Camp Sunshine: A Survivor Volunteer Perspective
By Caleb Scoville

Once again this summer I returned to that special place called Camp Sunshine. This was my fourth year to volunteer for the Brain Tumor Week at camp, sponsored by the Children's Brain Tumor Foundation. Each year that I return I am reminded of the magic that camp creates. As I arrive to the lakeside campus, located in Casco, Maine, I am greeted by volunteers and staff who have become old friends. I am also welcomed by the returning and new families that come together to experience this great week. Enduring friendships are renewed among the many returning volunteers and families every year during this week as well as many new friendships that are formed.

This year at Brain Tumor Week at Camp Sunshine, I was asked to be a counselor in the 6-8 year old group. Survivors and siblings alike would have activities like daily visits to the pool, lakefront, arts and crafts, inititiave games, an hour long rest period after lunch, and practice for the celebration show among other random activities such as a scavenger hunt.

As a volunteer, who is also a 13-year medulloblastoma survivor, I hope that I offer support and encouragement to the newly diagnosed families. Each year there are several brain tumor survivors who volunteer during Brain Tumor Week, who, if asked, are willing to share their own experiences. Parents have shared that they are incredibly appreciative of all volunteers but are remarkably moved when learning a volunteer had the same diagnosis as their child.

As a survivor at camp I have been privileged to be a part of a survivor panel during one of the parent group sessions. In these sessions I, along with other survivors, have been asked questions about surgery, treatment, and medications, as well as other social aspects about life, school, work, siblings, etc. I think the parents enjoy the opportunity to ask questions of us that their children may not be capable of, or comfortable, answering. My first year in the parent group, I was asked, "Is this harder for you or your parents?" to which I swiftly answered, "Definitely the parents." I think that surprised and comforted many parents in the session.

I realize that I am one of the fortunate survivors, who have the ability to volunteer and go to college/work. So many children are left with serious side effects of their tumor and the medical treatments used to treat their tumors. Thanks to the wonderful events Children's Brain Tumor Foundation sponsors, like Camp Sunshine's Brain Tumor Week, I feel that I can give back and make a difference by helping a family forget about present troubles for awhile and help a child just be a normal active kid like he/she should be able to. My life has been good to me as have the years at Camp Sunshine, and I hope to have many more.


Michael Lanosa and Caleb Scoville

Christine Merson Photography

Left:
McCarthy family-
Ed, Kelley,
William, and Jack

Below:
Jane Shiff,
Benjamin Shiff,
Miriam Barry,
Binyamin Novick,
Max Shemtob,
Eric Snyder,
Kyle Snyder


Christine Merson Photography

Carved Pumpkin Display


CBTF walkers: Taryn Murphy, Janet Hawkins, Alice Williams, Joan Kerpan, and others

Pumpkin Festival and Great Pumpkin Walk

Parents, children, friends, and dogs joined together for a walk through Central Park to raise awareness about pediatric brain tumors while raising funds for a brain tumor session at Camp Sunshine at the Great Pumpkin Walk on October 27th. The walk looped through the park finishing in front of hundreds of lit pumpkins. The sense of friendship and community was clear as participants gathered at the end, sharing stories, reconnecting with old friends, and making plans for future gatherings. The partnership between Camp Sunshine and CBTF has truly created a family within the community. One mother stated, "We may not share the same house, but we're definitely a family, and it keeps me going to know you all are out there." We thank everyone who participated in this event and look forward to future opportunities to come together again.

Rise to Action Conference

Children's Brain Tumor Foundation partnered with Children's Cause for Cancer Advocacy and several area non-profits and hospitals to bring this entertaining and educational event to New York City. Although brain tumor survivors are a part of the much larger community of childhood cancer survivors, they often are not treated in the same follow-up clinics and frequently experience their own unique challenges. This conference allowed young adult brain tumor survivors to network with other survivors, learn to be advocates for themselves, and celebrate survivorship.
Sunday was a day full of educational sessions on topics such as medical late effects, insurance, fertility, and advocacy. One of the unique aspects of the Rise to Action conference is that for each educational session, in addition to having an expert professional on the topic, a survivor was also present to discuss his own relevant experience. There were also two sessions designed specfically for brain tumor survivors. Overall there were over 110 participants and many connections made.

**Rise to Action –
New York Region**

a conference for young adult survivors of childhood cancer

Educating. Connecting. Empowering.

CBTF FACEBOOK PAGE
To help young adult survivors in the community continue to stay connected, brain tumor survivor, college junior, and CBTF intern Nicole Zdrojeski has helped CBTF to start our own Facebook group page. On the Facebook website search for Children's Brain Tumor Foundation and join the survivor team!
www.thefacebook.com
current members: 26

Thanks Nicole for the great idea!

CBTF and Service

Thanks to CBTF Board member, Lionel Leventhal, CBTF young adult survivors were able to participate in this year's New York Cares Day. With over 8,500 volunteers, this the largest day of volunteer service in the city. Our team painted classrooms and murals for PS 394-Mary Mcleod Bethune Academy.
CBTF plans to have quarterly activities for teen and young adult survivors and their siblings and friends to participate in. CBTF is glad to give back to the community that supports us in so many ways.

For more information email: swagner@cbtf.org

CAMP MAK-A-DREAM:
*Thanks to a generous grant from the Chait Foundation, CBTF is happy to annouce the first young adult brain tumor survivor week at Camp Mak-a-Dream.
Look in our next issue for more information...*

2007 Grants Award Reception

Providing basic science research money is fundamental to finding a cure for pediatric brain tumors. CBTF helps to find a cure by awarding basic science research grants to scientists across the nation. This year we were proud to award eight new and renewal grants at the annual Grants Award Reception on Tuesday, November 13th at the 3 West Club in mid-town Manhattan. In addition to the grant recipients, attendees included CBTF Board members, families, and variety of CBTF supporters.


Christine Merson Photography

Dr. Peter Phillips (left), Chair of CBTF's Professional Advisory Committee introduced the evening with information on the importance and quality of research being honored. CBTF Board President, Bob Budlow, discussed CBTF's history, accomplishments, and future goals, including CBTF's committment to quality of life programs.

First time recipient Suzanne Baker, PhD of St. Jude Children's Research Hospital, Department of Developmental Neurobiology received the 2007 LIMA International Award for Excellence in Pediatric Brain Tumor Research for her work on "Molecular Genetics of Pediatric high-grade Glioma."

Other new recipients included:

Karen Briski, PhD
University of Louisiana, Monroe

Louis Chesler, MD, PhD
UCSF Pediatrics

Ian Pollack, MD
Children's Hospital of Pittsburgh

Martine Roussel, PhD
St. Jude Children's Research Hospital


Christine Merson Photography

Cheryl Stoebenau (LIMA), CBTF Board member Susan Weiner, and Mary Verdegaal (LIMA)

Research Renewal Grants were awarded to:

Anat Erdreich-Epstein, MD, PhD
Children's Hospital Los Angeles

Anna Marie Kenney, PhD
Memorial Sloan-Kettering Cancer Center

John Glod, MD, PhD
Robert Wood Johnson School of Medicine

Quality of Life grants were awarded to:

Camp Sunshine and Friends of Karen
for their work with brain and spinal cord tumor patients and families.