

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



# Children's Brain Tumor Foundation

FALL 2008

## Letter from the President



Dear Friends,

It has been a busy summer at Children's Brain Tumor Foundation. In May our 6<sup>th</sup> Annual Dream & Promise Gala, produced by Charlotte Simon Productions, raised over \$1 million, a record! We honored Thomas P. Koestler, Ph.D., Executive Vice President of Schering-Plough and the President of the Schering-Plough Research Institute as well as Peter M. Kash, Chairman, Two River Group Holding, LLC. Our medical honoree was Dr. Larry Kun, Chair of the Department of Radiological Sciences at St. Jude Research Hospital. Melina Kanakaredes served as Mistress of Ceremonies.

In June, 42 families headed to Camp Sunshine in Casco, Maine for a week of fun and relaxation sponsored by CBTF and Jenna's Rainbow Foundation. Camp Sunshine provides an array of indoor and outdoor activities for kids with brain and spinal cord tumors, their siblings and their families. More importantly, it provides a safe and welcoming environment where parents can relax and meet other parents whose children have been stricken by the same diagnosis (often for the first time). Meanwhile, kids affected by brain tumors and their siblings spend time with others their own age in the care of several hundred volunteer counselors.

We also attended the annual International Licensing Merchandisers' Association (LIMA) Gala. CBTF greatly appreciates the support of LIMA, whose members have raised over \$1.5 million for research funded by CBTF in the last three years and

committed to raise another \$3 million to fund our exciting Tumor Tissue Consortium beginning this year.

July saw us return to the Circle Line's *Zephyr* to enjoy another Saturday morning cruising New York Harbor thanks to the generosity of the Mark R. Harris Foundation. The Happy Heartbeat Clowns were on hand as were CBTF Young Professional volunteers with support from Voices Against Brain Cancer. We even saw a NYFD fireboat shoot off its water cannons in a salute to us, thanks to the Harris family.

In August we headed to Montana for our first-ever Heads Up Conference of young adult brain tumor survivors. With a generous grant from the Sara Chait Memorial Foundation we brought 30 brain tumor survivors to Camp Mak-A-Dream outside Missoula, Montana, for a week of recreation and workshops. Workshop topics focused on transition to adulthood, including insurance, workplace readiness, personal relationships and health and wellness.

This effort complemented our in-house internship program for young adult survivors as well as our series of employment seminars held over the summer. These included sessions on resume writing and interview practice.

Last, but far from least, we are delighted to announce that Melina Kanakaredes, star of *CSI: New York* and, previously, *Providence*, has agreed to become CBTF's spokesperson! We are so excited by Melina's generosity and eager to form a partnership that will help us hasten cures with the power Melina's association will bring to the organization.

**Robert M. Budlow**  
*President*

Children's Brain Tumor Foundation

## 8<sup>th</sup> Annual Kids Cruise a Magical Event!

For the 5<sup>th</sup> consecutive year the Mark R. Harris Foundation sponsored CBTF's Kids Cruise in New York Harbor. On Saturday, July 26, 300 people from across the New York metropolitan areas came to the *Zephyr*, docked at South Street Seaport for a 3 hour cruise. There was brunch, dancing, face painting and the Happy Heartbeat clowns with the NYC harbor providing the backdrop of activities.

Support of this event honors Mark R. Harris. Mark was one of four children of Marge and Walter Harris, along with Paige, Lee and Brian. Mark was working towards his master's degree in elementary education when he was diagnosed with a brain tumor. Mark never questioned why he had been stricken by this disease, nor did he ever complain. His brother Brian says, "Mark was an inspiration who showed me what the true definition of bravery and courage really is about." Sadly, Mark succumbed to his illness in November 2001.

The Harris family decided to honor Mark's memory by creating the Foundation. Each year the Foundation offers two scholarships to a Massapequa High School student pursuing a career in education. They also have been the generous sponsors of the CBTF Kids Cruise for the past five years.

Not only does the Foundation sponsor this event, but the family also gathers supplies, volunteers in all aspects of the cruise activities, and offers hope to the families participating in the event. They do all of these tasks with joy and energy, dedication and love. They come together as a family to honor Mark and the journey of all families of children with a brain tumor.

The Kids Cruise has helped create happy memories for the over 1200 people who have sailed with us in the past five years- and has offered many a lasting memory of Mark- loved son, brother, uncle and friend- champion of children and hero to us all.

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# Children's Brain Tumor Foundation

Hope and help every day

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[www.cbtf.org](http://www.cbtf.org)

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

## Brain Tumor Session at Camp Sunshine

*By Janet Hawkins, parent*

Because the journey of families with a child with a brain tumor is often long and challenging, having a special time and place for respite is vital. Our family has had the privilege and pleasure to experience such a place, thanks to the enormous generosity of CBTF and Jenna's Rainbow Foundation.

Camp Sunshine meets the needs of unique families like ours. Each family is housed in their own suite that sleeps six, and their days are filled with recreation and psychosocial support.

The main entrance doors are a great example of the essence of camp. There are three of them, in graduating sizes: one for small children, one for older kids, and one for adults. To our family, they symbolize how Camp Sunshine works at meeting everyone's needs, and manages to lighten our spirits in doing so.

The 23-acre lakefront campus has a challenge course, climbing wall, mini-golf course, archery, volleyball, basketball, soccer field, and playground. Campers can also swim or use kayaks or paddle boats.

Camp Sunshine builds in optional discussion groups to the daily schedule. There are separate groups for parents, siblings, men, and women. The groups provide the rare opportunity for families like ours to share, vent, learn, grow, laugh and cry together. And yes, we do laugh...a lot! As wonderful as the camp facilities are, it is this fellowship with other brain tumor families that makes camp extraordinary.

It is amazing to watch the relationships that form amongst the kids, both siblings and survivors. For many of them, it is the first time that they haven't felt alone with their or their sibling's disease. Survivors with physical challenges often lose inhibitions and dance without reservation on the DJ nights. This is camp at its best.

Camp Sunshine can best be summed up by children's words. One young camper said, "The only bad time is woo when it's time to go home." But, my favorite is, "Mommy, can we live here?"; because I could live there, too.

## Camp Mak-A-Dream

Over a year ago, Children's Brain Tumor Foundation (CBTF) saw the need for a young adult camp specifically for brain tumor survivors. We recognized that many brain tumor survivors have many unique qualities and would benefit from meeting other survivors. We began planning for the first camp designed specifically for young adult brain tumor survivors. In addition to bringing survivors together, we wanted the experience to provide answers to questions all young adults have about employment, education and relationships.

A generous donation from New York City based Sara Chait Memorial Foundation enabled CBTF to bring 30 young adult brain tumor survivors together for the Heads Up Conference at Camp Mak-A-Dream in Gold Creek, Montana.

Although they came across the country and had many differences participants bonded instantly. They discussed being in a community where they did not have to explain why they might look, walk, think or act differently from other people. They understood each other completely.

Presenters spoke about medical late effects, exercise, health insurance, relationships and career choices. There was also plenty of time to connect and enjoy Montana life. The best times were when everyone got together for fireside chats, times in the pool, fishing, archery or just playing games.

As one young man wrote after he returned home, "It was really nice to make so many friends that would be your friend no matter what you looked like because they actually knew how you felt."

Through CBTF's Facebook group, survivors will continue to stay in touch. The community will be able to assist other survivors. Look for future survivor events on the CBTF Web site as well as Facebook.

## Research Hope for Kids Stricken by Brain Tumors

The Children's Brain Tumor Foundation has launched the initial phase of a tissue bank consortium designed to jump-start meaningful analyses that could lead to new treatment and cures. This is a collaborative undertaking with leading institutions in Philadelphia, Pittsburgh and Chicago.

Participating hospitals will collect and analyze tissue samples and share the data publicly, in a standardized database. In the second phase networks will be established to create a significant volume of uniformly processed tumor material. Researchers will then apply very sophisticated genomic research tools to understand the origin and genetic mutations responsible for pediatric brain tumors, with the hope of uncovering new therapeutic avenues.

Children's brain and spinal cord tumors are the toughest childhood cancer. Breast cancer, prostate cancer and melanoma have all seen dramatic treatment improvements recently because of tissue banks and their ability to analyze large volumes of tissue samples.

The International Licensing Industry Merchandisers' Association (LIMA), principal organizational contributor to CBTF, has committed to help fund the effort. This endeavor of cooperative research will increase new treatment and cures for pediatric brain tumors and cancer.

## 2<sup>nd</sup> Annual Eric Garland Memorial Race

The 2<sup>nd</sup> Annual Eric Garland Memorial Race took place at the Shellhammer's Speedway in Leesport, PA on May 24, 2008. When Eric wasn't building engines as a machinist he spent much of his time Go-Kart racing, winning several races throughout the East Coast.

Eric passed away from a brain tumor a week shy of his 34<sup>th</sup> birthday in 2007. In his honor friends decided to celebrate his life every year with a memorial race with proceeds going to CBTF. Eric's best friend Matt Linda describes him as, "the most easy going, kind hearted, determined, competitive icon and winning racer we all strive to be. Also, the best friend anyone could ever meet."



#21 Eric Garland's Go-Kart - driven by Zach Linsell

## My Great Awakening: Coming to Terms with A Brain Tumor

*By Evan Natelson*

When I was 13 years old I was diagnosed with a brain tumor—a benign astrocytoma. I had no idea of the sort of trauma I was about to suffer, but I quickly found out once the tumor was successfully removed at NYU hospital. I stayed in the hospital for about a month afterward, unable to talk, walk and function independently.

Following my stay in the hospital, I moved to a rehabilitation center, where I lived. It was a slow and painful process; but I eventually regained my ability to walk after three months, and then, after six months, I spoke my first word. Eight months after I had first arrived there, I walked out of the rehabilitation center.

From ages 14 to 18, I spent many hours laboring through the entire spectrum of therapies, my body relentlessly receiving pokes and prods from a continual stream of doctors, constantly trying different medications, repeatedly hearing the monotonous drone of the MRI machine, and attempting two unsuccessful eye surgeries to correct my double vision. I had a very complicated life that most had a hard time relating to.

I was clearly different from the other kids my age. I felt extremely self-conscious about my slurred speech, my lack of balance and coordination, and the incessant challenges I had to face. What hurt the most was that I would constantly remember who I was before the surgery—funny, popular, athletic, smart—and the realization that I was no longer the same person.

Nevertheless, I graduated high school, college and graduate school. I did have to find several ways to compensate for my many disabilities, but in the end, I managed. Despite my successes, though, all was not well. I suffered from extreme bouts of depression, struggled with drinking and drugs, and had a very negative attitude. I began to inch closer and closer to the brink.

But a book, or more importantly an idea, saved me. The book was "The Power of Now" by Eckhart Tolle, and the idea was that the essence of who I am and what I am is only important in the present moment; the ultimate reality happens, and always will happen, right now.

In other words, life is constantly changing. Once I discovered that existence is alive and constantly moving, I came to realize that everything that happens in life is merely a current in a great stream. I saw that my negativity towards everything was causing me to resist the flow of a life that I desperately wanted to tap into. Through yoga, meditation, and studying the great spiritual teachings of the world, I began to loosen my grip on that anger. Once freed of these shackles of negativity, my world began to open to unlimited possibilities.

My life has changed dramatically. Not only do I feel this fresh aliveness and intense bliss in every moment, but friends and family have commented that my attitude and behavior is so different. I know that there will be many other obstacles along my path, but I no longer stagnate in dread and hopelessness.

## Dream and Promise Dinner Gala



Honorees and co-chairs join Bob Budlow, Melina Kanakaredes and Dr. Peter Phillips at the 6th Annual Dream & Promise Gala.



CBTF Board member Nicole Ronco and three of her children including Luke, a brain tumor survivor, were joined by Dr. Mike Fisher and Tracy Moore, CBTF social worker. Nicole re-counted her family's journey responding to Luke's brain tumor.

## CBTF EVENT LIST

**Family Fun Day at Rockinghorse Rehab**  
Sunday, September 28th • 2:00 PM  
Essex Equestrian Center  
West Orange, NJ

**10<sup>th</sup> Annual Danny Jegle Open**  
Monday, October 6<sup>th</sup> • 10:00 AM  
Hempstead Country Club Golf Course

**Brain Tumor week at Camp Sunshine**  
Friday, October 10<sup>th</sup> through  
Tuesday, October 14<sup>th</sup>  
Camp Sunshine  
Casco, ME

**CBTF's Young Professionals Group Fall Festival**  
Thursday, October 16<sup>th</sup> • 6-9 PM • \$50  
Touch Nightclub, 240 West 52nd Street  
in Manhattan

**Survivor/YPG team event for New York Cares**  
Saturday, October 18<sup>th</sup> • 9:30-3:30  
NY PS to be determined

**The Great Pumpkin Walk**  
Saturday, October 25<sup>th</sup> • 5:00 PM  
NYC Camp Sunshine Pumpkin Festival  
Central Park, Cherry Hill, off the 72<sup>nd</sup> Street  
Cross Drive in Manhattan

**5K Adult and Pediatric Walk for Brain Tumor Awareness**  
Saturday, October 25<sup>th</sup> • 9:00 AM  
Rochester, MN

**20<sup>th</sup> Annual CBTF Day at the Big Apple Circus**  
Sunday, October 26, 2008 • 12:30 PM  
Damrosch Park at Lincoln Center  
62nd Street, between Amsterdam &  
Columbus Avenues in Manhattan

**Family Fun Day at Museum of Science**  
Saturday, November 8<sup>th</sup> • 10:00 AM  
Museum of Science  
Boston, MA

**CBTF 2008 Grants Awards Reception**  
Tuesday, November 11, 2008 • 6:30 PM  
3 West Club, 3 West 51<sup>st</sup> Street in Manhattan

**Brain Tumor/Oncology Holiday weekend at Camp Sunshine**  
Friday, December 5<sup>th</sup> through  
Sunday, December 7<sup>th</sup>  
Camp Sunshine  
Casco, ME

**Holiday Party**  
Sunday, December 7<sup>th</sup> • 12:00 PM  
Beth Israel-Phillips Ambulatory Care Center  
2nd Floor  
10 Union Square East in Manhattan