



# FAMILY SUPPORT & RESEARCH EDITION

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## President's Cancer Panel Report

The following article includes recommendations sent to the President of the United States on issues of concern for cancer survivors, specifically childhood cancer survivors and school re-entry. To quote the 2003 President's Cancer Panel Report, *Living Beyond Cancer: Finding a New Balance*, "...the Panel has developed this report and recommendations for legislators, policy makers, the scientific and medical communities, employers, insurers, advocates and others whose actions can so greatly affect the quality of life of people with cancer and their loved ones."

A year ago, the Pediatric Brain Tumor Foundation received a phone call from the National Cancer Institute to nominate young adults who were diagnosed with brain tumors as children to testify in front of the prestigious President's Cancer Panel. The PBTF recommended three families, and the President's Cancer Panel chose Adam, a 20-year-old brain tumor survivor who lives in Asheville, NC, and his mom, Pam, to discuss the issues surrounding cancer survivorship. Dianne Traynor, the Foundation's Director of Research and Advocacy, accompanied Adam and his mom to Denver last September for their testimony in front of this historic commission.

In its own words, The President's Cancer Panel consists of "three members appointed by the President, who by virtue of their training, experience and background are exceptionally qualified to appraise the National Cancer Program." Their charge is to monitor the development and execution of the activities of the National Cancer Program, reporting their findings directly to the President of the United States.

The current panel consists of Dr. LaSalle Leffall, Jr. of the Howard University College of Medicine; Margaret Kripke, PhD from the University of Texas M.D. Anderson Cancer Center; and six-time Tour de France winner and cancer survivor Lance Armstrong. Each year the panel produces an annual report to present its findings and recommend steps to

alleviate the severe burdens encountered by cancer survivors and their families. The following is an excerpt from the 2003-2004 report derived from testimony provided to the Panel last year. With regard to school re-entry by pediatric cancer patients:

Survivors of cancers diagnosed in childhood may need special assistance to re-enter the classroom setting successfully and may require accommodations to special learning needs resulting from their disease or its treatment.

The panel found that children who are being treated for cancer may be absent from school for weeks, months, even years at a time. Some survivors diagnosed in childhood receive treatment far from home and may all but lose contact with their friends. They may be returning to school without hair, with scars, having gained weight, or with other visible signs that they have been sick. Upon their return, survivors who have been in such situations may need assistance with social reintegration into the classroom environment, and some will require special arrangements to accommodate temporary or permanent changes in their mobility, energy level, dietary or medication needs, or learning abilities.

Some survivors were fortunate to experience a smooth transition back to the classroom; other survivors of childhood cancers who provided testimony to the Panel vividly described the stress of returning to school. One brain tumor survivor recalls being teased continually because he was bald and had a prominent scar on his head. Others reported being unnecessarily restricted from activities or play with other children, which heightened their feelings of isolation and being different.

For some, speaking to their classmates and



Adam and his mother, Pam, with Lance Armstrong at the President's Cancer Panel meeting in Denver in September 2003

teachers about cancer and their experience of it, though stressful, was empowering and helped them with their transition back to school. Another brain tumor survivor who testified was accompanied back to school by his art therapist, who helped him talk to his classmates and explain that he did not need any special treatment and was there to work hard.

Parents of pediatric cancer survivors had varied stories to tell. Both parents and survivors reported difficulties in finding suitable tutors to continue education during the treatment period. While the young survivors usually were not held back from progressing to the next grade in school, some felt they had not received an equivalent education and were therefore at a disadvantage academically upon returning to the classroom. Sometimes these disadvantages did not become apparent until years later when, for example, an inadequate foundation in middle school math skills made work at the high school or college level extremely difficult, even when the survivor had no learning disability.

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### Page 5

The Pediatric Brain Tumor Foundation awards 55 new college scholarships to brain tumor survivors. Find detail on page five and check out the new crop of star students.

# FROM THE PRESIDENT'S DESK

...by Mike Traynor



I recently had the good fortune to attend the annual Honda dealer motorcycle convention in Nashville, TN, to see the 2005 Honda motorcycles and to meet with hundreds of caring Honda dealers who have helped in many significant ways for the past 21 years as we have partnered with them to diligently pursue the answer to childhood brain tumors. I was also able to speak with several of the American Honda Motor Company executives who have consistently been some of the most supportive people in our fight to bring childhood brain tumors to an end. I was able to express the thanks of every family who has ever battled pediatric brain tumors and to a person they all said, “no you have it backwards Mike, it is we who thank you for giving us the chance to help such wonderful young boys and girls and their families.”

I also had a couple secret weapons with me for this meeting, two fine young men who are brain tumor survivors, 12-year-old Juston from Fresno, CA, and 19-year-old Gary from Utica, NY. Now, I thought I could get excited over a new motorcycle, but these two young chaps had me beat by a country mile in the testosterone department as we looked over the new Honda machines. And to add to the excitement, they loved meeting the dealers and Honda personnel.

I don't think I ever saw two young people so at ease at being in a huge convention center with a couple thousand folks considerably older than them. But they spent the entire two day period, day and night, visiting with total strangers, thanking them for their support of the Ride for Kids® and the Pediatric Brain Tumor Foundation. They were truly just genuinely being world-class ambassadors for the brain tumor community. I am not the shyest person in the world, but I did a lot more listening than talking when they were around.

Juston has been a typical brave young brain tumor survivor who has shrugged off challenges since his treatment and now shoots a low score golf game, drives his go kart, does his best in school and in general is having a great time being a kid.

Gary, both a brain tumor survivor and PBTF college scholarship recipient, is one of those people who never met a stranger. Well, actually, he spent the entire two days talking to people he had never met, posing for photos with the Honda motorcycle national racing champions and chatting up anyone who was within earshot, all in the relaxed fashion of an elder statesman.

Those two young men made friends in a way that those dealers and Honda people will never forget. At one point, we were in the hallowed auditorium of the Grand Ole Opry when we were introduced to a couple thousand of the attendees who gave us a rousing cheer. Since we were seated down front by the stage, we had to stand and turn around to wave at the crowd all the way up into the rafters – pretty neat stuff! When we stood up I was turned so I could not see the two boys. Later I asked Juston's mom, Sherri, if Juston did okay with all the excitement. She laughed and said, “I had to tell him to sit down, or he would still be there waving.”

The whole Ride for Kids® program and all the work of the Pediatric Brain Tumor Foundation is based on the children and their families. And on this occasion it was the children and their families that were giving back, in very large doses. I hope every family who joins us at a Ride for Kids® event knows that you and your children are not just the “stars” of the day, but you are the energy that propels all of us who work to raise the funds for our programs. As the task can sometimes get a bit weary for us, we are re-enthused by visions of our time spent with each of you.

Thanks to all the Justons and Garys – thanks to all the loving moms and dads.

Mike Traynor □

## Cancer Panel...

(continued from page 1)

The mother of a brain tumor survivor, whose treatment resulted in significant learning problems, voiced her frustrations in trying to work with a rigid school system that would not make accommodations for her son's learning needs. She also described the frustration of her son, who narrowly missed earning a passing grade on his high school equivalency examination. In his case, he received a certificate of attendance instead of his high school diploma. This has prevented him from becoming employed and self-supporting, his most important goal.

In another case, a parent of a brain tumor survivor stated that although her son has a good total IQ score, his visual, spatial, fine motor and information acquisition skills have been affected by his cancer – he is both gifted and in need of special education. The local school system does not recognize these problems as warranting special services. After countless attempts to secure help for their son, she and her husband, as well as their three other children, have taken on the job of home schooling him.

On a more positive note, one parent related that all of the teachers at her son's school attended a training session at the center where her son was treated so that they could understand and provide for his needs upon his return to school. These testimonies illuminated how important it is for parents to be adequately prepared to advocate and intercede for their child who is returning to school after cancer treatment. □

**Based on the information gathered, the Panel made the following recommendations with regard to school re-entry:**

- Qualified providers in the treatment setting should train and assist parents to assume their crucial roles in helping the child with cancer return to school and become an educator and advocate with individual teachers and the school system.
- Pediatric cancer centers should offer and promote teacher training as a part of their community outreach efforts to help ensure that the needs of pediatric cancer survivors returning to the classroom are met. Internet-based training modules also should be considered to extend the geographic reach of these training efforts. If possible, continuing education units (CEUs) should be provided to participating teachers.
- NCI (National Cancer Institute) and the Department of Education should explore collaborative opportunities to improve the classroom re-entry and reintegration of young people with cancer or other chronic or catastrophic illnesses (e.g., remote learning, teacher training).

A copy of the complete report appears on the President's Cancer Panel's website at <http://pcp.cancer.gov>, or it can be ordered by sending an e-mail to: [pcp-r@mail.nih.gov](mailto:pcp-r@mail.nih.gov).

# FAMILY SUPPORT

## School Re-entry Following the Diagnosis and Treatment of a Brain Tumor

Summarized from a Pediatric Brain Tumor Foundation Informed Parent Internet Conference (July 26, 2001) presented by Daniel Armstrong, PhD

Current statistics state that there are now more than 250,000 childhood cancer survivors. By the year 2010, it is predicted that 1 in every 250 young adults will be a childhood cancer survivor.

"It is very important to focus on what happens after treatment ends, and in particular, a child's re-entry into school," says Daniel Armstrong, PhD, professor of Pediatrics and Psychology at the University of Miami in Florida. "Schools are the workplace of children, a place where they learn very important life skills," says Dr. Armstrong, who feels it is very important for children who are receiving treatment to attend school whenever possible.

School re-entry can be a trying time for both the young brain tumor survivor and their family. Scarring and loss of hair can affect the appearance and consequently a child's body image, self-confidence and peer interaction. Many fear teasing and rejection by the other children. There are also physical symptoms that must be considered, such as nausea, vomiting, low blood counts and the side effects of commonly administered medications such as prednisone, which can cause mood swings and irritability.

As you begin the process of your child's re-entry into the school environment, it is important that you become his/her advocate with teachers and administrators to educate them about your child's special needs, and the school's responsibility to help your child.

One study conducted by the University of Minnesota showed that children who were home-bound throughout their entire illness had more difficulty with social-confidence and self-confidence ten years after their treatments had ended. This underscores the need for children to have the opportunity for social interaction with same-aged peers, as many pediatric brain tumor patients who are home-bound become highly skilled at dealing with adults, but have significant difficulty dealing with others their own age.

As a child prepares to re-enter the school environment, it is important to consider the cognitive effects on learning that can occur both during and after treatment. Some of the most common problems include fatigue from high doses of radiation therapy; high-frequency hearing loss from some combinations of radiation and chemotherapy, which may impair vocabulary development; visual loss as a result of tumors near the optic nerve; and partial paralysis

or weakness and growth delays as a result of radiation.

There are also a number of more long-term effects. What researchers discovered was that not all cognitive abilities are affected by a tumor and its treatment, and in fact, some skills are unaffected.

Further studies have suggested that there is a direct relationship between the age at which a child is first diagnosed and treated and the type and severity of long-term problems they demonstrate. The younger the age of onset, researchers found, the more numerous and severe the learning difficulties. Various factors, such as location of the tumor and the type of treatment selected, will also affect learning ability. Other important considerations are the long-term effects which may not become apparent for many years; although a child may not lose the skills they have acquired prior to treatment, they simply do not gain some skills after treatment.

While pediatric brain tumor patients are rarely hyperactive, they do have attention difficulties. They frequently "zone out" and are unable to concentrate for long periods of time. Sequences of information can be very difficult to remember, and visual memory is often impaired. Unfortunately, much of the emphasis in school focuses on reading and writing, two of the areas often most impacted by treatment.

A child's ability to organize, plan and schedule is often very much affected by treatment; the processing time is much longer, and it may take a child 4-6 hours to do something that

would take another child only 30 minutes. Despite this, information that is presented in a meaningful context can be stored, retrieved, remembered and used effectively. However, there are social ramifications of this, because slower processing times may make it more difficult to keep up with a conversation, understand

humor and to follow a train of thought. Some children have difficulty detecting

social cues, such as whether a person with whom they are interacting is happy, teasing, angry, neutral, etc.

Although paper-and-pencil tasks are often difficult for childhood brain tumor survivors, not all of their abilities are adversely affected. In general, most are proficient at learning information that they hear, understanding the application of a concept, using spoken language to communicate and recalling information if given enough time.

Consider recruiting a staff member on your child's medical team who can visit the school to educate classmates about your child's condition. Studies have shown that children do not tease a returning



## School Re-entry...

(continued from page 3)

child when they understand what has happened. This is perhaps the most effective way to alleviate your child's fear about being teased and questioned by other kids. Dr. Armstrong recommends having your child participate in this educational process by being the "assistant" to the presenting staff member, because this elevates him or her into the position of being the "expert." This will likely reduce any feelings of isolation from the group, and bolster self confidence and self competence.

After the treatment process and school re-entry have taken place, regular neuropsychological evaluations should take place at least every 18-24 months for the duration of your child's academic life. These should include an IQ test and cognitive/academic tests. It is very important to assess those areas often affected by treatment – memory – both verbal and visual; reading and listening comprehension; attention and concentration; visual, spatial and visual/spatial motor integration tasks; as well processing speed and planning and organization. These tests will enable you to identify your child's areas of strength and weakness, and in particular, things that go unnoticed at the time of treatment because they do not show up until later in a child's development.

A five-year-old patient, for example, would not be expected to demonstrate proficiency with multiplication. However, the deficiency may become obvious in the same child who at age 12 is unable to perform a multiplication task successfully when such skills are age-appropriate.

It is important to work closely with school administrators to create an on-going plan that meets your child's educational needs. This might consist of a special education placement, an inclusion under the federal 504 regulation for children with chronic health or physical impairments, or perhaps an individual education plan (IEP) that can specify such parameters as testing without time limits and allowing the child to demonstrate mastery of subject matter through verbal means while minimizing written work. Finding a peer who can assist your child in the classroom has also been very effective in helping with both social and academic development. Mobility limitations should be addressed so that your child can still participate to some degree in physical education activities.

There are several technological advances that can also help your child. Computer keyboards and voice recognition programs help eliminate the need to hand write assignments. Children who are treated for brain tumors often learn by hearing and demonstrate what they know by verbal communication; thus, talking books and books on tape are very beneficial for increasing comprehension and recall. Because visual alignment can be very difficult, tests that require "bubbling" for computerized scoring should be avoided.

Above all, stay on top of the issues surrounding your child's educational needs. Explore all the available options for schooling – public, private, charter, home schooling – to determine which is most appropriate. Find teachers and administrators who are willing to work with you to adapt, monitor and revise your child's plan.

Ensuring successful school re-entry is the desire of every parent whose child has been treated for a brain tumor. Understanding the cognitive limitations is an important first step. Of equal importance are the following:

- Have your child continue school work (in some form) during treatment and even when in the hospital.
- Arrange for your child to visit with friends and classmates, at school if possible, to maintain their feeling of connection.
- Work with the school system to develop a plan for school attendance. Some systems will allow a combination of hospital, home-bound and classroom learning.
- Adjust your child's workload and expectations so that they are realistic for his or her particular situation.

- Work closely with teachers to educate them about your child's condition – possible side effects of treatment, what is occurring outside of school, how much school has been missed, etc. Most teachers are willing to work with parents if they fully understand the situation.

The benefits can be remarkable. As you will read in this issue, the Pediatric Brain Tumor Foundation awarded 42 new college and technical school scholarships to young brain tumor survivors. These new scholarship recipients join 13 existing participants, proving that many young brain tumor survivors can go on to achieve their dream of higher education and training. □

*Editor's note: See additional information about school re-entry on page 1, as well as the article about PBTF scholarship recipients on page 5.*

## PICTURE OF HOPE



**Noah, a young brain tumor survivor, enjoys Halloween dressed as a bumble bee.**

**Parents: Remember...** please send in pictures of your young brain tumor survivors for possible use in future editions of *The Caring Hand*.

# PBTF Announces 55 College Scholarships

The Pediatric Brain Tumor Foundation is pleased to announce that it has granted 55 college scholarships to young brain tumor survivors from across the United States.

Forty-two new 2004 scholarship recipients will join the 13 young men and women who are currently receiving PBTF college scholarships. The Foundation's National College Scholarship Program, part of its Family Support Program, was created to help students and their families realize their dream of higher education. These funds help ease the financial burden placed on families with children diagnosed with brain tumors. Since the scholarship program's inception in the fall of 2001, a total of 61 scholarships have been granted by the PBTF.

This year's scholarships are funded in part by the *Cycle World* Joseph C. Parkhurst Education Fund. The fund, established by *Cycle World* magazine to honor their late founder's commitment to education, is supported by proceeds from a silent auction held annually at the *Dealernews* International Powersports Dealer Expo in Indianapolis, Indiana. Numerous motorcycle and aftermarket manufacturers, distributors and dealers attended the silent auction, which this year alone raised \$35,000. The funds were then matched by the PBTF for the scholarship program.

"*Cycle World* magazine founder Joe Parkhurst would be very proud of the industry's magnificent response to the auction, and even more satisfied knowing that the funds raised in his memory would play a key role in assisting these young heroes as they continue their education," said Larry Little, Vice President and Publisher of *Cycle World* magazine.

"The motorcycle community responded with their usual enthusiasm and generosity, and we had a great time at this auction," said Mike Traynor, PBTF president. "Thanks to their support, we are broadening our educational outreach to families in their time of need.

"Our scholarship recipients are extraordinary young men and women who have overcome seemingly insurmountable obstacles and are now able to realize their dreams and educational goals," Traynor added. "It is indeed a privilege to assist them, because they are an inspiration for all of us." ■

(This year's scholarship recipients are pictured to the right.)



**Alexander**  
Clark Univ.



**Nathan**  
Iowa State Univ.



**Kimberly**  
Central Florida C.C.



**Caroline**  
Bridgewater College



**Thomas**  
The College of  
St. Scholastica



**Scott**  
University of  
Northern Iowa



**Jeana**  
Baylor Univ.



**Jessica**  
University of North  
Florida



**Curtis**  
Univ. of Southern  
Indiana



**Carra**  
Northeastern Illinois  
Univ.



**Corey**  
Daytona Beach C.C.



**Zachary**  
New York Univ.



**Ruth**  
Univ. of Michigan



**Christine**  
William Peterson Univ.



**William**  
Univ. of Alabama  
- Birmingham



**Austin**  
Mt. Vernon Nazarene  
Univ.



**Caroline**  
Oakland Univ.



**Cody**  
Cal. State Univ. of  
Fresno



**Derek**  
Univ. of Montana



**Lee**  
Univ. of New Mexico



**Brian**  
Univ. of Toledo



**Elizabeth**  
Pace Univ.



**Kurt**  
Univ. of Illinois  
- Chicago



**Thomas**  
Florida Gulf Coast Univ.



**Shannon**  
Montgomery College



**Ryan**  
Iowa Lakes C.C.



**Michelle**  
Univ. of California  
- Irvine



**Daniel**  
St. Andrews Presby.  
College



**Lindsey**  
Brigham Young Univ.



**Amoryn**  
Brigham Young Univ.



**Jeremy**  
Montgomery College



**Guy**  
Stanford Univ.



**Joshua**  
Rappahannock C.C.



**Craig**  
American River College



**Adam**  
Farmingham St. College



**Joel**  
Univ. of Wisconsin  
- Madison



**Joshua**  
Auburn Univ.



**Daniel**  
Widener Univ.



**Ahmed**  
Columbia College



**Samuel**  
Waldorf College



**Adam**  
Washington and Lee  
Univ.



**Omar**  
Guilford College

# Words of a Caregiver

## “Follow the Yellow Brick Road...”

by Kathy Riley

I dreamed of a little boy with curly red hair, a boy who loved dinosaurs, Legos and me. His name was Peter. At just five years old, he was a master of disguise, a Teenage Mutant Ninja Turtle one day and Captain Hook the next. But through every adventure, every costume change, every hook and sword, there remained one constant – a worn pair of black cowboy boots handed down from his best friend, Ben.

Peter stole my heart. His love for each great adventure flooded my imagination with dreams for his future. I dreamed crazy, super-sized dreams. Dreams of Peter winning the most-valuable-player award in the Super Bowl or flying as the youngest scientist aboard one of NASA’s shuttles. But I also dreamed of ordinary things that now will only come by way of miracles: Peter earning a high school diploma, finding true and lasting friendship, driving a car and encountering his first love.

Five months before kindergarten, Peter was swept up in his most dangerous adventure of all, one I had never dreamed. He had been struggling with unexplained headaches and vomiting. After a long MRI and a trip to the local university hospital, a neurosurgery resident enthusiastically announced that Peter had an “impressive tumor” at the base of his brain. I learned a new, ugly word: medulloblastoma. It meant brain cancer. And within days of diagnosis, my red-haired future Super Bowl star had surgery to cut out the tumor. Suddenly Peter could no longer talk, he could no longer walk, he could no longer swallow his own saliva. Now, even the smallest of my dreams for his future seemed lost.

Over the course of surgery, radiation, chemotherapy and many, many months of physical and occupational therapy, the tumor stayed away, and Peter slowly learned again how to talk and walk and swallow. I started to believe that he was going to survive this terrible disease. But he didn’t come back the same adventurous and unstoppable boy I had said goodbye to months earlier before he was wheeled into the operating room.

I was grateful beyond words for Peter’s life and returning health, but I felt a terrible ache in my heart. The ache grew in intensity every time I drove past a high school football practice. I yearned to see Peter on the field but knew I never would. That ache rose during every school assembly when Peter was overlooked for an academic award even though I knew he had worked harder than anyone. And deeper questions haunted me. Questions about Peter’s ability to live on his own, to find a job he loved and painful questions about the possibility of marriage and family.

I felt guilty about the ache. How could I allow myself to feel so sad when Peter was right there beside me? Why couldn’t I just be happy with what I had left? What was wrong with me? The answers came from the most unlikely place, from a mother just like me whose son had had a brain tumor. But unlike Peter, this mother’s son did not survive his illness. Her words to me were surprising and deeply healing. “You’ve lost something too,” she said. “And no one has given you permission to grieve. I give you permission.”



(From L-R) Mike Traynor, Chris, Peter, Rachel and Kathy Riley and Bobbie Duffy at the 2003 Ride for Kids® Task Force Leaders’ Meeting

Permission to grieve.

The dreams I had stored up in my heart for Peter’s future had indeed taken a fatal blow, and this mother was telling me that it was okay to feel sad about my loss. But her answer brought me to a new question. Would I let go of the old and take hold of something new?

Psychologist Ken Moses speaks of the importance of embracing new dreams when old ones have been lost. At first, embracing new dreams for my broken boy seemed beyond my reach. But as I grieved what was lost, I discovered I was able to take my first, tentative steps toward the possibility of dreaming again. I felt like Dorothy following the yellow brick road on a journey of discovery, wonder and terrible danger. Upon reaching the end of her quest, Dorothy discovered her dream, one hidden deep in her heart all along but discovered only through peril.

What did I find at the end of my yellow brick road? I found Peter. A boy who deeply and profoundly cares about people. A boy who loves his family, his neighbors, his classmates and winning at chess. A boy with the best heart of anyone I have ever known. A boy with an unquenchable sense of humor and a keen mind stocked with dozens and dozens of knock-knock jokes. And I found a dreamer, a young man, almost seventeen now, who dreams of helping people by becoming a missionary or a teacher. And somewhere, somehow, deep inside, if I look hard and long, I can still see my astronaut and Super Bowl star.

Have I completely let go of my old dreams? Mostly. But every once in a while, I imagine a handsome, ruddy football player named Peter, with his face to the wind and the ball in his grasp, being cheered toward the goal line by thousands of screaming fans.

I’ve come to love Tolkein’s *Lord of the Rings*. I love it because Peter loves it, and because it’s about some very ordinary people on a dangerous journey, people like me, who would rather be safe at home than out fighting deadly battles. Tolkein writes about what I’ve learned on my own long journey: “The world is indeed full of peril, and in it there are many dark places; but still there is much that is fair, and though in all the lands love is now mingled with grief, it grows perhaps the greater.”

And so, with Peter, I will keep loving. Keep hoping. And keep dreaming. □

# RESEARCH UPDATE



## Neuro-Oncology Greatly Impacts Scientific Community

In 1998, the Pediatric Brain Tumor Foundation provided the founding grant to create the international medical journal *Neuro-Oncology*. The journal is sponsored by the esteemed Society of Neuro-Oncology (SNO). SNO is a multi-disciplinary, international organization comprised of the leading researchers and doctors from around the world in the fields of neuro-oncology, epidemiology, neurosurgery, pathology, pediatrics, psychology, radiology, radiation oncology and basic science. Its goal is to bring together the brightest minds in the above fields to share research findings to bring about a greater understanding of cancers involving the nervous system.

Since its inception, *Neuro-Oncology* has received great accolades from the scientific community. Dr. Darell Bigner, who is the editor of *Neuro-Oncology*, is also the Director of the Pediatric Brain Tumor Foundation Institute at Duke and chair of the PBTF's Scientific Advisory Board. Bigner said, "I want to thank the Foundation for all the support it has given the neuro-oncology community in so many ways. However, I think one of the most important things that the Pediatric Brain Tumor Foundation has ever done was making the creation of the journal (*Neuro-Oncology*) possible."

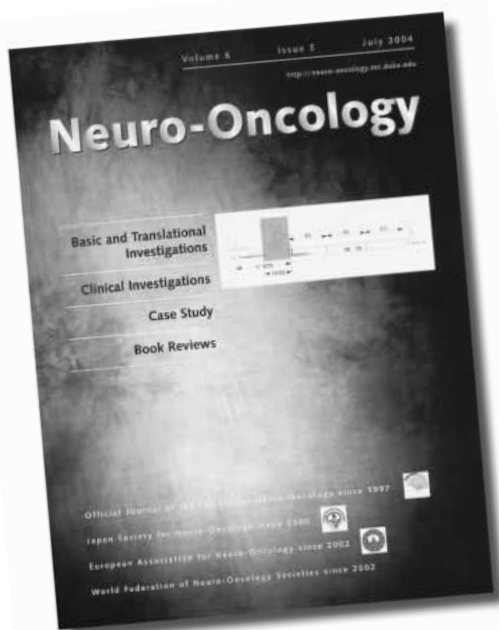
*Neuro-Oncology* has made quite an impact on the field of neuro-oncology according to the Institute for Scientific Information (ISI). The ISI ranks scientific journals based on the number of citations that the individual journal receives. The ISI impact factor is used by

editors, publishers and academic researchers to compare the positioning of one journal in relation to its competitors. *Neuro-Oncology* has received a quite formidable ranking considering that it is a relatively new journal.

Dr. Bigner commented, "Another positive indication for *Neuro-Oncology* is the increasing numbers of manuscripts being submitted. This enables us to publish only the best of the articles

we receive. The most

prestigious journals achieve their high impact factors by publishing only those articles that are truly excellent and truly important for their clinical and research communities, and those are precisely the papers we hope you will submit to *Neuro-Oncology*." According to the SNO website, *Neuro-Oncology* significantly outranks its main competitor's journal and compares very favorably with other prestigious journals, such as the *Journal of Neurosurgery*.



Dr. C. David James, Mayo Cancer Center and Mayo Clinic and Foundation, is also a member of the Foundation's Scientific Advisory Board. Dr. James remarked, "Simply put, the solid impact factor rating and associated category rankings of the journal (34th among 120 oncology journals and 16th among 135 clinical neurology journals) provide clear indication that *Neuro-Oncology* is serving as one of the most important sources of information on the study and treatment of brain tumors for both researchers and clinicians. The impact factor primarily reflects the frequency at which a journal's articles are cited elsewhere, which in turn reflects the perceived significance of the articles that the journal is publishing." Dr. James also added, "Because of the stringent review process that all manuscripts submitted to the journal must undergo, the journal is, and will continue to be, an influential source of information."

The editors of *Neuro-Oncology* ask that all SNO members submit their best research articles to *Neuro-Oncology* for first publication. Dr. Bigner adds, "We want to thank our authors for their past contributions, which have formed the basis of this continued high ranking of the *Neuro-Oncology* impact factor." Types of articles that are accepted include:

- Rapid Reports that are short, definitive reports of highly significant and timely findings in the field
- Basic and Translational Investigations or Clinical Investigations that report original experimental, clinical, translational, epidemiological, quality-of-life or other studies relating to neuro-oncology and that are well documented, novel and significant
- Case Studies that are brief, without an extensive review of the literature
- Case Illustrations that contain briefly written text and references and portray, by neuroimaging, those concepts better visualized than described
- Symposia on subjects selected by the Editor
- Reviews and Editorials on subjects of timely interest and importance to cancer researchers, written by invitation of the Editor
- Invited Meeting Reports
- Letters to the Editor offering considered opinions on manuscripts published in the journal within the last six months
- Book Reviews by invitation of the Editor
- Announcements of scientific meetings and courses of interest to *Neuro-Oncology* readers ■

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## An Update from the Pediatric Brain Tumor Foundation Institute at Duke

Recently, in the August 1, 2004 issue of *Cancer Research*, the work of Hai Yan, MD, PhD, a Principle Investigator at the Pediatric Brain Tumor Foundation Institute at Duke, was published. Yan, along with colleagues from Duke University, Johns Hopkins University Medical Institutions and the University of Utah School of Medicine, found that mutations in the gene PIK3CA occur spontaneously as part of the brain tumor development, rather than being passed genetically between generations.

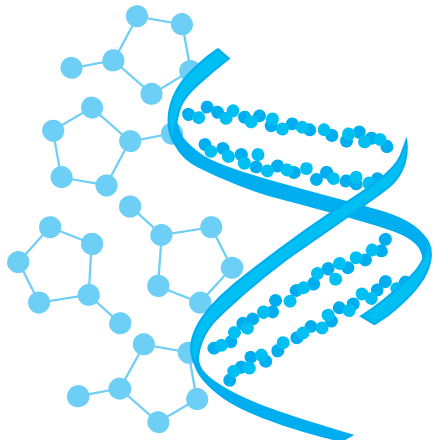
Yan's finding is important because it paves the way for possible screening techniques for brain tumors that can lead to improved treatment protocols.

The mutations were identified in 14 percent of anaplastic oligodendrogliomas, 5 percent of medulloblastomas, 5 percent of glioblastomas and 3 percent of anaplastic astrocytomas. No PIK3CA mutation variants were found in samples of astrocytomas or ependymomas.

His work also allows for the possible development of targeted molecular therapies to halt the growth of brain cancer cells through errant genes.

Brain tumors are the most deadly of all childhood cancers. Current treatment is often toxic to the normal brain, and survivors often have significant problems in brain and spinal cord function. Research, like Yan's, has yielded potential innovative treatments, including new diagnostic and therapeutic strategies.

Under the direction of Darell Biger, MD, PhD, the Pediatric Brain Tumor Foundation Institute at Duke opened in 2003 with a six-year, \$6 million grant from the Pediatric Brain Tumor Foundation. The primary goal of the Pediatric Brain Tumor Foundation Institute at Duke is to develop innovative and less invasive clinical treatments for children diagnosed with brain tumors. □



# WHERE HOPE SPRINGS ETERNAL

*Stories of Hope from Survivors, Care Givers and Researchers*

## Try and Try Again

Pediatric brain tumor survivor Caroline does not give up. Ever. Diagnosed with a brain tumor at age three, she has overcome challenges that healthy children never experience – challenges like radiation treatments, occupational therapy through first grade, followed by physical therapy through sixth grade and difficulty with learning.

When she was seven years old, Caroline was ready to learn to ride a bicycle. But the surgery and radiation seriously affected her balance and coordination. “After trying and trying to ride a bike, I thought that I would never be able to do it.”

Yet challenges like that are exactly what make Caroline shine. “I decided that learning to ride a bike was very important to me and that I would keep trying. Every time I fell off my bike I got back on. I ran into a pole. I ran into a fence at least two times. Yet I promised myself I wouldn't stop riding until I accomplished my goal.” Finally, at age 14, she did it. “Learning how to ride a bike was an amazing achievement for me, a real milestone in my life. If I didn't have confidence in my abilities, I wouldn't know how to ride one today.”

The experience became a metaphor for her life. “Having had a brain tumor and radiation treatments makes me work ten times harder, simply because it takes me longer to accomplish tasks,” says Caroline. “I always want to do the best that I can, so I have become used to working harder. By doing the best that I can, and being the best person I can be, I remain positive and focused.”

With boundless determination, she plowed into her school studies. It wasn't easy. “One day, I just accepted the fact that it takes me longer to do things,” she says. “I realized that if putting in more time is what I need to do to be successful, then that is what I am going to do. I have a very satisfying feeling when I finish my tasks and assignments.”

Caroline excelled in school. And she learned something more. She learned that helping others was important to her. “I tutored at a local elementary school every Wednesday afternoon to get community service hours for National Honor Society. Now, even though I'm done with all of the required hours, I tutor because I feel like I can teach children new things. Every time I do it I just feel great about my capability to help others. I wouldn't be the person I am today if I didn't have people helping me and cheering for me along the way.”

Two of those people are her parents. “I can't even describe the magnitude of what my parents mean to me. From watching me learn how to ride my bike, to sitting at my feet when I go to the hospital for MRIs, their faith in me makes me want to do my best, and their love for me makes me want to do anything I can for them.” Caroline also credits her sisters and her friends, who were at her side constantly. “I was never treated any differently from other kids my age because of what had happened to me. The help and encouragement I have gotten over the years has made me feel better about myself.”

Today, the 18-year-old has graduated from high school and is headed to college with a PBTF college scholarship. One of 55 deserving young brain tumor survivors who received a PBTF scholarship for 2004-2005, she will attend Oakland University in Rochester, Michigan, living at home and commuting to school. “As soon as I found out I'd been given the scholarship, I just brightened up,” she says. “Knowing that the PBTF will be behind me as I start this new phase of my life makes me more confident in my abilities.”

As usual, Caroline is looking ahead. “I hope to go into childhood education, psychology, or physical or occupational therapy. I think I would be a good teacher because I like working with children. I think that I would make a good psychologist because it would help me better understand myself and other people. I think being a therapist of any kind would help me succeed in my goal of helping others.” And then? “I'll decide what to do next when I get my bachelor's degree. I plan on furthering my education because I feel that going to school and learning new things is good stimulation for my brain.”

Caroline is wise beyond her years. Her hopeful words to a newly-diagnosed childhood brain tumor patient? “Never give up, never stop fighting, have faith in yourself and others. I know what it means to dedicate yourself to something and do all you can to accomplish it.” □



Caroline

# Ride for Kids®

## Ride for Kids® Continues Winning Ways

### Ride for Kids® Celebrates Largest Fundraising Weekend in PBTf History – Chicago and Utica Ride for Kids® Events Enter the Record Books

On Sunday, July 18th over 3,600 caring motorcyclists participated in two Ride for Kids® events, one in Chicago, IL, and the other in Utica, NY. At the end of the day, the two events raised a total of \$481,050 for the research and family support programs of the Pediatric Brain Tumor Foundation (PBTf). A new Ride for Kids® national record was set for a single weekend!

The 16th Annual Chicagoland Ride for Kids® took place under glorious, perfect blue skies. A record 2,700 motorcyclists and patient-families thoroughly enjoyed the safe police-escorted ride through the villages and countryside of Chicago's northern suburbs. During the Celebration of Life ceremony at Allstate Insurance Headquarters in Northbrook, under the massive, billowing "big-top tent," the riders learned they had raised a Ride for Kids® all-time record of \$368,271 for pediatric brain tumor research. Carra and Kurt, two Ride for Kids® "stars," were given PBTf college scholarships in memory of Brian Vermilyer, who lost his battle to a childhood brain tumor. Brian would have been 17 years-old the day of the 2004 Chicagoland Ride for Kids®. Extra special thanks to Chicagoland Ride for Kids® Task Force Leaders Vito Racanelli, Bob Wagner and Larry Dubisz and their hardworking volunteer force for an amazing event.

Further east, also on July 18th, in Utica, NY, participants in the 7th Annual Utica Ride for Kids® were enjoying spectacular summer

weather as well. The 900 motorcyclists, volunteers, fundraisers and patient families joined forces to raise a remarkable \$112,779 for childhood brain tumor research. The motorcyclists rode through beautiful upstate New York to the quaint village of Old Forge, which is an entrance to the majestic Adirondack Mountains. Special thanks to Utica Ride for Kids® Task Force Leaders Ken and Kathy Sweatman and Steve and Karen Clary and their dedicated team of volunteers for a wonderful event.



National Ride for Kids® Manager Richard Thompson interviews Cassandra, a Ride for Kids® "star," at the 2004 Utica Ride for Kids®.



Vito Racanelli, Chicagoland Ride for Kids® Co-Task Force Leader, and the Ride for Kids® "stars" proudly present the check at the record-breaking 2004 Chicagoland Ride for Kids®.

### Knoxville Ride for Kids® Delivers Southern Hospitality

The old saying that a rainy day will wash your troubles away couldn't be truer. One day before this year's Knoxville Ride for Kids®, which occurs annually in conjunction with the Honda Hoot, the city experienced the largest rainfall on record. By ride time on Saturday, June 26th, however, the weather was not as threatening, as over 325 motorcyclists, volunteers and family members pooled their efforts to raise \$72,218 for pediatric brain tumor research.

Thanks to Knoxville Ride for Kids® Task Force Leaders Dave and Nancy Miller, Geoffrey Greene and their hardworking volunteer Task Force for a super event.



Jessica and Dawn, two Ride for Kids® "stars," get ready to ride in the 2004 Knoxville Ride for Kids®.

### Colorado Ride for Kids® Debuts with True Blue Style

In the majestic Rocky Mountains some 1,300 miles across the country, Sunday, June 27th, marked the 1st Annual Colorado Ride for Kids®. Over 318 motorcyclists, volunteers, fundraisers and patient families gathered under deep blue Colorado skies for this special occasion. In the shadow of the towering Rocky Mountains, participants took a police-escorted ride through spectacular Deer Creek Canyon, winding past the famous "Tiny Town," the oldest "Kid Size Village and Railroad in the USA."

Thanks to Colorado Ride for Kids® Task Force Leader Dave Dickerson and his great team of volunteers for a wonderful event.



Devin, a Ride for Kids® "star," prepares to ride at the 2004 Colorado Ride for Kids®.

### The Indianapolis Ride for Kids® Rolls Through Scenic Farmland

On Sunday, July 11th, it was off to the nation's heartland for the 2nd Annual Indianapolis Ride for Kids®. Over 150 motorcyclists, fundraisers, volunteers and patient families gathered together for a beautiful early-morning, police-escorted ride through the state's famed corn fields and rolling farmlands.

continued on page 10

## Indianapolis Ride for Kids® cont'd

Afterwards, at the Celebration of Life program, riders learned that they had raised over \$14,117 for pediatric brain tumor research. Thanks to Indianapolis Ride for Kids® Task Force Leaders Donna and Eddie Cross, Betty and Jack Critchlow and their team of volunteers for organizing the Ride.

## Minnesota Ride for Kids® Sets New Record

There was something special in the Minnesota air on Sunday, July 25th, as 585 volunteers, motorcyclists, fundraisers, physicians and patient families gathered for the annual Ride for Kids®. Perhaps it was the spectacular sunrise, which then ushered in beautiful blue skies. Perhaps it was the fact that the motorcyclists and fundraisers outdid themselves by raising \$95,349 – a new Minnesota Ride for Kids® record.

Special thanks to Minnesota Ride for Kids® Task Force Leaders Tippy Scully, Denny Schouveler and their amazing volunteer force for a fantastic event.

*Will, a PBTF College Scholarship recipient and recent college graduate, thanks the motorcyclists for their fundraising efforts at the 2004 Minnesota Ride for Kids®.*

## 2004 Marysville Ride for Kids® Celebrates 13th Year!

As part of the Annual Honda HomeComing Celebration, Saturday, July 31st, marked the 13th Ride for Kids® in Marysville, Ohio. Under cloudy skies, over 450 motorcyclists, fundraisers, volunteers and patient families rode through the Ohio countryside and over several covered bridges on a police-escorted ride.

Capping off the event was the touching Celebration of Life program under a gigantic, celebratory “big-top tent.” Up on stage, four very special Ride for Kids® “stars” unfurled a grand total check to reveal that the motorcyclists had raised a record \$142,100. Special thanks to Marysville Ride for Kids® Task Force Leaders LouAnn McKeen, Altrece Hogans and their dedicated volunteer team for a successful event.



*Don, a Ride for Kids® “star,” is interviewed on stage by National Ride for Kids® Manager Richard Thompson at the 2004 Marysville Ride for Kids®.*

## Hudson Valley Ride for Kids® Undaunted by Rain

On Sunday, August 1st, the Ramapo Mountains in the picturesque Hudson Valley Region of New York provided

the backdrop for the 12th Annual Hudson Valley Ride for Kids®. The motorcyclists, fundraisers, volunteers and patient families



*Blake, a Ride for Kids® “star,” shows National Ride for Kids® Manager Kyle Clack her newly missing tooth!*



gathered despite the rainy, overcast weather to raise \$91,112 for childhood brain tumor research.

Thanks to Hudson Valley Ride for Kids® Task Force Leaders Jack Jones, Walter and Linda Buchanan and their volunteer force for a great event.

## Madison Ride for Kids® Makes Grand Debut

Sunday, August 8th, marked the 1st Annual

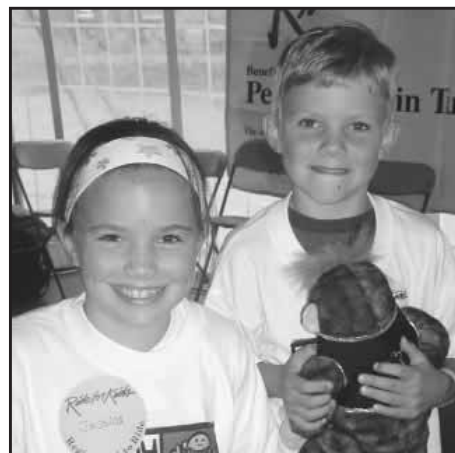
Madison Ride for Kids® in Wisconsin. And what a day it was for the 400-plus motorcyclists, fundraisers, volunteers and patient families who arrived in the early morning hours at Fireman’s Park in the town of Middleton. After savoring the fresh cinnamon rolls donated by a local bakery, the motorcyclists embarked on a police-escorted ride through the rolling hills of northwest Madison. The carefully-planned route wound past lakes, farmland and through Devil’s Lake State Park, where riders enjoyed breathtaking views of the lake and its adjacent rock cliffs.

The motorcyclists raised an amazing \$51,005 for pediatric brain tumor research.

Special thanks to Madison Ride for Kids® Task Force Leaders Joe Bentz, Mark Muhlenfeld and their extremely dedicated team of volunteers for a wonderful first-year event.

## New England Ride for Kids® Participants Brave Tropical Storm Charley

Even Tropical Storm Charley could not deter the determined riders who raised \$66,973 for the 7th Annual New England Ride for Kids® on Sunday, August 15th. The hearty and dedicated motorcyclists braved Charley’s rain and wind to enjoy a police-escorted ride through the foothills of Massachusetts and on to Mount Holyoke College in South Hadley, MA. Extra special thanks to New England Ride for Kids® Task Force Leaders Wayne and Shirley Anderson, Visitation Coordinator Dave Odess and the fantastic team of volunteers for a memorable event.



*Jessica and her brother Brodie, both young brain tumor survivors and Ride for Kids® “stars,” at the 2004 New England Ride for Kids®*



*Lauren, a Ride for Kids® “star,” has a ball on stage during the Celebration of Life at the 2004 Hudson Valley Ride for Kids®.*



*Anthony, a Ride for Kids® “star,” and his sister, Savannah, enjoy the 2004 Madison Ride for Kids®.*

## Asheville Ride for Kids® Remembers a Bright Spirit

On Sunday, August 29th, the rumbling sound of 425 motorcycles filled the early-morning air of the Biltmore Square Mall parking lot in Asheville, NC, as motorcyclists prepared to depart on the 11th Annual Asheville Ride for Kids®. With a North Carolina State Police escort that traveled in from neighboring Charlotte just for the event, and several local police agencies, the riders wound their way through the majestic mountains of Western North Carolina before arriving at picturesque Lake Lure, the site of the Celebration of Life program. There, under the blue and white striped “big-top tent,” over 750



Julia, a Ride for Kids® “star,” and PBTF college scholarship recipient, and Hannah, also a Ride for Kids® “star,” enjoy hanging out at the 2004 Asheville Ride for Kids®.

motorcyclists, volunteers, fundraisers, patient-families and researchers cheered when they heard that this year’s Ride had raised \$109,986.

The 2004 Asheville Ride for Kids® was in memory of Mary Ann Sluder, a precious young Asheville girl who lost her battle with a childhood brain tumor in 2003. Her father, Rocky, told the motorcyclists “I am truly humbled and honored by your fundraising efforts. Because of angels like yourselves, Mary Ann’s spirit will live on forever.”

Special thanks to Asheville Ride for Kids® Task Force Leaders Terry and Shelba Murray, Dave Huey and their team of dedicated volunteers for a very successful event.



Cara, a young brain tumor survivor, with her little sister Cami at the 2004 Ann Arbor Ride for Kids®

## Ann Arbor Ride for Kids® Greeted by Fall’s Early Arrival

Sunday, August 29th was an unseasonably cold and rainy day in Ann Arbor, Michigan. But the fall-like

weather could not put a chill into the warm hearts of the 425 motorcyclists, fundraisers, volunteers and patient families who gathered to raise \$106,239 at the 13th Annual Ann Arbor Ride for Kids®. Thanks to Ann Arbor Ride for Kids® Task Force Leaders Bill and Kathy Chapin and their dedicated team of volunteers for a well-run event.

## Puget Sound Riders Brave Rain for the Kids

On Sunday, September 12th, the early morning chill was broken by the warmth and generosity of 295 caring motorcyclists, fundraisers, volunteers and patient families who turned out for the 12th Annual Puget Sound Ride for Kids®. Adding to the day’s excitement was the noticeable number of new faces at this year’s Ride. There were smiles all



Sara, a young Ride for Kids® “star,” at the 2004 Puget Sound Ride for Kids®

around as the announcement was made that a new Puget Sound record of \$100,057 had been raised for pediatric brain tumor research.

Special thanks to Puget Sound Ride for Kids® Co-Task Force Leaders Dick Stryker and Ella Ralstin and their wonderful team of volunteers for a fantastic event.

## Columbia Motorcyclists Triumph Over Hurricane Ivan

Even Hurricane Ivan could not put off the determination of more than 1000 motorcyclists, fundraisers, volunteers and patient families who gathered on Sunday, September 19th, to celebrate the 13th Annual Columbia Ride for Kids®. With a spectacular early fall day as a backdrop, the crowd was thrilled to learn that they had raised \$200,000 for childhood brain tumor research.

Thanks to Columbia Ride for Kids® Task Force Leaders Jackie Cookie, Howard DePue, Bob Henig and their fantastic volunteer team for a great event.

## Blue Skies Abound for St. Louis Motorcyclists

On Sunday, September 19th, 650 motorcyclists, fundraisers, volunteers and patient-families gathered under stunning blue skies for the 4th Annual St. Louis Ride for Kids®. With smiles all around, the crowd celebrated the fact that they had raised \$87,702 for childhood brain tumor research.

Special thanks to St. Louis Ride for Kids® Task Force Leaders Guy and Margie Miller, Greg and Mary Hoette and their super volunteer force for a wonderful event. □

Brian, a Ride for Kids® “star,” had the best time at the 2004 St. Louis Ride for Kids®.



Ethan, a Ride for Kids® “star,” and his mom Kim get ready to ride at the 13th Annual Columbia Ride for Kids®.



## Planning a PBTF Fundraiser?

We appreciate the many fundraising events that are conducted to benefit the work of the Pediatric Brain Tumor Foundation. Please contact us early on in your planning process for the fundraiser that you will be holding. Each state requires that the PBTF gives permission for your fundraising efforts to take place. The Pediatric Brain Tumor Foundation is a federally recognized non-profit charitable 501(c)(3) foundation. The name “Ride for Kids®” is a registered trademark and may not be used in any form without the prior written consent of the Pediatric Brain Tumor Foundation. Infringement of this trademark is considered a legal violation. Any name similar to the “Ride for Kids®” name is considered to be a violation of the national federal trademark laws. For a fundraising event application and for more information, please call (800) 253-6530 or email [pbtfus@pbtfus.org](mailto:pbtfus@pbtfus.org). We thank you for helping all children with brain tumors. □

# United Kingdom Brain Tumour Society Holds Annual Conference

(Editor's note: With assistance from Zoe Hoppe, Executive Director, UKBTS)

The United Kingdom Brain Tumour Society, established seven years ago, is a national charity in the United Kingdom that works to conquer brain tumors through research, education and support.

In July of 2004, the UKBTS hosted their 4th Residential Educational Conference, "The Scientist-The Doctor-The Patient," at Nottingham University.



Mike and Dianne Traynor visiting with a conference participant at the 2004 United Kingdom Brain Tumor Society Meeting

This event has become a notable date in the UK brain tumor community's calendar, attracting over 70 patients, families, representatives from other brain tumor charities and scientific, medical and health professionals. The conference provides a forum for both formal presentations and

informal discussions and was experienced very positively.

Mike Traynor, President of the Pediatric Brain Tumor Foundation, was invited to deliver the Peter Best Memorial Lecture at this year's conference. Dianne Traynor, the Foundation's Director of Research and Advocacy, acted as moderator for a forum where charities came together to discuss possible collaborations. Other topics included:

- A Focus on Treatment
- A Celebration of Achievements in the field of research in the UK
- Living with a Brain Tumor

Participants of the conference came away with renewed hope and new friends and associations with professionals, patients and care givers who are like minded and facing the same daunting task of beating brain tumors.

One conference attendee commented, "I found that Mike and Dianne Traynor had so much useful experience and knowledge from which we can all benefit, and if we want a way that works, we need look no further than their example of patience, simplicity, understanding and tolerance."

Charities that were involved in the conference included:

- Ali's Dream
- Brain Tumour Foundation
- Brain Tumour Research Campaign
- Carlisle Support Group
- Cleveland Support Group
- Diana Ford Trust
- Doncaster Support Group
- Hammer Out
- Pediatric Brain Tumor Foundation
- Samantha Dickson Research Trust
- The Ellie Memorial Trust
- UK Brain Tumour Society



The UK Brain Tumour Society is committed to hosting this conference annually, in July, at Nottingham University. The event provides a rich opportunity for patients, medical, social work professionals and charities from the United Kingdom brain tumor community to come together, share knowledge and experience and at the same time, find strength from each other and explore new ways of tackling brain tumors. □

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## THE PEDIATRIC BRAIN TUMOR FOUNDATION

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