Children's Brain Tumor Foundation

# The challenge

*Embracing the challenge today gives hope for tomorrow*

Spring 2002 274 Madison Avenue, Suite 1301, New York, NY 10016 • Phone: 212.448.9494 Fax: 212.448.1022 Volume 10

# NEW FOCUS FOR RESEARCH GRANTS


Photograph Courtesy Jana Leon/Graphistock

After ten years of promoting cutting-edge scientific research into the causes of, and improved treatments for, pediatric brain and spinal cord tumors, the Children's Brain Tumor Foundation is narrowing the criteria used to select recipients for research grants. In order to build on the progress made in the last decade, the Foundation is adopting Priorities 1 and 2 of the *Research and Scientific Priorities* specified in the **Report of the Brain Tumor Progress Review Group** (BT–PRG), At the beginning of 2000, the BT–PRG accepted the charge of Dr. Richard Klausner, Director of the the National Cancer Institute, and Dr. Gerald Fischbach, Director of the National Institute of Neurological Disorders and Stroke, to develop a national plan for the next decade of brain tumor research. Priority 1 is to "Understand the signaling systems involved in mitogenesis, survival, and cell death for pediatric tumors." The goal of Priority 2 is to "Fully characterize the phenotypic and genetic alterations that are unique to benign and malignant pediatric brain tumors." The entire text of the report can be found at http://prg.nci.nih.gov/brain/pediatrics.html.

> "Thanks to the success of researchers across the country and the Progress Review Group recommendations, we know where we need to put the Foundation's money."

Since 1991, when our research grant program began with a $30,000 award to NYU Medical Center, the total awarded by CBTF for scientific research has topped **three million dollars** and has involved many of the leading research institutions throughout the country. "We felt it was realistic at this time to acknowledge that certain areas were showing great promise, but needed even more attention," said Joel Shiff, who sits on the Board of Directors and is Chairman of the Grants Committee. "Thanks to the success of researchers across the country and the Progress Review Group recommendations, we know where we need to put the Foundation's money."

Some of the barriers to advancement in the fight against childhood brain and spinal cord tumors are detailed in the PRG report. "On the largest scale," the BT–PRG writes, "the overriding challenge for research into pediatric brain tumors is to improve outcome for children with a host of different types of brain tumors. The predominant barriers are the relative infrequency of any individual tumor type, the presence of embryonal/primitive tumors that often disseminate to the leptomeninges, and the

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Photograph by Paula Scott

**The envelope please:** Dr. David Zagzag presenting at the 2001 Research Grants Award Reception. See page 4 for a list of recipients.

See inside

**Children's Brain Tumor Foundation**

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# Message from the President


Photo by Chi Chi Ubina

Nora Leary

In the past year we have seen a lot of changes in the world and at the Children's Brain Tumor Foundation. Although the tragic events of September 11 are never far from our minds and hearts, we remain dedicated to our mission to help children with brain tumors and their families. Thanks to everyone for their continuing support.

The end of the year is always a busy time at CBTF and 2001 was no exception. We had a great turnout in October for the Big Apple Circus. My family had a particularly good time since our good friend Charlie Miles was kind enough to volunteer for some clowning around and our daughter Emma, a five-year brain tumor survivor, danced the hand jive in the circus ring.

The third annual Danny Jegle Memorial Golf Tournament was initially postponed but friends and family made a tremendous effort to come out and play for CBTF even though a number of our supporters suffered tragic losses on September 11. Our special thanks go out to each and every participant in this event.

In November, CBTF was proud to award research grants to Dr. Ganjam Kalpana, Dr. Krzysztof Reiss, and Dr. Corey Raffel in the total amount of $300,000. I would like to thank our Professional Advisory Board and in particular, Dr. David Zagzag, for taking the time and effort to make sure that our grants program funds medical research that holds the promise of making a difference in the lives of children with brain and spinal cord tumors.

In December, we awarded five program or quality of life grants to hospitals treating brain tumor patients in the tri-state area in the total amount of $100,000. CBTF also sponsored a teleconference with Cancer Care on the unique issues that siblings, grandparents, and other family members face when a child is diagnosed with and is undergoing treatment for a brain tumor.

Thanks to all of you who responded to CBTF's first survey on how and whether our services are meeting the needs of brain tumor patients and their families. We welcome any and all of your comments on what we're doing, what we can do better, and what needs to be done in the future.

On that note, our Parent-2-Parent support program is under way and Tracy Moore, C.S.W., our Director of Patient Education and Support, will be conducting a training sessions for all parents who are interested in participating.

Finally, I would like to acknowledge the service of our retiring Board Members. Stewart Scharfman has been a dedicated member of our board since his son, Spenser, was diagnosed with a brain tumor ten years ago. Thank you to Stewart and to the whole Scharfman family for all of your generous support and service. You can read about Spenser's latest accomplishment on page one of the Kidz Korner.

I also want to thank Richard Kearns, Deena Shiff, and Roberta Epperhart-O'Neil for their dedicated service over the last three years. We're going to miss you!

Nora Leary

**Honorable Mention:** On November 7, 2001, Cancer Care, Inc. honored Judy Hurley and CBTF with a certificate "in grateful recognition of your dedicated commitment and support for this agency and the people it serves." Shown at the annual reception are (from left): Tracy Moore, C.S.W., CBTF's Director of Patient Education and Support, Priscilla Hartung, Director of Social Services at Cancer Care, Inc. and a member of CBTF's Professional Advisory Board, Judy Hurley, CBTF's Executive Director and Jeremy Shatan, CBTF's Development/PR Associate. We are looking forward to future collaborations!

# FROM AWARENESS TO ACTION

The North American Brain Tumor Coalition (NABTC) has changed the name of its yearly event from Brain Tumor Awareness Week to Brain Tumor *Action* Week (BTAW). This year, it will take place during the week of May 5-11. Representatives from CBTF and the other NABTC member organizations will hold their annual meeting in Washington, DC early in the week. Monday May 6 will be Advocacy Education Day, where volunteers will learn effective advocacy tactics. On Tuesday May 7, volunteers will make visits to the offices of their elected representatives on Capitol Hill, followed by a candlelight vigil. Visit www.nabraintumor.org, the NABTC website, to print a copy of the 2002 Action Guide.

*The Faces of Brain Tumors*, a book featuring stories and photographs about the lives of those touched by brain tumors proved to be an effective advocacy tool on Capitol Hill in 2001. Guidelines for contributing are posted at www.nabraintumor.org.

Volunteers across the country will also be doing their part locally by distributing materials at hospitals, schools and workplaces in their area. If you would like to participate in BTAW either by joining us in Washington to meet with Representatives or by setting up an information booth at your local hospital or workplace, please contact us at (212) 448-9494 or Info@cbtf.org.

CBTF Board Member Craig Lustig has defined advocacy in this arena as follows: "The systematic process of nudging, nagging, educating, and occasionally harassing, leadership of medical research organizations, Congress, pharmaceutical companies and providers of cancer care." Can you think of ways to put this definition to work during BTAW and the rest of the year?

## *Federal Funding for Brain Tumor Research* *by Susan Weiner, Ph.D.*

Advocacy News

Increases in federal research funding are critical if there are to be major advances in the understanding and treatment of children's brain tumors. The Children's Brain Tumor Foundation continues to provide much needed funds for hard to get start up grants as well as funds to extend investigators' larger research projects to enable them to ask relevant pediatric questions.

Private funds, however, will never replace the size and scope of federally funded research initiatives. The majority of funding for laboratory and clinical research on children's brain tumors comes from the National Cancer Institute (NCI). NCI is the largest of the 27 institutes and centers of the National Institutes of Health (NIH), part of the Department of Health and Human Services under Secretary Tommy Thompson.

In 1998, former Senator Connie Mack of Florida, a champion of cancer research, proposed that Congress double the budget of NIH within five years. This ambitious goal would bring more dollars to basic, clinical and translational research, to the hospital networks that evaluate new therapies in children and adults, to the NCI-designated cancer centers, to train young investigators and more.

In his budget for Fiscal Year 2003, President Bush is proposing to fulfill the Senate's commitment by completing the doubling of the NIH budget. Despite budget shortfalls and a new commitment to bioterrorism research, the President proposed $27.3 billion for NIH, an increase of $3.7 billion, 15.7 percent over the FY 2002 budget. This increase would allow NIH to support over 9,800 competing research grants – 477 over Fiscal Year 2002. The President's budget request would increase cancer research funding to $5.5 billion with NCI receiving $4.7 billion, a 12.2 percent increase over the Fiscal Year 2002 funding.

Action by the House and Senate is necessary to appropriate funds for spending bills. Congress works to reconcile its own spending priorities with the President's budget request before bills go to the President for signature into law. Under new budgetary shortfalls, it remains to be seen whether the NIH budget will actually achieve the doubling goal by 2003.

Each spring, the Children's Brain Tumor Foundation, working with the North American Brain Tumor Coalition and with many other cancer advocacy groups, has advocated in Congress to guarantee increases in biomedical research funding. While most of our focus has been on the NCI, we have supported the broader NIH funding proposal. Research important to children with brain tumors is also carried out at many other institutes and centers, such as the National Institute of Neurological Disorders and Stroke, the National Institute of Mental Health, and the National Institute of Genome Sciences.

We are committed to ensuring wide support for doubling the NIH budget by 2003, and once achieved, will continue to advocate for increases in funds for brain tumor research until effective treatments for children and follow up services for children and families are fully achieved.

# NEW FOCUS FOR RESEARCH GRANTS

(Continued from page one)

lack of interest in, focus on, and funding for research on these primitive tumors."

By directing its funds in this manner, the Foundation hopes help to eliminate some of the roadblocks that stand between the current state of science in the battle against pediatric brain and spinal cord tumors and a future when these tumors will be approached with a high rate of success and a low rate of harm to the children.

This past November, at the 2001 Research Grants Award Reception, the following grants were given out:

**The 2001 Jean & Nicholas Leone Research Grant** ($100,000 over two years) to Krzysztof Reiss, Ph.D., an Assistant Professor at the Temple University Center for Neurovirology and Cancer Biology for his study, "*Targeting Insulin-like Growth Factor I Receptor (IGF-IR) – JCV T-Antigen Functional Interaction in Cerebellar Medulloblastoma.*"

**The 2001 Sascha Feher Memorial Research Grant** ($100,000 over two years) to Ganjam V. Kalpana, Ph.D., an Associate Professor at the 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.*"

**The 2001 CBTF Research Grant** ($100,000 over two years) to Corey Raffel, M.D., Ph.D., Professor of Neurologic Surgery at the Mayo Clinic and Foundation for his study "*Murine Modeling of Human Medulloblastoma.*"

The following grants were renewed:

C. Damodara Reddy, Ph.D., at the Children's Hospital of Philadelphia, to continue his study "*IGF-I Receptor Targeted Therapy of Primitive Neuroectodermal Tumors.*"

Gordon J. Fishell, Ph.D., at New York University School of Medicine, Skirball Institute, to continue studying "*The Role of Notch Signaling during Mammalian Neural Stem Cell Proliferation and Differentiation.*"

Photograph by Paula Scott

**And now it's back to the lab:** From left: Joel Shiff, Chairman of the Grants Committee of the Board of Directors, Dr. Corey Raffel, Dr. C. Damodara Reddy, Dr. Krzysztof Reiss, Nora Leary, President of the Board, Dr. David Zagzag, an Associate Professor at NYU Medical Center's Department of Pathology, and the Chair of the Foundation's Professional Advisory Board, and Dr. Ganjam Kalpana at the 2001 Research Grants Award Reception.

Dear Ms. Hurley,

I regret that I was unable to attend the 2001 Research Grants Award Reception held in New York City this past November. However, I would like to thank and inform you and the Board of Directors of our recent success, which would not have been possible without the help of a research grant award from the Children's Brain Tumor Foundation. With this support we were able to complete the initial phase of our research project and have published the results in the October 2001 issue of *Nature Genetics*. The title of our paper is "Expression profiling of medulloblastoma: PDGFRA and the RAS/MAPK pathway as therapeutic targets for metastatic disease". A reprint of this article is enclosed.

I believe that this publication was instrumental in my recently securing NIH funding. Once again, my gratitude to you and the entire Board of Directors of the Children's Brain Tumor Foundation for supporting this work.

Sincerely,

Tobey J. MacDonald, M.D.
Clinical Director, Neuro-Oncology
Attending Physician, Hematology/Oncology
Children's National Medical Center

Please contact CBTF at (212) 448.9494 or Info@cbtf.org for reprints of articles by research grant recipients.

# Parent's Corner

## A PARENT'S PERSPECTIVE

by

Michelle Bogosian

When my child was diagnosed with medulloblastoma, I was overwhelmed, scared, and exhausted – by the illness, by the decisions and especially by all the information. In all of the mayhem I found one simple thing to be continually true: when I was calm so was my daughter. She could handle most anything. When I was not calm, neither was she and the simplest thing would send her into conniptions. So I came up with ten simple rules that I would try to do each day to help me stay calm and be there for her.

- Focus on the cure rather than the illness.
- As much as possible fit the illness into your life, rather than your life into the illness.
- Simply remain calm. That doesn't mean don't feel, it does mean take your fear outside of the room. If you are calm your child feels safe even when they are scared.
- When you feel something is not right, even if you are unsure, voice your feelings. I found that it can be good, when appropriate, to let your child see you sticking up for them. They need to know you are on their side.
- Breathe in and out.
- Take breaks.
- Talk to someone. A friend, a counselor, another parent. It's important to find time when your child is not present so you can really open up.
- Enjoy your child. Find something to be thankful for each day.
- Ask questions and if you don't understand the answer, ask until you do. When you know what is going on you feel more in control and control gives you a sense of calm.
- Admit that you are human. Ask for and accept help.

In all honesty some days were harder than others, but having this list helped. I hope it can be of some help to you too.

## 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.

# Quality of Life

In December 2001, Program Grants totaling close to $100,000 were awarded to the following institutions:

☺ $50,000 to The Children's Cause and The National Coalition for Cancer Survivorship and Lovett Productions for developing a videotape and accompanying materials focusing on survivorship issues entitled "Life After Childhood Cancer".

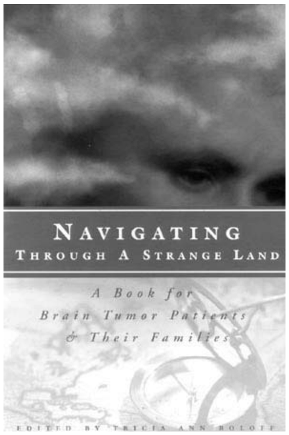
☺ $12,000 to Beth Israel's Hyman-Newman Institute for Neurology and Neurosurgery for a portable respirator allowing children to move about the hospital.

☺ $12,000 to the New York Medical College at the Children's Hospital of Westchester Medical Center for neuro-psychological testing for eight children.

☺ $9,750 to New York University Medical Center. for the purchase of therapeutic recreational equipment for the Hassenfeld Center.

☺ $9,000 Winthrop-University Hospital Cancer Center for Kids for six laptop computers for ambulatory and inpatient units.

☺ $5,000 to New York University Medical Center for the development of a bereavement program.



# Navigating Through a Strange Land

The Fairview Press is announcing the publication of the second edition of Tricia Ann Roloff's book, *Navigating Through a Strange Land: A Book for Brain Tumor Patients and Their Families*. This useful book includes professional guidance information and the moving personal stories of brain tumor patients, their family members, and their professional caregivers. The revised and expanded second edition contains new stories of hope and healing, along with an updated resource directory. The book can be ordered directly from the Fairview Press by calling (800) 544-8207. Mention the Children's Brain Tumor Foundation when ordering to receive a **20% discount and free shipping**.

# CBTF Expands Parent-to-Parent Network— Providing More Support for Families

The Parent-to-Parent Network (P2P) provides parents with a forum to explore the many complicated issues surrounding the diagnosis of a childhood brain tumor with someone who has been there. The program connects parents who request support with parent volunteers who have knowledge and experience. P2P can help with general issues and with such specific areas as initial diagnosis, treatment, survivorship, long-term follow up, and bereavement.

We anticipate holding future training sessions in the fall. If you are interested in becoming a volunteer or if you want to be matched with a parent, please contact Tracy Moore, C.S.W. at (212) 448-9494 or tmoore@cbtf.org. We look forward to hearing from you!

# Eventful Days and nights at CBTF

## New York City District Council of Carpenters generates over $200,000 in donations for children with brain and spinal cord tumors.


Tom Matthews

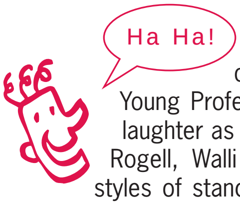
**Gene Maiello**

On Thursday, June 13, 2002 at 6:30pm, at the Seventh Annual Dinner Dance, CBTF will be honoring Gene Maiello, the Vice President of the New York District Council of Carpenters. This is the second year that we have recognized an executive of the District Council, which is well-known for its charitable efforts toward children.

The union and its many supporters have raised over $200,000 for CBTF. The union is not only committed to rebuilding lives but it is also helping to rebuild NYC in the wake of the tragedy from September 11th. The fact that their interest in children with brain and spinal cord tumors has not waned even after losing eighteen of their colleagues in the World Trade Center attack is truly a testament to the type of character these honorable men and women possess. CBTF considers it a privilege to be associated with such highly regarded members of our community.

Join us in celebrating Gene Maiello's contribution to our community by attending the Dinner Dance. It is a fun-filled evening with great music, food and raffles, held at Jericho Terrace in Mineola on Long Island.

Since its inception, the Dinner Dance has raised over 1.3 million dollars for CBTF's programs. If you are interested in being a part of that success, please contact us at (212) 448.9494 or Info@cbtf.org for information in how you can participate by purchasing sponsorships, dinner tickets, and raffle tickets.



**Cutting-edge comedy: On January 23, 2002,** A Night of Laughter 2, CBTF's second annual comedy night organized by the Young Professionals Group, featured such luminaries of laughter as Lewis Black, Greg Carey, Paul Mecurio, Greg Rogell, Walli Collins and Ben Bailey performing unique styles of stand-up. The audience roared with laughter and the event raised nearly $4,000 for CBTF! Thank you to Chris Mazzilli and everyone at Gotham Comedy Club for hosting the event again.

GOTHAM
COMEDY CLUB
NEW YORK CITY

## FORE!

**Better than par for the course:** The Third Annual Danny Jegle Open attracted a big crowd of duffers to the Pine Hills Country Club in eastern Long Island. October 12, 2001 was a gloriously beautiful day and the golfing was easy. There was a lively dinner and auction and over $35,000 was raised for CBTF! Thanks to all the generous sponsors and volunteers for making the event such a success. That's Danny Jegle's dad, Tim, showing off his swing.

GUARDIAN

**thank you** to the Guardian Life Insurance Company for throwing another amazing party for children with brain and spinal cord tumors and other life-threatening illnesses. Close to 400 people attended and had a great time with entertainment, food, activities and gifts. None of it would have been possible without the efforts of Mary McElrath-Jones, Jacqueline Kanas, and their team at Guardian Life!

## 3rd Holiday Party is Biggest yet!


Photograph by Stephen Grimsley

**The roar of the crowd:** The audience was enthralled by the puppet show.

**The gang's all here:** Ian Scott (second from left), a member of CBTF's Young Professionals Group, with friends.


Photograph by Stephen Grimsley

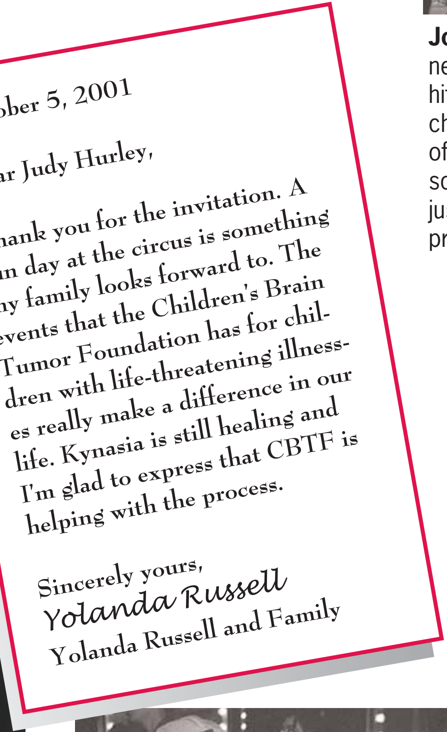
**Santa and friend:** This boy must have been good for goodness sake!

**Peas in a pod:** Jessica Reisman, C.S.W., a social worker at NYU's Hassenfeld Clinic and a member of CBTF's Young Professional Group, gets a special hug from an old friend.

# BIG APPLE CIRCUS

PHOTOGRAPHS BY TOM HAYNES

**For kids of all ages:** There are few things more magical than seeing the circus through a child's eyes.



October 5, 2001

Dear Judy Hurley,

Thank you for the invitation. A fun day at the circus is something my family looks forward to. The events that the Children's Brain Tumor Foundation has for children with life-threatening illnesses really make a difference in our life. Kynasia is still healing and I'm glad to express that CBTF is helping with the process.

Sincerely yours,
Yolanda Russell
Yolanda Russell and Family

**Jolly good show!** The Big Apple Circus' new show "Big Top Doo Wop" was a big hit in more ways than one! Hundreds of children and their families attended free of charge thanks to our generous sponsors. In it's 13th year, the benefit raised just shy of $200,000 for the Foundation's programs!

**Honorary Ringmasters:** In a demonstration of support and admiration, CBTF invited medical professionals and a few of the many inspiring children who joined us at the circus to come into the center of the ring before the show started.

**Three of a kind:** These good friends had a great day together!

**Getting into the act:** This little girl could not resist clowning around!

**What's up doc?** Mark Souweidane, M.D., Pediatric Neurosurgeon at New York Presbyterian Hospital and member of CBTF's Professional Advisory Board, with two buddies.

**What memories are made of:** This happy group will have something very special to look back on.

Children's
Brain Tumor
Foundation

274 Madison Avenue, Suite 1301
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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*

## Coming Attractions

**April 5, 2002, 7:30pm**
New Jersey Nets Basketball
Continental Arena, NJ

**May 5 - 11, 2002**
Brain Tumor Action Week

**June 13, 2002, 6:30pm**
Seventh Annual Dinner Dance
Jericho Terrace, Mineola, NY

**Summer 2002**
Kids Cruise 2
New York City
(Call for Date)

**September 24, 2002**
The Fourth Annual Danny Jegle Golf Open
Lido Golf Club, Lido Beach, NY

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

## 1-866-228-HOPE

## (1-866-228-4673)