Children's Brain Tumor Foundation

The challenge

Embracing
the challenge
today gives
hope for
tomorrow

Fall 2002 274 Madison Avenue, Suite 1301, New York, NY 10016 • Phone: 212.448.9494 Fax: 212.448.1022 Volume 11

Shedding Light Benign

The Benign Brain Tumor Research of Dr. Jeffrey Wisoff

Photograph by Andreas Rentsch/Courtesy Nonstock

> *The star which comes at close of day to shine*
> *More heavenly bright than when it leads the morn,*
> *Is friendship's emblem, whether the forlorn*
> *She visiteth, or, shedding light benign*
> *Through shades that solemnize Life's calm decline,*
> *Doth make the happy happier.*
> William Wordsworth (from "To I.F.", 1840)

Since 1985, Jeffrey H. Wisoff, M.D., Associate Professor of Neurosurgery and Director of Pediatric Neurosurgery at New York University School of Medicine and a member of our Professional Advisory Board, has been conducting exhaustive research into the cellular profile and treatment of benign brain tumors in children. Although he is working under the auspices of the Children's Oncology Group (COG), much of the work has been pursued on his own time, including yearly retreats with other researchers to review MRI films on the more than 600 patients from across the country whose cases he has been following. At Brain Tumor Action Week in May, Dr. Wisoff presented an overview of his findings during education day. The exciting science he discussed certainly helped to motivate the gathering of brain tumor advocates to go to Capitol Hill and talk up the Benign Brain Tumors Registration Act while meeting with their senators and representatives.

Recently, we sat down with Dr. Wisoff in his office to discuss his work in this area. A summary of his research follows the interview.

What personal motivation did you have to do this research on your own time? There has been minimal financial support for this work. Occasionally, I get a plane ticket or a hotel room but most of it has been the dedication of myself and other individuals to do this research. It is my belief that part of being a pediatric neurosurgeon is not just to maintain the status quo but to make improvements. A great surgeon once said, "Every patient should be your laboratory," and not in the sense of coldly experimenting on your patients but in learning from everything. All human interactions should be a learning experience—not just when you're dating! I feel an obligation to do research and to contribute patients to national studies and I am devoting

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U.S. Senate Passes Benign Brain Tumor Legislation

From the Congressional Record, August 1, 2002: *"Benign Brain-Related Tumor Collection: Committee on Health, Education, Labor, and Pensions was discharged from further consideration of S. 2558 to amend the Public Health Service Act to provide for the collection of data on benign brain-related tumors through the national program of cancer registries, and the bill was then passed."* These matter-of-fact words represent a significant victory for the brain tumor community. Thanks to the efforts of Senator Jack Reed (Democrat, RI) and his

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A Father's Promise

By Nick Schiaffo

On April 8, 1998, the lives of our family changed forever. It was on that day that our only child, Daniel, was diagnosed with medulloblastoma, the most common form of childhood brain tumor.

Three days later, our son underwent craniosurgery to remove the tumor, followed by 31 radiation treatments and 9 months of chemotherapy. It was determined in April of 1999 that Daniel was in remission. But later that same year, on December 9, we received the devastating news that the brain tumor had returned, and on Christmas Eve, he once again began his long journey into wellness. It

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Message from the President


Photo by Chi Chi Ubina

Nora Leary

It is back to school time again and a busy season at the Children's Brain Tumor Foundation! This issue of the newsletter brings attention to the importance of expanding federally funded brain tumor registries to include benign tumors. We hope we can count on you to support the house version of the *Benign Brain Tumors Registries Amendment Act*. The Senate version passed as we were going to press. Thank you, Dr. Jeff Wisoff for taking the time to speak to us about this critical topic.

Since our last newsletter we've had a number of fun fundraising events including our annual Dinner Dance where we honored Gene Maiello and all our terrific supporters from the New York City District Council of Carpenters. Josh Cohen's Fifth Annual 3-On-3 Neighborhood Classic basketball tournament was held in July, the Kids Cruise at the South Street Seaport took place in August, and the Danny Jegle Golf Tournament is this month. We are happy to announce that we were chosen once again as the beneficiary of this year's annual Banker's Battle in Huntington, Long Island. Thanks to the members of the Partnership Uniting Banking Leaders in the Community (P.U.B.L.I.C.) for believing so strongly in our mission. The Big Apple Circus will be on October 27 with better seating and more up-front action for everyone!

Our patient support programs are also in full swing. Tracy Moore, CSW, Director of Patient Education and Support, has trained a lot of parents who are now a part of our Parent-to-Parent network. If you're a parent who'd like to help out or if you need help, please call 1-866-228-HOPE to participate. Finally, December brings our annual teleconference, co-sponsored by the Brain Tumor Society and Cancer Care. This year, it will address bereavement issues.

Look for our research and program grant awards in November. In the meantime, I wish all our families and friends a happy and healthy new school year!

Nora Leary

Spreading the Word: Back in February, Jeremy Shatan, CBTF's Development/PR Associate, was invited to speak to the members of the Syosset-Woodbury Rotary Club, on Long Island. He told them about his son's illness and death due to a pediatric brain tumor and how that personal tragedy had led him to his job with CBTF. He also let them know all about CBTF's programs and fundraisers. The Rotarians were profoundly moved and expressed a strong desire to help. We look forward to working together with them in the future! Left to right: Denise Rogers,Secretary, Jeremy Shatan, and Craig A. Drucker, President.

U.S. Senate Passes Benign Brain Tumor Legislation

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staffer, Lisa German-Foster, the bill passed in less than three months. For the complete text of the bill, surf your way to http://thomas.loc.gov and enter "S. 2558" in the "search" box.

However, as we all learned in grade school, a bill needs to pass in both the Senate and the House of Representatives before it can be signed into law by the President. Unfortunately, the House version of the bill, H.R. 239, has been languishing since it was introduced in January of 2001. In that time, it has managed to gain 83 co-sponsors. Go to http://thomas.loc.gov/cgi–bin/bdquery/z?d107:HR00239:@@@P and see if your representative is representing *you* on this issue. If not, a letter to him or her can help get the legislative ball rolling again. The North American Brain Tumor Coalition has issued a "Call to Action" regarding the House bill. It is available at www.nabraintumor.org under "Legislative-Related and Other Issues" and has valuable suggestions for contacting elected officials.

CBTF awards $25,000 to CBTRUS

That may sound like alphabet soup, but it's just a quick way of saying that the Children's Brain Tumor Foundation (CBTF) has awarded $25,000 to the Central Brain Tumor Registry of the United States (CBTRUS). A not-for-profit corporation founded in 1992, CBTRUS is committed to gathering and disseminating current epidemiologic data on benign and malignant primary brain tumors. The goals of CBTRUS are to accurately describe the incidence and survival patterns of brain tumors and evaluate diagnosis and treatment, thus facilitating etiologic studies, establishing awareness of the disease, and, ultimately, leading to the prevention of all brain tumors. CBTRUS's collection of population-based data on the incidence of all primary brain and central nervous system tumors is the largest such aggregation in the United States.

CBTF's $25,000 donation will allow CBTRUS to safeguard their database and will help them move forward on such projects as increasing the interactivity of their website and publishing their next report, "Primary Brain Tumors in the United States, 1995-1999." So the next time you open a can of alphabet soup, remember that CBTF is proud to support the important work of CBTRUS!

CBTF Experts Advise Advocates During Brain Tumor Action Week by Susan L. Weiner, Ph.D.

Advocacy News

Anita Nirenberg, R.N., N.P., a CBTF board member, and Jeffrey Wisoff, MD, a member of CBTF's Professional Advisory Board, were featured at the North American Brain Tumor Coalition's (NABTC) 2002 Brain Tumor Action Week (BTAW) in early May. NABTC arranged a full-day educational program for advocates from all over the country to provide some background on the advocacy positions being presented on Capitol Hill the following day.

Dr. Wisoff led with a discussion of his multi-year study of pediatric low grade gliomas, concluding that low grade and so-called benign tumors can re-grow, be life-threatening and disabling. His talk directly supported NABTC's efforts to get Congress to pass legislation that would count benign brain tumors among the types of brain tumors tallied by cancer registries. Dr. Wisoff described their exclusion from cancer registries as hindering the scientific investigation of the incidence and treatment of brain tumors. Dr. Wisoff serves as Chief of the Division of Pediatric Neurosurgery at New York University Medical School.

Adult and pediatric brain tumor advocates have worked tirelessly in an attempt to guarantee that all cancer registries funded by the federal government would include benign brain tumors. Several pediatric brain tumors are considered benign, including pilocytic astrocytomas. Recently, there was a major victory in this quest when the Senate passed the Benign Brain Tumor Cancer Registries Amendment Act. All eyes are now on the House, waiting for them to move their version of the bill through.

Ms. Nirenberg, an advocate in her care of pediatric and adult brain tumor patients, moderated a panel on *Clinical Trials: How is Basic Science Brought to the Bedside?* NABTC advocates support a Patients' Bill of Rights, which would ensure patients' access to emerging therapies and other provisions supporting quality care for brain tumor patients. Versions of the patients' rights bill have been stalled in Congress for some time.

The clinical trials panel was conducted by scientists and physicians expert in cancer and brain tumors. Members included Richard Pazdur, M.D., Director of Oncology Drug Products Division, Food and Drug Administration, Howard Fine, M.D., Chief Neuro-Oncology Branch, National Cancer Institute (NCI), Jeffrey W. Sherman, M.D., Chief Medical Officer of NeoPharm, Inc., and Pam Del Maestro, R.N., B.Sc.N., Chair of NABTC. Ms. Nirenberg directs the Pediatric Oncology Nursing program at the Columbia School of Nursing.

Anita Nirenberg, R.N., N.P., speaking on clinical trials at the Education Day panel during Brain Tumor Action Week.

Pam Del Maestro and I presented NABTC's positions on brain tumor research, supporting implementation of the Brain Tumor Progress Review Group report, the first comprehensive, national plan to advance brain tumor research and treatment. Conducted two years ago by NCI and the NINDS (National Institute of Neurological Disorders and Stroke), advocates continue to press Congress, NCI, and NINDS to act on the plan. Progress has slowed on this and other disease-specific initiatives in the early tenure of Andrew Von Eschenbach, M.D., the new Director of NCI.

my heart and soul as a doctor to the Children's Oncology Group (COG).

How did you get started doing research on benign brain tumors? It really was serendipity. Earlier in my career I became known for my work with optic pathway tumors. Back in 1985, when the Children's Cancer Group (CCG, a predecessor of COG) turned its attention to benign tumors, Dr. Jonathan Finlay (now Director of the Hassenfeld Clinic at NYU) said, "This is a surgical question – we need a surgeon." I was then an upstart who was known for never keeping my mouth shut so I was chosen to be the first pediatric neurosurgeon to head the study on benign tumors.

Most treatment protocols are a patchwork of different disciplines with each thinking they know what is best but no one agreeing. It took us four years to hammer out a protocol for low-grade tumors. What we arrived at originally had two study arms. The first studied whether having a total resection of the tumor, i.e., 95% or more tumor removed, would lead to a cure. The second arm looked at if radiation would improve the rate of success for patients who had more tumor left behind. The idea was to have a randomized trial where some patients would receive radiation and some would not. This plan failed. It was very hard to sell it to patients and their families, many of whom see surgery as a given and anything beyond that as treatment. So people felt like we were asking them to accept the possibility of not treating their child at all, even though that was not the case. In the end, I think we had four patients for the radiation study before we closed it. We decided to just follow the natural history of patients who had received radiation.

Did any of your findings come as a big surprise? Based on my surgical beliefs, there were three things that surprised me. One was that unless you had a total resection, there was a significant rate of recurrence. The second was that the chance of a tumor recurring was the same whether a little tumor was left behind or a lot. The third was that the amount of tumor did influence which children died from their tumor. It seemed that the cut-off was having greater than 3 cubic centimeters of tumor left behind. One fascinating thing was that five years after surgery, even when you left tumor behind, you had half the children showing no progression. Sometimegeras isd

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A Father's Promise

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was this second time around that we witnessed grace, dignity, and courage from our son the likes of which we had never experienced before. Daniel never complained about his illness or the complications of it. In fact, he was only apologetic about it. One can imagine a parent's heartbreak upon hearing a child say he is sorry for being sick.

A week prior to the stem cell transplant that we hoped would save his life, I asked Daniel if he was scared. His reply was a simple "No." I was never so proud of anyone as I was of him at that moment. He was truly my hero. On May 29, 2000, just 4 days into the transplant, Daniel passed away in his mother's arms. Moments before he drew his last breath I promised him that I would do whatever possible to eradicate this disease.

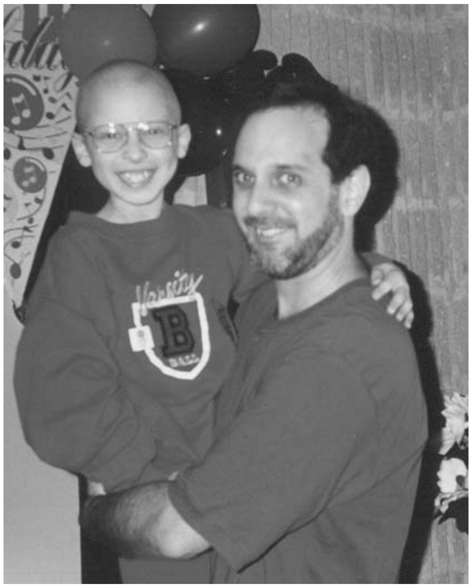
A few weeks prior to Daniel's passing I was asked to supply a picture and a story of Daniel to be displayed in Washington, DC, during Brain Tumor Action Week. I did so with the hope that seeing this wonderful child with the beautiful smile might bring awareness and understanding about the plight of brain tumor patients. The following year I became active with the North American Brain Tumor Coalition. Traveling to Washington and meeting others who had lost ones or were themselves afflicted with this horrible disease brought me perspective as well as inner peace and healing.

Although my wife and I thought that we were all alone in this fight, we learned that we were just one family of many.

Talking openly with others brought new realizations of the work that I could do-not only to support others but to help fight this disease.

I also became active in the Virginia Transplant Council and Old Dominion Eye Foundation, serving on their boards, working to bring awareness of the importance of organ donation. We ourselves had given the only gift we had, the gift of our son's corneas. Daniel now lives on in others.

After many months of lobbying, on June 19, I was on hand when the Senate Health, Education, Labor & Pensions subcommittee passed the Benign Brain Tumor Cancer Registries Amendment Act (S. 2558), which was given full approval by the Senate a couple of weeks later. The Act is aimed at improving data collection to understand the burden of both benign and malignant brain tumors, enhancing the brain tumor research effort, and advancing care for brain tumor patients. S.2558 will have a positive impact on brain tumor research and treatment, and hopefully, one day, lead to a cure.

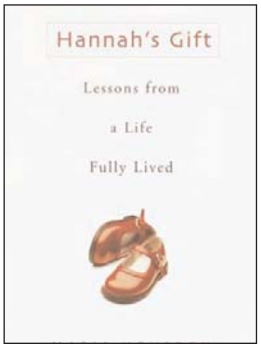


Smiling brighter than the candles: Nick Schiaffo with his son, Daniel, on Daniel's ninth birthday, March 19, 1999.

On that morning in Washington I felt a true sense of pride and accomplishment as a parent. Even though there are many battles yet to be won, I hope to see a cure for brain tumors and all cancers in my lifetime. Every night when I leave work I look up to one particular star and say "Goodnight Daniel." This star always appears to be looking at me, offering inspiration and hope. When a cure comes and I see that bright star winking at me in the night sky, I will have fulfilled my promise to my son.

Hannah's Gift by Maria C. Housden

Book Review by Karen Capucilli



By way of introduction, I am the mother of Jacob, an engaging, intelligent and happy boy. At the age of two and a half, Jacob passed away from a rare pediatric brain tumor. My husband and I are still very much living with this tremendous loss.

During the early days of our mourning we investigated many books, ranging in subject from general bereavement to specific writing on the loss of a child. Although I hoped I would find something in these books that would speak to my personal experience, I found little in common with the advice and observations expressed in them. I knew that others in my position had found them helpful but it seemed that my bereavement would need to proceed without books. I put them away, pursuing other avenues for support.

Recently, a member of my support group recommended a book called *Hannah's Gift*, a powerful memoir written by Maria Housden. *Hannah's Gift* chronicles Ms. Housden's journey through the diagnosis, treatment, death and mourning of her extraordinary daughter, Hannah, who died at the age of three from cancer. I recognized much of my own experience in this book, yet it is so much more than a mere depiction of adversity and survival. Beautifully written and poetic in feeling, *Hannah's Gift* is crafted using a series of short chapters. Each chapter is a little jewel, lending a voice to important aspects of this mother's experience.

I appreciated *Hannah's Gift* on multiple levels but most importantly, I felt it gave dignity and attention to what most people feel is unthinkable and unimaginable—the serious illness and death of a child. Although there was much sorrow in the book, there were also moments of humor and joy.

This intimate and inspiring book is not easily summarized in a few paragraphs. It is an understatement to say that *Hannah's Gift* is not an easy book to read, yet those able to open their hearts to it will be richly rewarded.

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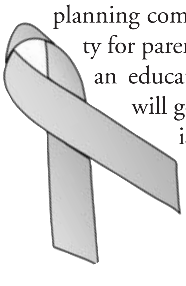
GOLD RIBBON DAYS

The National Childhood Cancer Foundation is sponsoring Conquer Kids' Cancer Gold Ribbon Days September 25 through 27, in Washington, D.C. and CBTF is proud to be a collaborating partner. Tracy Moore, CSW, Director of Patient Education and Support Services at CBTF, and David Hendricks, CBTF volunteer and brain tumor survivor, are on the planning committee for the event. This is a wonderful opportunity for parents, patients and survivors to come together to attend an education day and advocacy workshop. Those interested will go to Capitol Hill to promote specific pediatric cancer issues. It promises to be a very empowering experience! For more information and to register, go to www.conquerkidscancer.org.



CANCER AWARENESS STAMP

Wouldn't you like to raise money for childhood cancer research every time you mail a letter? Well, Cyndi MacKinlay, a parent advocate, has been educating the Citizens' Advisory Commission of the US Postal Service about the need for a Childhood Cancer Awareness Stamp. One possibility would be to create a "semi-postal" stamp such as those for breast cancer, prostate cancer, etc., which are currently raising awareness and money for their causes. The Department of Health and Human Services has agreed to accept any funds raised for childhood cancer research through a semi-postal stamp. Over 1,000 parents have taken steps to make this stamp a reality and you can help! Sending a letter telling the Postal Service why it is important to raise awareness about childhood cancer could make the difference. For a sample letter and more information, go to www.kidscancerstamp.org. Citizens' Stamp Advisory Committee c/o Stamp Development U.S. Postal Service, 475 L'Enfant Plaza, SW, Room 5670, Washington, DC, 20260-2437.

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Living Beyond A Brain Tumor: A Symposium for Brain Tumor Patients, Survivors, Families, Friends and Professionals is the 5th National Symposium hosted by The Brain Tumor Society. It takes place at the Boston Marriott Quincy Hotel in Boston, MA on September 20 and 21, 2002. The Children's Brain Tumor Foundation will be attending the conference as both an exhibitor and an interested member of the brain tumor community. If you would like to in participate, please contact The Brain Tumor Society at 800-770-8287 or visit their website at www.tbts.org.

Connecting in the Present; Looking Toward the Future is a video-broadcast brain tumor conference sponsored by the National Brain Tumor Foundation. Taking place in San Francisco, Denver and Phoenix, this conference will have speakers in each location speaking to participants simultaneously in the three cities. The conference is scheduled for September 20 and 21, 2002. For more information, please contact the National Brain Tumor Foundation at 800-934-2873 or visit their website at www.braintumor.org.

The Effects of Radiotherapy on Brain and Behavior Through the Lifespan is a conference hosted by the Department of Neurology and Neuro-Oncology Program at The Children's Hospital of Philadelphia in collaboration with The Hospital of the University of Pennsylvania. This important event will bring together researchers and clinicians from around the world to share the results of their work in both the pediatric and adult realms. It is hoped that pooling information will lead to improved radiotherapy treatments. The meeting will be at the Rio Mar Beach resort in Puerto Rico during the weekend of December 6-8 For more information, go to www.chop.edu/cme/radiotherapy.

Parent's Corner

Nathan, Danelle, Josh, Izaac and Luke Daughetee.

Volunteering for Parent-to-Parent by Danelle & Izaac Daughetee

In February of 1998, things seemed to be going very well. We had a happy, healthy two-year-old named Josh and a two-month-old named Nathan, better known as Nate the Great. We were scheduled to buy our first house at the end of the month. Within a period of five days our life was turned upside down. We went from worrying about what color carpet we wanted in our new house to feeling the isolation of knowing Nate had a brain tumor.

During this time we were surrounded by family and friends, all willing to do anything for us. They were doing everything right, yet we still felt very alone. During the first few weeks in the hospital we had the opportunity to meet and talk with families in similar situations. Connections were made, often without saying much. We realized then what a valuable resource we could be to one another. Talking and listening to each other proved to calm our troubled hearts.

When we heard about CBTF's Parent-to-Parent Network, we wanted to be a part of such a wonderful, necessary program, hoping that something that we learned through our experience could be of help to someone else. Nathan is now four and a source of inspiration to us. He has a wonderful outlook on life (most of the time) and can smile his way out of just about anything. Many thanks to everyone at CBTF for the opportunity to share with others while continuing to heal ourselves.

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.

Eventful Days and nights at CBTF

Seventh Annual Dinner Dance

June Event is Most Successful Ever!

PHOTOGRAPHS BY TOM HAYNES

The happy couple: Gene Maiello, Vice President of the New York City District Council of Carpenters, United Brotherhood of Joiners and Carpenters of America (NYCDC), and his wife, Stella, were thrilled that Gene was the Honoree at the Seventh Annual Dinner Dance. They had the time of their lives surrounded by family and friends. Everyone at CBTF was awestruck at the respect Gene commanded from his colleagues at the NYCDC and other unions. Thanks to them and all the other generous people who contributed to the event, the Dinner Dance raised over $320,000, the most ever for this event!

May I have this dance? Rob Leary, the husband of CBTF Board President Nora Leary, burned up the dance floor with his favorite partner, his daughter Emma. Emma was ubiquitous at the event and her high spirits inspired all who attended. The survivor of a benign brain tumor, Emma will be in second grade this fall!

Best friends: Bonnie Adlman and Paula Scott, both CBTF Board Members, were just two of the glamorous guests that glittered at Jericho Terrace on June 13, 2002.

The masterminds: CBTF Board Member and Dinner Dance Co-Chair Leonard Lustig and his wife, Susan. The Lustigs provided invaluable leadership, advice and assistance on nearly every aspect of the Dinner Dance. Many thanks to them and to Co-Chair Greg E. Dukoff.

Three of a kind: Gene Maiello (center) flanked by Michael Forde (left), Executive Secretary and Treasurer of the New York City District Council of Carpenters (NYCDC), and Peter Thomassen, President of the NYCDC and last year's Dinner Dance Honoree. They are holding the "Scroll of Honor" presented to Gene at the event.

A Daughter's Hope

Strength in numbers: The family and friends of Meghan Heisler, a nine year-old girl battling a very rare brain tumor, gathered together on May 5th, 2002, to honor her and raise money for CBTF. The first A Daughter's Hope Dinner Dance was held in Springfield, Illinois and 500 people attended. The event was extraordinarily successful, raising $35,000! Everyone at the Foundation was incredibly moved by the ability of the Heisler family to look beyond themselves. Pictured above, left to right: Judy Hurley, CBTF's Executive Director; Nora Leary, President of the Board of Directors; and Meghan, Shannon and Terry Heisler.

Irish pride: On a blustery Sunday in March, the CBTF banner was prominently featured in the Glen Cove St. Patrick's Day Parade. Much gratitude to (left to right): Tom Parks, Stephen Parks, Jim O'Neil, Victoria Carter, Leigh Ann Carter and Nicole Schlowmann. Other marchers not pictured: Janine and Stephen Parks and Rosanne Carter.

Hoop it up: On April 5th, Team CBTF, led by Andrew Hennessy, battled Broadview Networks at Continental Airlines Arena following a New Jersey Nets Game. Justin Lusk, at right with his mom, Claudia, got to meet Richard Jefferson of the Nets!

Children's Brain Tumor Foundation

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vitality Pharmaceutical Services & Children's Brain Tumor Foundation Present the BIG APPLE CIRCUS

14th Annual Benefit

Sunday, October 27, 2002, 12:30 PM

Under the Big Top

Damrosch Park, Lincoln Center, Columbus & 62nd Street, NYC

New Seating! No More Benches!

Prices range from $125 – $70 for adults
and $100 – $45 for children.

Can't attend?
Consider Sponsor Tickets – just $60!

Sponsor Tickets bring hundreds of children with serious illnesses and disabilities and their families to a day at the circus.

Call 212.448.9494 for tickets and sponsorship information.

Coming Attractions

September 24, 2002 The Fourth Annual Danny Jegle Golf Open Lido Golf Club, Lido Beach, NY	**December 4, 2002** Annual Teleconference “Bereavement: the Holidays and Every Day”
October 27, 2002 The Fourteenth Annual Big Apple Circus Benefit	**January 2003** A Night of Laughter 3 New York City
November 2002 Research Grants Award Reception, New York City	**May 4 - 10, 2003** Brain Tumor Action Week

If you need support,
call our Toll-Free
Patient Support Number:
1-866-228-HOPE
(1-866-228-4673)