



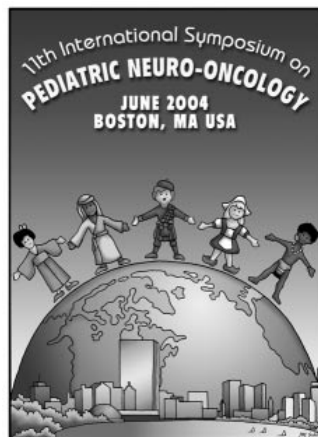
FAMILY SUPPORT & RESEARCH EDITION

July 2004 | Volume 1, No. 1

PBTF Funds International Symposium on Pediatric Neuro-Oncology

The Pediatric Brain Tumor Foundation (PBTF) was a Platinum sponsor of the 11th International Symposium on Pediatric Neuro-Oncology (ISPNO) held June 13-June 16, 2004 in Boston, Massachusetts. Mike and Dianne Traynor represented the Foundation at this year's symposium, marking the fourth time the PBTF has provided funding for the ISPNO's bi-annual meeting. Co-Chaired by Dr. Mark W. Kieran and Dr. Peter M. Black, this year's meeting was the largest in the symposium's history, with 600 physicians, researchers, nurses and advocates in attendance. Among the many countries represented were the United States, Croatia, Australia, Britain, Japan and South Korea.

The goal of the ISPNO is to bring together the world's premiere researchers and clinicians in the field of pediatric neuro-oncology to further advance the treatment of childhood brain tumors. "The International Symposium on Pediatric Neuro-Oncology provides an ideal forum for the world's finest practitioners and scientists to come together and



collaborate," said Mike Traynor, president of the Pediatric Brain Tumor Foundation. "The greatest challenge we face today is translating new research discoveries into modalities to treat pediatric brain tumors. This symposium facilitates the sharing of information to fast-forward that translation."

Researchers from the Pediatric Brain Tumor Foundation Institute (PBTFI) at Duke were on hand to present their recent research findings. The Foundation was pleased to have provided funding for two of the presenters at this year's ISPNO meeting, Dr. Jeremy Rich and Dr. Hai Yun. Both are Principle Investigators with the Pediatric Brain Tumor Foundation Institute at Duke. Dianne Traynor, Director of Research Funding and Advocacy for the PBTF, commented, "The work that both men presented are fine examples of the state-of-the-art research being done at the Pediatric Brain Tumor Foundation Institute at Duke for pediatric brain tumors."

On June 15, ISPNO attendees
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PBTF Announces Research Initiative with the Accelerate Brain Cancer Cure Foundation

On May 18, 2004, the PBTF undertook a new initiative in its fight against childhood brain tumors. Teaming with Accelerate Brain Cancer Cure (ABC²), the two non-profit organizations awarded a research grant to Tom Curran, PhD, co-leader of the Neurobiology & Brain Tumor Program at St. Jude Children's Research Hospital.

The grant will support Curran's work on the development of a treatment for medulloblastoma, which accounts for over 20% of all childhood brain tumors. Curran, who is also chair of St. Jude Hospital's Department of Developmental Neurobiology, has pioneered pre-clinical studies of the role of the sonic hedgehog (SHH)

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(L-R) Arthur Nienhuis, MD, Director, St. Jude Children's Research Hospital; Joanne Tremblay Salcido, PhD Manager, Scientific Programs, ABC²; Dianne Traynor, Director of Research and Advocacy, Pediatric Brain Tumor Foundation; and Tom Curran, PhD, Chair, Developmental Neurobiology, St. Jude's Children's Research Hospital



Photo credit: Ann-Margaret Hedges

FROM THE PRESIDENT'S DESK

...by Mike Traynor



This first edition of the *Caring Hand* marks another step forward in the Pediatric Brain Tumor Foundation's quest to better serve the patient families, clinicians and researchers of the world who daily are impacted by childhood brain tumors. With this publication, we have launched the Family Support & Research Edition of the *Caring Hand*.

Within these pages we will cover issues of interest and hopefully benefit to patient families, care givers and members of the clinical and research community who are bound together by their mutual efforts to care for and nurture childhood brain tumor patients.

The work of the Pediatric Brain Tumor Foundation was initiated in 1984 in response to the plight of the families and the children impacted by childhood brain tumors. It is therefore no surprise that 21 years later our focus remains riveted on the very reason we started this work two decades ago. It is fitting that as our efforts have matured, the funds we have raised increased and our ability to more fully respond to the needs of the medical and patient family community expanded. We now offer a newsletter to highlight the achievements of medicine and the heroic efforts of the children and their families as survivors of childhood brain tumors.

A question that has been frequently asked of us over the years is, "why would people who have no immediate relationship with a child afflicted with a brain tumor work so diligently to offer new hope to childhood brain tumor patients and their families?"

The answer is simple, "it is a privilege to work closely with true heroes and heroines who give us far more than we will ever be able to give to them". It is quite honestly an honor to work with the families, care givers, researchers and clinicians.

We invite you to give us feedback on this edition, and we warmly solicit your suggestions for topics to be covered that will be of most interest to the field of pediatric neuro-oncology and patient families.

Warmest Wishes,
Mike Traynor □

ISPNO...

(continued from page 1)

were treated to a visit to Boston's Fenway Park, home of the Boston Red Sox. As the participants took a VIP tour of the ballpark, including a stop at the infamous "Green Monster" left field fence, the name of the Pediatric Brain Tumor Foundation flashed up on the park's jumbotron TV screen.

Like the Boston Red Sox, these researchers and clinicians are committed to hitting one "out of the park" in their quest to find the cause and cure of childhood brain tumors. □



The Pediatric Brain Tumor Foundation featured on Fenway Park's Jumbotron

ABC² Initiative...

(continued from page 1)

signaling pathway in the development of medulloblastoma. His preliminary research demonstrated that a highly specific, non-toxic compound inhibits tumor cell proliferation and eliminates tumor volume, suggesting that SHH pathway inhibitors may provide a novel and effective treatment for medulloblastoma.

"The joint award from these two foundations will help my laboratory extend our translational research studies from models to human medulloblastoma," Curran said. "Those results will provide some of the pre-clinical data we need to bring this new approach to treating medulloblastoma into clinical trials. To date, research to identify specific molecular targets for therapeutic intervention in pediatric brain tumors has lagged behind similar efforts for adult cancers," he noted.

Equally as enthusiastic about Curran's research are the two organizations funding the grant. John Reher, ABC² Executive Director said, "By joining forces with PBTF, we are able to leverage our resources and accelerate the progress in our quest for new treatments for brain cancer."

"Brain tumors are the most deadly of all the childhood cancers," explained Mike Traynor, PBTF president. "Dr. Curran's research offers the promise of a new, effective treatment for medulloblastoma, the most common of all the childhood brain tumors. We are pleased to join with ABC² in this collaborative research effort which will take us one step closer to eliminating childhood brain tumors." □

FAMILY SUPPORT



Adolescent and Young Adult Survivors' Psychological Experiences

by Barbara Jones, CSW

Survival rates for childhood cancer have risen sharply over the past 20 years. In the United States, more than 77 percent of children with all forms of cancer are alive five years after diagnosis, compared with about 60 percent in the mid 1970's. Much of this dramatic improvement is due to the development of improved therapies at children's cancer centers, where the majority of children with cancer have their treatment.

Treatment advances in pediatric oncology have given us much reason for optimism. However, many of the young survivors report that the experience of childhood cancer has a profound emotional impact on their lives. Sometimes the child or adolescent will know immediately that they have been changed in some important way. For others, it takes time to understand the meaning of their unique experience. Many survivors simply want to go on with their lives and be normal. But what is normal for an adolescent or young adult, who has never faced cancer, may be very different than what is normal for a young cancer survivor. Returning to pre-cancer normal is unlikely, but young survivors can learn to create a new sense of normalcy that incorporates their experiences with childhood cancer.

Childhood cancer is unique because it occurs when children are developing physically and emotionally. The young cancer patient understands their experience in an age-congruent way. As they become older, they view their experience from a different developmental perspective and integrate the memories in a new way. Each adolescent or young adult will reintegrate his or her experience at each new developmental stage. With support and guidance, these memories can be incorporated into a positive sense of self and of survivorship.

It is not uncommon for young adults to experience the psychological effects of their cancer a year or more after they have finished treatment. Some of the life changes that they experience are incredibly positive and life affirming, such as triumphing over challenges and discovering meaningful relationships. Some of the changes may be more difficult to understand. Young adult survivors report a sense of being different than their peers. Many report a sense of loneliness and loss about having missed out on the "normal" developmental activities of their youth. Some report having different values than their peers, being less or more concerned about looks and

material possessions. Survivors may need to grieve the losses they experienced, which can include losing friends, losing hair, losing normalcy, and losing innocence. Some children can experience symptoms of trauma, anxiety, or depression about their cancer experience. It is important for these children to know that their experiences are not unusual and that they can talk about them with a caring adult. Sometimes counseling can help a young survivor make sense of their experiences and deal with the subsequent emotions.

Many adolescents indicate a sense of being positively transformed by the experience of facing childhood cancer. Many feel powerful and hopeful and determined. Self-esteem can be enhanced by the experience of surviving cancer. Many young adults search to make meaning out of their experience. For some that can appear as a career choice, such as becoming a doctor or nurse. For some it can be an enhanced sense of the importance of relationships and appreciation for support and love they received. Other young adults see themselves in a new and more positive light.

Common Experiences and Feelings of the Adolescent/Young Adult Survivor:

- Feeling different than peers
- Valuing relationships and time
- Identifying with adults
- Anxiety
- Sadness
- Anger
- Gratitude
- Joy and hopefulness
- Closeness with family
- Fear of losing loved ones
- Grief over losses, physical and emotional
- Sense of spirituality or meaning

Surviving cancer can be a transformative life experience and one that deserves our respect and support, even awe. Each survivor will make their own individual meaning out of their experiences with childhood cancer. What is important is to allow them to express their feelings without judgment, to help them to identify their own successes, and to provide unconditional support and help when necessary. □

Reprinted with permission from Barbara Jones, CSW, Assistant Professor School of Social Work, University of Texas at Austin and from the Association of Pediatric Oncology Social Workers.

Resource and Educational Materials Available

Resource and educational materials published by the PBTF are made available at no cost to patient families, the medical and social worker communities, and the general public. The materials include tumor-specific brochures. The Informed Parent Internet Conference Series is also available on compact disc. Please review this list of available publications. If you would like a copy of a specific brochure, please contact the Pediatric Brain Tumor Foundation's Family Support Coordinator directly at (800) 253-6530 or via e-mail at familysupport@pbtfus.org.

Available Publications:

- Questions For Your Medical Care Team When Your Child Has a Brain Tumor
- Basic Facts About Pediatric Brain and Spinal Cord Tumors
- Basic Facts About Medulloblastoma/PNET
- Basic Facts About Juvenile Pilocytic Astrocytoma
- Basic Facts About Astrocytoma
- Basic Facts About Ependymoma
- Basic Facts About Glioma

Audio CDs:

- Informed Parent Internet Series - The Importance of a Multi-Disciplinary Approach to Treating Children with Brain Tumors
- Informed Parent Internet Series - The Clinical Trials Process
- Informed Parent Internet Series - School Re-entry Following the Diagnoses and Treatment of Your Child's Brain Tumor
- Informed Parent Internet Series - Healing the Family
- Informed Parent Internet Series - Growth and Development: Endocrine Issues Facing Pediatric Brain Tumor Survivors
- Informed Parent Internet Series - Post Traumatic Stress: Helping Families Survive Childhood Cancer
- Informed Parent Internet Series - Sibling Issues: The Impact of Cancer on Healthy Siblings
- Informed Parent Internet Series - Brothers & Sisters & Brain Tumors: A Child's Point of View of Coping with Cancer in the Family
- Informed Parent Internet Series - Combining Curative and Palliative Care for Children with Brain Tumors

PICTURE OF HOPE

Lacey, a young brain tumor survivor, enjoys herself at vacation bible school.

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



RESEARCH UPDATE

2004 Peter Steck Award

One of the ways the Pediatric Brain Tumor Foundation (PBTF) recognizes excellence in pediatric brain tumor research is through its annual Peter Steck Memorial Lecture and Award. The prestigious lecture and award presentation, now in its fifth year, was held at MD Anderson Cancer Center in Houston, Texas, on Monday, April 22, 2004. The event honors the memory of Peter Steck and highlights the importance of his significant cancer research discoveries.

Prior to his death, Steck, a noted cancer research scientist, was a PBTF grant recipient for his work on the discovery of the MMAC1/PTEN gene. Since that time, thousands of research projects around the world have been linked to his findings. Steck's breakthrough not only has affected research in the field of childhood brain tumor research, but his work is also being used to find new treatments for other cancers, including melanoma and breast cancer.

The competition for the Peter Steck Young Investigator Award is open to young cancer investigators. The recipient of the annual Peter Steck Memorial Award is determined through a competitive peer review process. The award is given to recognize and encourage the scientific research of outstanding young investigators.

The 2004 \$5,000 Steck Young Investigator Award was presented to Dr. Michael D. Taylor, MD, PhD, by PBTF President Mike Traynor, who commented, "Research

provides the raw materials needed to find the cause and cure of childhood brain tumors, and we are pleased to present this award to Dr. Michael Taylor for his excellent research contributions."

Dr. Michael Taylor is currently a Pediatric Neurosurgery Fellow at

LaBonheur Children's Hospital and St. Jude Children's Research Hospital in Memphis, TN. He presented his Nature Genetics paper (17 June 2002): "Mutations in SUFU Predispose to Medulloblastoma".

The Peter Steck Memorial Lecture is given each year by an established cancer researcher with a distinguished career, who is highly respected for discoveries and contributions to the field of cancer research.

This year's Peter Steck Memorial Lecture was given by Dr. Tak W. Mak, PhD, Professor of Medical Biophysics, University of Toronto and Director of Advanced Medical Discovery Institute, Toronto. Dr. Mak has over 542 research publications. His lecture was entitled *Cancer Therapeutics: "tis death that makes life live."* - Robert Browning. The MD Anderson lecture theater was filled with scientists eager to hear Dr. Mak's presentation.

"The Foundation's mission is to find the cause and cure of childhood brain tumors. In order to do that, we must fund the best research currently being conducted," said Dianne Traynor, Director of Research and Advocacy for the Pediatric Brain Tumor Foundation. "Dr. Mak and Dr. Taylor are using cutting-edge technology to carry out their investigations. The PBTF is proud to be able to honor the memory of Peter Steck by highlighting the work of these two researchers who are making great strides in the field of childhood brain tumor research." □



Dianne Traynor, Director of Research and Advocacy for the Pediatric Brain Tumor Foundation, and Tak W. Mak, PhD



(L-R) Alfred Yung, MD; Mike Traynor, President, Pediatric Brain Tumor Foundation; Tak W. Mak, PhD; Dianne Traynor, Director of Research and Advocacy, Pediatric Brain Tumor Foundation; Gary Gallick, PhD; Michael D. Taylor, MD, PhD at the 2004 Peter Steck Memorial Lecture and Award

WHERE HOPE SPRINGS ETERNAL

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



Daniel, a brain tumor survivor, is truly an inspiration.

Determination is His Middle Name

These days, Daniel is busy painting his parents home as it undergoes a major renovation. His home makeover parallels his own life, and the complete “redo” he went through while battling a brain tumor.

In every way, Daniel was an all-American kid. A good student, he emerged as a young soccer star, a starting player for his high school varsity soccer team when he was only a freshman. A college soccer scholarship seemed imminent until December 21, 1997, when Daniel was diagnosed with a medulloblastoma and cranial hemorrhage. Soccer games quickly gave way to survival strategies, as Daniel endured his first surgery and then a year-long round of chemo and radiation therapy.

But Daniel’s soccer field determination could not be dashed. Starting from the ground up, he spent three months in the hospital, re-learned how to do what most of us take for granted – move, talk, feed himself, tell time, and identify something as simple as a cloud. Double vision even forced him to retrain his eyes. Remarkably, Daniel graduated from high school on time, despite several rounds of radiation and chemo during his senior year. And though his childhood dream of becoming a Secret Service agent may never be realized, he credits his parents and his physical therapist, Emmi, with showing him “how to be Danny again.”

“My mother taught me it was important to help others,” Daniel said. “She showed me I had an insight I could give other young people to help them.”

And provide inspiration he has. Daniel serves as a

testament that life does not end with cancer. He is also an invaluable resource for both parents and doctors, giving them a first-hand account of what it feels like to be a teen with cancer. He notes that there was not a lot of support for teens when he was battling his brain tumor. “There was not a very good support group for me when I was going through all of the radiation, chemotherapy, and surgery. There was help for young children and older people, but we teenagers kind of had to fend for ourselves. I want to help other teens understand life can still have meaning and be fun,” he says.

After two years at Athens Tech, Daniel is currently studying psychology at St. Andrews Presbyterian College. He is proud to be living on his own and building new friendships. He is working with the campus disabilities coordinator to plan for and identify the needs of disabled students, and plans a career to help young people like himself. “I want to repay the kindness that entered my life,” he says.

The 23-year-old’s philosophy of life reflects a wisdom that goes far beyond his years. “My father and a special teacher, Sergeant Major Gordon, taught me there are always struggles in life, and what you make of these struggles is who you are,” he says. “I just never knew how much or how far until I had cancer. I know what hard work is now, and I look at each day as an adventure, not just something to get through. We do not know what is going to happen to us, so we need to try to make a difference when we are here.” □

Join the PBTF Team

The Pediatric Brain Tumor Foundation is seeking an Executive Director to help the Foundation continue to grow in its mission to find the cause and cure of childhood brain tumors and to provide support for the families of childhood brain tumor patients.

The successful candidate must have a deep dedication to the mission of the Foundation, bring leadership, planning, considerable management experience in either a commercial or non-profit setting, possess strong fund raising skills and a commitment to work within budgeting boundaries.

This position reports directly to the President and requires the successful candidate to manage human and financial resources to insure the smooth and efficient working of the

Foundation while providing dynamic and strategic leadership with strong fund raising and management skills to take the organization to its next level of excellence and achievement.

This position provides the opportunity to make an important contribution in the fight against childhood brain tumors, the ability to work in a positive, upbeat environment and to touch all aspects of the Foundation, while working with caring people from all walks of life.

Candidates must have strong, relevant educational and professional background. Interested candidates should submit cover letter, including salary range, references, and resume to President, Pediatric Brain Tumor Foundation, 302 Ridgefield Court, Asheville, NC 28806, or to mtraynor@pbtfus.org. Position is located in Asheville, NC. □

Words of a Mom

by Kim Gumabay

What an interesting club I joined on May 4, 2002 when my three-year-old son Ethan was first diagnosed with a PNET brain tumor. Like each of you, I shuddered to imagine what lay ahead for us.

The logistics of the next year were somewhat easy to assemble: surgery, followed by four months of high-dose chemotherapy, six weeks of daily radiation, and finally another eight months of chemotherapy. Sprinkle in the placement of a central line and a stem cell harvest, and I could nearly map out how we would spend our next year.

What I could never have imagined was the emotional burden and reward that the year would hold for all of us.

The burden was intense. Every chemotherapy cycle brought on severe neutropenia and an inevitable complication that would land us in the hospital – sometimes for a few days, sometimes for a few weeks. The burden was compounded by the typical weight loss, hearing loss, a Hepatitis C scare, and the full knowledge of what I had consented to do to his tiny little body. Ethan also had a little sister at home. We both missed her first steps and her first words. Perhaps most disturbing of all was the realization that Ethan was probably forming his first memories.

I dreamed all year of Ethan's last day of chemotherapy. When that day finally came, I was unexpectedly torn with emotions. I was elated to end the toxicity, but felt very vulnerable - as if we were no longer fighting.

I also felt a great deal of sadness, leaving friends who had become as close as family. For more than a year, I had spent countless hours with other families from divergent social and cultural backgrounds. In the hospital and clinic, however, we were united by the same goal: to save our children, all of our children. We invested in each other and in each other's outcomes. Often times, I felt closer to the other cancer moms than I did to my best friend of 20 years. Like being a veteran of war, caring for a child

with cancer is a bonding experience that no one welcomes, but the strength of that bond is breathtaking. The abrupt change from seeing the families several times a week to not seeing them at all was painful – as if half of our social network was suddenly gone.

I also felt my share of guilt. I knew that some of the other parents would never get to experience the swirl of emotions that comes with ending treatment. I was grateful for Ethan's ability to tolerate the treatment, yet I was self-conscious around others who were not faring as well.

At times, I felt angry at the losses we all endured and the randomness of it all.

Upon ending treatment, I didn't feel like I belonged in the world of the sick or the world of the well. We were hovering in a strange middle place where the rules were murky at best. The first time Ethan got a fever, I felt so out of place calling his pediatrician rather than his oncologist. Frankly, I didn't even know if a fever warranted a call...

It turns out, though, that the reward was even greater than the burden. We've had time to take stock of our good fortune and to open our eyes to all that is wonderful in our lives. It was elating to see Ethan bathe without a central line and to run wildly into a water park for the first time! His first haircut after treatment was a much bigger deal than the first time around as a toddler. We can now schedule play dates and outings without counting days

on a calendar and anticipating blood counts. We can travel without devoting an entire suitcase to medical supplies. Through our experience with Ethan, we've developed friendships with other families and members of his treatment staff that would have never materialized in different circumstances. We now have an abundance of perspective on life and living. We've even been fortunate enough to be in a position of giving help, rather than receiving it. Survivorship has its own challenges, but it's an incredible journey with enormous rewards.

Welcome all of you to our little club. May we all love deeper and live richer lives because of it. □



Kim and her family at the 2003 Columbia Ride for Kids®

Ride for Kids®

2004 Ride for Kids® Season Kicks Off!

Houston Ride Breaks Record

The 2004 Ride for Kids® season kicked off on Sunday, April 25 with the 12th Annual Houston Ride for Kids® in Kemah, Texas. A slight drizzle did not dampen the spirits of the 800 dedicated motorcyclists who gathered to ride through Houston's southern suburbs to raise a record-breaking \$273,523 for childhood brain tumor research.

After the police-escorted ride, the motorcyclists gathered for a wonderful Celebration of Life program. The day's special guests were Ride for Kids® "Stars" from 15 patient families who ranged in age from six to 19. Neuro-oncologists Jack Su and Allison Bertuch were also on hand to help the riders understand the importance of pediatric brain tumor research. A 16-year-old brain tumor survivor named Darla won the hearts of the audience when



Darla, a young brain tumor survivor, wins the hearts of the audience while Garrett, another Ride for Kids® "star", and National Ride for Kids® Director Allen Hughes listen closely



Dr. Jack Su at the 2004 Houston Ride for Kids®

she commandeered National Ride for Kids® Director Allen Hughes' microphone to address the younger brain tumor survivors, telling them, "I learned a saying that I want to pass on to you. Please remember that rain always comes before a rainbow."

Thanks to Houston Ride for Kids® Task Force Leader Ronnie Lunsford and his amazing volunteer task force for such a successful event!

First-ever Triangle Ride for Kids® Draws Eastern North Carolina Riders

Sunday, May 2 marked the first annual Triangle Ride for Kids® in eastern North Carolina. The warmth from nearly 250 motorcyclists, volunteers and patient families provided a ray of sunshine despite the sudden downpour that kicked off the event. The riders raised a total of \$23,078 for pediatric brain tumor research.

After departing from Cary, NC, state and local police escorted the soggy motorcyclists on a memorable ride through the rural countryside before arriving at the destination point for the Celebration of Life program. There, under the yellow and white striped "big top" tent, the motorcyclists, patient families, and volunteers joined 12 researchers, clinicians, and staff members from Duke University Medical Center. Staff members were also on hand from the Pediatric Brain Tumor Foundation Institute at Duke. Everyone then enjoyed a program that celebrated the VIPs of the day, 11 Ride for Kids® "stars", all of whom are brain tumor survivors.

During the ceremony, Dr. Darell Bigner, director of the Pediatric Brain Tumor Foundation Institute at Duke, spoke passionately about the challenge to find a cure. "The Ride for Kids program inspires us to go back to our laboratories to continue our research. What we do is very expensive work. We work hard to be good stewards of the funds raised at Ride for Kids events," he said. Mike Traynor, president of the Pediatric Brain Tumor Foundation, told the Triangle riders they were pioneers for attending the inaugural event.

Traynor then had his hands full as he conducted an on-stage interview of the eleven Ride for Kids® Stars, whose jovial smiles and wiggly dispositions charmed everyone present. When asked how old he was, three-year-old Nicholas replied with a resounding, "I am 15!"

Thanks to Triangle Ride for Kids® Task Force Leaders LJ and Betty McDade and Rod and Maxine Gilvey and their incredible team of volunteers for a great event.



Nicholas, a young brain tumor survivor, and his dad at the 1st Annual Triangle Ride for Kids®

Pittsburgh Ride for Kids® Sets a New Record

On May 2, dedicated motorcyclists in Pittsburgh, Pennsylvania rallied to raise \$86,728 for childhood brain tumor research at the fourth annual Pittsburgh Ride for Kids® on Sunday, May 2. Under a rainy sky, over 500 riders departed Cranberry Township for a police-escorted ride through the scenic rolling farmland of western Pennsylvania. Most noted the irony of having Jon Burnett, a 20-year veteran meteorologist with KDKA TV Channel 2, in attendance that day. After enduring some friendly ribbing about the rainy weather, Burnett commented, "As a motorcyclist, I have been on many rides. The Ride for Kids is the friendliest, most organized Ride I have ever been a part of."

The post-ride Celebration of Life program was very moving, as five Ride for Kids® Stars and their families were in attendance under the white big top tent. Thirteen-year-old survivor Alyssa, who has attended the Pittsburgh Ride for Kids® for several years, captured the hearts of everyone there when she said, "I don't know all of your names, but I want to thank each of you. This is the only place I come where I get to feel like a normal kid."

Special thanks to Pittsburgh Ride for Kids® Task Force Leaders Bill and Janet Henze and Steve and Laura Kovac and their dedicated volunteer force for an amazing event.

Torrance Ride for Kids® Big Success for Kids

Sunday, May 16, marked the 13th anniversary of the Torrance Ride for Kids®. Under southern California's famed sunny blue skies, riders assembled in the early morning hours at American Honda's Torrance campus. Since 1991,

American Honda has been the presenting sponsor of the national Ride for Kids® program, and has graciously donated the grand prize Honda motorcycle that is given away at each Ride for Kids® event.

Michelle, a PBTF College Scholarship recipient and brain tumor survivor, gives National Ride for Kids® Manager Keith Knapp a hug at the 2004 Torrance Ride for Kids®



Allen Hughes, National Ride for Kids® Director, and Ryan, a young brain tumor survivor, share a giggle during the 2004 Pittsburgh Ride for Kids®

As a magnificent motorcycle parade wound its way along Redondo Beach and through the South Bay area, 950 motorcyclists, volunteers, fundraisers and patient families came together to raise \$186,419 for pediatric brain tumor research.

After the ride, the participants gathered under the big top tent for the Celebration of Life program. Ride Manager Keith Knapp was joined on stage for the program by nine courageous and inspiring brain tumor survivors. When asked if he would like to say something to the motorcyclists, 10-year-old Trent remarked, "Raise more money!"

Thanks to Torrance Ride for Kids® Task Force Leaders Mike and Lori Whitaker and Timm Browne and their dedicated volunteer team for a super event.

Atlanta Riders Rally for the Cause

June was another banner month for the Ride for Kids®. Kicking off the activities was the 21st Annual Atlanta Ride for Kids® on Sunday, June 6. Motorcyclists were escorted through the hills of North Georgia by Major Richard Davis and 104 members of the Fulton County Sheriff's Reserve. When the final count was in, 1800 motorcyclists, volunteers, fundraisers, patient families and researchers had rallied together to raise an outstanding \$267,717. Twelve gregarious young brain tumor survivors inspired the audience at the Celebration of Life program as Dr. Timothy Mapstone, an Atlanta neurosurgeon, proclaimed, "For the first time in my 25 plus years of research, I believe that there is a possibility that I will see children being cured of brain tumors without surgery."

Thanks to Atlanta Ride for Kids® Task Force Leaders Jim and Nona Unversaw and Tommy and Connie Smith and their amazing volunteer task force for a great Ride for Kids® event.



Tabitha and Adam, both brain tumor survivors, at the 2004 Atlanta Ride for Kids®

Richmond Riders Revel in Record Donations

While the Atlanta Ride for Kids® was taking place, a few states to the north the Richmond Ride for Kids® got underway on Sunday, June 6. In only its second year, 520 motorcyclists, volunteers, fundraisers, researchers and patient families worked diligently to raise a record \$94,069 for childhood brain tumor research.

After a police-escorted ride through the scenic Virginia countryside, participants gathered with eight beaming young survivors for a wonderful Celebration of Life program. The day took on special meaning as a young survivor named Tiffany thrust her arms skyward and remarked, "The worst thing that can happen to a child or teenager is being diagnosed with a brain tumor. We are true survivors!" Dr. Theodore Chung, a radiation oncologist, and Dr. Helen Fillmore, Assistant Professor of Neurosurgery at Virginia Commonwealth University were also in attendance.

Thanks to Richmond Ride for Kids® Task Force Leaders Mike Seibert and Kerry Abrams and their remarkable volunteer task force for a record-breaking event.



Kyle Clack, a National Ride for Kids® Manager, and Ethan, a young brain tumor survivor and "star" of the 2003 RFK Public Service Announcements, on stage during the 2004 Richmond Ride for Kids®

SoCal Dual Sport Ride Yields Funds for Childhood Brain Tumor Research

One week later on June 13, 240 riders wound their way through the Los Padres and Angeles National Forests during the 12th Annual Southern California Dual Sport Ride for Kids®, raising \$84,489 for pediatric brain tumor research. Ten-year-old Curtis Herrmann, who was inspired to join the cause after losing his younger sister Breeana to a brain tumor, was the Top Individual Fundraiser with a total of \$30,007. For the past several years, he has hosted a special "Laps 4 Love" fundraiser in her honor. Also in attendance that day



Buddies Brandon and Trent, both young brain tumor survivors, at the 2004 Southern California Dual Sport Ride for Kids®

Ride for Kids® Task Force, led by Task Force Leaders Jim Woods and Buddy Percin, for a great event.

Determined KC Riders Undaunted by Devastating Weather

On Sunday, June 13, while the riders in SoCal basked in the warm sunshine, the story in Kansas City was quite a different one. Despite torrential rains and damaging winds the night before, over 140 participants showed up to demonstrate their commitment to the 1st Annual Kansas City Ride for Kids®. Many of their homes had been damaged in the Saturday-night storm, and most were without power. As volunteers and riders pondered the remnants of the Celebration of Life tent that were strewn about the grounds as a result of the storm, they decided that the first-annual Kansas City Ride for Kids® must go on. Despite the devastation all around, the sun shone brightly as the motorcyclists rode along the perimeter of Smithville Lake north of Kansas City. In the end, the determined riders had raised \$17,000 for their cause, leaving smiles all the way around.

Afterwards, at the Celebration of Life program, young brain tumor survivor Ben told the crowd that he enjoyed his first ride in a sidecar, especially since his escort Lou Harding left the siren alarm on for the entire ride!

Thanks to Kansas City Ride for Kids® task force Leaders Vicky Harding and Larry Morrison and their dedicated volunteer Task Force for such an organized and well-run event. ■



Ben, a young brain tumor survivor, has a ball at the 1st Annual Kansas City Ride for Kids®

were Trent, a young brain tumor survivor, and his mother Hope. She told those gathered, "After attending the Ride for Kids event for several years, I am still amazed every time that all of these people care about us and want to help us. Thank you!"

Special thanks to the Southern California Dual Sport

FANTASTIC FUNDRAISERS

First and Goal Football Camp Fundraiser Benefits PBTF

When 57 football coaches from 34 schools get together, can there be just one game plan? On Saturday, June 5, the coaches had that and more at a new event dubbed “Lauren’s First and Goal Camp”. The camp, which took place at Lafayette College in Easton, Pennsylvania, raised \$20,000 to benefit the research and family support programs of the PBTF.

The one-day youth football training clinic was organized by John and Marianne, parents of seven-year-old survivor Lauren, who was diagnosed with multiple brain tumors at age two. “We learned about the great work the Foundation was doing when we attended the Hudson Valley Ride for Kids in Harriman, New York, just after Lauren was diagnosed,” said John. “We made a point of attending every year after that—this year will be our sixth Ride, and we really look forward to it.”

“So many aspects of this disease are out of your control,” Marianne added. “We had been thinking for a long time about what we could do. We wanted to make a difference, not only for Lauren, but for the other kids and their families, too.”

At the annual NCAA convention in January, John - the defensive coordinator at Lafayette - and his fraternity of coaching friends hatched the idea of organizing a

youth football camp to raise funds. The cold and rainy weather neither dampened the spirits of the coaches who drove or flew in from throughout the region nor those of the 350 kids who attended the camp.

“I can’t express how thankful I am to everyone who contributed to the camp,” said John. “The kids raved about the coaching they received. We also thank the college for donating the facilities and helping promote the event.” Added Marianne, “These coaches have so little time off, so to spend a day with us and Lauren was just amazing. Everyone left with a great feeling of accomplishment.”

What lies ahead? “We plan to start earlier next year,” said John. “With more time to organize and promote, we will accomplish even more.” □



Army head coach Bobby Ross and Lauren share a smile at Lauren’s First and Goal Football Camp.

Building a Path for the Cure

A stroll down the garden path takes on special meaning for visitors to Eastside Honda in Baytown, Texas. The path, winding around the lake behind the dealership, will be paved with stones and lined with shrubs and trees donated in honor or memory of loved ones and friends, with the proceeds going to the PBTF.

“Rhonda, the wife of our sales manager ‘Uncle Dave’, came up with the idea of a path paved with stones that people could build themselves,” said Chris Davis, Eastside’s general manager. When approached with the



Eastside Honda’s Path for the Cure

idea, owner Ralph Oler expanded on the concept and decided to build a “path for the cure” to raise funds for the PBTF.

“Some of us have lost family and friends to cancer, and there are also survivors that we wanted to honor,” said Davis. “People can make a donation for their own path stone or a plant, and then we’ll place it along the path, which will eventually circle the lake.” Davis added that they are also soliciting local businesses to sponsor larger items such as park benches.

The path will start at the butterfly garden behind the store. A large 2000 pound slab of Texas pink granite, quarried in Marble Falls, will be erected in the garden and will have a bronze plaque inscribed with a poem Oler has written.

Donations start at \$10. For more information, contact Eastside Honda at (281) 385-0700 or visit their web site at www.eastsidehonda.com. □

PBTF Provides Funding for APOSW Conference

The 28th Annual Association of Pediatric Oncology Social Workers (APOSW) Conference was held May 19-22, 2004 in St. Louis, Missouri. The theme for this year's conference was *Gateway to Growth: Advancing Psychosocial Practice in Pediatric Oncology*. The APOSW's main goal is to promote the quality and effectiveness of clinical social work in the field of pediatric oncology.

For the second year, the Pediatric Brain Tumor Foundation was pleased to provide funding for the pre-conference educational meetings. This allowed pediatric oncology social workers the opportunity to attend seminars they might not otherwise be able to attend due to funding restrictions. Sessions included the following topics: Information for new Pediatric Oncology Social Workers, Social Work End of Life Curriculum, and a course on Spirituality.

Bobbie Duffy, PBTF's family support coordinator, represented the Foundation at this year's conference. "Pediatric oncology social workers are our best source of networking directly with patient families," Duffy commented. "Many pediatric oncology social workers would not be able to attend the educational sessions if it weren't for the PBTF's funding." Duffy added that pediatric oncology social workers also distribute the Foundation's educational materials about pediatric brain tumors and its college scholarship information to the patients. ■



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