Children's Brain Tumor Foundation

The challenge

Embracing the challenge today gives hope for tomorrow

Spring 2004 274 Madison Avenue, Suite 1301, New York, NY 10016 • Phone: 212.448.9494 Fax: 212.448.1022 Volume 13

A Dream & Promise Fulfilled

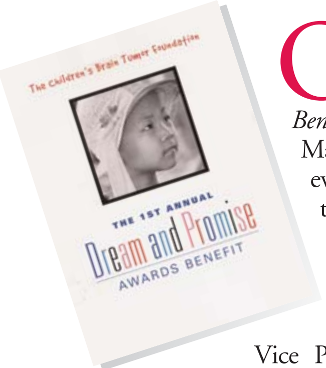
CBTF Awards Over One Million Dollars for Research and Support

Jeffrey Weiss
CEO of American Greetings

L–R: Peter Yarrow, Mario Lopez, Ali Landry & Dr. Fred Epstein

Peter Yarrow sings a duet with his daughter, Bethany, for Dr. Epstein and his wife, Kathy

Leigh Anne Brodsky
SVP at Nickelodeon



The Children's Brain Tumor Foundation

THE 1ST ANNUAL
Dream and Promise
AWARDS BENEFIT

On May 29, 2003, CBTF made a little bit of history and held its *First Annual Dream & Promise Awards Benefit*, a corporate gala at the New York Marriott Marquis in Times Square. This event was a milestone for the Foundation that could not have happened without the generosity and hard work of our co-chairs: Leigh Anne Brodsky, Senior Vice President, Consumer Products, Nickelodeon; Michele Buck, Executive Vice President and General Manager, Kraft Foods Confections Division; Kevin Kay, Executive Vice President, Programming and Productions, Spike TV; and Martin von Ruden, former Executive Vice President and General Manager, WE: Women's Entertainment. The efforts of this Benefit Committee helped raise over $600,000 for CBTF!

Jeffrey Weiss, CEO of American Greetings, was honored for his legacy of philanthropy toward children's causes and the esteemed Dr. Fred Epstein received the Pioneer Award for his leadership around the world in Pediatric Neurosurgery. We are grateful to our distinguished presenters: Dr. Luis Schut, Alan Abramson and Leigh Anne Brodsky.

Judy Hurley, Executive Director of CBTF, and Joel Shiff, CBTF's board President, flank Jeffrey Weiss, his wife Karen, and their three beautiful children: Laina, Dara, and Jacob.

The renowned Peter Yarrow of Peter, Paul and Mary fame served as Master of Ceremony for the evening. We were indeed fortunate to have his daughter Bethany Yarrow, a talented and established singer in her own right, join him in performing many classic songs such as "*Puff the Magic Dragon*" and "*Blowin' in the Wind*." Mr. Yarrow lent not only his singing talents to the evening; he generously donated signed guitars while serenading the highest bidders. Leila Dunbar from Sotheby's New York kept up by working the crowd into a bidding war for such big prizes as a birthday party at the Times Square Toys R Us, a walk-on part in a commercial for *SpongeBob SquarePants*, a portrait by the incredibly talented and famous Peter Max, and a luncheon and shopping spree with Ali Landry from the television show *Full Frontal Fashion*.

A film presentation featuring several families and children affected by pediatric brain tumors quieted the audience and reminded them of why they were there trying to raise money for research. The video was beautifully produced under the direction of Kevin Kay and Brooke Kessler from Spike TV.

The real culmination of the event came nearly five months later in November, at CBTF's 15th Anniversary Celebration at the Children's Museum of Manhattan (see page 3). Thanks in no small part to the funds raised at the Dream and Promise Awards Benefit, CBTF was able to award over $1,000,000 in grants!

The *Second Annual Dream & Promise Awards Benefit* will be held on June 7, 2004 at the New York Marriott Marquis. Dr. Peter Black will be receiving the Pioneer Award for Pediatric Neurosurgery and Leigh Anne Brodsky will be honored for all of her hard work and dedication to CBTF.

Children's Brain Tumor Foundation

274 Madison Avenue, Suite 1301,
New York, NY 10016
Phone: 212.448.9494
Fax: 212.448.1022
Website: www.cbtf.org
E-mail: info@cbtf.org
Toll Free Patient Line: 866.228.HOPE
(866.228.4673)

Board of Directors
President
Joel Shiff
Vice President
Timothy Jegle
Vice President
Susan L. Weiner, Ph.D.
Secretary
Leonard Lustig
Treasurer
Robert Budlow

Bonnie Adlman
Miriam Barry
Craig Lustig
Anita Nirenberg, R.N., M.S., N.P., A.O.C.N.
Paula Scott
Jane Shiff

Executive Director
Judy Hurley
Director of Support Services
Tracy Moore, C.S.W.
Director of Special Events
Jeremy Shatan

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.

Editors
Judy Hurley Jeremy Shatan
Kidz Korner Editor
Jeremy Shatan
Design Jeremy Shatan
Volunteer Contributors
Stacey Bergman, MA, MSW, LCSW
Nancy Cincotta, ACSW
Judy Hurley
Tracy Moore, CSW
Neal & Nancy O'Brien
Joel Shiff
Susan Weiner, PhD

A Message from the President

Joel Shiff

In recent years, CBTF's board members and staff have worked to transform this organization into one that is truly national in scope. Expanding the eligibility for research grants beyond the northeast area and increasing the outreach for the Parent-to-Parent Network are just two examples of these efforts.

Now, CBTF is collaborating with other organizations across the country to make sure as many families as possible are receiving support and to ensure our available funds are used most effectively for promising research.

For instance:

- CBTF co-sponsored its 2003 educational teleconference with the National Brain Tumor Foundation, a non-profit based in California. NBTF is also referring families with pediatric issues to CBTF and together we are planning a National Family Conference..
- CBTF has established a collaboration with the Friends of Karen, which provides emotional, financial and advocacy support to children with life-threatening illnesses and their families. CBTF has created a designated fund to be administered by Friends of Karen, which has over 20 years of experience in direct granting to individuals in the tri-state area, to be used solely for the financial needs of families who have a child with a brain or spinal cord tumor.
- CBTF is a member of several collaborative groups pursuing issues relating to advocacy and research. See Susan Weiner's Advocacy News article for more information about CBTF's work with the Alliance for Childhood Cancer, the Brain Tumor Funders Collaborative, and the North American Brain Tumor Coalition.
- CBTF sponsored Brain Tumor Week at Camp Sunshine in Casco, Maine, creating the first camping experience exclusively for families who have children with brain or spinal cord tumors. Articles by CBTF's own Tracy Moore and Camp Sunshine's Nancy Cincotta explore this in more depth elsewhere in this issue.
- CBTF is co-sponsoring the *11th International Symposium on Pediatric Neuro-Oncology*, which will be taking place in Boston from June 13 – June 16, 2004.

Collaborations such as these can only happen with the support of the committed donors that we value so highly. Corporate sponsors like American Greetings and Viacom and major local unions like the New York City District Council of Carpenters are among our most committed sponsors and we are very proud of the relationships we have developed with them. However, we also treasure all the many dedicated individuals who contribute to CBTF.

Ann Berger, who sends in a gift once a month like clockwork, is one such person. She has been doing this since 1994, when she heard about a local boy who passed away due to a brain tumor. So on her tenth anniversary of giving, we salute her and all the generous people like her who have been moved to contribute to CBTF's cause. Thank you for your support!

Best regards,

Joel Shiff

Joel Shiff

HAVE YOU HEARD?

If you missed "Childhood Brain Tumors: An Update on Survivorship," CBTF's 2003 teleconference, it can now be downloaded from www.cbtf.org and replayed.

This excellent presentation was made by Dr. Daniel Armstrong, a member of CBTF's Professional Advisory Board and Professor and Associate Chair, Department of Pediatrics and Director, Mailman Center for Child Development at the University of Miami School of Medicine.

Plans are in the works to have teleconferences from 2000, 2001 and 2002 available on www.cbtf.org as well so please check back soon!

CBTF goes to CMOM

Children's Museum of Manhattan

Event at Children's Museum of Manhattan
Honors 15 Years of Progress
Over $1,000,000 in grants awarded!

Recently named "Best Museum" in New York Magazine's Best of New York issue, CMOM was the perfect choice to host CBTF's 15th Anniversary Celebration. Kids of all ages attended and explored the exceptional array of interactive exhibits. The bleachers were packed with doctors and donors for the awards ceremony and the grant recipients seemed sincerely honored to be a part of CBTF's legacy.

CBTF Takes the Cake: The party, on November 19, 2003, featured this beautiful (and delicious!) cake.

Old Friends: Linda Angel, at right, had some catching up to do with Miriam Barry. Both are former presidents of CBTF's Board of Directors.

Fun For All Ages: Happily, many who attended brought their whole family. They all found plenty to do at the Children's Museum of Manhattan.

Past, Present and Future: Current and former Board members posed with CBTF's biggest "big check" ever! L–R, Front: Joel Shiff, Craig Lustig, Anita Nirenberg, Jane Shiff, Miriam Barry, Nora Leary and Leonard Lustig. L–R, Second Row: Bonnie Adlman, Linda Angel, Paula Scott, and Susan Miller. L–R, Back: Susan Weiner, John Ferrelli, Robert Budlow, and Timothy Jegle.

2003 Scientific Research Grant Recipients

In addition to the doctors listed below, the following researchers received renewal grants: Peter Canoll, MD, PhD, Columbia University; Charles Eberhart, MD, PhD, Johns Hopkins School of Medicine; Michael Sheldon, PhD, Texas Children's Cancer Center; and Robert Wechsler–Reya, PhD, Duke University Medical Center.

Jonathan Eggenschwiler, Ph.D.
Princeton University, New Jersey
The Role of Novel Hedgehog Signaling Antagonists in Medulloblastoma Tumorigenesis

The Rab23 and FKBP8 proteins normally silence Hedgehog signaling, which can cause medulloblastoma if inappropriately activated. Using genetics in a mouse model system, this study will determine if these proteins are bona fide "tumor suppressors."

Martine F. Roussel, Ph.D.
St. Jude Children's Research Hospital, Tennessee
Role of Cyclin-dependent Kinase Inhibitory Proteins in Cerebellar Development and Tumorigenesis

These studies will allow us to screen human medulloblastoma for mutations in the Ink4 proteins and provide mouse models for the testing of novel therapeutic agents.

Daphne Haas-Kogan, M.D.
University of California at San Francisco, California
Histone Deacetylase Inhibitors as Potential Therapeutic Agents for Pediatric Gliomas

The ultimate objective of the proposed work is to incorporate promising histone deacetylase inhibitors into the treatment of glioma patients.

Mark W. Kieran, M.D., Ph.D.
Dana–Farber Cancer Institute, Massachusetts
a_vß$_3$-receptor-based Novel Imaging in Orthotopic Models of CNS Malignancy after Biologic and Anti-Angiogenic Therapy

The goal of this project will be to evaluate the distribution of a new molecular imaging agent, the RP748 compound, in the cells and blood vessels of tumor models, as well as surrounding normal tissues. This will lead to improved evaluation of new inhibition–based drugs.

Scott L. Pomeroy, M.D., Ph.D.
Children's Hospital Boston, Massachusetts
Wnt and TGFß in Medulloblastoma Oncogenesis

Understanding the molecular mechanisms that lead to the growth of tumors in the developing brain, so that targeted molecular therapies can be devised that specifically block the mechanisms of tumor growth, is the goal of this study.

Manuel Utset, M.D., Ph.D.
University of Chicago, Illinois
A Transgenic Mouse Model of Interferon-Gamma Induced Medulloblastoma

Identifying the molecular pathways activated by interferon–gamma in medulloblastoma cells may reveal important targets for future drug therapies of human medulloblastoma.

Did you know that you can direct your gifts to research? Special thanks are due to those who made a contribution specifically toward pediatric brain tumor research in memory or in honor of a loved one. CBTF thanks the families of Louis Kaplow, age 14; Hannah Miller, age 11; Katie Nielson, age 15; Joseph Stella, age 31; Jonathan Patrick White, age 6; Ian Hammond Williams, age 13; and Meghan Heisler, 3 year survivor. To find out more, please contact us at 212.448.9494 or info@cbtf.org.

2003 Quality of Life Grant Recipients

FRIENDS OF KAREN

The mission of Friends of Karen is to provide emotional, financial and advocacy support to children with life-threatening illnesses and their families. In awarding Friends of Karen a $55,000 grant for a fund specifically to help families dealing with brain tumors, CBTF recognized their 25–year history of providing direct financial assistance. Through this fund in 2003, Friends of Karen helped 25 families in New York and New Jersey who have children with brain tumors with a variety of expenses, from hospital phone bills to mortgage payments.

CAMP SUNSHINE

Camp Sunshine, located in Casco, Maine, is a retreat for critically ill children and their families. In 2003, CBTF sponsored the first week ever in the United States to be dedicated solely to families whose children have been diagnosed with brain tumors.

The Brain Tumor Week, held June 29-July 3, 2003, was attended by 33 families, and included approximately 100 children. Below, Nancy Cincotta, Psychosocial Director of Camp Sunshine, describes this special week at the camp.

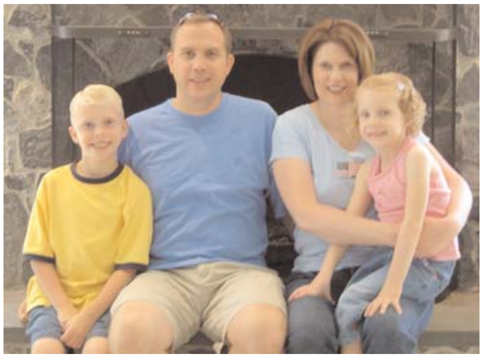
Families forge magical Bond at Camp Sunshine

by Nancy Cincotta, ACSW

Camp Sunshine is a magical place that blends the fun of camp (for children and adults) while minimizing some of the isolation a family may feel when a child is diagnosed with a life-threatening illness. At camp families have the opportunity to come together in the silliest of activities and also in discussion groups.

Over the last several years, it seemed to me that in the support groups, I was hearing more consistently from parents of children with brain tumors. Now unless all parents of children with brain tumors have the same personality (highly unlikely), it seemed that families needed their own place to gather and to talk. Thankfully, CBTF had that same vision and with their generous support, Camp Sunshine was able to have a camp session exclusively for families of children with brain tumors in 2003.

Although much time has passed since that first session at Camp Sunshine, the feeling from that week still stands out in my mind. What was the magic? Was it in the sounds, the energy, the communication, or the connection? If you were there, you probably know what I am referring to. From the minute people walked in, before any words were spoken, it seemed as though everyone had known each other for many years. Children were seeing kids that "looked" like them; families knew everyone had not just a similar experience, but an experience that almost paralleled their own. There seemed to be magical communication everywhere—it was about the children on stage, and their parents who enabled them to get there, about a child being unable to see and it not seeming like an impediment. What mattered was that everyone was willing to leave the familiarity of home and come to this place to have fun and deal with the impact of living with a child with a brain tumor.



Tight-Knit: Clint & Jamie Paulson brought their whole family from Utah to take advantage of the program at Camp Sunshine.

Coping with a brain tumor means something different for everyone. Perhaps everyone does not have the same surgery, or even the option of surgery and not always the same issues post-operatively, but in the end everyone lives and copes with the initial impact of the diagnosis, the reality of living with a brain tumor, the fear of recurrence, loss of function for some, and for others the differences in the emotional profile that they once knew in their children.

Camp Sunshine became a place where it was not only safe, but also fun to be who you were, express what you had experienced and to talk about what you wanted to. From the minute the session ended we have been anticipating the next one. There was so much to be said, so much to do and so much energy to embrace. It was evident that the bond between families was more than therapeutic.

We know the time will come quickly when there are more families than there are spaces in a session at camp, but as we are all growing, we will work towards addressing the growth of the program each year. In the meantime, families of children with brain tumors are also welcomed to apply to any cancer session at Camp Sunshine. We were delighted to have some families of children with brain tumors in our winter programming and ultimately look forward to having families of children with brain tumors enjoy every season at Camp Sunshine.

Camp Sunshine could not be happier in this partnership with CBTF. We look forward to meeting any families, volunteers, board members and staff who can come to this year's session June 27–July 2.

With each day we learn so much from families, and appreciate the privilege to be part of the journey for families living with a child with a brain tumor.

Nancy Cincotta is the Psychosocial Director at Camp Sunshine. For more information, go to www.campsunshine.org.

Family Focused Support

by Tracy Moore, CSW • Director of Support Services

Reaching Out: Robert & Patricia Hillery, from Long Island, came to Camp Sunshine with their four kids–it looks like they had their hands full!

The impact of a childhood brain tumor is often described by the experiences the individual child faces. The effect of the diagnosis on each member of the family and their critical interpersonal relationships is often left on the back burner. Sadly, this can take a toll on relationships within the family.

Setting time aside to reconnect as a couple or as a family can be a daunting task. Everyday household and career stresses are magnified when juggling the many appointments for doctor visits, scans, physical therapy, occupational therapy, and school meetings. Soccer practice and family dinners cannot compare to the importance of scheduling or administering chemotherapy doses and monitoring blood counts.

The Children's Brain Tumor Foundation, as a parent driven organization, recognizes the intense struggle between “patient focus” and “family focus” models of support. The balance is one that each family needs to find for themselves. CBTF offers some options that we hope are helpful to the entire family.

One such option is Camp Sunshine, a family focused camp located in Casco, Maine. Unlike most camps of its kind, Camp Sunshine invites the whole family to attend camp for a week, giving parents, patients and siblings the opportunity to reconnect with each other.

Camp Sunshine is described as a camp whose “focus is on alleviating the strain that a life threatening illness takes not only on the sick child but also on other family members. Families have an opportunity to rebuild their relationships together and meet other families facing similar challenges.”

For the second year in a row, CBTF has awarded a grant to Camp Sunshine in order to sponsor a full week session for 40 families from across the United States to attend for free. This is the only camp in the U.S. that has a full week program just for children with brain or spinal cord tumors and their entire family.

Camp Sunshine is a fun–filled camp experience that combines boating, swimming, and campfires with group activities that focus on relationship building exercises. Children are placed in groups by age rather than diagnosis, allowing for patients and siblings alike to experience camp without defining labels. Parents have an opportunity to join in the daily parent support group, allowing for the exploration of many complex feelings and the development of close peer relationships.

Last year's activities included a costume party, karaoke night, lobster toss, and group puzzles. Families had a chance to spend time on their own enjoying a variety of recreational activities such as miniature golf and canoeing. Couples took advantage of “date night” while the children enjoyed campfire chats.

One parent described her camp experience by saying, Camp Sunshine “helped me to remember and reflect on the fact that I have a life, it is important to do silly things, play games, and cut up. You forget who you were before this all happened, this week made me want to remember who I was and am.”

This year, CBTF's sponsored Brain Tumor Week at Camp Sunshine will be held June 27-July 2. If you are interested in attending, or learning more about this incredible family experience, please check out our Website at www.cbtf.org or visit www.campsunshine.org. You can also feel free to contact us at the office directly at 866-228-HOPE (4673).

Dear Judy Hurley & CBTF,

Our family was privileged to attend Camp Sunshine's first Brain Tumor Week. Our daughter, Lauren, was diagnosed with a JPA brain Tumor in November 1998. She has had surgery and a full year of chemotherapy. This was a very difficult time for Lauren and our whole family as Lauren got very ill during the chemo treatments. Now, 2 1/2 years off of chemo, Lauren is doing very well. One of the great memories during her recovery has been Camp Sunshine. With all the great staff and volunteers our whole family had a wonderful time. A big part of recovery is emotional, and Lauren smiled the whole time we were there. Her older sibling, Nicole, had an equally fun week, and her younger sibling, Mikaela, loved the attention of the volunteers in the toddler program. We, the parents, even got a night together with a gourmet meal without the kids.

We want to thank you for your sponsorship and generosity. Our whole family had a wonderful time. It was great to get together with other parents who can directly relate to what we have been through and also understand what is ahead of us. Because of the success of the first Brain Tumor Week and some of the unique problems that brain tumor patients and families face, Camp Sunshine will be having a Brain Tumor Week again next year. The families came together as strangers but leave as friends, hoping to meet again next year.

Thank you once again, John & Susan Davies
Nicole, Lauren & Mikaela

Kayak Kid**:** One of the children attending Camp Sunshine enjoys one of the camp's many water–based activities.

Divide, Conquer, and Communicate: How to Keep the Relationship Going After Diagnosis

by Stacey L. Bergman, MA, MSW, LCSW

The diagnosis of a brain tumor in a child can bring with it a complex array of feelings including despair, uncertainty, anger, and loss. Leaving behind all they had previously known, families are asked to quickly modify their perception of daily life and integrate new and challenging responsibilities. In the first several months following diagnosis, the family's focus centers around the child and his or her schedule for treatment, surgery, and doctor's visits. While the parents endure this necessary yet challenging phase, their own needs often fall by the wayside.

Mothers and fathers play an important role as parents but also play an equally important role as spouses to one another. Given the significant stressors that these families face, it is not unreasonable to expect their new situation to have a significant impact on their marriage. The ways in which each spouse reacts to and copes with the stress of their child's illness has a dramatic influence on their relationship. Each partner deals with powerful feelings in their own individual way. Often times, this is the first time that parents see how their partner copes with tremendous disappointment and loss. Some coping styles are complementary while others are not. For example, one partner may be very expressive about how they are feeling, while the other may need space and time to sort through their feelings.

> Is it possible for couples to advocate for the needs of their child and the needs of their marriage at the same time?

Societal expectations dictate how parents should respond further reinforcing the demands specific to each partner. Mothers often feel pressure to continue to meet the needs of their husbands and other children while keeping up with their household obligations. Thus, they are often the first to neglect their own needs and leave their jobs. Fathers commonly state that there is an increased need to continue to provide for their families while under duress and to fight the stigma associated with being vulnerable or sad. They feel they should be brave, strong, and in control. In doing so, they let go of their need for expression, connection, and time with their family. Over time, the pressure to fulfill these demands becomes too great. Parents are bombarded with financial, emotional, and physical burdens. They are confronted with social isolation, communication breakdown, sibling resentment, conflict, role reversal, and a loss of intimacy.

When both partners are hurting, it is difficult for them to be supportive of one another. Spouses become convenient targets for each other's anger and frustration. Stress and the threat of loss intensify our need for attachment and modify our expectations about how our partners should behave. These modifications only highlight any potential insecurities or difficulties that may already be part of the relationship. The sense that one can count on a loved one has been linked to resilience and the ability to deal with stress. This feeling of secure attachment then acts as a buffer against ongoing stress and the negative effects that stress might have on a relationship.

In the greatest race of their life, couples often forget which team they are on and turn against one another. In the face of such adversity, we often ask what options couples are left with. Is it possible for couples to advocate for the needs of their child and the needs of their marriage at the same time?

Couples maintain their relationship by adopting methods of communication that work for them. Spouses need to identify one another's needs and means of expression. Setting aside time each day to touch base with one another will prevent communication breakdowns and the build-up of resentment. Couples need to practice active listening. During active listening, each partner reflects and communicates what they have heard back to the other. This enables each partner to feel truly heard by the other and to promote a genuine sharing of their experience. For couples that find this an impossibility, the creation of a daily sharing notebook that is passed back and forth can maintain connection and enhance communication. The sharing of emotions such as anger, fear, and hope fosters attachment and intimacy.

There are a number of different ways that couples can create necessary opportunities or events that promote bonding. Some couples plan a scheduled date night every week. Although this seems difficult, couples find it enhances their relationship. Finding a friend or a family member that they trust to baby-sit for them can make this a real possibility. Other options include selecting one activity that is regularly done by just the two spouses or planning a time of day that they always spend together. It is not important what couples choose to do, but rather that they make it a regular priority to do something together. When couples spend positive time alone together they can begin to engage in and respond to one another's needs. These positive interactions promote open communication, the ability to empathize, and hear each other's perspectives in a way that builds trust, intimacy, and security.

It is not uncommon for couples to need some outside assistance from professionals during this time. Communication skills and the art of compromise are often looked upon lightly. However, in the midst of a crisis, it is quite difficult to master these tasks. Parents may choose to pursue short–term couples counseling to enhance communication practices, work through differences, or repair old wounds that have been brought to the surface in light of the recent crisis. The tools obtained will not only benefit the family in the short–term but will carry them through the rest of their marriage.

The diagnosis of a brain tumor in a child is a devastating event for all those involved. Parents are confronted with a challenge they are not prepared for and are asked to relinquish control of their daily life. Parents take on a host of new roles, becoming medical experts, advocates, and insurance warriors. In doing so, their own needs often get neglected and their marriages go unnoticed. Despite the needs that the illness brings with it, parents must find a way to support one another and meet their own needs as well. In doing so, they will not only help themselves but they will create a secure foundation to provide the best support possible for their child.

Stacey L. Bergman is a clinical social worker in the Pediatric Oncology Department of Hackensack University Medical Center.

Parent's Corner

Just Like College…

By Neal and Nancy O'Brien

The current school year has been one filled with dramatic changes, challenges and discoveries as our son, Neal, has seen his school education move from a daily program into a residential school setting.

Neal was diagnosed with a malignant hypothalamic brain tumor in June of 1991. He was six years old and had just finished kindergarten. The diagnosis was catastrophic: the prognosis was terminal brain cancer. Four days after the discovery of the tumor Neal underwent an eight hour brain surgery at Children's Hospital Boston to resect the tumor. Within two weeks of surgery, Neal began a six week, daily regimen of radiation therapy. As the summer and treatments came to an end, we prepared for Neal to enter the first grade.

One night during the first week of the new school year we received a phone call from the hospital, telling us that the radiation treatment had not been successful. We were also told that Neal would require further surgery. Neal had a shunt surgery in the middle of September 1991. Throughout the fall of 1991, Neal was tutored at home. However, in the fall of 1991 his condition worsened so severely that home hospice replaced home tutoring. It certainly appeared to everyone that Neal was getting ready to leave us during that gloomy winter of 1991.

Immediate Family:(Clockwise from top) Neal, Nancy, Neal, Jr., and Maura

Miraculously, Neal survived and his condition slowly improved. Nevertheless, he has been faced with many challenges to his daily life.

By the fall of 1992 Neal was once again able to attend school, but now he was a student with very special needs. Initially we hoped that Neal would attend public school in our home town. Unfortunately the school system could not adequately provide the services which Neal required. After a few months, we started to consider looking into a private placement for Neal's education.

We were fortunate to find a private school that seemed to have all the services that Neal needed. The only problems were distance (25 miles) and the stress of notifying our town of our decision. As the process unfolded, the Special Education Director from our hometown became very supportive and helpful and Neal started a new and wonderful school experience in the fall of 1993.

Neal settled in nicely and commuted daily to a truly special school. After ten years it became clear to the school administration that they could no longer meet Neal's daily needs. This was something that we had difficulty accepting. Forced change brings out an awful lot of anger, frustration and stress.

Once again we had to evaluate what was best for Neal and after looking at several options we came to the very difficult realization that Neal would be best served in a residential school setting.

When it was time to tell Neal of this decision we explained that he would be living away from home and that had he not gotten sick, he would be on his way to college. Neal agreed that he was nineteen years old and should be going to college, but that he would miss his family. We told him he would be coming home every Friday for the weekends and he thought this was a good idea.

Today, Neal is a residential student at the Massachusetts Hospital School. He leaves home late in the day each Sunday and spends the school week in an environment which is a school during the day and a fully-equipped hospital at night. Neal returns home each week on Friday afternoon.

Neal has been extremely dependent on us over all these years, but his journey has also proven how dependent our family is on him. Each of us bring special gifts to our family, gifts which make us complete. Neal is remarkably gentle, yet amazingly determined. There is a wonderful circle of goodness and love, which not only encircles him, but truly radiates from him. Neal is in a special and guided zone. As parents, we are called to teach our children. In our case, we have become students, absorbing the lessons taught by Neal. For so many years our lives have centered on Neal, and his needs. Now we have embraced the weekends with a new sense of family togetherness. Even Neal's 15-year old sister Maura misses him and looks forward to our family dinner on Saturday. Weekends are a mixture of joy as Neal arrives home and sadness when he prepares to go back to school.

The current school year is two-thirds complete. We continue to work through the changes and challenges of our daily lives. We look forward to our weekends and vacations with Neal yet we must come to accept that his going away is part of the "new normal" for our family.

> Neal has been extremely dependent on us over all these years, but his journey has also proven how dependent our family is on him.

CBTF's Newest Program

P2P Bags Hit the Street!

In March, Lindsey Hubler, a CBTF intern from Columbia University's MSW Program, delivered the first Parent–to–Parent Bag to a family at Memorial Sloan-Kettering Cancer Center. Since then, bags have gone to families at other hospital in New York City.

The bag contains a selection of items geared to making things easier during hospitalization. Plans are in the works to expand the program throughout the country, using a distribution network of Parent–to–Parent volunteers.

Lindsey, at left, is shown here with Tracy Moore, the Director of Support Services.

An important message from the Executive Director of the Children's Brain Tumor Foundation

Children's Brain Tumor Foundation
Embracing the challenge today gives hope for tomorrow

Dear Friends:

This Foundation has certainly grown over the past 15 years, yet the dedication toward the mission has not wavered. This is due primarily to the fact that the majority of the leaders responsible for the stewardship of CBTF are parents, family members and friends who have been personally touched by the impact of a pediatric brain tumor.

This grass-roots approach and personal experience continues to drive the core values and growth of this Foundation. Since CBTF's inception, funding effective research, providing families with support, sharing the latest in pediatric brain tumor information through education and changing the landscape of national research funding through advocacy has been the focus of this Foundation.

Last year we awarded over one million dollars to provide brain tumor research and support services to families. To what do we attribute the achievement of this milestone? The answer to that question is quite simple: **Volunteers!**

They say that success has many parents. While that statement couldn't be more literal here, it is in the role of volunteer that these parents serve CBTF. Moms and pops do more than just roll up their sleeves for us; they engage their families, friends, businesses and corporations to do the same.

To continue making important inroads toward changing the future for children diagnosed with brain or spinal cord tumors, we need your help. Whether it is by sitting on the Board of Directors or a Board Committee, running a fundraising event, serving in our Parent–to–Parent Network or being an advocate: we need volunteer support. We need you!

I invite you to contact me if you are interested in volunteering or have ideas on how we can work together toward accomplishing our mission. We are committed to finding a place for your voice to be heard here at CBTF.

Sincerely,

Judy Hurley

Judy Hurley
Executive Director

274 Madison Avenue, Suite 1301, New York, NY 10016 • ph. 212-448-9494 • fax 212-448-1022 • www.cbtf.org

Volunteers Make Things Happen at CBTF!

Dynamic Duo: Bonnie Adlman (right), long–time chair of the Big Apple Circus Benefit Committee, with fellow board member Paula Scott.

Fairway Foursome: Tim Jegle (left) and his family have been holding the Danny Jegle Open since 1999. Their hard work has created an incredible legacy in memory of their son, raising nearly $200,000. Here, Tim poses with his golf buddies: Martin Nearon, Dave Morgan, and Matt Dunn.

Golf For A Good Cause: Spencer Craig (right) presents a check from Aetna, one of the many sponsors of his First Annual Charity Golf Tournament, to Judy Hurley, CBTF's Executive Director. The New Jersey event raised over $11,000.

Seadog Central: The Mark R. Harris Foundation provided both financial sponsorship and hands–on help at the Fourth Annual Kids Cruise. At the end of the day, Walter Harris, Brian Harris and Chris Nolan paused for a moment with Jane Shiff, a member of CBTF's board of directors.

It's a Tough Job…: Elizabeth Brunn went the extra mile and clowned around when she volunteered to sell raffle tickets at the Dinner Dance!

Hoops with Heart: When Josh Cohen heard about a friend's sister who passed away due to a brain tumor, he started organizing the Long Island Neighborhood 3-On-3 Basketball classic. That was in 1998—since then, he's raised over $40,000 for CBTF!

Fore! for Family: Jeremy Shatan, CBTF's Director of Special Events, presents a plaque to Patricia and John White after their Second Annual Jonathan Patrick White Memorial Golf Tournament, held in eastern Massachusetts. This family has raised over $40,000 for research!

Laugh Riot: Regina Epperhart and Jackie Flicker (right) were just two of the Young Professionals Group members who made A Night of Laughter 4 a smashing success. Famous comedian Will Durst (right) was the headliner. This event has raised nearly $24,000 since 2001 !

HOW CAN YOU JOIN IN THE FUN?

CBTF is always looking for help with our signature events. There are many ways to volunteer, from mailing invitations to your friends and family or soliciting for raffle prizes to tearing tickets at the events. We can use your help!

Our **Circus Benefit Committee** is looking for new members to join us in planning for this wonderful fall event. The planning begins in the spring. Do you have friends with young children? What about a generous corporate work environment looking for a fun event to take your employees to? Please consider helping us in filling up the tent and join us in clowning around this fall.

Is golf your thing? Foursomes…hole sponsors…auction prizes-there are many ways to participate in golf events, even if you don't know a birdie from a bogey!

Are you a young professional looking to combine a fun night on the town while raising funds for critical programs for kids? Then consider joining the **Young Professionals Group—New York Chapter**. Plans are under way for A Night of Laughter 4 1/2 to be held in September in NYC. Don't live near the Big Apple? How about initiating your own chapter in your local area? Just call our office and we can help you start today!

Create an Event and Create a Future of Hope for Kids! Many supporters around the country have held their own events to raise funds for CBTF. Golf tournaments, "dress-down days," garage sales, dinner dances—the possibilities are endless! We will be happy to advise you and give you the help you need to get your whole community involved.

Volunteering is not just for Adults—Take a look at these Young Philanthropists!

Sibling Harmony: 12 year-old Becky Rosefelt (at right in picture) made pottery and fleece berets and sold them at a block party to raise funds for CBTF. She was moved to do this in honor of her brother, Maurice (at left), a ten-year-old brain tumor survivor. Becky raised about $150 for CBTF. You go girl!

An Offer No One Could Refuse: How could you not buy drinks and snacks from this adorable twosome? That's Luke Ronco, a five-year-old brain tumor survivor, on the right, with his little sister, Alexis. The little cuties turned on the charm and raised $16 for CBTF's family support programs!

Catching Up With Dr. Finlay

Regular readers of The Challenge might recognize Dr. Jonathan Finlay as one of CBTF's Medical Directors but there is much more to know about the man. Trained in England, Dr. Finlay has been prominent in the field of pediatric brain tumors since at least 1985 when he was named Chairman of the Brain Tumor Strategy Group of the nationwide Children's Cancer Group (now Children's Oncology Group). In 1989, he moved to New York to head up the pediatric neuro-oncology program at Memorial Sloan-Kettering Cancer Center. Following his time there, Dr. Finlay became the Director of The Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders at NYU Medical Center.

During his tenure at Hassenfeld, Dr. Finlay created an environment of complete dedication to helping children with the most difficult tumors. The Head Start protocols, which he developed, became known as the first option for treating very young children aggressively without resorting to radiation.

A New Start His most recent move, in October 2003, took him across the country to California where he took up the reins as Director of the Neural Tumors Department at Childrens Hospital Los Angeles and Professor of Pediatrics at the Keck School of Medicine.

First we asked Dr. Finlay how he was feeling about his move to the Golden State. "I am having a great time," he told us, "This was a great move for me, both personally and professionally. The situation is different than in New York where there is so much going on for children with brain tumors. Considering the population here, there are very few brain tumor programs. For example, there is currently no neurofibromatosis clinic in Los Angeles. We're going to establish one."

Dr. Finlay went on to tell us about the excellent team he found in place at Childrens L.A., including nationally known neurosurgeons Dr. Mark Krieger and Dr. Gordon McComb and pathologist Dr. Floyd Gilles. "We have a tremendous behavioral health program which is very educationally focused and a big retinoblastoma program. Also, we combine laboratories and translational research for neural tumors and neuroblastoma. There's a valuable cross-fertilization between teams that helps all tumor types. In short, I love New York and miss it but this is the best job for me. There was a need for me here."

Bold Beginnings Dr. Finlay has mentored over 50 undergraduate students, medical students, medical residents and fellows in clinical research projects since 1982. In his short time at Childrens L.A. he has already added to his team by successfully recruiting from Harvard and New York City and plans to continue his fellowship program. Speaking of all the students he has worked with led us to ask Dr. Finlay what originally led him to work with pediatric brain tumors over 22 years ago.

"When I was just starting out, my mentor, Dr. Richard Hong, advised me to find my own niche and told me there were three ways to go about doing that. The first is to find a brand new area, the second is to find something that is so convoluted and tedious that no one wants to do it, and the third is to choose an area that is depressing and unpopular. When I came to Stanford University in 1980 I was originally recruited for lab research. Because I was the new guy, I was given the most unpopular area: brain tumors in children. The outcomes were bad and the quality of life for the kids was terrible." Dr. Finlay was already a survivor of cancer himself, "which only convinced me that this was what I wanted to be doing."

Successful Studies Dr. Finlay saw a tremendous need and opportunity in the field of childhood brain tumors and has always tried to establish programs and train more people to work in the field. "This is not altruism," he says, "it is my immortality!" Speaking of long-lasting accomplishments, Dr. Finlay told us that one of the most gratifying things in his career is his work on the Head Start protocols. "It hasn't been a home run but, from a clinical perspective, it is much better than what came before."

The main difference between Head Start I and II was the addition of high–dose Methotrexate to the arsenal of chemotherapy, which led to a better disease–free survival rate for the high-risk patients that got it. "For Head Start III, everyone will get Methotrexate," Dr. Finlay told us, "but only for three cycles instead of five. We are hoping this will lead to not only maintaining the standard we've reaching with high-risk patients but to doing better with standard-risk patients."

Head Start III is on track and Dr. Finlay has just received funding to follow up the previous Head Start Studies. "I can look back over 18 years and say that I contributed to a new standard of treatment," Dr. Finlay told us with well-earned pride. "What am I going to do from here? A major direction is to figure out how we can predict *at diagnosis* who can best avoid radiation. For this we need to use molecular tools and we are seeking funding for a study using microarray genomic technology."

Rare and Incredibly Complex
Dr. Finlay is also known for his work with germ cell tumors, a category that includes such wildly divergent tumors as germinomas, embryonal carcinomas and teratomas. In fact, over ten years ago CBTF awarded him a grant for an international collaborative study in this area. "Two–thirds of these tumors are germinomas, which are fairly pure and are exquisitely sensitive to chemotherapy and radiation," Dr. Finlay explained, "however the rest are mixed types that are a nightmare pathologically."

To continue the work he started with CBTF's grant, Dr. Finlay is hosting the Second International Symposium on CNS Germ Cell Tumors in November 2005. The symposium will take place in L.A. over several days and will include a half-day program for patients and families including information on such issues as quality of life, education and insurance. Dr. Finlay has been talking to Craig Lustig, a CBTF board member and two–time brain tumor survivor, about participating.

As we wound up our conversation, Dr. Finlay reassured us that he has not gone Hollywood. New York will still figure in his future plans. "Despite the distance, I'm still working with neuro-psychologist Steve Sands at Columbia and I've just given Grand Rounds on Head Start at Memorial Sloan-Kettering Cancer Center. It was so well received that Nai-Kong Cheung [head of the Neuroblastoma Program at MSKCC], Ira Dunkel [a pediatric oncologist at MSKCC] and I are planning to work together on joint studies of their radiolabeled monoclonal antibody for intrathecal use, both within the Head Start III study (as a MSKCC pilot), and in recurrent brain tumor patients."

Since CBTF has recently supported research in California, Boston, New Jersey, Chicago and Tennessee, it seems only fitting that one of our Medical Directors is on the west coast. Everyone at CBTF is looking forward to continuing a long and fruitful relationship with Dr. Finlay and we will watch with great excitement as he accomplishes more great things for children, both in the laboratory and at the bedside.

CBTF's Advocacy Leadership by Susan Weiner, Ph.D

Three exciting initiatives in the past year exemplify the leadership of CBTF's advocates in the national brain tumor and childhood cancer communities. Brain Tumor Action Week (BTAW), the Alliance for Childhood Cancer and the Brain Tumor Funders Collaborative all depend on active participation from CBTF.

This year, CBTF Executive Director Judy Hurley transformed the way advocates prepare for BTAW (sponsored by the North American Brain Tumor Coalition (NABTC)) to an easy to access format. CBTF has successfully conducted free teleconference seminars on topics of interest to families of children with brain tumors. A teleconference format was used for this spring's NABTC advocacy education forum, which took place on April 21. The pace of federal legislative activity is slower during the current election year and the free teleconference allowed advocacy training to take place in local communities. The conference seminar included what's new in NABTC's advocacy activities and tips on how to best interact with your legislator's home office and on Capitol Hill. Advocates will still be making visits to Capitol Hill on May 4, during BTAW.

Craig Lustig, a long-time CBTF board member, has also emerged as a leader in the Alliance for Childhood Cancer, a Washington-based federation of 22 national patient advocacy and professional groups. In fact, he was elected as this year's co-chair. The Alliance convenes quarterly to discuss national childhood cancer policy. Craig recently led an Alliance meeting at which Food and Drug Administration (FDA) Commissioner Dr. Mark McClellan addressed the group about FDA efforts in pediatric oncology. Tracy Moore, CBTF's Director of Support Services, capably adds to CBTF's presence at the Alliance. Examples of action items on the Alliance agenda include inadequate appropriations for childhood cancer research, legislation on pediatric palliative care and patient access to new cancer therapies.

As a major national organization that funds pediatric brain tumor research, CBTF board and staff have long considered whether coordinating the funding efforts of various brain tumor organizations could accelerate the pace of brain tumor research. The Brain Tumor Funders Collaborative, a new federation of 12 brain tumor research funders (still in formation), has been deliberating how to realize this vision. The Brain Tumor Funders Collaborative has been identifying critical barriers to treatment progress that the group can address. The Collaborative held a meeting in April to hear from the nation's leading researchers on animal models of brain tumors and how this research strategy can be more effectively used to evaluate new drugs and provide insights into brain tumor disease. I recently described this initiative at a national meeting of biomedical foundations: “Partnering to Advance Health Research: Philanthropy's Role.”

As research reveals an increasingly complex picture of the development and treatment of cancer, more partnerships of the sort CBTF is participating in are emerging as opportunities to advance cancer research and treatment. Patients and families are vital to the partnerships forming among private funders, government agencies, and the pharmaceutical industry. As advocacy partners, CBTF is lending the insights and strength of the community of children with brain tumors and their families to build new approaches to treatment and quality care.

A transcript of the April 21 Advocacy Conference is available on www.nabraintumor.org. *To learn more about advocacy at CBTF, call our office at 212.448.9494.*

BTAW

BRAIN TUMOR ACTION WEEK is scheduled for May 2–7 this year and the North American Brain Tumor Coalition (NABTC) has outlined four important positions for advocates to present to legislators and their aides.

1 **Support the Genetic Information Nondiscrimination Act, S. 1053** — Groundbreaking research on brain tumors has resulted in the development of valuable knowledge about the genetics of these tumors. Soon, patients may be able to use this information to find appropriate treatments. This bill will prevent discrimination in employment or health insurance based on this type of information. It has been passed in the Senate and endorsed by the White House. Now, we need our Representatives in the House to take action!

2 **Eliminate the Two-Year Waiting Medicare Period for Brain Tumor Patients** — Currently, an adult must wait five months from being deemed disabled until receipt of Social Security Disability Insurance (SSDI) payments. In addition, that individual must wait a full two years from receipt of SSDI payments until becoming eligible for Medicare benefits. Obviously, asking a brain tumor patient to wait two years for benefits does not recognize the realities of such a diagnosis. The NABTC is still looking for a sponsor to create legislation for this crucial issue.

3 **Foster a Strong Brain Tumor Research Program at the National Institutes of Health** — Since the publication of the report by the Brain Tumor Progress Review Group, there have been positive steps taken to advance research at the NIH and its agencies. However, more is needed and the NABTC is recommending several initiatives to keep making progress

4 **Report Language on Brain Tumor Research for the Fiscal Year 2005 Labor–HHS–Education Bill** — The NABTC is asking legislators on this committee to adopt this report language, which states that the most pressing need is a committed leader for the extramural brain tumor research program at NCI.

YOU can make a difference by visiting the local offices of your elected officials during Brain Tumor Action Week or at any other time. Full details on these and other issues, as well as advice on how to be an advocate, are available at www.nabraintumor.org.

Children's Brain Tumor Foundation

274 Madison Avenue, Suite 1301
New York, NY 10016

Embracing the challenge today gives hope for tomorrow

CHANGE SERVICE REQUESTED

It costs the foundation valuable resources to mail you this newsletter.
Please let us know if you move, get multiple copies or would like to be removed from our mailing list

Ninth Annual Dinner Dance

Thursday, June 17 at 6:30pm
Jericho Terrace, Mineola, NY

HONORING **DENIS SHEIL**
Vice President
The New York City District Council of Carpenters,
United Brotherhood of Carpenters and Joiners of America

Live Music by Head Over Heels!

Chinese Auction!

Raffle–Prizes Include:

• Two night stay for two in Puerto Rico •
• VIP Tickets to Macy's Thanksgiving Day Parade •
• Spa Day in NYC • Movado Watch • Burberry Handbag •

For more information on attending or sponsoring this event, please call 212.448.9494 or email info@cbtf.org

Coming Attractions

June 7, 2004
The Second Annual Dream and Promise Awards Benefit
New York Marriott Marquis

June 13 – 16
11th International Symposium on Pediatric Neuro–Oncology
Boston, MA

June 17, 2004
Ninth Annual Dinner Dance
Jericho Terrace, Mineola, NY

June 27 – July 2
Brain Tumor Week at Camp Sunshine, Casco, ME

July 27
Kids Cruise, New York City

August 1 & 8
3–On–3 Neighborhood Basketball Classic, Jericho, NY

September 10
Golf Tournament, Miry Run Country Club, New Jersey

October 18
The Sixth Annual Danny Jegle Open, Hempstead Golf & Country Club, Hempstead, NY

If you need support, call our Toll-Free Support Number:
866-228-HOPE (4673)