Children's Brain Tumor Foundation

The challenge

Embracing
the challenge
today gives
hope for
tomorrow

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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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Message from the President


Joel Shiff

As the Children's Brain Tumor Foundation honors its fifteenth anniversary, I find myself thinking of both our humble beginnings and our exciting future. It's hard to imagine that those few parents and doctors who got together in 1988 could have dreamed that their idea would grow into a national organization giving out over $1,000,000 for research grants and family support programs. Or that CBTF would hold a glittering fundraiser, *The First Annual Dream & Promise Awards Benefit*, at the New York Marriott Marquis, which would go on to raise over $600,000 in one night.

This year we have increased our awards for research by 50%, and will be giving out $900,000 to six prestigious institutions across the country. We have also been able to expand what we do for families. This year alone, we have sponsored a full week for children with brain and spinal cord tumors and their families at idyllic Camp Sunshine up in Maine and given $55,000 to the Friends of Karen to provide financial support for other families dealing with this challenging disease. We have also just published our first children's book, *Parker's Brain Storm*, which will serve for newly diagnosed children as an introduction to the world of the hospital.

Everything we do is made possible by the generous folks who respond so enthusiastically to our fundraising efforts. That said, I look forward to seeing and hearing from you in 2004 at such events as *A Night of Laughter 4*, *The Second Annual Dream & Promise Awards Benefit*, *The Ninth Annual Dinner Dance*, *The Danny Jegle Open* and *The Big Apple Circus Benefit*. You can find all the details on the back page of this newsletter.

Looking back over my first year as board President and looking forward to the next, I feel a great deal of pride for all CBTF has accomplished so far and a great deal of enthusiasm for what lies ahead.

Best regards,

Joel Shiff

Joel Shiff

It is with great sorrow that the Children's Brain Tumor Foundation acknowledges the passing of one of the most remarkable people it has ever had the privilege of associating with: **Nicholas Leone**. For six years, Mr. Leone donated the services of Jericho Terrace, his beautiful reception hall on Long Island, to host the CBTF Dinner Dances. His generosity allowed the event to be established as one of CBTF's most important fundraisers. Since the first one in 1996, the Dinner Dances have raised nearly $2 million.

To honor this great man, who did so much for the children and families we serve, CBTF has permanently named a research grant in his memory.

Why Am I an Advocate?

MORE THAN JUST WORDS

by Craig Lustig

Photo by Nancy Nichols Jagelka

Speaking Out: Craig Lustig in Washington, DC, October 1997

The cancer experience comes with its own lexicon. Like most people diagnosed with cancer, I was confronted with learning a medical vocabulary and a dictionary of acronyms in a short and stressful period. As I underwent surgery, chemotherapy and radiation therapy, family, friends and medical professionals caring for me supported me with words and phrases providing hope and encouragement. Trudging through each round of chemo I was bravely "hanging in there," and a "trouper." Towards the end of radiation therapy, I was "winning the battle," "beating the odds."

At the end of active treatment, I heard words suggesting that cancer was not simply a disease I had overcome. People talked of "gaining perspective," "finding the silver lining," and even "the gift of cancer." Of course cancer isn't a gift, and my struggle to beat the disease wasn't valiant or the feat of bravery. But the cancer experience changed me and served to motivate me to become an advocate for other people facing cancer.

As a young survivor, I needed to redefine my personal and professional life after cancer. Learning the language of cancer and the challenges of navigating and coordinating health care systems was an education I felt could be helpful to share with others. Support from family, friends and so many others was an important part of my healing. Sharing that same support with other patients and their families, especially as a survivor, was and is an important role for me now. I know it helps others, and it provides a sense of satisfaction for me.

The lessons and encouragement I received throughout my cancer experience have also enabled me to represent patient interests in many medical research forums. I am called on to speak about important national research and healthcare policy issues from the cancer survivor's perspective. And I am honored to serve patient organizations, like the Children's Brain Tumor Foundation, which funds research and provides education and support for children with brain tumors, survivors and their families.

The words of my cancer journey have instructed, supported and strengthened me. It is a privilege to share these lessons with others and to work to use my experience to aid the next person in the cancer journey.

Craig Lustig is Director of Survivorship Programs at the Children's Cause and a board member at the Children's Brain Tumor Foundation

Did you know?

In 1997, Craig Lustig was featured in an article in the Daily News called *Getting to the Heart of Cancer Fear* by Patrice O'Shaugnessy.

Here are the first couple of paragraphs: "When he was diagnosed with brain cancer at 28 years old, Criag Lustig was an advertising account manager, a hotshot in a highflying profession, pitching everything from coffee to cold remedies.

"He underwent surgery and chemotherapy, and then Lustig left the advertising world, not because the brain tumor made him sick, but because it gave him a robust resolve to do more meaningful work.

" 'It tapped into something in me...now the idea of helping others is a central part of my life,' said Lustig, now 33 and studying health care policy at Columbia University, hoping to change the system to benefit the ill, especially children."

Later in the article, Craig discusses the recurrence of his brain tumor: "When it came back, it was scarier. The first time you think, we have the technology, the best medical science, we can take care of this, but then it happens again.

"I can't plan for a third time."

Fortunately, Craig has been cancer-free since 1994 and his "robust resolve" to help others has not weakened. Besides his work for CBTF, Craig is one of the masterminds behind Brain Tumor Action Week and is now the Director of Survivorship Programs at the Children's Cause.

Meeting and Greeting: On Tuesday, May 4, advocates from CBTF met with the Honorable Carolyn Maloney, Representative from New York. Left to right: Jeremy Shatan, David Hendricks, Judy Hurley, Carolyn Maloney and Bob Budlow.

BRAIN TUMOR ACTION WEEK

On May 4, members of both the CBTF board of directors and staff traveled to Washington, DC to participate in Brain Tumor Action Week (BTAW), hosted by the North American Brain Tumor Coalition (NABTC). This year advocates from across the country visited Capitol Hill to urge legislators to:

- Provide federal support for a research assault against brain tumors.
- Fund the Benign Brain Tumor Cancer Registries Amendment Act.
- Support S. 303, the Human Cloning Ban and Stem Cell Research Protection Act of 2003.
- Support legislation to waive the two-year waiting period for Medicare eligibility.
- Request that a permanent director be named to head the National Institute of Neurological Disorders and Stroke.

Details on these positions, as well as other information about BTAW, can be found at www.nabraintumor.org.

Increasing the Reach: National Advocacy and CBTF by Susan Weiner, Ph.D

Photo by Nancy Nichols Jagelka

Loud and Clear: Susan Weiner in front of our nation's Capitol, speaking at a Brain Tumor Awareness Week rally.

Fifteen years ago, a national advocacy voice of families and survivors for children with brain tumors was lacking. Support services and educational materials for families and children were scarce, pediatric brain tumor research funding for local academic medical centers was thin, and the 50-60 percent survival rate for children with brain tumors had remained nearly constant for twenty years.

Dramatic changes have come about since then. Leadership from past and present Children's Brain Tumor Foundation (CBTF) board members and staff has helped ensure that the voices of patients, families and survivors are now heard in Congress and in federal agencies responsible for funding research and approving new treatments. In 1991, CBTF helped start a federation of nonprofit brain tumor organizations, the North American Brain Tumor Coalition (NABTC), to do what no one group could do alone. NABTC, which includes organizations that serve adults and children, came together to focus on national issues of common concern to brain tumor patients and their families. As a founding member of NABTC, CBTF has been a powerful national advocacy voice for children and families.

As advocates, we learned the lessons of AIDS and breast cancer advocates — how to lobby Congress and how to draw from our personal experiences to voice the larger concerns of our constituency of patients, families and survivors. As NABTC policy positions and activities grew, CBTF advocates helped shape its annual Brain Tumor Action Week in Washington, speaking at rallies and educational panels. In recent years, CBTF has produced "The Faces of Brain Tumors," a poignant volume of pictures and stories from patients, survivors and families for NABTC advocates to distribute on Capitol Hill.

Our New York research grant giving and fundraising gave us insights on how important increasing the federal biomedical research budget is to improve the outlook for brain tumor patients. We brought the message of brain tumor patients' dire need for more rapid treatment progress in testimony before Congress, to the National Cancer Institute (NCI) and the Food and Drug Administration (FDA). Members of CBTF helped craft the groundbreaking National Institutes of Health "Brain Tumor Progress Review Report," which charted brain tumor research needs over five years. At NCI we have served on advisory panels, as reviewers of grant applications, and as mentors of other advocates. We support the Pediatric Brain Tumor Consortium, an NCI-funded network of 10 children's hospitals and academic centers dedicated to bringing novel therapies to children with poor prognosis. At the FDA we have testified, participated in committee hearings and served as reviewers of new treatment strategies.

Our issue advocacy broadened and deepened as we learned the ways of Washington. We advocated for better healthcare for children and families by endorsing insurance coverage for the routine costs of clinical trials and for children's access to specialty care. We also collaborated with the brain tumor community to ensure congressional passage of a bill to include data on benign (slow growing but damaging) brain tumors in cancer registries for a more complete picture of these difficult disorders.

More recently, CBTF also became a charter member of the Alliance for Childhood Cancer, a coalition of professional and patient advocacy groups focusing on national policies affecting children with cancer and their families. In this forum, we helped bring policymakers' attention to the palliative and end-of-life care needs of pediatric brain tumor patients, which will receive increasing attention from Alliance members over the next year. While the number of children surviving brain tumors increases, many are left with persistent and sometimes debilitating cognitive late effects of treatment and disease. As national attention turns to childhood cancer survivors, CBTF advocates will make sure that the special needs of pediatric brain tumor survivors are included.

As we look to the next decade, CBTF will work vigorously to encourage research on pediatric brain tumor treatments that are less toxic and more effective, and new science will yield insights into the mysteries of prevention. As an influential national voice for pediatric brain tumor patients, survivors and their families, CBTF can be proud of its record of vigorous advocacy over these past 15 years, and of the growing number of articulate, responsible advocates in its ranks. If you are interested in participating in national brain tumor advocacy, call the CBTF office at 212.448.9494.

Did you know?

In 1991, current board member Susan Weiner and former board members George and Kathy Poteat went to Atlanta for a meeting of various brain tumor organizations. Here's what went on, as recorded in the minutes of CBTF's May 1991 board meeting: "The attendees at the meeting voted to form the North American Brain Tumor Coalition (NABTC). George made a motion, seconded by Miriam [Barry], that we endorse the formation of the coalition and our membership in it, which the group approved. Other items accomplished at the Atlanta meeting included:

- Officers of the coalition were elected and committees were established; George and Susan will chair the Long Range Planning Committee.
- A mission statement was developed.
- The formation of a Central Brain Tumor Registry was approved. This will permit the development of statistics on the incidence of brain tumors: children will be specifically included as a sub-group in these statistics."

Parent's Corner

A Mother Looks Back

By Miriam R. Barry

It was nearly fifteen years ago that I found myself in the unenviable position of discussing my daughter's newly diagnosed brain tumor with the top pediatric neuro-oncologist in New York.

"There's not much we know about ependymoma," he said. "All we have is a bunch of journal articles, maybe a hundred or so. There just isn't that much research going on in brain tumors. We'll treat it as best we can, and hope for the best."

"And her chances for survival?"

"We don't know. Maybe fifty/fifty."

This was how I learned about the state of affairs for pediatric brain tumors in 1988. My child, just 12 years old, now faced the certainty of chemo and radiation following a difficult surgery. She also faced a very uncertain future; it was incomprehensible.

How could my child have cancer, and how could the medical establishment offer so few treatment options with such a vague prognosis?

I consulted with experts all over the country but I couldn't find the certainty I sought anywhere. I called an old family friend in Boston who was renowned for studying rare pediatric conditions, to help me get things into perspective.

"Miriam," he said, "You're worried about her quality of life in 10 years, but if you don't treat her now, she won't be around in ten years."

We plunged ahead with treatment because we had no choice.

It was at this critical juncture that we found CBTF – or rather CBTF found us. It was newly formed by parents just like me, parents whose children were struggling with terrible brain tumors. We all felt the same; there must be better options for our children. And if they didn't currently exist, we had to make them exist. The only way to make that happen was to fund research, very little of which was being done in pediatric brain tumors at the time. Research takes money, and that was where we began.

This point was brought home to me by something I experienced about a year after my daughter began treatment. I had the opportunity to speak with the mother of a fourteen-year survivor of medulloblastoma, which was treated similarly to ependymoma. Her son had been left seriously damaged by his treatment and several complications, but he was a survivor. Over the course of our conversations, I discovered that her son had pioneered the treatment that my daughter received. While I was happy that the treatment had given her son such longevity, I was dismayed to learn that in fourteen years, treatments had not much changed. At CBTF, we had our work cut out for us.

Our first office was housed in a member's extra bedroom upstate, and was staffed by volunteers. Early meetings were held wherever we could find donated space. Meetings with serious agendas were interjected with conversations about how to handle chemo treatments, and where there were summer camps for kids with cancer. At first, all we did was raise money. This was followed by the far more difficult task of deciding how and where to spend it so it could have an effect. Committees were formed, ideas thrown about, recommendations made, and motions passed. Each step we took was a learning experience, and we got better at it as we learned more. As I struggled with my own child's diagnosis, I found our gatherings cathartic. I could share my concerns, but I was also doing something concrete to make a difference.

A Mother's Love: Miriam R. Barry has been on the board of CBTF since 1989, when she attended the first Big Apple Circus benefit. She has served as President and Executive Vice President.

We were all aware that what ever impact we would have on brain tumor treatments would likely occur too late to benefit our own children. It really didn't matter. Certainly someone else's child would benefit.

Along the way there were triumphs and setbacks. We cheered our survivors and deeply

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Did you know?

In 1990, Miriam Barry represented CBTF in a letter published in the October issue of Discover magazine. In it she eloquently wrote: "... the term *benign* doesn't always mean 'cured.' Many benign or low-grade tumors recur in the brain or spinal cord at a later date, necessitating further surgery. Sometimes these relapses occur at inoperable locations and may not respond to other treatments for brain tumors, which include radiation and chemotherapy. In addition, brain tumors and their treatments can leave a host of residual side effects in the patient, ranging from such problems as minor memory loss to more serious neurological deficits, seizures, and infertility."

She also said: "In spite of recent breakthroughs in many cancers, such as some forms of leukemia and Hodgkin's disease, brain tumors continue to have a high fatality rate. In fact a child diagnosed with a brain tumor has only a 30 percent chance at being cured. Those odds are only a touch better than those for adults, which are a scant 20 percent.

"[Your] article calls attention to a most devastating illness. Anyone who has been affected by this diagnosis in a family member knows all too well the emotions that the author so poignantly describes. We fervently hope that someday the term *brain tumor* will no longer spell unequivocal disaster."

Fortunately, some of what Miriam wrote about has changed. For example, survival rates have improved for many tumor types. Of course, benign tumors can still be deadly and the diagnosis of a brain tumor can still mean catastrophe for families.

STRIVING AND THRIVING

A Virtual Panel Discussion Among Young Survivors

Thanks to improved treatments, more and more kids who have or have had brain tumors are going to college. Surgery, radiation and chemotherapy can lead to a variety of challenges so we thought it would be valuable to talk to some young survivors about their experiences in higher education. For this article we spoke to a great group of people who are recent graduates or who are still in school. They were Regina Epperhart, Andrew Karasek, Ron Scotto, Iva Segalman, Zach Steinhorn and Mischa Zimmerman.

The first thing we asked was whether there were any instances during their college experience where by receiving some sort of accommodation, they lost out on something else given to others who did not need the same exception.

Zach, an 18-year-old freshman at New York University, responded vociferously as he related the ins and outs of setting up his living arrangements for his sophomore year. "I am now in the process of thinking about my dorm choice for next year," he said, explaining that due to NYU's lottery system, most sophomores are put into dorms at one of two locations far from the main campus. However, they do usually get to choose their roommates. "Due to the problems with my eyesight," he said, "neither location would ever work for me since both are very far from campus and have no dining services. So after discussing this with the housing and disability offices, I have been told that I will get one of three dorms which are all within walking distance of classes. However, in order to get these dorms, I basically have to lose my right to choose to be with two friends I would like to room with since they have no special needs. Over the past couple of weeks, I have been thinking a lot about this situation and it makes me angrier every day. Being in walking distance to campus is not a choice for me. It is a necessity. Why should I be prevented from being with my friends?"

Iva, a 24-year-old who recently graduated from the Pratt Institute with a Bachelor of Industrial Design degree, decided to avoid the whole issue. "I never used any official accommodations to attend college," she said, "I was afraid that this might negatively reflect on my accomplishments. However," she went on, "from the start my college experience was profoundly affected by my needs as a student. The first was the walking. All told, I'd say I visited ten schools. I reluctantly turned down the best colleges in my field due to campus sprawl, stairs, and campus geography. At one school there was a 20+ minute all-terrain hike from the dorms to North Campus. Then the college that was considered the 'best' in my field was built on a steep hill. Although I have little trouble walking, if there is an icy, steep hill, I'm toast."

Iva also found that not all colleges are prepared to accept students with disabilities in every way possible. "None of the colleges were equipped with everything: no exterior stairs or ramps, working elevators, parking lots near buildings, or accessible supply stores on campus. There was a lot of compromising." Like many people who were treated for childhood brain tumors, Iva did not grow as tall as she might have. Her small stature became an issue when she chose to get an industrial design degree. "While my department promised help carrying and building my large projects and storing my work at school, as it turned out, words were cheap. It took so long and so much cajolery to arrange and get simple assistance, it became emotionally draining as well as a major time-sink." She resorted to paying other students to help her and found them treating her as if they were doing her a big favor. "My solution was to take my curriculum in hand and make it as manageable for me to do on my own as possible. I became an expert in working in the small scale." She also learned to say "no" and mean it to assignments that could not be scaled down. "So I can't do everything," she said, "I was penalized for this small mutiny grade-wise a few times but, oh well. I'm much happier, and my work is better for it."

> " My battle with cancer has undoubtedly shaped who I am today and is an important part of me, but it is by no means all there is to me. "

Andrew, a 19-year-old freshman at Stanford and Mischa, a 20-year-old attending New York University, did not feel as strongly about this issue as Zach and Iva. "Accommodations were beneficial for me," Mischa said, "even though I had to ask for several myself." Andrew has not received many special accommodations, although he will be getting placed into a specific type of room for sophomore year. This, he explained, has an unintended benefit: "Through this, I will not enter the regular housing draw, which I am told is a pain."

Many survivors take longer to complete their college degree, due to taking fewer classes per semester, missing school for periods of time, etc. We asked our group how they and their family have dealt with the increased expenses and other issues that resulted from this.

Regina, who is now 22 and graduated from Bucknell with a psychology degree, had this to say: "Due to my learning disability, I was taking a reduced course load through most of college. In the summers, I would take college courses at local colleges, which were also less expensive than my college." She was also lucky to receive scholarships from Rotary and Kiwanis clubs for working towards a degree while having a medical condition. "I chose to use that money to purchase a laptop computer so I could use my computer to take notes during class." Regina also mentioned that some schools charge the same tuition regardless of the number of classes taken, which could increase the expenses for students taking reduced course loads. "I know of students who spoke with the deans," she said, "and were able to reduce their tuition because they were taking a reduced course load due to their medical history."

Iva took longer to get her degree for a very common reason: Indecision. "I started in engineering and then changed my mind and switched majors midway through. I had to start all over, in a new school that offered the degree I wanted. What can I say for myself? It seemed like a good idea at the time." She was able to do this because of the excellent scholarships she had right from the start. "I filled out every scholarship application I

could find," she said, "Not only did I win a full ride to my state school, I earned many grants and departmental scholarships besides. This served not only to earn me money for school, but proved to distinguish me from the masses. I had mentors galore and found some ready-made friends in my fellow scholarship recipients."

> "If I feel isolated, I just go find somebody and talk to them. Try and relate my feelings. Feeling isolated doesn't solve anything."

Although he is not sure how long it will last, Mischa was also the lucky recipient of a good scholarship, from Kellogg's, which was presented to him on an episode of The Rosie O'Donnell Show. Andrew's treatment actually began only recently so he and his family do no know what impact it will have on his college expenses. "We understand that I may need extra time to finish my major if I choose something demanding like mechanical engineering, though," he said.

A major issue for these kids is feeling isolated from their peers, because their experience has been so different. We asked our group how they have dealt with those feelings.

Iva was quick to respond: "Of course I've felt isolated from other people because some of my experiences have been unusual, making them hard to share. Just getting by has been more difficult for me than some," she continued, "This makes me more interested in becoming friends with people who are a bit uncommon...not only do they sometimes understand me better, they are so much more exciting to talk to. Easy is boring."

Andrew has a simple solution. "If I feel isolated, I just go find somebody and talk to them. Try and relate my feelings. Feeling isolated doesn't solve anything." He also mentioned that although he had met other students with brain tumors at Stanford, that was not enough to make him fast friends with them.

Regina took advantage of a wide variety of services to deal with her situation. Having undergone treatment just 15 months before starting college, she was not surprised to feel separated from the other students. "I made use of the on campus counseling center to discuss these feelings," she said, before going on to say that she learned that more than 50% of the students on her campus went to counseling at some point during college, "so I didn't feel so isolated! Additionally, I attended support groups specifically for teenagers with brain tumors organized by Making Headways. The support group was very helpful for preparing both academically and socially for college. Group members who were in college gave great pointers on how to deal with issues that might arise; for example, when to tell friends about the tumor, parties, roommates, and speaking to professors about special academic needs."

Ron, who graduated at 29 from Rutgers with a bachelor's degree in Mass Media & Communications, had a very positive take on the question. "Absolutely," he said, "but isolated in a good way. Without question, my battle with, and ultimate triumph over, brain cancer brought me a sense of perspective in life and appreciation for the opportunities (scholastic or otherwise) that life affords us every day. I just knew that my cancer experience granted me a view of the world, and my place in it, that others could not truly appreciate."

> "The support group was very helpful for preparing both academically and socially for college."

Zach found college an improvement over the high school scene. "It is easier to have a social life in a dorm setting," he told us, "where eating dinner with friends, working in study groups, or watching sports on TV with floor-mates comes naturally. I have found that people in college are simply more accepting of differences than those in high school. With maturity comes acceptance, I guess. At times, I still feel a bit isolated as I often do not share the popular college fascinations with going out drinking or the 'club scene'...not yet."

Mischa's inability to walk has made it physically impossible to be with his peers at times, a situation which he has simply had to accept. "I have learned to deal by doing things that I can on my own like watching a movie or making phone calls."

Finally, we asked our panel how much, if any, of their story they revealed to other students before getting to know them.

Both Mischa and Ron answered quickly, saying "As much as they want to hear." "Mine is a story of great personal triumph," Ron continued, "I know how fortunate I was. I know that I could not have done any of it by myself. The truth is, I am proud. Through conversations with several wonderful doctors, surgeons and nurses, I gained a strong understanding of the odds that were stacked against me… People, some almost complete strangers, have told me that my story is very inspirational. Some people just stare at me and shake their head in disbelief. Others have just thanked me for sharing it with them. Others still, are scared or uncomfortable asking me about it." He finished by saying, "I'll talk about my cancer all day to complete strangers. If they don't want to hear it, it's their loss."

Regina played it a little closer to the vest. "Usually I would not discuss my story with other students until I became friends with them. Before bringing up my story and medical history, I would usually talk about how I volunteer working with kids with cancer, to get a sense of their reactions. In general, I don't have a specific timeline or perfect situation when I disclose my story. It is usually done on an individual basis based on how comfortable I am with the person. Once I got to become better friends with some of the students, then I would disclose that I had a learning disability because I had a brain tumor. Sometimes that was a good icebreaker to discuss my story."

When Andrew started school, he tended to lay his cards on the table. "When I first moved into the dorm," he told us, "I ended up telling some people right away, like my roommate. Because I am so tall, I get asked if I play sports for Stanford. To respond, I give part of my story, the fact that I have severe exercise induced headaches. Sometimes I use that as a

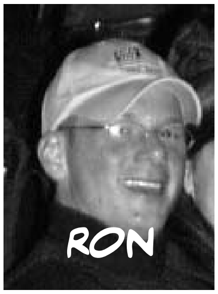
Continued on next page

Striving and Thriving–continued from previous page

transition into the brain tumor, but that's usually if I already know the person. I have no problem telling strangers or slight acquaintances that I have a brain tumor. It just doesn't come up much, and if I bring it up myself I think it sounds very strange, like I'm bragging or something."

Iva found that sometimes revealing too much information could lead to negative consequences. "Okay, it's all a learning process," she said, "Telling no one feels almost impossible since it's such a big part of who I've become. Sadly, I'm finding it necessary. Instructors and school administrators thought I couldn't handle the load, often suggesting that I either drop out or choose another major. Students thought I'd missed out on life by being 'sick' and didn't have their wisdom. As if what? As if I'd spent years cryogenically frozen? Everyone mistakenly believed that I'd been given special consideration just to get into college (by affirmative action perhaps). Since I've always been a good student, I've found that there is nothing more aggravating than having to go the extra mile to prove myself worthy to half-wits."

Even after graduating, Iva has found that people can be scared off by her history.



"Now, job interviews are sketchy because I went to college through a lot of health crises and I'm really proud of it, but I made the stupid mistake of saying so at a job interview. The woman went from, 'How soon can you start?' to 'I'll be getting back to you after I see some other people….' I'm open and talkative and have gotten myself into the sticky situations I've just mentioned, so certainly now I think holding your tongue is a smart move."

> "I'll talk about my cancer all day to complete strangers. If they don't want to hear it, it's their loss"

For Zach, the question pointed to the bigger issue of how he sees himself. "I have stayed away from sharing the details of my past with others before really getting to know them," he told us.

"Once you develop a relationship with someone, I think it is beneficial for them to know about your story as they will understand and possibly even help you with the difficulties that you may presently face (in my case, vision). However, I would never feel comfortable openly sharing this information with anybody, as I would never want my identity as a cancer survivor to overshadow my identity as 'Zach.' My battle with cancer has undoubtedly shaped who I am today and is an important part of me, but it is by no means all there is to me."

In a way, Zach's final comment summed everything up. Though these young survivors have had different experiences than their peers and have been changed by them, they are in most ways the same as the other kids on campus. They want to meet compatible people who will accept them for who they are and they want to succeed in the world. Not so much to ask, it would seem, and surviving a brain tumor could lead anyone to believe that anything is possible!

Teens: Join CBTF's telephone support group! Call 866.228.HOPE for more information.

Parent's Corner–continued from page 5

mourned the children we lost. One of our early members arranged to film a fund-raising video. Four children were chosen to appear in the video, and my daughter was among them. By the time the production was complete, three of the children had died of their tumors or treatment.

My daughter was the only survivor of the group.

Over the years, I, along with other volunteers, spent a lot of hours on the phone with parents of kids with brain tumors. For me, it was a way of giving back, but it was also one of the most difficult things to do. I got to know so many parents and caregivers over the years, people whose faces I didn't know, but whose familiar voices spoke of my own uncertainties and fears. Sharing our concerns, we recognized that the situation could always change for the better or for the worse.

I remember one particular family that stands out as being characteristic of many the families we dealt with. A grandmother who had spoken with me many times about her young grandson and his tumor sent a thank you letter to me, and included the program from the child's memorial service. I held his picture in my hand and I thought of the devastation of his loss, the bereaved family, and of the boy who would never grow into a man. As difficult as that moment was, I felt grateful to the grandmother for allowing me to share her grief.

There were many such moments over the years, and I was often asked why I continued to speak with families and share my story and experience, since it was so painful for me. As the mother of a child in "continuous extended remission," I felt I needed to encourage parents to have hope, to help them pursue proper treatments, and to find support where it was available. It was not medical treatment or financial support, but it was a hand reaching out to lift up the family. By doing this, I was lifted up in turn. These families, *our* families, were the reminders of the urgency of our work.

As I look back on CBTF's early days, it amazes me to see what we have become. We have evolved from being a local volunteer group to a professionally staffed organization with national influence. Most importantly, we have witnessed a change in the way pediatric brain tumors are treated and have funded some of the research that has caused that change.

And the 12 year old child diagnosed in 1988? She is now a young woman, a wife and a mother. I am awed by the miracle of her survival. My colleagues on the CBTF board and staff share that joy with me, as we move forward together, continuing to change the world of pediatric brain tumors for the better. We will do so until this work is no longer necessary.

Parents: If you have other insights, ideas, or questions feel free to send them to the Children's Brain Tumor Foundation at 274 Madison Avenue, Suite 1301, New York, NY 10016, or send an email to info@cbtf.org.

CBTF's Biggest Program

SCIENTIFIC RESEARCH GRANTS

Passion. That is the guiding force behind CBTF's scientific research grants program. The passion of families who have lost children to brain tumors, still dealing with feelings of grief, not wanting tragedy to strike another family. The passion of those with surviving children, hoping to make treatments easier for their own children and for others in the future. With this in mind, a new grant was created: the *Inspiration Award for Pediatric Brain Tumor Research*.

The passion of the Heisler and White families inspired each of them to hold events in 2002 to raise money for research. The dollars they brought in funded the *Inspiration Award*,which was given to Dr. Peter Canoll's for his project, *The Role of Eph-Ephrin Interactions in Glioma Migration*.

Dr. Canoll is an Assistant Professor at Columbia University and he proposed to study how certain molecules may guide the infiltration of cancer cells into the brain. Using time-lapse videomicroscopy, Dr. Canoll will monitor glioma cells migrating in living slices of rat brain. Then, using molecular and pharmacological techniques, he will interfere with the signaling that triggers the infiltration, which will hopefully affect the migration of glioma cells and lead to improved treatment strategies for pediatric gliomas.

Peter Canoll, M.D., Ph.D.

Other grants were given to:

- Robert Wechsler-Reya, Ph.D., Assistant Professor, Duke University Medical Center for his study, *Molecular Evolution of a Brain Tumor: Analysis of Pre-Tumor Cells in Murine Medulloblastoma*;
- Michael Sheldon, Assistant Professor, Texas Children's Cancer Center for his study, *Detection of Chromosomal Imbalances in Pediatric Ependymoma*; and

Charles Eberhart, M.D. Ph.D., Instructor in Pathology, Johns Hopkins School of Medicine, for his study, *Analysis of Notch Signaling in Medulloblastoma*.

Grant renewals were given to:

- Ganjam V. Kalpana, Ph.D. of Albert Einstein College of Medicine of Yeshiva University Department of Molecular Genetics for her study, *Gene Expression Profile Analysis to Study the Tumor Suppressor Function of INI1/hSNF5 in Atypical Teratoid and Rhabdoid Tumors*; and
- Corey Raffel, M.D., Ph.D. of the Mayo Clinic and Foundation for his study, *Murine Modeling of Human Medulloblastoma*.

After her first year of funding, Dr. Kalpana had this to report: "Our studies illustrate that gene expression profile analysis of tumor-derived cell lines is an excellent means to determine the tumor suppressor mechanism and underscore the importance of the method in devising effective and novel treatment strategies for AT/RT tumors in a highly informative way."

Dr. Raffel told us, "In the past year, with the help of the CBTF grant, we have continued our work on manufacturing murine models of medulloblastoma. Our project involves making a mouse line that expresses the avian retrovirus receptor in the developing cerebellum. After we have successfully developed this line, we will infect the cerebellum with avian retroviruses containing genes that we think will cause the mouse to develop medulloblastoma. At this time, we are injecting our receptor construct into mouse embryonic stem cells. I anticipate that we will have no difficulty in developing the proposed models in the second year of funding. I am most appreciative of the support given by CBTF."

Photo by Paula Scott

Grant Group: At the 2002 Research Grants Award Reception in November, CBTF board members were proud to pose with two of the scientists who received funding. From left to right: Current board President, Joel Shiff; Professional Advisory Board Chair and Professor at the NYU School of Medicine, Dr. David Zagzag; grant recipient, Michael Sheldon, Ph.D.; grant recipient, Robert Wechsler-Reya, Ph.D.; former board president, Nora Leary; and Executive Director, Judy Hurley.

The White family (L–R: John, Nicholas & Patty) has held two golf tournaments in memory of their son, Jonathan Patrick White, raising nearly $50,000 for CBTF's scientific research grant program.

Here's Meghan Heisler with a very special friend. Her mom and dad, Shannon & Terry, recently had a dress-down day to raise money for research.

Camp Sunshine

In late June, 2003 about 40 families from across the country went to Casco, Maine for a week at Camp Sunshine when CBTF sponsored the first program there exclusively for families dealing with brain and spinal cord tumors. Neil O'Brien, Jr. (above) was one of the happy campers, along with Alexis and Nicole Ronco (below). Tracy Moore, CBTF's Director of Patient Education and Support Services was there to witness the activities, which included everything from a "date night" for parents to canoing. "Some of these families had never met anyone else with a brain tumor so it was truly remarkable to watch everyone bond together," she said.

Campsunshine.org has a lot more info.

Eventful Days and nights at CBTF

THE EIGHTH ANNUAL DINNER DANCE

Friends In Deed: Michael J. Forde, the Executive Secretary–Treasurer of the New York City District Council of Carpenters was the honoree at CBTF's Eighth Annual Dinner Dance, held at Jericho Terrace on June 19, 2003. Mr. Forde, at far left with Peter Thomassen, President of the Disctrict Council, attracted quite a crowd and helped raise over $300,000 for CBTF!

The Big Apple circus is all about family!

Photographs by Tom Haynes

Happy Together: Benefit Committee member Andrea Hirsch, far right, with husband Charles and children Alex and Jennifer. In May, 2003, Alex celebrated his seventh birthday and a clean MRI!

Them There Eyes: Little Chase Carlucci, seen here with his dad, Michael, seems permanently surprised by the hilarity he witnessed under the Big Top!

Smile for the Camera: Rob and Marianne Ziegler, came with Seth and Luke, two of their surviving children.

BIG APPLE CIRCUS

Kids Cruise 2003

Ahoy There! This year's Kids Cruise was sponsored by the Mark R. Harris Foundation. Brian Harris (left), with Judy Hurley and friend, brought a bunch of volunteers to the event and saw all the smiling faces!

THE FIRST ANNUAL DREAM AND PROMISE AWARDS BENEFIT

Pioneering Neurosurgeon: On May 29, 2003 CBTF paid special tribute to world-renowned physician Dr. Fred Epstein by presenting him with the *Pioneer Award for Pediatric Neurosurgery.* On the left is his wife, Cathy, and on the right is Alan Abramson, who spoke movingly of Dr. Epstein's treatment of his son before presenting the award.

Troubadour: Peter Yarrow of Peter, Paul & Mary was the Master of Ceremonies at this very special evening. His humor and music kept the program at the New York Marriott Marquis going. He even led the distiguished crowd in a rousing sing-along of that old favorite, *Puff the Magic Dragon.*

Sold to the Highest Bidder: Leila Dunbar, auctioneer extraordinaire from Sotheby's New York, donated her services and made the evening's auction a rousing success. High rollers bid on such items as a portrait painted by Peter Max and a birthday party at Toys R Us in Times Square. The event raised over $600,000!

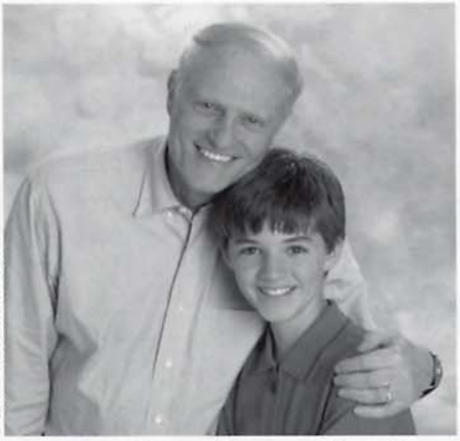
HOLE IN ONE!

Fore! Tim Jegle, CBTF board member, and his wife, Patricia, are behind the **Danny Jegle Open**, the enormously successful golf outing they hold in memory of their son. The Fifth Annual, held at Hempstead Golf & Country Club on October 20, raised over $60,000 and featured a 50/50 raffle and a raucous live auction in addition to 18 holes. Danny certainly would have been proud!

SHOW ME THE FUNNY!

Third Time's the Charm: Bob Budlow (left), CBTF board member and Chair of the Young Professionals Group, with Marion Grodin, who hosted **A Night of Laughter 3** at the Gotham Comedy Club on February 5, 2003. The event was completely sold out and raised nearly $6,000 for CBTF! Many thanks to Chris Mazzilli and his staff for welcoming CBTF and making sure everything ran smoothly. Thanks are also due to all the Young Professionals Group members for inviting friends and family.

GOTHAM COMEDY CLUB New York City



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Dear Friend,

Children are my heroes and my teachers. My work with them over the past 30 years has given me a window into the extraordinary strengths that we all had as children—especially courage, resilience, and perseverance. I'm convinced that children who have faced and overcome adversity can be role models for us adults as we face obstacles in our own lives. We all wonder what we're made of. These kids have been tested in ways that most of us can't even imagine. They're not just survivors—they're thrivers. *If I Get to Five* shares the lessons I've learned from these brave young people about facing life head-on, without fear and without inhibition.

This book is for everybody who has had to face a crisis, who has had to dig deep inside themselves to do what's hardest, to rebuild their lives, and to reclaim their dreams. I hope this book is as meaningful for you to read as it was for me to write.

Sincerely,

Fred Epstein

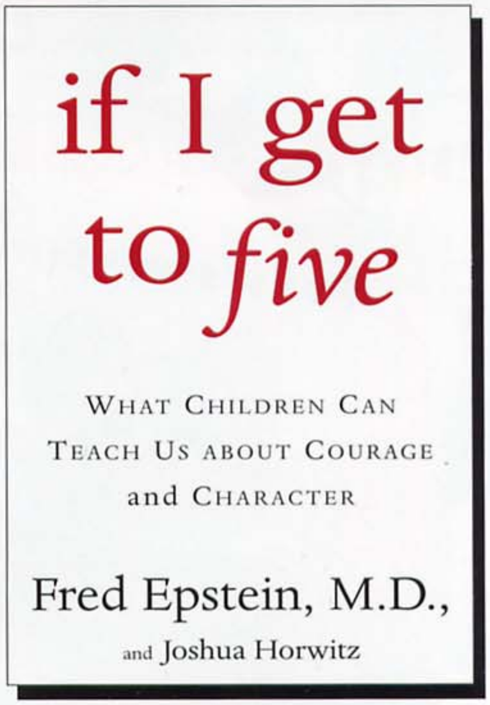
Fred Epstein, M.D.

"To shake hands with Dr. Fred Epstein is to be touched by an angel in a scrub suit."
—STEVE DUNLEAVY, *NEW YORK POST*

In *If I Get to Five*, world-renowned pediatric neurosurgeon Dr. Fred Epstein shares the life lessons he's learned from his exceptional young patients. Dr. Epstein credits these children as his most important teachers. "We tend to think of children as fragile, little people," he writes. "To me they're giants." *If I Get to Five* illuminates the stories and lessons that will help everyone in crisis—whether of body or of spirit—to expand their own boundaries of healing and learning. These lessons include:

- LIVE IN THE MOMENT
- FACE YOUR FEARS
- BELIEVE IN MIRACLES
- PLAY TO YOUR STRENGTHS
- LOVE WITHOUT BOUNDARIES

No one who reads this inspiring and uplifting book will ever look at children—or adversity—in the same way.



if I get
to *five*

WHAT CHILDREN CAN
TEACH US ABOUT COURAGE
and CHARACTER

Fred Epstein, M.D.,
and Joshua Horwitz

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"This book is a testament to the extraordinary depth, power, and resiliency of children's spirits. It is also a fresh reminder to all parents of what a precious gift each child is."—MARIAN WRIGHT EDELMAN, PRESIDENT, CHILDREN'S DEFENSE FUND

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CBTF's newest publication!

Written for young children, *Parker's Brain Storm* tells the story of a little bear who has a brain tumor. When he meets Dr. Spott E. Dogg, he learns about what is going on in his head and how surgery may help. Newly diagnosed children will get a clear picture of what lies ahead as their treatment begins and reading the book may help open a dialogue between parents and kids.

Coming Attractions

December 3, 2003

Teleconference: Childhood
Brain Tumors: An Update on
Survivorship

February 2004

A Night of Laughter 4
New York City

May 2004

Brain Tumor Action Week

June 7, 2004

The Second Annual Dream and
Promise Awards Benefit
New York Marriot Marquis

June 17, 2004

Ninth Annual Dinner Dance
Jericho Terrace, Mineola, NY

Summer 2004

Camp Sunshine Week
Casco, ME

July 2004

Kids Cruise
New York City

Fall 2004

The Sixth Annual
Danny Jegle Open
Hempstead Golf & Country
Club, Hempstead, NY

If you need support, call our Toll-Free Patient Support Number:

1-866-228-HOPE (1 -866-228-4673)