



Children's Brain Tumor Foundation



*Embracing
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today gives
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tomorrow*

Winter 2004

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Volume 14

Hidden Under Our Hats

See Page Four for the Full Story on this National Advocacy Project



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The Challenge is published by the Children's Brain Tumor Foundation, a non-profit organization dedicated to improving the treatment, quality of life, and long-term outlook for children with brain and spinal cord tumors through research, support, education and advocacy for families and survivors.

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A Message from the President



Joel Shiff

One of the major dividends of the *Dream and Promise Awards Benefit* we have held for the last two years is the relationship that has developed between CBTF and our latest partners in progress, the International Licensing Industry Merchandisers Association (LIMA). A trade association with 1,000 member companies, LIMA was formed in 1985 to foster the growth of the licensing industry, to recognize excellence, and to maintain ethical standards in that field. They also make it part of their business to help charities and encourage philanthropy among their members. Leigh Anne Brodsky, whom we honored at the *2nd Annual Dream and Promise Awards Benefit* this past June, sits on the board of LIMA and is a co-chair of their charity committee with Cheryl Stoebenau. After the tremendous success of that event she and Ms. Stoebenau thought it would be a natural fit to forge a bond between CBTF and LIMA and proposed that we be selected as their charity of choice. Her colleagues were overwhelmingly in favor of the plan and recently announced their goal to raise \$1 million for CBTF over the next five years.

To say that we are thrilled with this development would be a gross understatement. To have our cause championed by a billion-dollar industry is nearly beyond belief and is just another sign of how far CBTF has come since its humble beginnings. Who ever thought that Judy Hurley, our Executive Director, would be mingling with the Care Bears (see back cover) and other luminaries at an international licensing show?

LIMA will be directing their support to scientific research and at this year's *Grants Award Reception* we were proud to give out the inaugural LIMA International Award for Excellence in Pediatric Brain Tumor Research to Tom Curran at St. Jude Children's Research Hospital. The other grantees are listed elsewhere in this issue.

Also in this issue is news about advocacy, including information about CBTF's participation in the Hidden Under Our Hats project, and an exciting report about progress made by Dr. Charles Eberhart due to CBTF-funded research. You will also find a moving piece by Emily Curran, a young woman struck with what is usually a children's disease, and a wrap up of events organized by CBTF and others, including three inspiring families.

All of us at CBTF wish you the best for a terrific holiday season with your families and a happy and healthy New Year.

Best regards,

Joel Shiff

Joel Shiff

New Friends: CBTF was pleased to welcome representatives from LIMA at the *2004 Grants Award Reception*. From left: Peter Van Raalte, President of LIMA's board of directors and Vice President, Consumer Products, Scholastic Entertainment; Cheryl Stoebenau, co-chair of LIMA's charity committee and President, CAS Marketing; grant recipient Tom Curran, Ph.D., Member, St. Jude Faculty, St. Jude Children's Research Hospital; and Joel Shiff, President, CBTF board of directors.



Research Funded by CBTF Leads to Breakthrough

In 2002, CBTF awarded a grant to Charles Eberhart, M.D., Ph.D., of Johns Hopkins University, for his study: *“Analysis of Notch Signaling in Medulloblastomas.”* As reported below and in the November issue of *Cancer Research*, his work is leading to some exciting results.

New Gene Target Found for Common Brain Tumors in Children

By Vanessa Wasta, Johns Hopkins Medicine

Scientists at Johns Hopkins have linked a stem-cell gene called Notch2 to a portion of one of the most common childhood brain cancers, opening the door to tailored therapies that block the gene’s tumor-promoting ability. The gene, whose pathway is known to be an important factor in regulating brain stem-cell growth and survival, has been studied in fruit flies for almost a century. The research team at the Johns Hopkins Pathology Department and Kimmel Cancer Center found that a protein made by the gene promotes cancer cell growth by 27 percent in a childhood brain tumor called medulloblastoma. Their studies, reported in the Nov. 1 issue of *Cancer Research*, also revealed that children with high Notch2 gene activity fared worse in the course of their disease than those with less activity in Notch2.

The researchers report that a drug first developed for Alzheimer’s disease called DFK-167, which blocks activation of all Notch proteins, reduces growth of cancerous cells in cul-

ture by 80 percent, although unwanted side effects and dosing problems may make it a poor choice for treating human brain cancer. But the investigators are testing more potent drugs of the same class and developing new ones that block only the Notch2 pathway.

No clinical trials with any drug have yet been planned, the researchers emphasize.

Scientists say that gene amplification — a process in which cells make too many copies of a gene — is one of the most reliable indicators of a gene’s importance to cancer development. The Johns Hopkins team found Notch2 amplified in six of 40 medulloblastomas and other similar brain tumors.

“Just like genetic mutations, amplifications are long-lasting DNA mistakes, as opposed to transient changes in the production of proteins and other gene products,” said Charles Eberhart, assistant professor of pathology. “Finding amplification of Notch2 is a smoking gun tying it to the development of these brain tumors.”

In their study, the Johns Hopkins scientists compared levels of a protein marker for Notch2 gene activity to the survival of 35 medulloblastoma patients. Of 11 patients with high levels, seven died; of 24 patients with no detectable protein, only six died.

Standard surgery and radiation for medulloblastoma cures approximately 60 percent of children but often results in many neurologi-

cal and learning disabilities.

“We’d like to develop a drug that only affects the Notch2 pathway, since blocking other members of the Notch family may actually have the opposite effect and encourage cancer growth,” said Xing Fan, first author of the study and postgraduate fellow.

In 25 of 30 of the medulloblastomas it studied, Eberhart’s team also found lower levels of Notch1, compared to Notch2, gene products. Notch1 proteins normally provide a brake on growth of medulloblastoma cells, and blocking their activation would cancel out some of the drug’s effects. “The net effect of any drug will depend on how much of each Notch1 and Notch2 is present, and since we found more Notch2, we think the scale can be tipped toward stopping the cancer,” Eberhart said.

This research was funded by the Children’s Brain Tumor Foundation, National Institute of Neurological Disorders and Stroke, and National Cancer Institute. Other JHU research participants are Irina Mikolaenko, Ihab Elhassan, Xing Zhi Ni, Yunyue Wang and Douglas Ball.

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“Finding amplification of Notch2 is a smoking gun tying it to the development of these brain tumors.”

A Home Run: CBTF Sponsors ISPNO



attracted the leading lights in the field. Dr. Judah Folkman, a pioneer in the field of anti-angiogenesis, gave the keynote lecture. In addition, there were forums on tumor biology, treatment, survivorship, quality of life, and other crucial topics. CBTF’s multimedia information booth was well-attended and it was quite a thrill to see our name in lights on the scoreboard during a gala held at Boston’s historic Fenway Park. Supporting conferences like ISPNO is another way CBTF is active in influencing the development of scientific advances in the field of pediatric brain and spinal cord tumors.

CBTF was proud to be a Platinum Sponsor of the 11th International Symposium on Pediatric Neuro-Oncology, which was held in Boston this past June. Dana-Farber Cancer Institute, Children’s Hospital Boston and Harvard Medical School were the hosts and they



Susan Weiner, Vice President of CBTF’s board of directors, and Judy Hurley, Executive Director, greeting visitors to CBTF’s table at ISPNO.

Hidden Under Our Hats



I survived," was the powerful statement 17-year-old brain tumor survivor Kara Winter painted on a hat at CBTF's *Kids Cruise* last summer. During brain

tumor week at Camp Sunshine this past June, a parent created the desperate message, "Please Help Me" on the hat shown here. These hats and many others will be CBTF's contribution to a national advocacy project called "Hidden Under Our Hats."

The hat project was created by Kris McAlvanah, a founder of the Brain Tumor Action Network. She has collected over 1,000

hats from around the world, hundreds of which were displayed last May during *Brain Tumor Action Week*. They are now traveling the country in a continuing effort to raise awareness about brain tumors. "I want people to be aware. I want all of these hats, all of these individuals that have passed away from brain tumors or fighting them and surviving them, to have a voice in Washington," Ms. McAlvanah said in a segment that appeared on the Tampa Bay Channel 10 News.

Ms. McAlvanah hopes that the attention the hat exhibit generates, coupled with vigorous lobbying in Congress, will help bring about the necessary legislation and funding for research to successfully battle brain tumors. When Ms. McAlvanah lost her husband to a brain tumor she pledged to keep crusading and working to find a cure. She has kept that promise.

"It is tremendously important to the mis-

sion of CBTF that pediatric brain tumors have a high profile in all advocacy efforts," said Tracy Moore, CBTF's Director of Support Services. "It is also a gift we are giving to the children and families associated with CBTF. When they express themselves on a hat it can be a cathartic and empowering experience."

The traveling gallery of hats has already traveled to Florida, Georgia, New Jersey, New York, Ohio, Oregon and Washington and will soon be seen in Virginia. CBTF will be donating 75 hats so that our children will not be forgotten. When CBTF's hats join the collection, they will become part of a national conversation that will hopefully lead to a brighter future for everyone experiencing a brain tumor diagnosis.

This article was prepared with the assistance of Heather Ryan.

Building a Strategy to Fund Collaboratively by Susan Weiner, Ph.D

CBTF is increasingly involved in projects that have far-reaching national implications. Organizations that fund brain tumor research, including CBTF, are developing a coordinated national strategy to fund projects that no one funder—including the National Institutes of Health—is likely to do alone.

The Brain Tumor Research Collaborative, a coalition of 12 private brain tumor research foundations and funding nonprofit organizations, includes any brain tumor research funding group willing to participate, regardless of the size of its grant portfolio. The Collaborative has held several meetings with researchers to identify critical barriers to the development of more effective brain tumor treatments.

Discussions focused on the domain in which basic laboratory research findings are translated into human clinical trials, including a workshop last spring with many of the nation's outstanding translational researchers. These investigators model the growth of brain tumors in animals and then evaluate new compounds prior to turning them into medicines to be brought into the clinic. We asked researchers about the lessons they have learned from screening drugs in preclinical animal models and what are the critical barriers to improving animal models so that they can be better predictors of treatment efficacy in people.

Funders were told that too often there is a disjunction between basic science experiments with human clinical trials in design and communication about the science. For example, combination therapies, the norm in treating people, are not used in animal screening, where drugs are tested one at a time. The human blood-brain barrier can also be a substantial obstacle to getting drugs into the brain, yet tumors in mice are typically grown on the flank. Clinical trials typically enroll patients with recurrent tumors that have failed to respond to available therapies,

and who have much more complex disease than the tumors grown in mice. Finally, mouse models of brain tumors do not, and ultimately cannot, mimic the genesis and full range of complexity that human brain tumors manifest.

Workshop participants identified several candidate projects for the collaborating funders. As one example, funders are considering the creation of a database that could analyze and coordinate brain tumor data from preclinical studies and Phase 1 and 2 clinical trials. This project could result in more valid and efficient relationships between animal models and human testing. A second possible project might involve the creation



of an "Ideal" Preclinical Model System/Consortium of brain tumor laboratories for screening new drugs. Researchers and funders agreed that the current preclinical system was fragmented and discussed what an ideal, distributed network/consortium of labs of brain tumor models might look like to screen new agents more effectively.

The Collaborative's discussions and planning are ongoing. The Society for Neuro-oncology met in November, and funders and researchers will meet again to discuss these and other project ideas and make further plans. As an active participant in this exciting initiative, CBTF has guaranteed that, regardless of the eventual project, children's brain tumors will be included in the search for more effective treatments.

My Other Family

Emily Curran

I had been symptomatic for a couple of years. I was originally diagnosed with several things, including benign-positional vertigo and blood vessels in my brain that were constricting so badly they gave me headaches. Eventually, during my junior year of college, I went to see the campus doctor. Maybe he would give me a blood test or something. He set up an MRI for me at the local hospital for the next afternoon.

Upon hearing this, my friend Johann immediately said that he would take me. I, thinking I was being patronized, told him in no uncertain terms that I could handle

There I was, twenty years old, and I couldn't even walk by myself. Even in my state, I found it a little embarrassing. I was not a fan of my limitations.

everything by myself. We argued about it but in the end Johann convinced me of my silliness. And I am so glad. I never could have made it alone through those first few moments after I was told I had a mass on my brain. I needed to get out of there and go back to school where I knew my friends would be.

Word spread around quickly about what was going on with me. No one really knew what to do, including me. Sally, my roommate, stayed with me as I called my parents and Student Services to begin the business of leaving school. Friends consoled me, gave me hugs, and baked cookies. That night,

people helped me pack and stayed with me until I went to bed. My sorority sisters came and sang to me. I knew there were so many people who would help and care for me when I came back.

My parents picked me up the next morning. Later, the Mayo Clinic diagnosed me with a medulloblastoma, something my neurologist found particularly odd because I was twenty at the time—over twice the age of most patients who present with that kind of tumor.

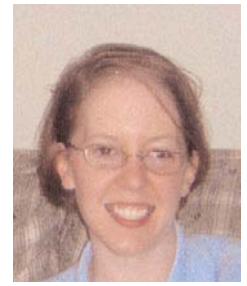
After recovering from surgery, I returned home unable to do anything for myself. That was a very weird feeling. There I was, twenty years old, and I couldn't even walk by myself. Even in my state, I found it a little embarrassing. I was not a fan of my limitations.

Throughout my recovery, many of my friends came to visit and I was deluged with reports of daily "Emily Updates" that my parents would e-mail to my voice teacher for her to share with everyone at school. I received so many cards, many from people I had never met. My friends from high school came as often as they could. My voice teacher and my choir director drove from Indiana to Wisconsin to see me—twice!

The thing that really got me is how they all would cry. I would cry about myself, but I felt I had good reason. After surgery, I knew I was going to be OK and get back to school. I knew it would take A LOT of work to get there, that's all. Sometimes I felt like people were coming to mourn me. That got me down a little. But as I got better and better, their spirits, as well as mine, were lifted.

After surgery, I had chemotherapy and radiation therapy, both of which were lousy.

I am terribly afraid of needles so getting chemo through an IV was a bit daunting. I think my veins staged a rebellion and eventually bent a needle. Sickness-wise, chemo was kind of a descending staircase for me—I got very ill the first time, but gradually growing less so until the end when I was just very tired. Radiation was incredibly worse. I had radiation every day for a little over two months and I was sick every day. Radiation is often played down as chemo's less offensive cousin. To me, that was a gross misrepresentation.



After treatments, I had physical, occupational, and speech therapies. Logically, I understood the need for each, but my parents watched me do so many assessments that would have been unnecessary if my file had carried information about evaluations done by other therapists.

Looking back, I know I never could have made it without the love and support my other family freely gave me. Though I often felt I was nowhere near the person I was before all of this happened, I had an unlimited supply of people to alternately comfort me and tell me that I had to get past it and move on.

I graduated from Valparaiso University with a degree in Music Education, and am a music teacher at Trinity Catholic Elementary School. It is now five years since my diagnosis. I'll never forget what happened to me, and I'll always remember all of the people who made it just a little bit easier.

2004 Grants Announced

On November 15, a distinguished array of guests gathered for the 2004 Grants Award Reception, held in a stunning location with a spectacular view of the glittering lights of midtown Manhattan. Research grants were awarded to the following doctors:

- Tom Curran, Ph.D., St. Jude Children's Research Hospital, for his study, *Molecular Analyses of Atypical Teratoid/Rhabdoid CNS Tumors*;
- Ching Lau, M.D., Ph.D., Baylor College of Medicine, for his study *Genomic Profiling of Intracranial Germ Cell Tumors*;
- Jim Olson, M.D., Ph.D., Fred Hutchinson Cancer Research Center, for his study, *Necessity and Sufficiency of Nmyc in Sonic Hedgehog-*

Mediated Medulloblastoma Genesis;

- Vidya Gopalakrishnan, Ph.D., University of Texas M.D. Anderson Cancer Center, for her study, *Mechanism of REST/NRSF-Mediated Medulloblastoma Tumorigenesis*.

Friends of Karen received a Quality of Life grant, funding another year of their program that provides financial assistance to families served by CBTF.

* Eventful Days and Nights at CBTF *

Dream & Promise Benefit

The evening of June 7 saw a crowd of several hundred gathered for the *2nd Annual Dream and Promise Awards Benefit*. Leigh Anne Brodsky, President, Nickelodeon and Viacom Consumer Products, was honored for her charitable work. She headed the benefit committee at 2003's inaugural Dream and Promise event and the staggering success of that night made her an easy choice to honor this year. Another easy choice was awarding the Pioneer Award for Neurosurgery to Dr. Peter Black, who has been pushing forward research into the treatment of brain tumors for more than 30 years. Dr. Black holds titles at Harvard Medical School, Brigham and Women's Hospital, Children's Hospital Boston, and Dana-Farber Cancer Institute. We were privileged to have Meredith Viera (right) as mistress of ceremonies and noted singer-songwriter Jim Dawson as a special musical guest. The co-chairs of the Benefit Committee helped raise nearly \$700,000! They are pictured here with the honorees (left to right): Sheri S. McCoy, President, Global and U.S. Baby/Kids and Wound Care Franchises, Johnson & Johnson; Ms. Brodsky; Lynn Lehmkuhl, Former Publisher, Ladies' Home Journal; Dr. Black; Meagan Kennedy Burrows, President, Paramount Home Entertainment.



Dinner Dance

The *Ninth Annual Dinner Dance* on June 17 was attended by 260 guests and raised over \$250,000 for CBTF. The event included a Chinese auction, a raffle and an exciting live auction which led to a furious bidding war between two guests. Left: Honoree Denis Sheil, Vice President, New York City District Council of Carpenters, and Peter Thomassen (President). Below left: Brain tumor survivor Jimmy Torres had a fantastic night—he even took home a prize from the Chinese Auction! Right: Honoree Denis Sheil's grandchildren spent some time on the dance floor.



Kids Cruise

One lucky sailor had a chance to steer the boat during the *Fourth Annual Kids Cruise* on July 27. The boat rides and picnics were attended by a total of over 175 people—the biggest year yet! Thanks once again to the Mark R. Harris Foundation for sponsoring the event.



Madame Tussauds New York hosted a wonderful holiday gathering for CBTF on December 12. Members of the Ragusa family, at right with Madame Tussaud herself, were among the lucky attendees. The party included breakfast at Applebee's and goodie bags chock full of great stuff!



Big Apple Circus Benefit

For the 16th year in a row, hundreds of children with brain and spinal cord tumors attended the *Big Apple Circus Benefit* thanks to the efforts of the Benefit Committee (pictured below with Joel Schiff, decked out in CBTF red). As usual, the clown known simply as "Grandma" was a highlight of the show. Grandma also found time to visit with the families and made their day truly special.



Danny Jegle Open

There is no doubt that every golfer at the *Sixth Annual Danny Jegle Open* would have liked to brag of scoring 68. Instead, they were even happier to report that they were part of CBTF's most successful golf open yet! The event, held at Hempstead Golf & Country Club on October 18, raised over \$70,000. Tim Jegle (at left in picture) and his family were overwhelmed by the generosity of everyone who participated. It didn't hurt that the crystal clear skies had the greens glistening, making for a beautiful day in Danny's memory. There were several pictures of him on display, reminding all who attended of the importance of their involvement.



Throughout the year, CBTF is contacted by special families who want to use their experience with childhood brain tumors as an opportunity to help others. On this page, we are spotlighting three families who held fundraising events in 2004. The Docu family of New York, the Kojeszewskis from Pennsylvania and Russ Felker and Leslie Omlin from Washington put a tremendous amount of time and effort into their events and learned a lot about fundraising along the way. Their hard work paid off and everyone felt positively about the experience. They are now looking at their

Inspirational Families

calendars to plan their next event!

Anyone who is interested in creating an event should feel free to contact the CBTF office. We can give you the guidelines to get started and advice on how to have a successful event.

Nicky Docu Golf Outing May 7, 2004 Van Cortlandt Park, Bronx, New York

When Nicky Docu first showed symptoms of having a brain tumor, he was in school. His teacher, Pat Hund, accompanied him to the hospital and was with him every step of the way. During Nicky's treatment, Pat organized a golf outing in the Bronx. After Nicky passed away, she and the Docu family decided to have a second fundraiser to benefit CBTF. About forty golfers participated and more friends and family joined in the dinner and raffle that followed the 18 holes.



Above, Left to right: Tom Docu, Alexandra Docu, Walt Hund, Pat Hund, Christina Docu, and Tom Docu, Jr. Left: A picture of Nicky graced the table that displayed the raffle prizes.

Corinna Felker's "Drive Fore" Cancer September 11 & 12, 2004 Moses Lake, Washington



"Corinna taught us to never give up or give in," reads one line in the letter sent out by Russ Felker, Leslie Omlin, and Marvin Clinesmith soliciting funds for their golf event in Corinna's memory. The first annual "Drive Fore" Cancer consisted of a golf outing for adults on Saturday and, as the

nine-year-old Corinna was an avid golfer, a children's golf day on Sunday. Above, from left: Russ Felker, Marvin Clinesmith, Roxann Sherwood and Jeanette Coppersmith.

Below left: Corinna Felker. Below right: Amateur 13-18 year old golfers at the Children's Golf Day.



Madeline's Heart October 16, 2004 Mountainhome, Pennsylvania

When Kristen Kojeszewski decided to have a fundraiser in honor of her daughter Madeline, she got very busy very quickly. First she created little bear keepsakes and other craft items to sell. Then she and her husband Kevin called dozens of area businesses and asked them to donate goods and services to the cause. Their community was tremendously supportive and the Kojeszewskis were quite overwhelmed with the response. They also



sold baked goods and held a raffle. Madeline, the four-year-old survivor of a juvenile pilocytic astrocytoma, had a great time! Above, clockwise from left: Kristen, Ben, Kevin and Madeline Kojeszewski.



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Meet our New Friends!

See inside for details...



Coming Attractions

March 2, 2005

A Night of Laughter 5
Gotham Comedy Club, NYC

May 2005

Brain Tumor Action Week

May 25, 2005

Third Annual Dream & Promise
Awards Dinner
New York Marriott Marquis

June 2005

10th Annual Dinner Dance

July 2005

Fifth Annual Kids Cruise

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