



Children's Brain Tumor Foundation

SPRING 2008

Letter from the President



Dear Friends,

As we mark our 20th Anniversary, I want to briefly reflect on our historical and recent achievements helping families with children with brain and spinal cord tumors. I hope you will know from reading this how much your help is valued and needed.

In our 20-year history, we have been able to award over \$6 million in research grants at leading institutions across the country. In a recent review of our researchers' efforts a number of grant recipients cite our funding as a starting point for continuing research in this field. Also, many report their research is cited by other researchers, an important measure of its importance to the field.

Also exciting to us is the launch of PRICE CBC, the Parents' Research Investment Collaborative to End Childhood Brain Cancer. With a re-commitment of support from the Licensing Industry Merchandisers' Association we are developing a multi-institution collaboration that will enable researchers to characterize and share pediatric brain tumor tissue samples and, in turn, identify genetic markers and pathways that can lead to treatment. The scope and depth of this effort is unprecedented.

We also make it our duty to see that children enjoy the best quality of life possible. In 2007, grants went to Camp Sunshine in Casco, Maine, which held two separate "Brain Tumor Weeks," a full week of therapeutic recreation and relaxation for children with brain or spinal cord tumors and their families. Jenna's Rainbow Foundation made the second of these weeks

possible. We also supported Friends of Karen that provides financial assistance to families facing pediatric brain cancer. In addition, we sponsored families attending the Big Apple Circus, sailing aboard Circle Lines' NYC Harbor Cruise and attending small-group events in the New York area.

A good portion of our efforts go into educating families. This year, the fourth edition of *A Resource Guide for Parents of Children with Brain or Spinal Cord Tumors* was distributed to over 1,000 parents, professionals and friends. In addition, the Foundation further expanded its web site and continued to provide toll-free counseling with social workers.

We also continued this year developing the Survivor Program to address the support, information and advocacy needs of survivors and their families. Thanks to a grant from the Sarah Chait Foundation we are organizing a first-ever week at Camp Mak-A-Dream in Montana for young adult brain tumor survivors.

The path has been a long one and will, in truth, continue to be. We will be here until our help is no longer needed, and we will strive to make that day sooner than later with urgency and commitment and passion. We thank you for your help to that end.

Robert M. Budlow
President
Children's Brain Tumor Foundation



The new musical *Hear Our Song* helped raise over \$30,000 on December 1st and 2nd at the Edgemont Theater in Scarsdale, NY. Everyone involved: the creators, writers, musical arranger, musical director, all talent, sound and lighting personnel, graphic designers, and publicist offered their time and talent free of charge.

Hear Our Song is a heartfelt and uplifting musical that reveals the universal stories and stages of life through the experiences of five remarkable women performed by Trish Rapier, Toni Seawright, Sonia Perez, Karissa Staples, and Navida Stein with music from *West Side Story*, *Company*, *Baby*, *Songs for a New World*, *Hairspray*, *The Last Five Years*, *Follies*, *Brooklyn*, *Aida*, *Oh, Kay!*, *La Cage Aux Folles*, and *Dreamgirls*.

The idea was originally conceived by former actor/director and marketing executive Joel Ehrlich. The show is directed by Joel and was co-developed and created with award-winning writer and publicist Joan Lazer, who also produced the show. Renowned pianist and composer Jonathan Ido Friedman was the musical director and arranger, and the book was done by Susan DiLallo.

This event was made possible by CBTF's Honorary Board Member (Past President) Linda Angel. She worked diligently on many aspects of the show including securing donations for both the live and silent auctions. Linda's friends and family turned out to support her in large numbers, including her husband Dennis who volunteered his time playing the trumpet in the band.

CBTF would like to thank all of those who helped, attended and supported this event!



Linda Angel and Karissa Staples

Friends and Family Remember a Beloved Son

In 2008 the Hempstead Country Club will play host to the 10th Annual Danny Jegle Golf Tournament, commemorating Tim and Tricia Jegle's son Danny, who died of a brain tumor at the age of 3 in 1998. As an event that continues to bring the Jegle's family and friends together, year after year, the tournament testifies to the enduring love the Jegle family has for Danny.

Tricia explains, "The golf outing started as an idea that my sisters, Helen and Eileen, and I thought of. We were looking for a way to keep the spirit of Danny around so that none of his cousins would ever forget him. The first year was a learning experience. The outing was held in September and half of my own family didn't make it because we got food poisoning at my older brother's wedding. The first year we raised about \$5,000.

The following years it just got bigger and better. The year of 9/11 we almost cancelled because it was to be held on 9/17 and we didn't feel it would be appropriate. The course let us postpone until the following month, and by that time it was much needed. The tournament today remains a simple way of always keeping Danny in our hearts and minds year after year."

Tim noted many friends and family have been at the event every year. He says the experience of being together to commemorate Danny's life with those who remain closest to Tricia and his family is important to him. "When I tell people that I have been blessed with everything that has ever happened to me, they sometimes look at me funny. But the 144 people that have come to the golf outing for the last 10 years

know me and my family. They feel our love for Danny. They understand what it all means. They know that Danny's spirit is with them. That's why the guys who come are my heroes. To quote Danny, "You go - we go!"

According to Joe Fay, Executive Director of Children's Brain Tumor Foundation, "In the nine years of its existence the Danny Jegle Golf Tournament has raised over \$500,000.00. Those funds enable us to support Camp Sunshine in Maine for families with kids suffering from brain and spinal cord tumors, help us underwrite our Parent 2 Parent network connecting parents who might not otherwise know another family experiencing this challenge, and help us support our toll-free telephone service staffed by pediatric oncology social workers to answer questions for families. The Jegles, their friends and family have had a profound impact on the families we serve, and we thank them for that."

The 10th Annual Danny Jegle Open

- Monday, October 13th
- Hempstead Country Club Golf Course
- Hempstead, NY • 10:00 AM

\$275.00 Includes Golf, Dinner w/Open Bar, Prizes and Raffles

***entry fee is tax deductible in excess of \$205 per golfer ***

Sponsor a Tee at each course: \$200



Juan Martinez, Matt Dunn, Tim Jegle, Dave Morgan



Ed Shinnick, James Buhse, Greg Kolondinsky, Marty Egan



Phil Seskin, Jerry Tudisco, Manny Velez, Pat Murphy

Meeting the Dinosaurs and Soaring to Space!

On Sunday, March 2 fifteen families attended CBTF's Family Fun-Day at the American Museum of Natural History. The day started with a show in the planetarium, where all enjoyed learning about the creation of stars, planets and solar systems. It was an awesome sight to share. We all quickly ran to see the dinosaur exhibits and all of the 41 exhibit halls. There were giggles and cheers along the pathway as we all searched for "Dum Dum" who is many children's favorite character from the movie *Night at the Museum*. Families joined together for a chance to connect, share stories, and laughter during lunch in the museum cafeteria. It was a beautiful family day made special by being with old and new friends. For more information about CBTF's Family-Fun Days, please contact us at Tmoore@cbtf.org



Kicking Off Young Adult Survivor/Young Professional Events

For several years, Children's Brain Tumor Foundation (CBTF) has had an active Young Professionals Group (YPG). The group consists of highly motivated young professionals who are familiar with and sensitive to the brain tumor survivor community. This year, under the leadership of Jaime Sussman and Akiva Zablocki, the group is beginning a new direction. As leaders in the community, they are going to work with young adult brain tumor survivors in building a stronger survivor community, providing mentorship, and increasing survivors' connections with the professional community.

Although there are a growing number of brain tumor survivors, many still feel alone in their challenges and search for someone who understands what they are going through. Children's Brain Tumor Foundation hopes to end this isolation through their Support Services and Survivor Program.

One way of doing this will be through quarterly young adult survivor and YPG events. In addition to building a business network, these events allow survivors the opportunity to meet other survivors. Our first event was held on Saturday, March 29th at Chelsea Piers. The event allowed the group to display their bowling and golf skills. Although there were no recruiters from the Professional Golf Association or the United States Bowling Congress, there were a lot of laughs shared and friendships built. This event was made possible through a generous donation by the New York Stock Exchange Foundation.

In addition to their role with young adult survivors, YPG also assists CBTF with family events. They are instrumental in both the behind the scenes activity coordination and volunteers the day of the event in a variety of capacities. Additionally, they participate in the coordination of one fundraising activity. If you live in the New York City area and are interested in more information or involvement with the YPG group, please email ypg@cbtf.org.

If you are a brain tumor survivor, family member or have been personally touched by the issue, please join Children's Brain Tumor Foundation's Facebook group. Through this network, we connect survivors, parents, and siblings, create discussions on relevant topics, and share CBTF events. Visit at www.facebook.com.



Hope and help every day to fight the toughest children's cancer

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www.cbtf.org

Toll-free Support Line: 866-228-HOPE(4673)