



The Childhood Brain Tumor Foundation

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877-217-4166 301-515-2900

Neurotransmitter

Communicating our message.

[Http://www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

CBTF is a nonprofit 501(c)(3) all-volunteer organization, founded in 1994.

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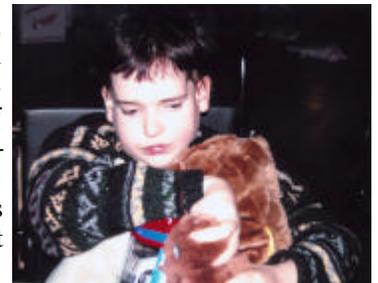
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10th Anniversary Gala and Casino Party



On Saturday, December 6, 2003, Dr. Roger Packer and Mrs. Bernice Packer hosted the Childhood Brain Tumor Foundation's 10th Anniversary Gala and Casino Party at the Torpedo Factory Art Center in Alexandria, VA. Despite inclement weather on the days that preceded the event, CBTF supporters took advantage of the opportunity to come out to enjoy the gala and to recognize the founders, advisors, and contributors for furthering our mission. During the evening our guests were formally welcomed by Bernice Packer, who familiarized them with CBTF and the evening's activities.

The Irvin family, our founders, were in full attendance. Family members from CO, WV, VA, MD, IL, CT, and MA came to cheer for the Irvins. Bill and Liz developed the CBTF mission that continues today to support scientific and clinical research, and to improve the quality of life for affected children. Keith Irvin was acknowledged for designing the CBTF logo (slogan by Linda Quackenbush), and his brother, Russ, our special guest, was recognized for his tremendous courage and sweet demeanor in battling his brain tumor for the past 16 years. Jeanne Young, President, was delighted to recognize CBTF founders, Bill and Liz Irvin with their sons Keith and Russ



Our special guest, Russ.

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Kayleigh with friends, Michal and Molly at the Northeast Proton Center at Massachusetts General Hospital in Boston.

Kayleigh's Story

This story is about my daughter Kayleigh. She is currently 12 years old and has been battling a brain tumor, a craniopharyngioma to be exact.

It all began in 1999 when Kayleigh's third grade teacher called to say that she noticed Kayleigh squinting while reading and looking at the blackboard. She suggested an eye exam. I thought this a bit strange because just ten months prior, Kayleigh had a complete eye exam with an ophthalmologist and was fine. I really wasn't alarmed because neither my husband or myself or any of our other children needed glasses. I took her advice and had her examined by an optometrist. He gave her an extensive exam and felt the need to have Kayleigh examined by an ophthalmologist. After an extensive exam with the ophthalmologist, he felt "something" was wrong with her right eye but couldn't be sure because he wasn't used to examining children. He referred us to a pediatric

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Kayleigh's Story (continued from page 1)

ophthalmologist and diagnosed her with unexplained vision loss in her right eye. Well, after about a ten minute exam by this specialist, I was taken into the hall and told by the doc that Kayleigh was perfectly fine and that she was "faking" -- someone in Kayleigh's class must have just gotten glasses and Kayleigh wanted them too. Case closed, we thought. She was fine. End of story.

Fast forward to December 2000. Kayleigh's 4th grade teacher mentioned that she had noticed Kayleigh having trouble reading while viewing the blackboard. I assured her Kayleigh was fine and was examined by three different doctors and was declared perfect. In the meantime, I had noticed that Kayleigh's grades at school were starting to slip and thought it was probably due to holiday excitement. Just prior to the Christmas break, her teacher again mentioned the vision to me. This time she said that when Kayleigh really focused she noticed her eyeballs bouncing. I watched Kayleigh read and saw the same thing. This sort of validated things for me and I made an appointment with an optometrist (who our insurance made us go to first). He examined Kayleigh and immediately knew there was something seriously wrong. He told me she had something called a seesaw nystagmus and that this is almost never seen by eye doctors.....he said they only learn about in a text book. Still unaware of a tumor, we took Kayleigh to another pediatric ophthalmologist, this one closer to our home. This new doctor examined Kayleigh and immediately knew it was something serious. He told us that she would need an MRI to rule out a tumor. He still never mentioned the words brain tumor. He suggested we go to a facility that he dealt with so that he could get immediate results. On January 23, 2001, Kayleigh had an MRI. I knew it was serious when the technician came in, halfway through the MRI to ask what her symptoms were. My heart sank.

After dropping Kayleigh off at school, I headed straight to work. When I walked into my office my boss told me the doctor had called two times already and he needed to speak with me immediately. The fear and panic that came over me was indescribable. When I phoned the doctor's office he asked me if I was sitting down. He told me that Kayleigh had a brain tumor, a craniopharyngioma. He also said that the radiologist could not believe that Kayleigh did not have any symptoms other than eye problems because the tumor was extremely large and needed to be removed immediately. The conversation was a blur.....I was sobbing uncontrollably.....I just could not believe that this beautiful little girl had this "thing" growing inside of her. I could barely make rational decisions but I knew that I needed to get her to New York City. We live in upstate New York and knew of many friends and relatives treated by top-notch doctors.

A friend of ours was a nurse at Columbia Presbyterian Hospital in New York City and was able to get us an appointment that very same day. At 2:00 we were in the office of Dr. Neil Feldstein, Director of Pediatric Neurosurgery. He

explained this tumor is benign but had all the characteristics of a malignant tumor. Dr. Feldstein explained that Kayleigh's vision was very bad and based on the MRI, the tumor had wrapped itself around the optic nerves and optic chiasm and was crushing her pituitary gland. He asked many questions regarding symptoms and was not too surprised that Kayleigh had no other symptoms other than vision. He did ask about nighttime vomiting and I realized that just weeks earlier she had awoken in the middle of the night and was vomiting, but by the time morning rolled around she was absolutely fine! I had no idea that nighttime vomiting was a symptom of brain tumors!

Feeling as though we were sucker punched and looking like we were in a train wreck, my husband and I had to muster up enough strength to come to terms with what was about to happen. Dr. Feldstein told us that Kayleigh needed emergency surgery. He said that if we did not operate as soon as possible, Kayleigh was in danger of going completely blind. He explained everything that he was going to do and told us to prepare for a 7-12 hour surgery. He also gave us the most valuable piece of advice....he said "You must be strong for your daughter, she looks to both of you for strength. If she senses fear in you than she will be afraid. Don't let her see you cry.....leave the room, do it when she is not with you, but don't let her see you cry." They are words I will never forget. After digesting everything we had been told, I knew that we were making the right choice with Dr. Feldstein. Not only was he brilliant, he was so very kind and compassionate that I knew Kayleigh would be okay. Our next stop was to the endocrinologist. Dr. Sharon Oberfield, Director of Pediatric Endocrinology was waiting for

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Seventh Annual Becca's Run



Becca's Run was held on October 4, 2003, a chilly Saturday morning, but that did not discourage 1,100 participants from attending the event. Becca's Run has been held annually since 1997 and continues to grow. The event is held in memory of Rebecca Erin Lilly. Becca was diagnosed in 1991 and the annual walk/run helps to fund childhood cancer organizations that make a difference.

The Childhood Brain Tumor Foundation is very grateful for the continued support shown by the Lilly family. Together, we strive to improve the quality of life for children affected by brain tumors.

Gala and Casino Party (continued from page 1)



on behalf of the Foundation and its supporters. Our Co-Chairs assisted with presenting their gifts.

Throughout the evening everyone enjoyed the scrumptious food, our entertaining bartenders and casino dealers. Along with the buffet dinner, open-bar and casino, we had an impressive silent auction organized by Yvonne Soghomonian. Fabulous items were donated from businesses

such as, Elizabeth Arden's Red Door Spa and Salon, Secrète Jewelers, Blanca Flor, Baltimore Ravens, Baltimore Orioles, Redskins, Chevy Chase Opticians, Bank of America, Chevron Texaco, Ripken Baseball, The Pottery Shop, Queenstown Golf, Arena Stage, Aras Jewelers, Marrakesh Moroccan Restaurant, Big Dog Foundation, Bank of America and so many others.

As the evening rolled along, we enjoyed the continuous video slide show created by Theresa Santelli, revisiting photographs of past CBTF events, supporters and those who have been remembered for their bravery. Musical entertainment was provided by Tom O'Brien, disc jockey, and Dr. Phil Pearl and his jazz band. Anne Gallagher did her usual stellar job in designing the beautiful floral designs that provided ambiance to the event.



Jeanne, thanking supporters and recognizing Founders and Advisors.

Later in the evening, Jeanne took great pleasure in recognizing everyone that has supported the Foundation's events. Special recognition was given to our long-standing medical and scientific advisors; Peter Burger, MD, Johns Hopkins University (JHU); Kenneth Cohen, MD, JHU; Marianna Horn, MD, Northern Virginia Pediatric Oncology Group (NVPOG), Eva Perdahl, MD, PhD,



Drs. Eva Perdahl and Marianna Horn; Elizabeth Schaefer; and Drs. Kenneth Cohen and Peter Burger.

NVPOG, Aziza Shad, MD, Georgetown University (GUMC); Gilbert Smith, PhD, National Institutes of Health (NIH); Phil Cogen, MD, PhD, formerly of Children's National Medical Center (CNMC) and recognition to Roger J. Packer, MD for being our Senior Medical Advisor and founding member of the advisory. All of these individuals have voluntarily dedicated their time to CBTF, providing invaluable advice and ensuring that we fund the most viable research. In addition, we acknowledged our newest additions to the advisory: Francisco Bracho, MD, GUMC; Derek Bruce, MD, CNMC; Tobey MacDonald, MD, CNMC; and Katherine Warren, MD, National Cancer Institute, some of whom have already participated in one grant review.



Above: Dr. Roger Packer receiving his award. Below: Rabbi Fink, Bernice Packer with guest, and Lorraine Schoenfeld.



Following the presentation for special awards, a live auction was held. Featured items included; an autographed bat from The Kelley and Cal Ripken Foundation, an exquisite diamond necklace from Mervis Diamond Importers, four airline tickets from SouthWest Airlines, and a beautifully framed art piece from The Great Indoors. The crowd ral-



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Gala and Casino Party (continued from page 3)

lied for the auction and we congratulate the lucky bid winners and thank them for their support.

This gala event raised a record-breaking sum. Proxima Therapeutics, Gold Coast Landscaping, and the Joseph Sanford Memorial Foundation. were corporate sponsors. In addition, we also received a very generous donation of \$20,000 from the Lilly Family and Becca's Run. This was in honor of Becca, our 10th anniversary, and most importantly to support invaluable research. This event and the funds from Becca's Run will enable CBTF to provide funding for one full grant, up to two years. Grant announcements will be made in the Fall 2004 newsletter edition.



We are deeply appreciative of our co-chairs, Roger and Bernice Packer, the supporters who braved the snow to attend the event, our party committee, volunteers, patrons, sponsors, and auction donors. A big thanks goes out to all of our CBTF supporters from 1994 to 2004, our Founders, Advisors and Board Members, past and present! Our slogan is "Together, reaching for a cure," and we believe that with continued dedication of friends, families, event holders, supporters, advisors, volunteers, and dedicated researchers, we will find a cure.



The Childhood Brain Tumor Foundation -- An Overview

Families of children with brain tumors, with their friends and physicians, founded CBTF because progress in the treatment of pediatric brain tumors has been frustratingly slow, mainly due to lack of research funding. The foundation was incorporated in October 1994 and registered with the IRS as a 501(c)(3) nonprofit organization. We work closely with clinicians and researchers in oncology, neurology, neurosurgery, rehabilitation, psychology, social work, endocrinology, genetics and biomedicine.

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

Each spring, Our dedicated Medical/Scientific Advisors play a tremendous role in our annual grants review process -- they donate their time and knowledge to review each research proposal that is submitted to The Childhood Brain Tumor Foundation. Their recommendations guide our Board of Directors in deciding which clinical or basic science grants to fund. We are pleased to welcome new additions to the Medical Advisory: Francisco Bracho, MD; Derek Bruce, MD; Tobey MacDonald, MD; and Katherine Warren, MD.

Our goal is to improve the treatment options for childhood brain tumors by developing more effective and safer therapies.

Our Childhood Cancer Ombudsman Program is free to families. This program is staffed by legal experts and helps with second medical opinions, informed consent, employment, insurance and educational rights, and understanding of the Americans with Disabilities Act. We also work closely with other foundations through the North American Brain Tumor Coalition. In March 2004 CBTF is collaborating with another brain tumor organization in a comprehensive mini-conference in Washington, DC.

We provide patient education and emotional support through our 800 hotline, quarterly newsletters, Web site articles, annual family retreats, and conferences. CBTF also provides resource information and will provide contact information for medical professionals or institutions for second opinions and consultations.

In the last ten years we have held all types of fund-raisers from casino parties to biathlons, and have funded over 20 research studies and programs within a broad spectrum of disciplines. We are always open to new ideas and fresh faces -- we welcome new members and supporters as we continue to reach for a cure.

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Run with the Saints



All Saints Day, Saturday November 1st, marked the fifth anniversary walk/run event held by St. John Paul II School in Houston, Texas.

It was a gloriously beautiful and sunny day. As always, our dedicated friends, Bernie Weber and Mary T. Callahan, organized a wonderful and successful event. Over 400 supporters participated and they all enjoyed the day.

The race began after Marty Lockard, Lauren's mother, fired the start gun that sent the participants on their way. As always, Lauren continues to be remembered for her courage and spirited nature by her friends who feel fortunate to have known her. Shortly after the main race, special guest Pierce Dean, a one-year survivor of a immature teratoma pineal tumor, fired the start gun for the Kid's Run, to get that enthusiastic group started. Pierce is a 5th grader at St. John Paul II and is an absolute delight -- he loves to share jokes and maintains a very positive attitude about everything.

After the culmination of the race, Bernie and Mary T. presented awards, many of which were artistically designed by Bernie. As always, it was a terrific event and enjoyed by everyone.

Proceeds from this event are donated to St. John Paul II School and The Childhood Brain Tumor Foundation in memory of Lauren Lockard. As always, a heartfelt thanks goes out to the supporters of Lauren Lockard's Run with the Saints, and to Bernie and Mary T. for their dedication to this event.



Pierce Dean signals the start of the Kid's Run, while Mitzi Weber looks on.



Kayleigh's Story (continued from page 2)

us. She explained what the pituitary gland was and what its function was. We also learned that people can live without one and that medications can replace what the pituitary can't make. We were told by Dr. O that Kayleigh would be on replacement hormones the rest of her life. She also told us that 90% of people diagnosed with craniopharyngioma will become overweight and in some cases become obese. We thought that we could live with all of these problems just as long as we had Kayleigh.

January 25, 2001 at 7:00AM Kayleigh was taken down to the operating room. We were allowed to go in with her. This brave, brave little girl never ever complained about all the testing she endured the prior day, nor did she cry about the surgery. Little did I know then that her courage would get me through the day. Twelve grueling hours later, Dr. Feldstein told us that the surgery went well, but he was only able to remove 70% of the tumor because of the way it was wrapped around the optic nerves. If any more had been taken, she would have lost her vision. He said that her optic nerves were stretched so much that they were "clear" and nearly severed! She was down to only tunnel vision prior to and after the surgery but had learned to adjust to the loss before the tumor was discovered.

Kayleigh was awake when they brought her up from recovery and was talking to everyone. She hated the foley catheter and all the IV's. After two days, Kayleigh was walking around without help and was released from the hospital ten days later. She had developed diabetes insipidus but quickly recovered. All was well with Kayleigh and she continued to amaze the medical staff, friends and family with her quick recovery.

A routine MRI July 2001 revealed that the tumor had grown completely back. Dr. Feldstein did not want to operate again and felt the we should consider radiation. After speaking with Dr. Sharon Oberfield, Dr. Jeffrey O'dell, Kayleigh's eye doctor and Dr. Feldstein again, it was decided that he would operate again instead of radiation due to the fact that Kayleigh was only ten years old. Dr. Feldstein felt that the condition of her optic nerves were not strong enough to stand another surgery and had prepared us for the worst; Kayleigh could very well come out of surgery blind! We prayed for the best and prepared for the worst.

On July 25th, 2001 Kayleigh underwent a second craniotomy. This time the surgery was longer and her recovery was longer. She did come out with her vision intact! Dr. Feldstein explained that when he got inside, he was able see that her optic nerves had healed and that they were pink and thick and had blood flowing thru them! It was because of this that her vision was spared. A small miracle I am sure. The doctor was able to remove 99% of the tumor this time because he was able to be a little more aggressive around the optic nerves. Ten days later Kayleigh was home and enjoying the remainder of the summer. Her pituitary was damaged during the second surgery and she did develop diabetes insipidus, thyroid problems and the inability to make cortisone. She was declared panhypopituitary. Again, she took this in stride. We thought we were on easy

Kayleigh's Story (continued on page 6)

Kayleigh's Story (continued from page 5)

street, that was until a routine MRI in July 2002 revealed that a new tumor had appeared. This tumor was cystic in nature and was in addition to the 1% left behind after the second surgery. Again, we felt as though we were sucker punched. Why her, we thought? I just could not bring myself to tell this child after her life was just settling down. Again, this brave child took the news in stride. It was determined that she would undergo radiation treatments as opposed to another craniotomy. Dr. Feldstein felt that another surgery would only offer a 65% cure rate with the possibility of serious damage. Dr. Oberfield and Dr. Odell felt that radiation was too harmful for an 11 year-old child and Dr. Jeffrey Wisoff at NYU Medical Center felt he could do exploratory surgery but could only offer a 65-70% cure rate. We were told that the tumor was aggressive and due to her age, it wanted to grow. Ultimately, my husband and I were left to make this medical decision. After agonizing over it and researching radiation treatments we decided that she would have proton beam radiation treatments under the care of Dr. Nancy Tarbell at Mass General Hospital in Boston, MA.

Kayleigh started radiation treatments on 12/02/02 and received six weeks of radiation. The only short term side effect that she experienced was fatigue. It lingered for close to a year after treatment -- it was very severe a month after and began to improve with time. Her tumor continued to grow during treatment and her final day we were told she would need a shunt or another surgery because the radiation may not start working for six months to a year. Again, we prayed for the best and prepared for the worst. Dr. Feldstein said that he would wait until a critical stage in hopes of the radiation "kicking in." A CT scan a few weeks later showed the tumor shrinking!! It continued to shrink the entire year. It is one year post-radiation and Kayleigh's tumor is completely gone. It went from 3.0 cm X 3.0 cm on 1-31-03 to 1mm X1mm on 12-19-03!! We could not have asked for a better Christmas gift.

Kayleigh is still the same child she was prior to the diagnosis. She has a magnetic personality and her smile can light up any room. Kayleigh is an amazing child and it is her incredible disposition that fuels the strength of those around her. Life for Kayleigh will always be a challenge, but for now, she is just enjoying being a kid.

~

Written by Lisa Brunet, Kayleigh's Mom, an Independent Bank and Title Closer in Newburgh, NY. Lisa and Kayleigh are strong supporters of the Kyle's Heroes event and CBTF.

Arsenic Trioxide in Treatment of Diffuse Infiltrating Gliomas of Childhood

The Childhood Brain Tumor Foundation is pleased to announce its funding of a study entitled, "Arsenic Trioxide in Treatment of Diffuse Infiltrating Gliomas of Childhood," led by Dr. Kenneth Cohen, pediatric oncologist, Johns Hopkins University. The Foundation thanks Kyle's Heroes, CBTF supporters, for helping to fund this study with CBTF. Our hopes are that this clinical trial will prove to make a difference in children with infiltrating gliomas. Pontine gliomas are a particularly devastating diagnosis in children, as there are currently no effective therapies, so newer therapies must be explored. Preclinical data on arsenic trioxide suggests its multiple potential modes of action against gliomas.

Brainstem gliomas occur most often during the first decade of life and are broadly divided into categories: tectal, cervicomedullary and diffuse intrinsic pontine gliomas (DIPG). DIPG is pathologically a fibrillary astrocytoma, some being low-grade fibrillary with the majority being high-grade lesions. The limited options for treatment is generally due to tumor location and their frequent high-grade pathology. Surgical debulking is not a treatment option, although in questionable cases biopsies are done. Radiation therapy is the standard treatment approach, providing some stabilization, but not cure. Alternative therapies currently include: chemotherapy after radiation therapy; high-dose therapy with stem cell rescue; and radiosensitizing chemotherapy used during radiation therapy. The poor prognosis for DIPG warrants further investigation of novel and more effective treatments.

Historically, arsenic trioxide was first tested in China in solid tumors and forms of leukemia. A consistent remission rate has been demonstrated on acute promyelocytic leukemia. Reports from China show response rates at 50-70% in both relapsed and untreated patients, with 28% of patients alive ten years post treatment. Studies in the United States have yielded similar results. Although experience with solid tumors is a bit limited, further evaluation is underway.

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CBTF thanks past advisors that volunteered their time to grant reviews and writing articles for the Foundation: Drs. Philip Cogen, Paul Graham Fisher, Joseph Gootenberg, Michael D. Medlock, and H. Stacey Nicholson, and Aziza Shad.

Amy's Run 5K

by Jean Santiago

It was a chilly October morning when the 600 runners and walkers left the starting line for the first Amy's Run 5K in Crofton, Maryland and helped raise \$22,500 for the Childhood Brain Tumor Foundation. Rob, Lisa, and Allison Schiller and a dedicated team of volunteers worked for nearly a year to put together the successful event. The proceeds will help fund one year of a two-year study to be selected in the spring of 2004.

The course started in front of the Crofton Country Club and toured through the town of Crofton, located about 15 miles west of Annapolis. The relatively flat course, on what the locals call the "Parkway," mixed in a few rolling hills and a fast finish allowing men's winner, Ted Poulous of McLean, VA, to come in at 16:55, and Crofton resident, Brian Daugherty, following, with a time of 17:08.

Another Crofton resident, Jennifer Garman, enjoyed the home course advantage becoming the first woman to cross the line in 20:20. May Wedlund of Annapolis was just steps behind Jennifer, finishing in 20:23. Cheering for every finisher were the rousing Redskinettes cheerleaders; Louie, the Bowie Bay Sox mascot; and many supporters. For a complete listing of Amy's Run results and race sponsors, go to www.amysrun.org.

Soon after the adults took off, a mass of more than 40 kids sprinted in the opposite direction in a .1 mile Kids Fun Run. All participants, ages 5-11, received a ribbon and enjoyed a drawing for some fun prizes like free pizza, mini golf, and signed Redskin magnets.

Amy Danielle Schiller, the inspiration for the race, was a sweet, intelligent, fun-loving girl who lost her battle with brain cancer on September 11, 1999, a month shy of her third birthday. In an effort to put an end to this terrible disease, her family and friends created this race to raise money for the Childhood Brain Tumor Foundation. All proceeds from the race benefited the Foundation whose mission is to raise funds for scientific research and to heighten public awareness of this devastating disease and to improve the prognosis and quality of life for those who are affected.

Although honorary chairman, former Redskin quarterback and Super Bowl XXVI MVP, Mark Rypien, was unable to attend, he was a strong supporter of the race. Rypien's son, Andrew, also died of a brain tumor.

After the race, runners and walkers stayed for the award ceremony and some great prizes. Poulous, the men's winner, won a luxury suite for the 2004 Bowie Bay Sox baseball season. Ms. Garman won a two-night stay in a deluxe room at the Avenue Inn & Spa at Rehoboth Beach. But you didn't have to be the first across the finish line to receive

one of the more than 50 prizes from local vendors and supporters including a cruise on the Dandy, Baltimore Raven football tickets, Washington Capitals tickets and a signed jersey, discounts from Southwest Airlines, a quilt from Zuzu from the movie *It's a Wonderful Life*, and gift certificates to local restaurants including the Sly Horse Tavern, Applebee's, and Glory Days Grill.



The Schiller Family



Main race



Sharing Hope
A Symposium for Patients,
Survivors
and Families.

Friday, March 26 and
 Saturday, March 27, 2004
 at
 The Metro Marriott
 Washington, DC

Co-Sponsored
by the
American Brain Tumor Association
and the
Childhood Brain Tumor Foundation

Thank you to Premier Sponsor
GENENTECH

Speakers include: Drs. Wm. Broaddus, Peter Burger, Lawrence Chin, Elana Farace, Howard Fine, Robert Keating, Andrew McCarthy, Tobey MacDonald, Mary Ann McCabe, David Schiff, Constantine Stratakis, Gilbert Vezina, and Moody Wharum. Educational speaker: Kathryn Sawetz.

This conference will provide invaluable information about adult and pediatric brain tumors. Embrace this opportunity to learn from renowned professionals and meet others to share experiences.

Sunday, April 25, 2004
The Dan Fiduccia
Spring Biathlon



500 yd. Swim/5K Run to be held at Madeira School, McLean, VA. Participants can be as individuals or as a team. Top 3 male and female finishers in each age group will receive medals: 10 and under, 11-14, 20-29, 30-39, 40-49. Have some fun, take the challenge. Sponsorships are encouraged.

For more information contact:
 Gib Smith, Race Director
 540-822-4355 or check our website:
<http://www.childhoodbraintumor.org>

Brain Tumor Action Week
May 2004

For more information about Brain Tumor Action Week check our Web site or the North American Brain Tumor Coalition's Web site this spring.
<http://www.childhoodbraintumor.org> and/or

CBTF Overview (continued from page 4)

Grants Funded by CBTF and Other Sponsorships since 1994

- 2004 --Sponsorship 11th International Symposium on Pediatric Neuro-Oncology
 **Promotes education and scientific communication exclusively for pediatric brain tumor professionals.
 --Second year funding and 2004 spring grants (due April 15) will be announced in the fall newsletter edition.
- 2003 --"*Arsenic Trioxide in Treatment of Diffuse Infiltrating Gliomas of Childhood*," Kenneth Cohen, MD
 **Clinical grant
 --"*Retinoids and Vitamin D3 analogues*," C. Damador Reddy, MD (two year funding). **Aims to characterize molecular basis of cell death.
 --"*Preclinical Evaluation of Valproic Acid as a Novel Treatment for Brain Tumors*," Xiao-Nan Li, MD, PhD, PI, (two year funding) **To establish the anti-tumor potential of VPA and establish preclinical rationale for clinical trials.
 --Second year funding: "*Molecular cytogenetic characterization of pediatric ependymoma*," Michael Sheldon, MD
 --Second year funding: "*A new transgenic mouse model for medulloblastoma*," Robert Weschler-Reya, MD
- 2002 --Sponsorship 10th International Symposium on Pediatric Neuro-Oncology, for medical professionals
 --"*Molecular cytogenetic characterization of pediatric ependymoma*," Michael Sheldon, MD, (two year funding)
 **Genomic technology grant to ascertain defects at the level of chromosomal DNA that might correlate with clinical factors for outcome and survival.
 --"*A new transgenic mouse model for medulloblastoma*," Robert Weschler-Reya, MD (two year funding)
 **focuses on molecular mechanisms that control normal cerebellar development and how mechanisms are dysregulated in medulloblastoma. **Cellular and molecular study.
 --Sponsorship toward Brain Tumor Action Week, May 5-11, 2002, **Promotes awareness to policymakers about ongoing issues.
- 2001 --"*Gene Expression Analysis of Medulloblastoma*," Tobey MacDonald, MD, **Gene expression profiling/regulation
 --Funding, toward the Childhood Cancer Ombudsman Program. **This program assists pediatric cancer patients and their families nationwide with insurance, educational and employment issues.
 --Inova Fairfax -- James Cooney, development of computer based teaching for patients that miss school while hospitalized to ensure they continue to stay up-to-date with their schoolwork. **Education assistance for patients/support.
 --Sponsorship toward CNMC conference entitled, "*Late Effects in Long-Term Survivors of Childhood Cancer*."
 **Support and education for families.
 --Sponsorship toward *National Brain Tumor Awareness Week*, May 6-12
- 2000 --"*Role of Methylation and Deletion of DNA in HIC-1 Expression in Childhood Brain Tumors*." Brian Rood, MD,
 **Methylation and gene inactivation
 --"*Wingless Signaling in Medulloblastomas: A Murine Transgenic Model*." Charles Eberhardt, MD, PhD,
 **Study about expression of stabilized b-catenin.
 --Funding, for the Childhood Cancer Ombudsman Program, California.
 --Sponsorship of the "*9th International Symposium on Pediatric Neuro-oncology*," San Francisco, CA.
 --Small award, given to *Candlelighters of Illinois* for an Support/Educational Retreat Day for Moms.
 **General parent support
- 1999 --"*Development of a syngeneic model of murine medulloblastoma*," Robert Martuza, MD and Pablo Hernaiz Driever, MD
 **Molecular genetics-medulloblastoma-mutations in human homolog of the Drosophila patched gene.
- 1998 --"*Role of SETA in Childhood Glioma*," Oliver Bögl, PhD, **Learning about gene function .
 --Sponsorship for "*Mile High Challenges in Nursing, a CCG/POG Workshop*,"
 **general conference support for educational purposes for nurses
 --Small grant award to Carol Jean Cancer Foundation in support of their efforts toward the brain tumor families.
 --Funding for the Childhood Cancer Ombudsman Program, San Francisco, CA.
 ** CBTF supports CCOP for the important advocating support they give families regarding educational, employment and insurance issues.
 --Brain Tumor Symposium, collaborative effort between two foundations, held in Arlington, VA
- 1997 --Grant funding was allocated to the Pediatric Oncology Departments of our supporting institutions: Children's National Medical Center, Georgetown University Hospital, Inova Fairfax, and Johns Hopkins University Hospital
 ** Enabled social workers to provide for families where needed.
- 1996 --"*RSU-1 in Glioma Progression*," Mary Lou Cutler, PhD
 **Genetic expression in glioma progression.
 --Sponsorship of the "*7th International Symposium, Pediatric Neuro-Oncology*," Hyatt Regency, Capitol Hill, Washington, DC.
- 1995 --"*Antisense Oligonucleotide Therapy in Pediatric Brain Tumors*," Eliel Bayever, MD
 ** study supported learning about gene function in medulloblastoma

The majority of our funding efforts are for basic science and clinical research. However, we also hold educational meeting and/or provide support for conferences annually for families.

Once again, thank you so much to all of our supporters who make it possible for us to fund excellent grants and programs!



WHEN GOD CALLS YOUNG CHILDREN
TO DWELL WITH HIM ABOVE,
WE MORTALS SOMETIME QUESTION
THE WISDOM OF HIS LOVE.

FOR NO HEARTACHE COMPARES WITH
THE DEATH OF ONE YOUNG CHILD,
WHO DOES SO MUCH TO MAKE OUR
WORLD SEEM WONDERFUL AND MILD.

PERHAPS GOD TIRES OF CALLING THE
AGED TO HIS FOLD
SO HE PICKS A ROSEBUD BEFORE IT CAN
GROW OLD.

GOD KNOWS HOW MUCH WE NEED
THEM,
AND SO HE TAKES BUT FEW.
TO MAKE THE LAND OF HEAVEN MORE
BEAUTIFUL TO VIEW.

BELIEVING THIS IS DIFFICULT
STILL SOMEHOW WE MUST TRY,
THE SADDEST WORD MANKIND KNOWS
WILL ALWAYS BE GOOD-BYE.

SO WHEN A YOUNG CHILD DEPARTS,
WE WHO ARE LEFT BEHIND
MUST REALIZE GOD LOVES CHILDREN,
ANGELS ARE HARD TO FIND.

HEAVEN HAS JUST RECEIVED A NEW
ANGEL

ERIC W. RICHARDSON, JR.
"MOE"



Erica Holm

Remembrances

Eliana Tova Andersen
Stephen Boyce
John Boyles
Jeff Brown
Kelley Bula
Charles Byrum
Catherine Cason
Ryan Caspar
Laira Caverly
Josetta Chiang
Andrew Conk
Ryan Crozier
Shawn Edwards
Clay Eich
Barbara Waxman Fiduccia
Daniel Fiduccia
Margo Flamini
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Courtney Shelby
Steven Sliwerski
Lisa Soghomonian
Teresa Stargel
Symphony Ann Taylor
Jaime Vanderheyden
Swetha Vasudevan
Ellen Elise Waldron
Matthew Wierzbicki
Ian Hammond Williams
Josie Wynn

Hope is the thing with
feathers~
That perches in the soul~
And sings the tunes
without the words~
And never stops~
at all~

Emily Dickinson



Laira Caverly

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The Childhood Brain Tumor is deeply appreciative of all of our advisors, patrons, sponsors, event organizers, workplace campaigns, and volunteers.

A big thanks goes out to all of our CBTF supporters!

Vehicle Donation Program

CBTF now accepts vehicle donations. Donate Online or call 866-332-1778 and designate the Childhood Brain Tumor Foundation as your charity of choice.

QUICK FACTS FOR DONATING

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Find out details by checking the Foundation Web site; [Http://www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

WORKPLACE GIVING

Thank you to those who choose us as their charity! CBTF is in the

- Combined Federal Campaign (National)
- Children's Charities of America (National); and
- United Way

Campaign donations can be made for the United Way through the "donor option" or "donor choice." Please check with your employer in reference to United Way campaigns.



CBTF has a website!

visit us at:

<http://www.childhoodbraintumor.org>

Thanks to Tim Ratliff, Web Master.

If you would like to receive our newsletter publications or other information, please notify us with your contact information.

Gift Matching Opportunities

Many companies offer a matching gifts program to support charitable organizations. Your human resources department can tell you if such a program exists in your organization. Generally, they have a form that would be sent to the Childhood Brain Tumor Foundation reporting a contribution, stating they will match the contribution. We return the form to the employer with the proper acknowledgment and information required.

CBTF can now accept donations via stock securities through Bank of America Investment Services, Inc. Contact our Broker, Steven P. Burroughs at 301-897-7699.

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