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Check Out Our Website!

<http://www.childhoodbraintumor.org>

The Visual System and Childhood Brain Tumor

Childhood brain tumors present with visual symptoms about 50% of the time. Additional children will develop visual symptoms and or signs during and after treatment. Such signs may become permanent or may resolve. The input of an ophthalmologist in the overall treatment plan may be important in monitoring the oncologic therapy, as well as suggesting simple interventions to prevent unnecessary loss of vision or ocular motor function.

The testing of vision in a child involves determination of the visual acuity in each eye independently. Reduction of acuity in one eye establishes a problem somewhere between the eye and the chiasm. Abnormalities affecting the visual sensory system from the chiasm all the way to the occipital lobe will generally preserve normal central vision, as long as there is one side functioning normally. Color vision may be tested in slightly older children. Loss of color vision is a marker for optic nerve and optic chiasm disease. Visual fields are also tested. In younger children this may include simply placing some toys in varying parts of the field of vision and watching the child turn toward the toy. With maturity, more rigorous computerized visual field tests are possible. These are used to carefully watch for changes in the function of the visual pathways, helping to monitor the tumors growth/shrinkage. Ab-

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Fall Family Retreat

The Childhood Brain Tumor Foundation welcomed families from Maryland, Virginia, and Washington D.C. to its annual Fall Retreat held September at Camp Friendship in Laytonsville. The retreat brought together families, speakers, and volunteers for a day filled with fun, facts, and camaraderie. "The retreat gives families an opportunity to network and learn more about important issues. This one focused on school rights for children with brain tumors, but other retreats have dealt with specific medi-

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Lauren's Bus preparing to

Lauren's Bus

After ten days of rain, August 5th dawned sunny and dry. A baseball game at historic Fenway Park between the Boston Red Sox and the Kansas City Royals was the perfect way to spend a sunny, summer Saturday.

Our guests of honor were Lauren Davies (age 6-1/2) and her family, her mother Susan, father John, sisters Nicole (age 8) and Baby Sister Mikaela (age 5 months).

Lauren's Bus departed Tolland, Connecticut at 9:30 a.m. sharp arriving in Boston at Fenway Park in time for batting practice. Game time was 1:15 p.m. allowing for many trip participants to spend some more time exploring the neighborhood. Lauren and her family had a wonderful time feeding the birds in the Public Gardens

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Visual System (continued from page 1)

normalities in front of the chiasm affect only the visual field of that eye, while those behind the chiasm affect the visual field of both eyes in a similar manner. normalities in front of the chiasm affect only the visual field of that eye, while those behind the chiasm affect the visual field of both eyes in a similar manner.

The two tumors of childhood which most commonly affect the vision of children are the optic glioma and the craniopharyngioma. The optic glioma is a well-differentiated tumor arising in the optic nerve, optic chiasm, or optic tract that compresses and destroys the nerve from which it originated. The craniopharyngioma is a tumor that arises in the region of the chiasm. As it gets larger it may compress the chiasm, the pituitary gland, hypothalamus and the third ventricle. Each of these tumors in children are fairly silent, with the key symptoms being slow visual loss. Other symptoms of endocrine dysfunction and headache, common in adults, are uncommon in affected children, often leading to difficulty in diagnosis. Warning signs in the visual system would be unexplained visual loss, jiggling or nystagmus of the eyes, exotropia (an outward deviation of one eye), and amblyopia that does not improve with conventional therapy.

The prognosis for vision with optic pathway gliomas is variable. Some of these remain stationary both in terms of their deleterious effect on vision and of their size on MRI. Others may worsen, while a few seem to completely disappear without any treatment. For the most part therapy is used when there is evidence of an increase in size and worsening of vision. Surgery cannot cure these lesions and retain vision, because the tumor replaces the nerve. However, surgery may be performed to reduce a large mass arising from one nerve when it is compressing the fellow nerve, the chiasm, or the hypothalamus. Chemotherapy and radiation therapy are the most common treatments prescribed.

Craniopharyngiomas present similarly to optic nerve tumors, usually as unexplained visual loss. The treatment is surgical removal and on occasion adjuvant radiation therapy. The visual prognosis for these children appears to be governed by their vision at the time of surgery. Most retain that level of vision, but they do not typically recover any of the lost vision. Most have significant optic nerve atrophy at the time of tumor diagnosis, which is likely why there is no recovery.

The ocular motor system is a complex interconnection between the brainstem (pons and midbrain) which is responsible for the final control commands for eye position and nearly every other part of the brain which is responsible for producing or modulating those commands to the eye movement centers.

Ocular motor testing includes having the patient move the eyes in all directions of gaze. Deviations may be measured by the physician or technician with prism to allow sequential monitoring. Binocular vision is measured with polaroid glasses and 3-D books. A change in alignment or in depth perception signals a similar change in the function of the ocular motor system.

Ocular motor nerve problems may occur from direct pressure by a tumor. A brainstem glioma would be a common cause. Other posterior fossa tumors, like a medulloblastoma, cerebellar astrocytoma, or ependymoma, may cause weakness through the remote effect of raising the pressure in the brain, causing the abducens nerve to work more poorly and the eyes to deviate inwards. On occasion the surgery to remove these tumors may required damage to these nerves and their consequent dysfunction. Radiation therapy to the brainstem in children does not damage these structures.

The visual system of children under the age of 8 years is still developing and abnormal visual input when the eyes are not aligned properly may lead to a permanent impairment, known as amblyopia. The young brain is able to eliminate the double image seen when the eyes are not properly aligned, by turning off the image from the deviating eye in the visual cortex. While this adaptation is good because it allows easier function, it does lead to permanent impairment of vision from the deviated eye. This could be important if the eyes are realigned or the better eye for some reason is damaged in the years that follow. The treatment is simple in concept, make the child use the less favored eye, either with a patch, blurring lens, or blurring eye drop. The actual performance of this therapy is impacted by the oncologic treatments, the child's current health, and prognosis. The parents and the physicians need to have a thorough discussion about this issue before deciding to institute therapy.

Some ophthalmological exams are performed to monitor the state of the optic nerve. Usually the referring doctors are interested in whether there is swelling of the optic disc, often called papilledema. The presence of papilledema means that the pressure within the skull is too high, or in other words, Increased Cerebrospinal Fluid Pressure. Such a sign may frequently be present at the time of the diagnosis of a brain tumor and alerts the neurosurgeon to the need to do a shunting procedure. If the swelling of the optic nerve is allowed to persist, the child may have persistent headache and vomiting, but most importantly may suffer irreversible optic nerve atrophy and consequent loss of vision. Other eye exams are performed to monitor the quality of the optic

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Lauren's Bus (continued from page 1)

pre-game, while others hit the sports shops and food vendors along Yawkey Way. The sights, sounds and smells surrounding Fenway Park are impossible to describe. You have to experience it first-hand to fully appreciate pre-game at Fenway. For Lauren, the game itself was somewhat of a "snoozer" but both she and her sister, Nicole, were trivia winners on the bus ride so all in all it was a fun day, definitely one for the memory books!

The Red Sox lost 7-5 in an exciting game. There were no sad faces though because when you grow up a Red Sox fan, heartbreak is commonplace! The trivia games on the bus ride, good company and knowledge that the day was more than just another ballgame left everyone smiling and looking forward to next year. With any luck, Lauren's Bus will become Lauren's Busses!

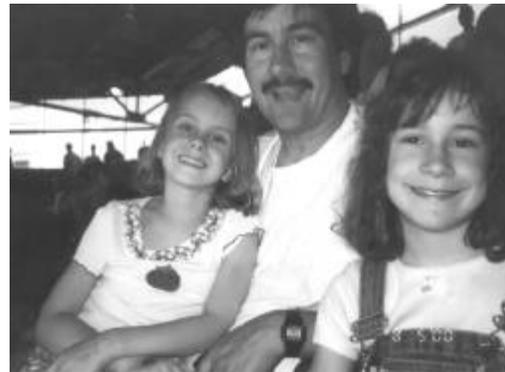
John Davies, Lauren's father, works at Gerber Technology, Inc. where there is an independent employee team, the Community Service Team, formed solely to assist in charitable giving within the community, both corporate and surrounding towns. During a medical insurance information session, John asked a question regarding prescription coverage for his little girl who is undergoing 48 weeks of chemotherapy treatments. A member of the Community Service Team was present, brought the information back to the Team, and the idea for Lauren's Bus was put into action.

Respecting the Davies' privacy was a priority so the first step was to see if John and his wife approved of our fundraising idea. By their own admission if this had been a year earlier John and Susan would have kept their daughter's illness private but in the past 18 months they have learned that *they are her voice, they are her best advocates*. Public awareness will benefit research by having more people earmark their charitable giving to pediatric brain tumor research.

John advised us of the dates for National Brain Tumor Awareness week. The sale of tickets for Lauren's Bus to Fenway Park coincided perfectly and a fundraiser was born! Our fundraising total was \$367 donated to The Childhood Brain Tumor Foundation, Inc. by request of Lauren and her family. An announcement was made during the bus ride home informing everyone of the ability of Gerber employees to designate CBTF #2742 on our Gerber/United Way Payroll enrollments in this year's campaign.



Supporters enjoying the day at Fenway Park.



John Davies with daughters Lauren and Nicole.

9th International Symposium on Pediatric Neuro-Oncology

The 9th International Symposium on Pediatric Neuro-Oncology was held on Sunday, June 11 through Wednesday, June 14, 2000 at the Sheraton Palace Hotel in San Francisco. The conference was coordinated by Dr. Mitch Berger of University of San Francisco, Dr. Roger J. Packer of Children's National Medical Center and Dr. Archie Bleyer of MD Anderson who made opening remarks. In addition to the above institutions, the program was sponsored by Children's Hospital of Philadelphia and Dana Farber Cancer Center. Expert medical professionals came from all around the world to discuss pediatric brain tumor treatments, detection, and statistics. The symposium featured topics were: Biology/Epidemiology, Neuroimaging, Radiation Oncology, Therapeutic Advances, New Agents, Germ Cell Tumors, Late Effects, Surgery, High-Dose Chemotherapy, and individual tumor types.

The following information is based on a selection of some topics that were covered. Epidemiology of Pediatric Brain Tumors was the opening topic. Dr. Archie Bleyer provided numerous informational facts. Brain tumors may be as common as leukemia when you include

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9th International Symposium (from page 3)

all brain tumors. For Y2K 1 in every 3-4 cancer deaths in children are due to CNS tumors. Children numbering 20,000-25,000 die annually from brain tumors. Less progress is made with brain tumors than any other type of cancer. In conclusion, the central nervous system provides the greatest challenge in pediatric oncology and despite the tremendous advancements of the past decade, more advancements need to be made. The cooperative groups, such as the Children's Oncology Group and the Pediatric Brain Tumor Consortium, continue to work together to find a cure for central nervous system tumors.

Dr. Robert Zimmerman from Children's Hospital of Philadelphia presented Advances of Pediatric Neuro Imaging. He explained the significance in the measurement of choline ratios in tumors stating that the more malignant tumors have increased choline levels. Improving cure rates, reducing radiation or eliminating when possible, modifications of delivery and techniques are key goals for improvements in radiation oncology. The Director of Radiation Oncology from St. Jude's Hospital, Dr. Larry Kun presented the topic Fractionation and Conformal Techniques in Radiation Oncology. In diagnostics and planning 3 dimensional imaging provides gross tumor volume, target volume and physical volume, all of which factor into the treatment planning. 3D coplanar planning is where dose homogeneity within the target at defined dose level can minimize dose to treatment area. Intensity Modulated Radiation Therapy (IMRT) is similar to 3D conformal and use of IMRT is dependent on tumor size. Dr. Nancy Tarbel radiation oncologist, Massachusetts General Hospital, provided updates about Focused Radiation. Details were given regarding stereotactic radiotherapy and surgery.

Dr. L. Liau reviewed current information regarding Tumor Vaccines, current studies and strategies. Radiolabeled antibodies have proven to be better when injected in surgically created cavities than in solid tumors. Anti-idiotypic antibodies are made to minimize the tumor antigens. Dr. F. McCormick covered Gene Therapy Strategies. He explained how gene therapy is engineered to replicate selectively. Dr. Lucy Rorke neuropathologist, Children's of Philadelphia, provided information on Tumor Classification and poorly differentiated ependymal tumors. Dr. Roger J. Packer of Children's National Medical Center's Update on U.S. Cooperative Group Trials was very informative. His talk focused on medulloblastoma and Dr. Packer coordinated a discussion on new therapeutic approaches for medulloblastoma.

The topic Infant Tumors included speakers Dr. Gilbert Vezina, Imaging Advances; Dr. Jacqueline Biegel, Biology Update; and Dr. R. Geyer, Clinical Trials. Infant brain tumors have a disproportionate malignant history behavior and poor prognosis. Hydrocephalus is often a factor for the infant and

patients with widespread disease. Radiologist, Dr. Gilbert Vezina explained that atypical teratoid/Rhabdoid tumors mimic PNET tumors pathologically and radiographically. These tumors show intense contrast enhancement and are more resistant to therapy than PNET. Medulloblastomas are more hemispheric and disseminate. Generally, 5-10% do not enhance on imaging.

Neurosurgeon, Dr. Jeffrey Wisoff, NY University Hospital, discussed surgical strategies: Extent of Resection and Outcome in Low Grade Gliomas and was followed by Dr. Joan Ater, oncologist, covered Chemotherapy Trials in Low-Grades. Dr. Ater suggested that conservative surgery with chemotherapy would provide a better quality for these patients and that delaying radiation would be wise. Dr. Judiah Folkman was present to give a special lecture about Antiangiogenesis. In the first evening there were focused breakout sessions. Dr. Packer led the session discussing the long-term effects of treatments and spoke on the results of the Childhood Cancer Survey Study. Dr. Phil Cogen, for the Children's National Medical Institute, led the biology breakout session and discussed his work on medulloblastoma. Dr. Tobey MacDonald participated in the New-Agents breakout session. The Germ Cell breakout session was coordinated by Drs. Jeffrey C. Allen and Jonathan Finlay.

The symposium concluded with Updates and Advances. Speakers included Drs. C. Kalifa, Henry Friedman, and Jonathan Finlay. Dr. Finlay, oncologist, Memorial Sloan Kettering, presented information about recurrent, resistant disease. He reviewed treatments using myoblastic chemotherapy with Autologous Stem Cell Rescue (ASCR). He indicated that patients who have benefited from this combination include recurrent medulloblastoma/PNET, malignant glioma, and central nervous system germ cell tumors. He focused on toxicity of chemotherapy with ASCR and mentioned the patients at risk being, patients with bulky residual tumor, prior spinal irradiation, patients with sub-optimal stem cell yield, those who have had prior high-dose cranial radiation and neurotoxicity. Many advances have been made, techniques improved and new chemotherapeutic agents, alkylating agents, radiation and surgical techniques are always under investigation for improvements to provide a better quality of life and cures for patients. Clearly, this frontier has further investigations ahead.

This conference was very beneficial and provided CBTF representative, Jeanne Young, the opportunity to remain current about the latest treatments and investigations for pediatric brain tumors. Several other brain tumor organization members were present and this also afforded us the opportunity to network with each other and the medical community.

Retreat Day (continued from page 1)

cal issues. Families are interested in staying current and appreciate hearing local doctors and other professionals speak,” says Jeanne Young, president of the foundation.

The Carol Jean Cancer Foundation and Camp Friendship helped sponsor the event providing not only its facilities but also lunch and activities for the children. “We like doing the retreat as a joint effort. So many of the kids that come to the camp have brain tumors, and I have a particularly fondness for them since my sister had a brain tumor, too. We help out by tapping into the friends of Camp Friendship to help out at the retreat,” says Bev Gough, director of the Carol Jean Cancer Foundation and Camp Friendship. One friend, B.J. Pumperknickel’s partially donated lunch, Danny Gottlieb helped serve and helped with the children, and Patrina Goldstein provided her trademark Beady Buddies craft project for the children. Unicyclist extraordinaire and all-round funny guy Paul Hadfield closed out the event with his unique blend of vaudeville comedy and slapstick humor.

Other volunteers who made the event possible include teenagers Drew Suarez, Shannon Will, and Ashley, Amanda, and Bryan Young. “In Montgomery County, high school students are required to complete 75 hours of community service before graduation. We are greatly indebted to all the teenagers who have chosen to work with the foundation to complete that requirement. They are truly invaluable,” says Jeanne Young.

While the children enjoyed crafts and entertainment, parents attended two sessions. Ray Immerman, parent of a brain tumor survivor and special educator, led the first session giving detailed information about Individualized Education Programs and how to work with the schools to create an appropriate program for a child with a brain tumor. “The laws change every year and the paperwork can be intimidating. It is important to stay current and know the procedures to get the best for your child,” says Immerman.

The second session, facilitated by Laurie Weiss LCSW, brought together childhood brain survivors Fio Carmelino, Colleen McGowan, Michael Schoenfeld, and Jason Shook to answer a wide range of questions about their experiences. From the role their parents played in helping them through to the positive aspects of having a brain tumor, the panel’s candor was greatly appreciated by the audience.

The Childhood Brain Tumor Foundation would like to extend its heartfelt thanks to all the volunteers, participants, families, speakers, and panelists who made this worthwhile retreat possible.

Written by Colleen Snyder.



Laurie Weiss, LCSW and survivors panelists Fio Carmelino, Michael Schoenfeld, Colleen McGowan, and Jason Shook.



Paul Hadfield entertains families with juggling and humor.



Volunteers making Beady Buddies with the chil-

Memories of an Adolescent Tumor

Christmas vacation had just ended and it was the beginning of a new year, 1993. I was fourteen-years-old, a freshman in high school, and had not been feeling well for some time. However, my physical complaints were quite vague which made it difficult for my pediatrician to identify the problem. Supposedly many things can cause headaches and as for the “aliens talking to me,” no one quite understood what I meant.

In January, the end of the junior varsity basketball season was approaching, and our team was going to be in the championships. Unfortunately my symptoms would not disappear. I was determined to fight against them and tried hard to ignore my left temporal lobe migraines and the strange “sensations” occurring in my mind. These “sensations” caused me to lose concentration and made me unable to speak coherently or comprehend what other people were telling me. When I had a blackout on the basketball court, my parents took me to a doctor, and that was when I was soon to have an unexpected turn in my life.

My neurologist, a good friend of our family, immediately sent me for an EEG due to my recurrent awkward “feelings” and the blackout. Although the first EEG was relatively inconclusive, he recommended that I have an MRI just to be certain that nothing was wrong. The MRI was one of the scariest moments in my life. I was stuck in a large confined machine with banging all around which was not a typical situation for a young teenager. From that moment I could not let my parents out of my sight.

Once the MRI was complete, I did not give it much thought. I assumed that nothing was wrong until my doctor came to our house to give us the terrible news. The moment I knew he was coming to our house to personally give results, I knew that there was something wrong with me. At first, I refused to go into the living room with my neurologist and my parents since I was very nervous, emotional, and scared. Shortly thereafter, I was told that the scans revealed a left temporal lobe brain tumor which had to be removed. My awkward “feelings” were diagnosed as seizures. I was put on medication and my surgery was scheduled quickly. My only thought was *Why did this happen to me?* I was determined to get it over with so that I could go back to a normal high school life. By mid-March I was sent to the Johns Hopkins Hospital and was

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Funded Research Studies



CBTF is proud to announce the funding of two excellent grants for Y2K. We were fortunate to receive many worthwhile grants that showed promise of being excellent studies.

One grant funded is entitled, *‘Role of Methylation and Deletion of DNA in HIC-1 Expression in Childhood Brain Tumors.’* The research will be conducted by Brian Rood, M.D. of Children’s Research Institute, Children’s National Medical Center. Another grant funded is entitled, *‘Wingless Signaling in Medulloblastomas: A Murine Transgenic Model’* and the research will be conducted by Charles Eberhardt, M.D., Ph.D., of the Johns Hopkins University Hospital.

Dr. Rood’s study *‘Role of Methylation and Deletion of DNA in HIC-1 Expression in Childhood Brain Tumors,’* will investigate two of the molecular genetic mechanisms of silencing tumor suppressor genes, deletion and methylation. Previous studies have exhibited a consistent loss of DNA sequences located on the distal short (p) arm of chromosome 17 in medulloblastoma, ependymoma and astrocytoma. The tumor suppressor gene, *HIC-1*, resides in this frequently methylated in some pediatric brain tumors showing deletions. There specific aims of this study are: 1) determination of the frequency of allelic deletions of *HIC-1*; 2) determination of the frequency of *HIC-1* methylation; 3) correlation of the results of these studies with *HIC-1* expression to determine the relative roles of deletion and methylation in transcriptional repression. This study will determine if the combination of allelic deletion and DNA methylation inactivates the tumor suppressor gene, *HIC-1*, thereby contributing to the formation of pediatric brain tumors.

Dr. Eberhardt’s study, *‘Wingless signaling in medulloblastomas: a murine transgenic model’* will focus on medulloblastoma. These small cell embryonal tumors are located in the cerebellum and represent the most common malignant childhood brain neoplasm. The specific aims of this study will be 1) to create a transgenic mouse medulloblastoma model by overexpressing the oncogene bet-catenin in the cerebellum; 2) to characterize the murine tumors and identify the cell(s) of origin; and 3) to analyze the genetic interactions between wingless pathway members in medulloblastoma development. The transgenic model will facilitate further genetic dissection of medulloblastoma tumorigenesis and the evaluation of new therapies.

Memories (continued from page 6)

privileged to have one of the most well known pediatric brain surgeons perform my surgery, Dr. Benjamin Carson. I was eager to learn about Dr. Carson since I was putting my life into his hands; therefore, I read his autobiography called *Gifted Hands*. In addition, I felt special after watching Dr. Carson on the news and the Oprah Winfrey show. After listening and reading about Dr. Carson's life and achievements, I felt more comfortable as I checked into the Johns Hopkins Children's Center. The first night I was in the hospital, two terrifying things happened. The first was that I had to sign a set of death papers, and the second was when I was placed on an IV at midnight.

My surgery was scheduled for 8 a.m. the next day, March 16 1993, the day after my mom's birthday. I remember wearing my new pajamas, and my parents telling me "we'll see you soon, lovie..." I do not remember much after that, but I later learned that the anesthesia kicked in within minutes. Ten hours later, I awakened in the ICU unit. I had my personal nurse Rob feeding me ice because my mouth was so dry. Supposedly my family and grandparents came into the ICU to visit me, but I was too fatigued to even remember. My left eye was completely swollen and purple, and I was wearing a big white bandage across my head.

I was in the ICU overnight. Unfortunately the day after my surgery, I was so weak due to a lack of blood that I immediately needed a blood transfusion. For the first couple days my mom had to bathe me, feed me, and help exercise by walking me down the hallway with my IV. In addition to my anticonvulsant, Tegretol, I was taking steroids regularly to avoid any swelling. The amount of dosage and types of medications I was taking daily was unreal.

I do not remember much until a few days later when I was more awake and rested and receiving a continuous flow of visitors. The only comforting thing about being in the hospital was knowing how much my family, friends, and teachers cared about me. I was one of the luckiest children in the Johns Hopkins Hospital with the number of visitors, flowers, balloons, cards, and other gifts I received. The nurses also mentioned to me how I was such a considerate patient since I gave the children, who were without visitors, some of my balloons and flowers.

I was recovering nicely and had so much energy and optimism after my brain surgery that my doctors let me check-out six full days after my surgery. However, the horrible factor was that my head needed to "breathe." All week I refused to have my bandage removed because I was too scared to see what I looked like. I was satisfied with it especially after my family decorated it with different colors and stickers. As Dr. Carson removed my bandages I noticed the neutral faces and silence coming from my family. At this point I was not sure what to expect. My first reaction to its removal was "Give me a mirror!" The

left side of my head was shaved and the scar was huge! It was a scar shaped as the letter "C" and it was full of forty big staples. I remember crying for several hours until my parents finally calmed me down. I started trying on new hats and headbands and received many compliments which made me feel much better.

After resting a couple of weeks, I began home-schooling and continued with an amazing recovery. However, I still suffered seizures, but it was on a weekly to monthly basis rather than day to day. It was also emotionally difficult for me to cope with the fact that I would not be driving by the age of sixteen due to my seizures. After six weeks I went back to school. It was not easy for



me because I received constant questions and stares especially since I disobeyed the school policy by wearing a hat everyday. My own identity became the *Hat Girl*. I felt as if people were scared of me since they knew I had "awkward moments", otherwise known as seizures, which students were certainly not familiar with.

Over time, things for me cooled down. I had the staples removed, my hair began to grow, and I switched from hats to fabric headbands. I was still given constant attention from my family, teachers, church members, and other friends to see how I was doing. I eventually learned that my tumor was rare, but it was diagnosed as "dead" therefore had stopped growing. My thick brown hair took two years to grow back to its normal length, and I am convinced that as it grew it became thicker than it was before it was shaved.

It has been over seven years since the tumor diagnosis and surgery and I feel extremely fortunate. I continue to have annual MRIs and appointments with my neurologist and soon I hope to be off medication. I have been seizure-free for four years and was legally able to get my license last year. I graduated from Bucknell University in January 2000 with a Bachelor of Arts degree in Psychology and hope to pursue a career in the health care field. It is not easy putting my entire experience behind me; however, I have grown up knowing it is an experience in my life that has contributed a great deal to who I am today. Surprisingly, I am now able to openly discuss what had happened to me, and I have learned a lot about life. One of the things I will always know about this experience is that I was one of the lucky survivors!

This article was written by Marina Caminis, brain tumor survivor and graduate of Bucknell University.

Newly Formed Brain Tumor Progress Review

In the hopes of hastening medical and scientific progress in the fight against brain tumors, the National Cancer Institute (NCI) and the National Institutes of Neurologic Disorders and Strokes (NINDS) of the National Institutes of Health (NIH) recently established the Brain Tumor Progress Review Group (PRG) to review brain tumor specific issues and to outline and set priorities for a national agenda to hasten medical and scientific progress in the fight against brain tumors. The PRG is comprised of prominent members of the medical and scientific community, along with representatives from community advocacy groups whose primary interest is brain tumors.

At the first meeting of the PRG, which was held in Virginia July 5-7, 2000, Jeanne Young, from the Childhood Brain Tumor Foundation, along with other advocates from the North American Brain Tumor Coalition, was in attendance. Advocates were invited to join the PRG group to offer perspectives of brain tumor survivors and their family members. Each member of the PRG was assigned 3 sessions, from a total of 16 sessions being conducted, at which they offered insight and recommendations. The first session on Jeanne's agenda was the session on Tumor Immunology led by Co-chairs Drs. Daryl Bigner and Richard Ransohoff. This session addressed Tumor Immunology, exploring antigen recognition, immunosuppression, cell trafficking, immunologic privilege, tumor vaccines, targeted treatments, immuno-gene therapy and animal models. Other breakout sessions at which Jeanne was in attendance included Neurobiology: Migration and Trafficking, led by Drs. James Goldman and Rolando DelMaestro, at which cell migration, migration into the central nervous system, effects of tumor cells on normal nervous system, and cellular substrates of imaging were discussed. The third session at which Jeanne was in attendance was the Pediatrics session, led by Drs. Roger J. Packer and Ian Pollack. This session explored the unique aspects of congenital/infantile tumors, including etiology/epidemiology, clues to development of other tumor types and genetic uniqueness, the developing nervous system and clues to the development of cancer and therapeutic issues, and the integration of neurobiologic/immunologic therapy in pediatric brain tumors. Issues of risk, orphan tumors and the issues of available agents were also discussed.

All advocates in attendance agree that this first meeting of the PRG was extremely enlightening and are eagerly looking forward to future developments that occur based on the recommendations and efforts made by the group as a whole. The PRG is an important step in the communication efforts in the fight against brain tumors by the medical, scientific and advocacy communities. We will keep you informed of any new insights by this group as they become available.

Visual System (continued from page 2)

nerve fibers, looking for the presence of atrophy or a change in the quality of the atrophy. In older children with minimal optic nerve damage, optic nerve photographs may be taken to be used to monitor the nerve. If there is substantial damage, both photos and clinical exams are much less sensitive than the measurement of acuity, color vision, and visual field.

Brain tumors may also impair sensation of the eye and blinking of the eyelids. Sensation is part of the Trigeminal Nerve (CN V) and blinking is controlled by the Facial Nerve (CN VII). Damage to these nerves can lead to poor wetting and erosion of the cornea. If this is unchecked there can be permanent scarring and opacification of the cornea which will damage vision. In some cases the only correction is a corneal transplant, which is always a difficult procedure in young patients.

For complete article, which includes more detail on eye anatomy and its relationship to brain tumors and treatments, please see CBTF's website.

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Website and other resources for the visually impaired/blind:

- American Council for the Blind - <http://www.acb.org>
- American Federation for the Blind - <http://www.afb.org>
- <http://www.hicom.net/~oedipus/blind.html#disclaim>
- National Association for the Visually Handicapped - <http://www.navh.org>
- National Federation for the Blind - <http://www.nfb.org>
- Resources for Parents and Teachers of Blind Kids
<http://members.home.net/ddays/blindkids.html>
- *Seeing in Special Ways, Children Living with Blindness, 1989. Thomas Bergman*
- *Listen for the Bus, David's Story, 1995. Patricia McMahan*
- *Naomi Knows It's Springtime, 1993. Virginia Kroll*

See page 9 for additional website listings.

Remembrances

Stephen Boyce	Lauren Lockard
Jeff Brown	Margie Kane
Kelley Bula	Zanvyl Krieger
Janice Carpenter	Emily Mau
Caitlin Caruso	Donald McGettigan
Catherine Cason	Bernard Miller
Ryan Caspar	Jill Munn
Ryan Crozier	Theresa Myers
Dash Dunbar	Rebecca Lilly
Shawn Edwards	Grace Powers
Alexandra Flores	R. Randolph
Vanessa Gonzalez	Nicole Ringes
Katie Harris	Jay Rowley
Erica Holm	Lynda Santelli
Samuel Robertson Johnson	Burt Schwab
Tommy Kelleher	Luke Shahateet
Mitzi Levine	Amy Schiller
Jodi E. Lewis	Teresa Stargel
Wesley Hall Lewis, II	Jaime Vanderheyden
Wesley Hall Lewis, Jr.	Josie Wynn

**In Loving Memory of
Jill Alexandra Munn
9/9/87 - 7/16/96**



WHEN I COME TO THE END OF THE ROAD,
AND THE SUN HAS SET FOR ME,
I WANT NO RITE IN A GLOOM FILLED ROOM.
WHY CRY FOR A SOUL SET FREE?
MISS ME A LITTLE — BUT NOT TOO LONG,
AND NOT WITH YOUR HEAD HELD LOW.
REMEMBER THE LOVE WE ONCE SHARED.
MISS ME — BUT LET ME GO.

FOR THIS IS A JOURNEY WE ALL MUST TAKE.
AND EACH MUST GO ALONE.
IT'S ALL A PART OF THE MASTER'S PLAN,
A STEP ON THE ROAD TO HOME.
WHEN YOU ARE LONELY AND SICK AT HEART,
GO TO THE FRIENDS WE KNOW,
AND BURY YOUR SORROW'S IN DOING GOOD
DEEDS,
MISS ME — BUT LET ME GO.

AUTHOR UNKNOWN
SUBMITTED BY PAM LEONOWICH, JILL'S MOM

**CBTF Board of Directors, Medical,
Scientific and Legal Advisors for the
next two year term**

Our Board Members for the next two-year term are:

Officers: Jeanne Young, *President*, Claire Wynn, *Vice President/Secretary*, James Young, *Treasurer*.

Directors: Matthew Burke, Michelle O'Brien, RN, Linda Quackenbush, Stephen Schoenfeld, CPA and Gib Smith, Esq.

Community Representative: Patricia Macy, JD, Buffalo, NY, Peggy Killeen, NJ

Scientific Advisor: Gil Smith, Ph.D.

Legal Council: Fred Rickles, Esq., NY, NY

Senior Medical Advisor: Roger J. Packer, M.D.

Medical Advisors: Peter Burger, M.D., Philip Cogen, M.D., Ph.D., Kenneth Cohen, M.D., Marianna Horn, M.D., Eva Perdahl-Wallace, M.D., Ph.D., and Aziza Shad, M.D.

Welcome to our newest Board Members, Matthew Burke and Michelle O'Brien.

We appreciate the continued support of many former board members and our supporters. Thank you to our independent grant reviewer, Dr. Paul Fisher from Stanford University Hospital in Stanford, CA.

CBTF will miss Dr. Michael Medlock who has taken a position at Massachusetts General Hospital.

Additional Websites:

- Children's Oncology Group - http://nccf.org/nccf/aboutccg/COG_who.htm
- **NEW!** Find Cancer Experts, provides excellent information related to pathology - <http://www.findcancerexperts.com>
- National Brain Injury - <http://www.biausa.org>
- National Rehabilitation Information Center, disability resources - <http://www.naric.com>
- Pediatric Brain Tumor Consortium - <http://www.pbtc.org>
- SEER--Surveillance, Epidemiology and End Results - <http://www.seer.ims.nci.nih.gov>
- Trials and info - Cancernet.nci.nih.gov

Future Events:

Spring Biathlon fundraiser, Sunday, April 29, 2001- 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

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 2000
campaign is
#2742
Thank you to those who choose us as their charity!***

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

BECCA'S RUN

We will report on Becca's Run in our next newsletter edition. If you were a participant in the event that benefited the Childhood Brain Tumor Foundation and would like to see the run results please check Becca's Run website: <http://www.beccasrun.org>

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Thank you to Elizabeth Irvin for providing websites for the Visually Impaired/Blind.