline, 3) Creatine, and 4) Lactate. NAA is found only in normal nerve cells and their processes (fibers).(7) Brain tumors are thought to replace or destroy the normal NAA-containing cells, thereby causing a decrease in NAA levels on ¹H-NMRS. Increased choline levels have been associated with an increased number of cells, a greater rate of cell membrane synthesis, and increased cell turnover, which are processes associated with tumor cell division.(8,9) Creatine is a marker of cell energy, which lactate is an indicator of oxygen deficiency, which is typical of dead or dying tissue. Ratios of these chemicals within parts of the brain can be measured before treatment and followed over time.

At the National Institutes of Health, a method for measuring these chemicals in contiguous small areas of the brain was developed.(10) This method allows investigators to look at these chemicals in a large portion of the brain, rather than in one specific area. This method has been applied to the study of children with a variety of disorders. In children with metabolic disorders, areas of abnormal white matter on MRI images correspond to abnormalities in NAA, Choline and Lactate by ¹H-NMRS. Other studies have shown NAA to be altered in disease states that involve neuronal damage. In children with brain tumors, the patterns of chemicals may help distinguish active tumor from brain swelling and dead tumor, and may also be predictive of outcome.(11)

Because both subacute leukoencephalopathy and cortical atrophy involve damage or loss of neurons, determination of changes in brain tissue chemicals, particularly NAA, by ¹H-NMRS imaging may be helpful in characterizing and predicting neurotoxicity. In the Neuro-Oncology Branch of the National Cancer Institute, we are currently studying patterns of metabolites from ¹H-NMRS imaging of patients with brain tumors in both normal and abnormal appearing areas of the MRI. We are comparing these results with results of neuropsychological testing to determine if any correlation exists. We hope to use this information to objectively determine when patients are developing

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My Story: Persistence Brings Answers

My name is Kyle Killeen, I'm 17 and in my senior year at Mater Dei High School in New Monmouth, NJ. Being a teenager is a lot of fun, but it can also be pretty stressful sometimes, especially if you feel that you're different from all your friends.

That's how I felt for a long time.

I stopped growing when I was about 13 and the headaches that I had lived with most of my life became unbearable. Most mornings I could barely lift my head up, the pain was so intense. On several occasions the headache was so severe my parents took me to the emergency room. As I got older, things just kept getting worse.

At 15, as a sophomore I weighed about 90 lbs. I tried everything to gain weight and grow but no matter what I did, nothing changed. My mom was really worried; she took me to all kinds of doctors. We saw an ear, nose, and throat specialist who determined I needed sinus surgery. He was convinced the reason for the terrible headaches, my pale skin color and the black circles under my eyes was a combination of allergies and closed sinus passages that continually became infected. I had the sinus surgery in August of 1996; to date this is still the worst experience of my life. The post surgery pain was awful but it was nothing compared to the visits to his office for post-operative maintenance. And worse still was that after enduring all that pain my headaches were still there.

As a family we didn't give up the search for what was making me so ill. We continued to see doctor after doctor. One diagnosed me as having allergies. So for two years every Wednesday I went for allergy shots. The headaches not only persisted they became worse. Some doctors thought I had an eating disorder, some thought I had asthma. I saw a pediatric cardiologist to see if there was anything wrong with my heart. One doctor even thought I was depressed. Which of course I was becoming, because no one knew what was wrong with me. I couldn't play soccer anymore and when my friends wanted to go out I had no energy. Schoolwork seemed impossible. I was pretty scared. I knew something was really wrong with me and I thought we would never find out what that something was.

My family physician, Dr. John Haddad was great. He always believed me when I told him how I was feeling. He was convinced that something was medically wrong and frustrated that so far we had no answers. Thankfully he never gave up, he'd say "Kyle I want you to see this specialist or take this test... I promise we will find out what's going on with you." When I was 15 and my health continued to decline, Dr. Haddad

sent me to an endocrinologist. It was a terrible office visit. The questions were so personal, and I felt like I had answered the same ones a million times. It was a teaching hospital, so a lot of medical students were in and out of the room, staring at me, examining me, I felt like a freak. The good thing was he was a smart guy and he sent us for another MRI, this time with a contrast agent.

The next morning he called my Mom and said the MRI showed that I had a brain tumor. My mom thought there was some mistake, but I knew right away that he had to be right. He diagnosed the tumor as a Craniopharyngioma. We couldn't even say it much less spell it. We called Dr. Haddad, as always he was great. He told us to pick up the films and come to his office. By the time we arrived there that afternoon he had contacted a surgeon at Columbia Presbyterian and had set up an appointment for the next morning.

This was how I came to know another great doctor, Dr. Neil Feldstein. As soon as I met him I really liked him. He talked directly to me and answered all my questions. He told me I needed to have surgery to remove the tumor and gave me all the details of what it would be like, how long it would take, and how I would feel afterward. He let me know what my recovery would be like. He even told me all the things that could go wrong. It sounds funny but after I talked to him I was so relieved. It was okay that I had a brain tumor because at least now I knew what it was and how it could be taken care of.

My surgery was on March 19, 1999 at Columbia Presbyterian Babies & Children's Hospital in New York City. It lasted almost eight hours just like Dr. Feldstein said it would. The hospital was great and everyone took really good care of me. All my family was there. My mom slept there every night. She never left the whole fourteen days. My Dad came back and forth every day and so did my Nana and my Aunt Peggy. My uncles (I have five) also came to visit. My cousin Joseph is a New York City fireman in Harlem, and he bought me N.Y.F. D. tee shirts. Everyone at the hospital wanted one. Having all my family there really helped a lot. A lot of people sent me cards. Everyone at my school, at my church and in my neighborhood prayed for me to get better. I met a lot of doctors at Columbia and they were all really nice, but one in particular was really great,



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Successful Cancer Treatment Begins...

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article on CBTF's website by Dr. Peter Burger and Dr. Kenneth Cohen describes in detail the aspects of tumor examination. It is a common misunderstanding that a cancer diagnosis can be made on the basis of X-rays, blood tests and physical examination. While these studies may cause a great concern to your doctor that a cancerous (malignant) tumor is present, it is only when the pathologist studies a biopsy from this suspicious mass that a definite diagnosis of cancer can be made. This leads to another important guideline for newly diagnosed patients: except in rare emergency conditions, specific treatment should not be started until the diagnosis of cancer is absolutely confirmed by a pathologist.

The reality is that mistakes can be made in the diagnosis of cancer. Accuracy depends on the individual pathologist's training, experience and judgment. In fact, a number of scientific articles have confirmed that errors occur in cancer diagnosis on an average of 2-4% of cases. Brain and spinal cord tumors are uncommon. Therefore, most pathologists, while maintaining competence in many areas, may be faced with diagnosing a neural tumor perhaps a few times a year. Once recent study revealed major neuropathology disagreements in 8.8% of cases.¹ These errors can lead to incorrect and inappropriate treatments that may cause serious medical complications. If a patient or family member is aware of this possibility, there is an easy solution to catch most of these mistakes. It is important to obtain a second opinion from an expert neuropathologist. These individuals have spent many years developing expertise in this field of cancer diagnosis. Most are based in universities or major cancer centers and are available to do consultations on pathology microscopic slides.

FindCancerExperts.com is a new interactive Web site that provides just such an expert pathologist referral service. The site contains an in depth educational component about different cancer types, how pathologists make a diagnosis, frank discussions on medical errors and reasons to obtain a second opinion. The staff has assembled a network of over 50 nationally prominent expert pathologists (including neuropathologists) who are available to patients for second opinions. The site is financially independent and receives no funds from pharmaceutical companies or hospitals. The pathology consultants do not pay to be listed on the site.

The American Cancer Society and the American Society of Clinical Pathologists recommend a second opinion for cancer diagnosis. The modest effort and expense necessary to obtain a consultation can be rewarded by the comfort of knowing that an original diagnosis was indeed correct. On the other hand, an

erroneous diagnosis can be detected so that inappropriate and potentially damaging treatments can be avoided.

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¹*Cancer 1997; 79:796-803*

My Story, by Kyle (continued from page 3)

Dr. Barney Softness. He was my endocrinologist. I learned a lot from him. When my hospital stay was done and I had to choose an endocrinologist to see, I told my mom it had to be Dr. Softness. As a result of the surgery my pituitary does not function at all, so Dr. Softness and I see a lot of each other. He has a cool office in Greenwich Village, and I really like going into the city to see him.

The surgery was a year and a half ago. My pituitary gland is still not functioning so I have what they call Hypo-Pituitary Syndrome. I also have Diabetes Insipidus, so I take a lot of medicine. Every day I take Hydrocortisone-Steroid, Synthroid for my Thyroid, and DDAVP for the Diabetes Insipidus. I used to get a testosterone shot once a month, which was awful. It was painful and having a full dosage all at once really affected my personality. I told Dr. Softness about it and he checked into the patch. Now I wear a testosterone patch every day and that's working a lot better. I also give myself a daily injection of growth hormone. It was scary in the beginning but I'm pretty used to it by now.

Most days it's really OK, I don't think about it too much. But sometimes it's a little overwhelming, and I just wish I didn't have to deal with it all the time. If I get sick I have to double my steroid right away, because my body just can't adjust itself like most people, I have to help it along.

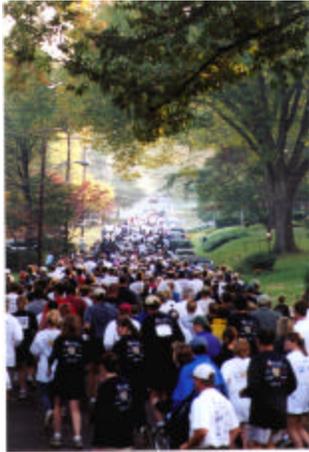
All in all though I'm pretty lucky. I have three great doctors, and there is medicine that can help me when my body can't. Although the tumor can come back at any time, it's not something I worry about, except when I go for my MRI every six months.

A lot of good things came out of this experience. My family really pulled together to help me. They organized a group called Kyle's Heroes. Kyle's Heroes has an

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Becca's Run (continued from page 1)

The event took place in the lovely Woodmoor neighborhood of Silver Spring, Maryland. Over 1,400 runner and walkers participated. Together with the participants, over 200 volunteers, donors, and sponsors, Becca's Run raised \$40,000 for the Childhood Brain Tumor Foundation (CBTF).



In the past the Lilly family has designated proceeds to childhood cancer related causes, including Candlelighters Childhood Cancer Foundation, Children's National Medical Center's Research Institute, and Special Love.

Male winners of the 2000 event were Joe Abernathy, College Park, 16:27; Jay Ulfelder, Silver Spring, 16:52; Ted Poulos, McLean, 16:58; and Peter Kirk, Rockville, 17:22. Top female participants were Liz Heawey, Silver Spring, 21:01; Patty Guay-Berry, Garret Park, 21:11; Kiersten Murray, Doylestown, PA, 21:20; and Wendy Ponvert, Bethesda, 21:28. Ian Hahn was the top fund-raising participant this year.

The Childhood Brain Tumor Foundation thanks the Lilly family, Kristen and Mark Savercool, volunteers, participants and all that supported the event, making it a tremendous success. CBTF appreciates being the chosen recipient of the event's proceeds and will use the funding wisely to fund promising research and other projects.



Don Colburn of The Washington Post who wrote a series of articles about Becca during her battle with cancer, speaking with Dr. Roger J. Packer.



County Councilman, Doug Duncan speaking to the crowd.



Maureen Lilly proudly presents Ian Hahn with a "Becca Bear" in recognition of his tremendous efforts in raising the highest sponsorships and bringing a crowd of supporters.

Skate -a -Thon

On Saturday, October 7, 2000, Skate Frederick Ice Sports held an exciting fund-raiser filled with special activities: a Family Skate and Skating Exhibition, a Skate-a-Thon, and an exciting exhibition game between the Washington Capitals and the Colorado Rockies (CHC) All Stars. The event included give-a-ways, contests, refreshments, and raffles. All proceeds were donated to the Susan G. Koman Foundation, The Childhood Brain Tumor Foundation and The American Cancer Society. Participants enjoyed the event immensely. The Childhood Brain Tumor Foundation appreciates the support shown by Skate Frederick and Ian's hockey friends for pediatric brain tumor research and other projects.



Classic Hair Design

Bountiful Basket of Salon Products Benefit CBTF

During the holiday season of 2000, Classic Hair Design of Gaithersburg, MD, donated a beautiful basket filled with more than \$150 worth of salon products for a raffle in honor of Ian Hahn and his family with proceeds to benefit the Childhood Brain Tumor Foundation. Clients of Classic Hair Design purchased raffle tickets in support of the foundation and were excited over the prospect of winning the raffle. Debbie DaSilva was declared winner of the basket on December 24, 2000. The salon stylists were delighted with the support shown by their many clients. The Childhood Brain Tumor Foundation wishes to thank Classic Hair Design, their designers, and clients for being so generous and supportive.



Dana Alliance

The Dana Alliance for Brain Initiatives formally announced the upcoming dates for Brain Awareness Week, March 11-17, 2001.

Joined by partners around the world, the Dana Alliance campaigns to promote public awareness about the progress and benefits of brain related research. Together, government agencies, patient advocacy groups, scientific organizations, volunteer organizations and educators bring information about the progress of brain research to the general public and policy makers. Over 250 organizations have signed on.

Information about Brain Awareness week is available on the Dana Foundation's web site at: www.dana.org/brainweek.

Brain Research for the Life of Your Mind

Brain Tumor Awareness Week

May 6 - 12, 2001

Brain Tumor Awareness Week (BTAW) is a collaborative effort of the brain tumor community. Families, patients, medical professionals, and friends come together to educate the public about brain tumors. BTAW is only one of the activities of the North American Brain Tumor Coalition (NABTC).

Please check our website:

<http://www.childhoodbraintumor.org>

or call us 301-515-2900 for more details about ongoing activities or for a copy of the Brain Tumor Action Guide.

Report of the Brain Tumor Progress Review Group

Check either of the following websites to read the reports that were produced from the Brain Tumor Progress Review Group meetings.

http://osp.nci.nih.gov/Prg_assess/PRG/BTPRG/

http://www.ninds.nih.gov/about_ninds/brain_tumor_progress_review.htm

Casino Party

On Saturday, November 18, 2000, the Childhood Brain Tumor held its annual fundraising Casino Dinner Party at Rockville Civic Center's Glenview Mansion. The evening included a casino, live music by Redline, a silent auction, an art auction directed by Jason Deitz of the Gallery L'Chaim, a floral design auction, door prizes, dinner, and an open-bar. We appreciate the continued support shown by Kraft Food and TRW, Inc., our corporate sponsors.

This year Montgomery Central Derwood Lions Club also provided a generous sponsorship toward the event. Our auctions were a tremendous success.

Thanks to our many local businesses for their generous donations including a swing set from Creative Playthings; autographed items from the Baltimore Orioles, Frederick Keys, Baltimore Ravens, Washington Mystics, and Georgetown Hoyas; floral arrangements from Flowers by Anne of Mt. Airy, MD; and an exquisite ring from Aras Jewelers. We would also like to thank Fitness First, Bally's Casino/Resort, Claridge Resorts and Casinos, Olney Theater, California Pizza Kitchen, the National Baltimore Aquarium, and many more. Betsy Schaefer donated a popular item, a baseball autographed by Cal Ripkin. We express our appreciation to Jock Hutchinson and the Soghomonian family for their continued support.

Midway through the evening's festivities two children, Ian Hahn and Joe Sanford, were recognized and presented congratulatory gift baskets for completion of their treatment protocols. Attendees enjoyed the gaming tables and the musical entertainment by Redline, while taking time to check their bids on auction items of interest to them.



Dr. Roger J. Packer awaiting his special award being presented by Jeanne P. Young and Claire Wynn on behalf of CBTF, in recognition for his constant dedication.

Jeanne Young, President and Claire Wynn, Vice President, presented special awards and certificates to the three advisors who have been with the Childhood Brain Tumor Foundation since its inception in 1994: Dr. Roger J. Packer, Senior Medical Advisor; Dr.

Eva Perdahl, Medical Advisor; and Dr. Gilbert Smith, Scientific Advisor. All advisors were recognized with certificates of appreciation for their dedication and loyalty to CBTF. The most important role for all advisors is the rigorous review process for our scientific grants. Dr. Roger J. Packer ultimately compiles the information after full advisory review and he has also written many informative articles for the foundation. Drs. Packer and Perdahl were recognized for the dedication they give not only to the foundation, but also toward their patients.



Dr. Eva Perdahl holding recognition award for

Redline wrapped up the evening with lively musical entertainment after the awards. A big thank you to Redline and our casino dealers for always making the Casino Party an exciting evening with something for everyone.



Blackjack dealer, Wayne Nebel checking bets with Joe Sanford watching.



The Sanford family and friends applaud Redline.



Jennifer Stahl and friends, Pearson and Jena Chodak.



Guests enjoying the craps table.



50-50 raffle winner, Matt Burke, addresses the crowd and graciously donates his winning to the foundation.



Anne Gallagher, Cass Cooney, and Jeanne Young enjoying the party event.

Neurotoxicity: (continued from page 2)

neurotoxicity, and potentially avert further damage by changing therapy.

Kathy Warren, M.D. is a Pediatric Oncologist in the recently formed Neuro-Oncology Branch of the National Cancer Institute and National Institute for Neurologic Disorders and Stroke. This program is under the direction of Howard Fine, M.D. Its mission is to develop an integrated clinical, translational and basic research program for the purpose of developing novel experimental therapeutics for children and adults with tumors of the Central Nervous System. Investigators in the branch conduct both laboratory and clinical research aimed at improving the prognosis and management of patients with brain tumors.

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My Story, by Kyle (continued from page 4)

annual golf outing and in just two years we have raised close to \$ 20,000. We donate a portion to the Childhood Brain Tumor Foundation for research. We use some of the money raised to help with my medical expenses, and we have also donated to other charity groups as well. Being able to help other people makes all of us at Kyle's Heroes feel really good.

At the end of January I am going on a trip to The Hague in the Netherlands with some of my classmates. I will spend a week with a Dutch family and go to the model United Nations every day. When we leave Amsterdam we'll go on to Ireland for a week. I've been to Ireland before; it's such a beautiful country I can't wait to see it again. In March my senior class is going to Disney World in Florida. That should be awesome. Before I know it I'll be graduating and going away to school. I plan to study Industrial Design because I love art, and I love to build things that are 3-dimensional.

Sometimes I think about how I felt before the surgery. If I still felt like that now, I know I never would have been able to do any of these things. Now I'm happy to be growing (5'6 and 120 lbs.) and feeling better every day.

I guess what I'm most grateful for is just feeling good when I wake up in the morning and being able to have a normal day.



*Written by Kyle Killeen, survivor
Thank you to Kyle, his family and friends for the support they have shown CBTF.*

Thank you to Jane Young, Tanya Santelli, and the many friends who continue to help us with our bulk mail.

Remembrances

Beverly Anderson
 Stephen Boyce
 Jeff Brown
 Kelley Bula
 Christopher Burse
 Janice Carpenter
 Caitlin Caruso
 Catherine Cason
 Ryan Caspar
 Laira Caverly
 Edward Chimilewski
 Ryan Crozier
 Dash Dunbar
 Alexa Noelle Dyer
 Shawn Edwards
 Alexandra Flores
 Vanessa Gonzalez
 Perry Hall
 Eileen Hall
 Dennis Hanlon
 William Hanlon
 Katie Harris
 Erica Holm
 Ryder Allen Howie
 Rebecca Johnson
 Samuel Robertson Johnson
 Tommy Kelleher
 Mitzi Levine
 Jodi E. Lewis
 Wesley Hall Lewis, II
 Wesley Hall Lewis, Jr.

Rebecca Lilly
 Lauren Lockard
 Margie Kane
 Zanyvl Krieger
 Emily Mau
 Donald McGettigan
 Bernard Miller
 Jill Munn
 Theresa Myers
 Herschel Parham
 Audrey Petersen
 Grace Powers
 R. Randolph
 Nicole Ringes
 Daniel Roever
 Jay Rowley
 Lynda Santelli
 Burt Schwab
 Luke Shahateet
 Amy Schiller
 Lisa Soghomonian
 Wade Stanley
 Teresa Stargel
 Jaime Vanderheyden
 Josie Wynn

*Right:
 In memory of
 Alexandra Flores*



A Tribute to Emily Mau

By Sherry Mau

Our Emily went to her new home two years ago on January 11, 1999. She was 11-years-old and in 6th grade. Her birthday is February 6th and she would have been 14-years-old this year.

Let me go back to the day she was born. It was a difficult delivery and we almost lost her then, but the Lord let her live so we could have her with us for 11 years.

She was the youngest of five girls, Becky, Margie, Katie, and Rachel. They all loved her so even though Katie loved to tease her and say, "You know mom and dad got you at Kids' R Us and they still have the receipt and can take you back anytime."



*Rachel, Marge, Becky
 Katie and Emily, Christmas
 1996.*

It was in May of 1997 at ten years of age that Emily was diagnosed with a cancerous brain tumor on her brain stem. I could hardly believe it when the doctor told us. I kept thinking this is a bad dream and please, Lord, let me wake up. It was such a rollercoaster ride for 20 months and through it all Emily was so brave. She never liked pain very much; but whenever she had to have something done to her that would hurt, she would never complain. She had two Hickman's (central lines) put in and neither worked right and on top of that, it was hard to draw blood from her veins. They were very tiny (like her mom's) and sometimes would collapse.

She went through various treatments, but in the end the tumor took over. She had different chemotherapies, but they only seemed to make the tumor grow. She had radiation; but the amount is limited that can be given in the brain stem area. That slowed things up for a while.

She had surgery in New York with Dr. Fred Epstein. Of course, we knew in the brain stem area that he could only go so deep without doing major damage.

Then she had photodynamic surgery. A dye called photofin is injected into the tumor cavity. The dye heads for the bad cells and then a laser light is put by it and the bad cells die. Again, the laser light could only go so deep and wasn't able to kill all the bad cells. I understand now a more intense light is available for this procedure.

So through all this I can see there needs to be more dollars for research in the area of helping children with inoperable brain tumors. Children should not have to suffer through this terrible disease.

Since Emily has gone, we have had one daughter graduate from high school, two daughters get married and we have celebrated other holidays without her here with us. When I look at pictures of those special days, they never seem complete because our Emily isn't there. We only have the memories of her that now live on in our hearts.

✍

Future Fundraising Events:

Annual Spring Biathlon, Sunday, April 29, 2002 - 500 yd. Swim/5K Run to be held at the Madeira School in Great Falls, VA. Participants can be as individuals or as a team. Have some fun and take the challenge. Sponsorships are encouraged. Call (703) 849-1980 for more information or check our website for a downloadable brochure.

Fall Family Retreat Day - Retreat Day will be held at Camp Friendship on a Sunday at Camp Friendship, Layotonsville, MD. Call us for the specific date. Informational flyers will be sent this summer.

Our mission is to support and fund basic science and clinical research for childhood brain tumors. We are dedicated to heightening public awareness of this devastating disease and improving the quality of life for those that it affects.

CBTF has a new website address!

visit us at:

<http://www.childhoodbraintumor.org>

Thanks to Tim Ratliff, our webmaster!

**CBTF is now in the
Combined Federal Campaign and
United Way, and
Children's Charities of America.**

**Our designated number for the Fall 2001 campaign is
#2742**

Through research, there is hope for cures. Help fund vital clinical research, provide support, education, and advocacy to children suffering from brain tumors.



Do you have questions about treatment options? brain anatomy? late effects? obtaining educational services for your child? insurance rights? or any other issue related to pediatric brain tumors? Send them to CBTF:

20312 Watkins Meadow Drive
Germantown, MD 20876;

e-mail:

cbtf@childhoodbraintumor.org;

or call 301-515-2900.

We are planning a series of interviews with experts using questions from parents of children with brain tumors. Please help us get the answers you need to advocate and care for your child.

Thank you for your support!

**The Childhood Brain Tumor Foundation, Inc.
Donation Form**

Enclosed is my contribution of \$: _____

In Memory of: _____

In Honor of: _____

On the occasion of: _____

General donation: _____

Please send remembrance card to:

Name: _____

Address: _____

City/State/Zip: _____

Optional Phone: _____

Please make checks payable to:

The Childhood Brain Tumor Foundation

20312 Watkins Meadow Drive

Germantown, Maryland 20876

301-515-2900

Charge my: _____ MasterCard _____ Visa

Card# _____ exp. ____/____

Note: minimum charge donation is \$20

Name: _____

Address: _____

City/State/Zip: _____

Optional Phone: _____

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