



The HELPING HAND

PEDIATRIC BRAIN TUMOR FOUNDATION

April 2004

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Ashley Embodies Courage

At age 14, Ashley was a picture of health. The athletic eighth-grader, whose family had just relocated to Belleville, Illinois from Ramstein Air Base in Germany, ran track, enjoyed movies and ice cream with her friends, and was a big sister to six-year old brother Breon. Occasionally she suffered from allergies, but there was no indication of the life-altering change she and her family were about to endure.

"In January of 2001, we were at the eye doctor and he noticed that Ashley's left optic nerve was swollen," recalled Ashley's mother, Pam. The doctor ordered a CAT scan. "They discovered a tumor sitting on her brain stem and they told us they had to operate immediately." Their lives suddenly careened into unknown territory.



Ashley and her family enjoy their first Ride for Kids® event at the 2003 Chicago Ride for Kids®.

Ashley's father, Sedric, recalled the shock of the diagnosis. "I had to tell Ashley about her tumor and she asked me, 'Why did God allow this to happen to me?' Then she said, 'If it has happened, it happened for a reason.' My wife and I were numb and Ashley was already comforting us."

Ashley's surgery was conducted on the next day. The neurosurgeon discovered a juvenile pilocytic astrocytoma (JPA) that had spread down to Ashley's vertebrae. The tumor's size and the surgery to remove it left Ashley with significant challenges. "The doctor told us Ashley would be paralyzed, but we had faith in God and we were not going to accept this," Pam said.

This determination characterized the family's positive approach throughout Ashley's recovery. She remained in the hospital for six weeks after her surgery, requiring extensive rehabilitation to overcome damage to her vision, balance, speech, and memory. Pam and Sedric were by her side every day. Pam, trained to help autistic children, knew that she had to keep Ashley continually active and engaged. "We walked all over the hospital and she talked to her friends on the phone all the time," she said.

Loved ones throughout the world comforted Ashley and her family. "Being in the Air Force, we knew people in Germany, Florida, Alabama, Texas and New Jersey," said Sedric. "While we had not lived in Belleville long enough to know many people, our friends were there for us and provided emotional and even financial support. We can never thank them enough."

Ashley's rehabilitation continued



Ashley enjoys being active in high school athletics, including track and field.

after her discharge from the hospital. Pam drove 65 miles round trip, twice-a-day, for the next four weeks for Ashley's outpatient treatment.

Remarkably, Ashley returned to school part-time in May and graduated from eighth grade that summer with her classmates. Her achievement is a testament to the unwavering determination of Ashley, her family and her teachers.

When Ashley entered the ninth grade, she was eager to resume her life. "I joined the track team as a freshman, running the 100-yard dash and the long jump," she said proudly. "It was hard, but it has helped me improve my vision and even my walking." Ashley also takes dance lessons and enjoys drawing. "Sometimes I do well and sometimes I do not, but I always try at everything I do." Like most teenagers, Ashley also enjoys shopping at the local mall, now that she has her driver's license.

Early in 2003, Ashley and her family learned about the Ride for Kids®. "The Foundation sent us a letter, some books and a flyer for the Chicagoland Ride," said Pam. "We had never been to Chicago and we thought, 'Let's go!'" Ashley was excited too. She commented, "I had never been on a motorcycle and seeing all those motorcycles was really fun." So much fun, in fact, that they also attended the

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FROM THE PRESIDENT'S DESK

...by Mike Traynor



This edition of the *Helping Hand* contains a compendium of honored brain tumor patients and many of the men and women who provide a helping hand to those patients and survivors. We are reminded as we look through the lengthy list of memorials and honorees that each of these names represent a life well-lived, a kindness well-bestowed.

For those of you who are patient family members, as well as surgeons, clinicians, nurses, social workers and other care givers who interact with pediatric brain tumor patients, Ride for Kids® participants, sponsors, police officials and all the rest of our caring supporters, these names represent people very special in our lives.

Someone once said that a man (or woman) never stands so tall as when he (she) stoops to help a child. This remarkable listing of individuals reminds us that the children we seek to help and the disease we strive to overcome have brought us all together to create a greater good that literally saves the lives of children in our home towns and around the world. And each of us is better for having worked to help the kids.

We are about to enter into the exciting and soul-stirring 21st Ride for Kids® season, which will bring diverse members of society together, where each person sets aside their individuality and joins with their neighbor to achieve a common goal, the saving of a child's life. I look forward with great anticipation to seeing many of you at one or more of our 29 Ride for Kids® events this year where we will gather under the big top tent to truly "Celebrate Life." In particular we will celebrate the lives of the children who will giggle and wiggle as they are interviewed on stage at the Ride for Kids® event that you attend.

We thank you for your wonderful support and look forward to the day when we can come together under the big top tent to celebrate the end of the disease of childhood brain tumors.

Let's Ride,
Mike Traynor ▣

FAMILY SUPPORT

Basic Facts About Glioma Now Available

The PBTf is pleased to announce the publication of a new information booklet about childhood brain tumors. Entitled *Basic Facts About Glioma*, the free educational booklet is available from the Foundation by writing to familysupport@pbtfus.org, or calling (800) 253-6530. Other educational booklets include:

- 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 (JPA)
- Basic Facts About Astrocytoma
- Basic Facts About Ependymoma
- Basic Facts About Glioma

These booklets may also be ordered online at www.pbtfus.org. ▣



Ashley...

(continued from page 1)

nearby St. Louis Ride for Kids® in September. "I really felt special, and I got to see Melanie (another brain tumor survivor) from Chicago again," said Ashley. Sedric was so impressed with the program that he joined the St. Louis Ride for Kids® volunteer Task Force.

Today, at age 17, Ashley is in eleventh grade and looking forward to college. Her young years belie her maturity and wisdom, and she is an inspiration for us all. "I want to join the Air Force and become a pediatrician to help kids," she says. "I know what it is like to be scared. I want to tell other kids that if you think of a peaceful place when you are scared, before you know it, it's over and you go on with your life. Once you accept your problems," she added, "life will get better." ▣

At Ride for Kids® events,
Ashley can tell you that
young brain tumor patients
get the royal treatment.



2nd Annual Cycle World Joseph C. Parkhurst Education Fund Silent Auction helps PBTF Scholarships

The 2nd Annual Cycle World Joseph C. Parkhurst Education Fund Silent Auction benefiting the Pediatric Brain Tumor Foundation was a tremendous success, raising \$34,800 to support the Foundation's College Scholarship Program.

The silent auction occurred during the annual *Dealernews* International Powersports Dealer Expo in Indianapolis, Indiana, February 14-16. The Joseph C. Parkhurst Education Fund was created by *Cycle World* magazine to honor the memory of the publication's founder, Joe Parkhurst. Parkhurst was passionate about life and learning; his legacy lives on through the education fund, which enables young brain tumor survivors to continue their education through college scholarships granted by the PBTF.

The silent auction consisted of unique and exciting historic motorcycling memorabilia, including such items as Miguel Duhamel's racing helmet, a vintage Evil Knievel lunch box and a signed poster from racing legend John Surtees. Special thanks go out to all of the donors and participants at this year's silent auction. As a result of their generous support, young brain tumor survivors across the country will now have an opportunity to make their dreams of higher education come true.

The 2004 Cycle World Joseph C. Parkhurst Education Fund Silent Auction featured historic and collectible motorcycling memorabilia.



The PBTF's College Scholarship Program, an important part of the Family Support Program, was created to help students who are brain tumor survivors realize their dreams of continuing education. These funds help ease the financial burden that often occurs after living with a life threatening diagnosis. Funds raised by the silent auction in 2003 helped the Foundation increase its total number of college scholarships.

Julia, one of the Foundation's college scholarship recipients remarked, "Having a brain tumor has been very hard on me. As a result of radiation, I have been diagnosed with a learning disability and it makes learning three times as hard as it normally would have been. Thanks to the Pediatric Brain Tumor Foundation, I now have a scholarship to help pay for a small school where I can grow and learn at my best. The college scholarships given by the Pediatric Brain Tumor Foundation make all of the difference to many kids with brain tumors who might not be able to afford college otherwise." □

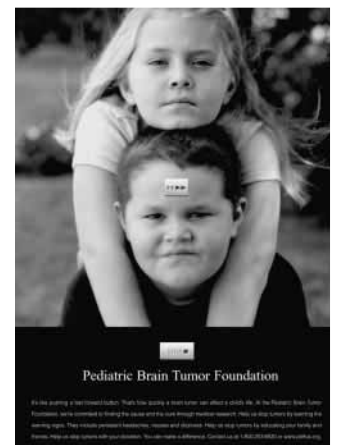
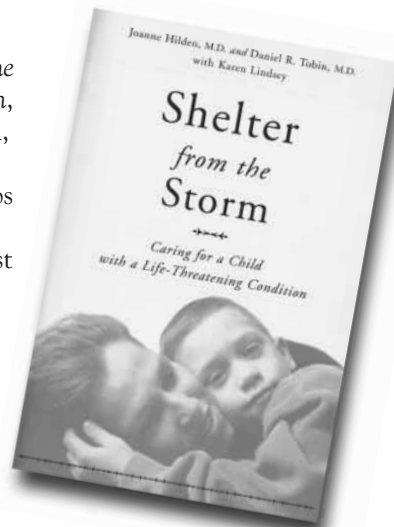


Mike Traynor and Larry Little, publisher of Cycle World, at the 2004 Cycle World Joseph C. Parkhurst Education Fund Silent Auction.

Shelter from the Storm: Caring for a Child with a Life-Threatening Condition

The Foundation now has available for distribution a limited number of copies of the book, *Shelter from the Storm: Caring for a Child with a Life-Threatening Condition*, co-authored by Joanne M. Hilden, MD, Daniel R. Tobin, and Karen Lindsey. A wise and compassionate guide to caring for a critically-ill child, *Shelter from the Storm* helps parents and caregivers make informed, loving, and protective choices on behalf of their children in the most trying of times. The book is based on the National Advanced Illness Coordinated Care program and the stories and advice gleaned from co-author Dr. Joanne Hilden's years of work as a pediatric oncologist. To request a copy, call (800) 253-6530 or e-mail familysupport@pbtfus.org. □

(Editor's note: Dr. Hilden was the presenter of the most recent PBTF Informed Parent Internet Conference: *Combining Curative and Palliative Care for Children with Brain Tumors*. The conference, hosted by INB Radio, is archived at <http://www.pbtfus.org/InformedParent11.htm>.)



The PBTF National General Awareness Campaign continues to be a huge success, recently appearing in the March edition of Parenting magazine

WHERE HOPE SPRINGS IS ETERNAL

Stories of Hope from Doctors and Patients

PBTF Funded Researcher Discovers New Treatment Using the Common Cold to Kill Glioma Cells

Could a common cold virus be used to kill brain cancer cells? This was not foremost in the minds of young cancer researcher Juan Fueyo, MD and his wife, neurologist Candelaria Gomez-Manzano, MD, when they came to the U.S. in 1995 on a one-year grant to conduct cancer research at the University of Texas MD Anderson Cancer Center in Houston.

"We looked at a number of institutions in the U.S.," said Fueyo, a 1984 graduate of the University Autonomus of Barcelona, Spain. "Only MD Anderson offered us an opportunity to work together on the p53 and Rb genes." To the layperson, it is difficult to understand the significance of this statement. Yet in May, 2003, Fueyo, Gomez-Manzano and their colleagues published a study in the *Journal of the National Cancer Institute* that told the world's scientific research community that they had found a way to kill malignant glioma cells in mice using a modified cold virus (adenovirus). The virus sought out and killed cancer cells that were deficient in these two tumor suppressor genes.

After their arrival in Houston in 1994, Fueyo and Gomez-Manzano worked tirelessly for nine years to understand the genetic footprint of glioma cells, one of the deadliest forms of brain cancer. p53 is a tumor suppressor gene or protein, and transfer of p53 using an adenovirus induces apoptosis, or programmed cell death, in glioma cells with abnormal p53. The difficulty with this approach was that delivery to glioma cells was not easy.

Fueyo and Gomez-Manzano turned their focus to the Achilles heel of many cancer cells, the retinoblastoma (Rb) protein. In normal cells, the Rb protein acts to slow cell division. When it is absent, cells reproduce rapidly and form a tumor. Several years ago, Fueyo and Gomez-Manzano co-authored a paper where they

described an adenovirus that would replicate itself and destroy cancer cells that lacked the Rb protein. They named the virus Delta-24.

The strategy worked – the virus did kill cancer cells, when it could get inside. There was the rub. An adenovirus needs to grab hold of a "receptor" protein on a cell's surface to get inside, and most gliomas don't have the adenovirus's style of hand holds. So Fueyo and his colleagues, in collaboration with the University of Alabama at Birmingham, modified the virus again, endowing it with grips for the common proteins (integrins) found on the glioma cell's surface.

In the most recent study published last year – supported with a PBTF funded grant – this new "improved" virus known as Delta-24-RGD was able to destroy human glioma tumors implanted in mice 60

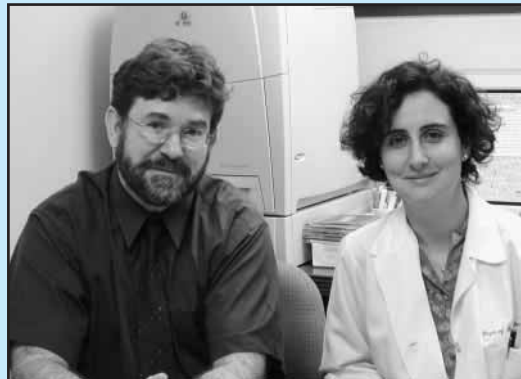
percent of the time. "The injection to the brain tumors in this model cured the animal," Fueyo said. "It's amazing." After four months, all that was left where the tumor once thrived was an empty cavity and scar tissue.

"We've never seen this kind of response before with any other treatment tested," Fueyo said. Still, Fueyo says that the therapy needs more study. "Nature has designed viruses to kill cells," he said.

"Some toxicity is expected and we need to design strategies to prevent it." Fueyo suggests this approach can be made even more effective by combining it with other therapies.

The National Cancer Institute was so impressed with the study that it committed \$1 million to develop a drug-grade version of the therapy to test in humans. Researchers say phase-one clinical trials could begin by late 2004, once FDA approval is granted.

Fueyo cautions that it is not known whether this therapy will work on other cancers. "Gliomas are unique in that they do not spread, or metastasize. At this time, we do not have any experience with the systemic delivery that might be required for [metastasized] cancers." Yet there is reason for optimism. In March, 2004, Fueyo and his colleagues learned that a recent



Juan Fueyo, MD and his wife Candelaria Gomez-Manzano, MD, work diligently to find the cause and cure of childhood brain tumors.

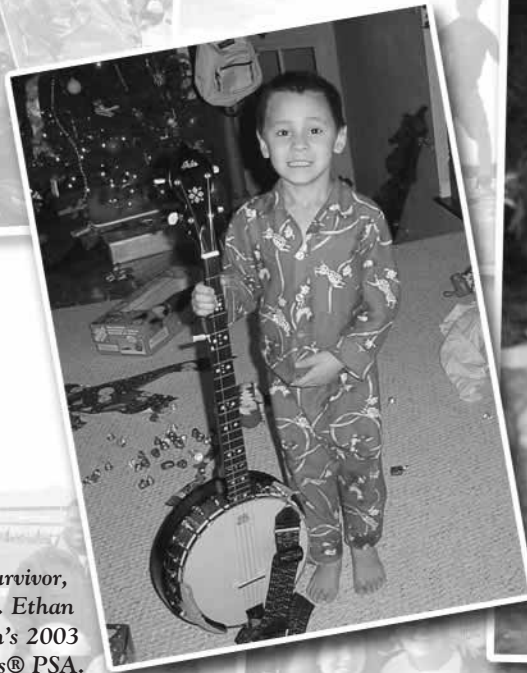
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PICTURE OF HOPE

Parents: Remember...

...please send in pictures of your young brain tumor survivors for possible use in future editions of the *Helping Hand*.

Ethan, a young brain tumor survivor, enjoys his new banjo from Santa. Ethan was featured in the Foundation's 2003 Ride for Kids® PSA.



Jenna, a young brain tumor survivor, has a ball at Discovery Cove in Orlando.

Where Hope Springs Eternal...

(continued from previous page)

paper they submitted describing this same gene therapy applied successfully in vitro (a "test-tube" setting) against medulloblastoma had been accepted for publication. Medulloblastoma is the most common form of pediatric brain cancer.

Fueyo and his colleague's accomplishments are garnering well-deserved world-wide attention. The PBTF proudly notes that his research has been made possible by PBTF support. In addition to being a PBTF grant recipient, Fueyo received the Peter Steck Memorial Research Award from the PBTF in April, 2003.

When they aren't in the lab or responding to the scores of media inquiries and e-mails that this significant study has generated, Fueyo and Gomez-Manzano are your average parents, busy raising their three American-born children, ages 7, 5 and 3. Fueyo is especially proud that his children are native citizens of, in his words, "the greatest country in the world." When asked what message of hope he can deliver to parents of children with brain tumors, he said, "This is a time of progress and optimism, yet we must move carefully and deliberately in our work. Be strong." □

Help PBTF Find the Cure

Your donations will help save children's lives. Here are several ways you can help:

Make a tax-deductible donation to the Foundation in honor of, or in memory of, a loved one.

Include the Foundation in your will or estate plans. Ask your lawyer to insert a provision such as "Give the sum of ___ (or ___ percent of my estate) to the Pediatric Brain Tumor Foundation of Asheville, NC."

Find out if your company offers a matching gift program and if so, take advantage of the program to increase your contribution.

If you are a civil or military employee of the U.S. government, make a charitable contribution through the Combined Federal Campaign (CFC) to the PBTF, listed under "national/international organizations," contribution number 2925.

For more information, visit www.pbtfus.org/donations, e-mail donations@pbtfus.org, or call (800) 253-6530. □

FANTASTIC FUNDRAISERS

Want a Norton? Here's Your Chance!

It's not too late! *Cycle World* magazine and the Pediatric Brain Tumor Foundation (PBTF) want to remind you about the fourth edition of the popular *Cycle World/Ride for Kids®* motorcycle raffle. The winner of this year's grand prize will receive a Norton 952 Commando donated by Kenny Dreer and his team at Norton Motorsports.

"Motorcyclists are the core of the Pediatric Brain Tumor Foundation," commented Mike Traynor, president of the PBTF. "For over 20 years, the national Ride for Kids program has been raising funds to support pediatric brain tumor research. Today, more children die from brain tumors than from any other childhood cancer. With help from motorcycling enthusiasts from across the country, we will continue our search for the cause and cure of childhood brain tumors. We are grateful for the support that *Cycle World* and Norton Motorsports have given us."

Prices are \$5 for one (1) ticket, and five (5) tickets may be purchased for \$20.

Tickets can be obtained by mail. Please make checks payable to the Pediatric Brain Tumor Foundation. Send to: Pediatric Brain Tumor Foundation, ATTN: Norton Motorcycle Raffle, 302 Ridgefield Court, Asheville, NC 28806.

Please be sure to include your mailing address and phone number with the funds.

Tickets can also be purchased by phone via credit card. Please call (800) 253-6530 and ask for the Accounting Supervisor. A minimum purchase of \$20.00 for five (5) tickets is required for phone orders.

The drawing for the winner will be held at 12 noon EDT, on May 3, 2004 at the PBTF headquarters in Asheville, NC. You need not be present to win. Proceeds benefit the research and family support programs of the PBTF. **The deadline to purchase tickets is Friday, April 30th at 5:30 P.M., EDT. □**

Norton®

Be sure to enter for your chance to win this Norton!
Call (800) 253-6530 for more information or visit www.rideforkids.org.



Pennies from Heaven

Have you ever wondered what happens to the coin you tossed into the wishing well at the local mall? Cindy Smith, who works in the manager's office at White Marsh Mall in Baltimore, Maryland, not only knows, she was determined to see that the thousands of loose coins in the mall's water fountain went to the PBTF's research and family support programs.

Smith and her husband, Tim, have attended the Columbia Ride for Kids® since 1999. They have a special passion for the ride – each year they dedicate their funds to the memory of Cindy's nephew who died of a brain tumor in 1998.

In May, 2003, Smith approached

the mall's manager and asked him if he would permit the pennies, nickels, dimes and quarters to be donated to the PBTF. It was helpful that the caring owners of the mall, The Rouse Company, also owned The Mall in Columbia – site of the annual Columbia Ride for Kids®. Smith's manager was more than willing to agree. After contacting the PBTF to discuss the fundraiser, Smith and her fellow employees swung into action.

"We clean the fountain and collect the coins several times a year and present the money to charity," she said. "When the staff cleaned out the fountain last September, we filled eight five-gallon buckets with the change!" Smith and her volunteers presented



The water fountain at White Marsh Mall in Baltimore, Maryland

the coins to the PBTF at the Columbia Ride for Kids® in September, which totaled \$1,570.50.

Asked what her plans are for 2004, Smith replied, "We hope to collect the coins from The Mall in Columbia also. And because it takes a long time to clean and count these coins, we will start earlier this year, with more volunteers to help." □

Incredible Edibles Nets Funds for PBTF

How do you combine a love for great food and a passion to help children battling brain tumors? If you are the Gold Wing Road Riders Association (GWRRA) Texas Chapter C in the Houston area, you publish all of your best recipes in a cookbook, sell it every way you can imagine, and send the proceeds to the PBTF.

The idea of a cookbook to raise funds for the PBTF came from Houston Ride for Kids® fundraiser Nancy Norris. "I love cookbooks and have a healthy collection of great tried-and-true recipes," she said. "Since we had some great cooks in Chapter C, we hatched the idea of using something we love and are good at doing as a means to raise money for the kids we love."

Norris and her top-notch volunteer committee worked diligently for months to make certain they produced a great cookbook. After gathering the yummy recipes from Chapter C members, the book was published. Then the

committee put into place a well-orchestrated campaign to get the word – and the books – out in the marketplace.

At this writing, over \$33,189.68 has been sent to PBTF, with more to come. Nearly 2,800 cookbooks have been sold in 29 states and seven countries. "85 percent of the books sold have been to the community and our neighbors, not just motorcyclists, said Norris. "People have been educated about PBTF, their mission and the kids."

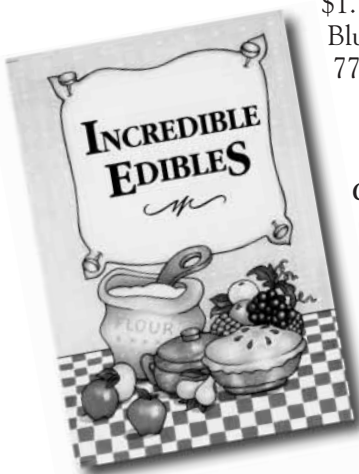
What does she think made the project so successful? "Teamwork. We have kept the vision before us, kept our successes in front of the chapter and that kept us inspired," said Norris. "It was blessed."

To buy your copy of *Incredible Edibles* (limited quantity), visit www.txchapterc.org/cookbk.htm or send \$14.00 + \$1.75 S/H to: Nancy Norris, 3411 Bluewing Drive, Dickinson, TX 77539 – While they last! □



Gold Wing Road Riders Association (GWRRA) Texas Chapter C cooks it up for the Pediatric Brain Tumor Foundation.

Gold Wing Road Riders Association (GWRRA) Texas Chapter C's Incredible Edibles cookbook benefits the Pediatric Brain Tumor Foundation.



Snowman Fundraiser at University of Illinois-Chicago Memorializes Young Researcher

Snow was in short supply in Chicago last December, but that didn't stop the faculty and staff of the University of Illinois at Chicago from participating in a snowman decorating contest which raised nearly \$650 for the PBTF. Nine contestants, competing on behalf of their favorite charity, constructed snow people out of Styrofoam balls and then let their creativity run wild.

The fund raiser was the brainchild of Amy Schuppert Smith, MD. "We try to bring a charitable element to our holiday party every year, but this was the first time we tried this. It was a great success." Entries included "Frosty the Genome-man" and "Snowman, RPh". Competition was fierce and, in the Chicago tradition, the entire college community was invited to vote early and vote often by contributing money to their favorite entry.

Richard Gemeinhart, PhD, a research specialist with the Biomedical Polymer Sciences Laboratory, submitted the winning entry. His "Orchid Snowman" was dedicated to the memory of his friend and colleague, Michael Dutt, PhD, who died of a brain tumor several days before the competition. Dutt was a young researcher working in the laboratory of W. Mark Saltzman, PhD at Yale University. "Mike was to become a leader in science, but he was never given the chance," said Gemeinhart. "I wish the amount raised could have been ten times the amount given, but we must fight this disease with pennies if necessary. No one should have to endure what this young man (and his widow) did."

Donations in memory of Michael Dutt can be sent to the PBTF at 302 Ridgefield Ct., Asheville, NC 28806. □

The winning snowman, "Orchid Snowman," was done in memory of Michael Dutt, PhD, to benefit the Pediatric Brain Tumor Foundation.
(Photo courtesy of Cassie Richardson)



Planning a PBTF Fundraiser?

Contact us early in your planning process. Each state requires that the PBTF give permission for your fundraising effort to take place. For an event application and more information, call (800) 253-6530 or e-mail pbtfus@pbtfus.org. □

Ride for Kids®

Celebration of Life Program Stirs the Soul

Ask any motorcyclist at a Ride for Kids® event what they remember most and they are likely to say, "Riding with my friends was fun, but when I saw the children and their families at the Celebration of Life, I knew why I was here."

At the end of every scenic Ride for Kids® ride, motorcyclists, volunteers, doctors, nurses and patient-families gather for the Celebration of Life program under a big-top tent. The one-hour program serves to introduce the young brain tumor survivors to the motorcyclists, acknowledge sponsors, recognize fund raisers, educate participants about advances in brain tumor research and, most importantly, provide support for the local patient-families who are battling childhood brain tumors.

During an emotional part of the program, a parent speaks to the audience, describing in heart-felt and poignant language the fight for their child's survival. And yet the event is also a time of joy, as grateful parents thank the motorcyclists for bringing a

smile to their children's faces. At the 2003 Chicagoland Ride for Kids®, Loretta, mother of 13-year old survivor Melanie, commented, "We feel there is hope because of you. You will never know how grateful we are. Thank you for every day of our daughter's life."

The highlight of every Celebration of Life ceremony is when the children who are young brain tumor survivors assemble on the stage to be interviewed by the PBTF's Ride Manager. Art Linkletter's phrase, "Kids say the darndest things", is certainly evident as these youngsters speak to the crowd. When six-year old Garrett, who attended the 2003 Louisiana Ride for Kids®, was asked where he got his adorable freckles, he responded, "The Internet!"

Time stands still as the children, ranging from toddlers to teens, talk about their brothers and sisters, their pets, and their favorite (or least favorite!) class at school. Many of them recount with wide-eyed wonder the excitement of the motorcycle or sidecar ride they enjoyed during the morning's police-escorted event.

Thankfully, as the number of survivors grows, it is not uncommon for youngsters who



Ride for Kids® VIP "stars" during the check presentation at the 2003 Sacramento Ride for Kids®

have grown into adulthood to return to the Celebration of Life program year after year. Mandy and Julia, who are both attending college on PBTF educational scholarships, are nine-year veterans of the Atlanta Ride for Kids®. Mandy commented, "I look forward to the Ride every year – it's a blast. And every year it gets bigger. I know the riders are there to help people like me. Words can't express how grateful I am that they take time out of their busy lives to raise money to help cancer kids fight their battle."

It's safe to say that there is scarcely a dry eye in the house at the end of every Celebration of Life program. PBTF Treasurer and co-founder Dianne Traynor puts it all into perspective. "There is nothing more inspiring than seeing these kids grow up and begin to realize their own dreams. Their success underscores the importance of finding a cure." □



Brennan has the best time at the 2003 Sacramento Ride for Kids®.

Sacramento Ride for Kids® is a Family Affair

Several years ago when Dr. Michael Edwards, pediatric neurosurgeon, was asked to support the then fledgling Northern California Ride for Kids®, he enthusiastically gave his approval and invited a large number of his patients and their families to join in the Ride. He not only encouraged the kids and their parents to come, but he also rode his own motorcycle to the event. Needless to say, his young patients were ecstatic in seeing their trusted surgeon joining in the fun and the “Celebration of Life” ceremonies. This was the beginning of a wonderful relationship with dozens of families whose children are brain tumor survivors, in part because of the outstanding surgery and care given by Dr. Edwards.

The next important ingredient in this success story comes in the form of the truly dedicated and excellent organizational efforts of Northern California motorcyclist Kathy Carlson. Kathy saw that with the continued annual increase in survivors and the growing number of parents and siblings who were coming to the Ride, she needed to create a program that would be certain the specific needs of each family member were met. She especially focused on the large number of family members who wanted a ride on the back of a motorcycle or in a sidecar during the Ride’s parade procession.

“In the early days,” said Carlson, “we developed a plan to have a team focused and organized to make the entire family feel included and special.” Carlson’s team is comprised of hand-picked volunteers “Most of our core

group has been working with the kids for six or seven years,” she said. “Last year, we had 14 volunteers on the day of the event and each of them had a specific job.”

Carlson is keenly aware of the needs of the patient-families. “Our theme is ‘Kids get to be just kids,’ and to make that happen you have to do some special things,” she said. “At the start point we have a clown, which couldn’t be a bigger hit. Each family is given special attention by their own task force volunteer, who stay with the family while they are registered, get their event t-shirts and have their picture taken. Families were pleased with the way it is organized and the kids, siblings and mom and dad have a great time,” Carlson added.

Not one to seek the limelight, Carlson commented, “The Ride for Kids has received tremendous support from neurosurgeon Dr. Mike Edwards and his top notch staff. They have supported our ride for so long, they are part of our family,” said Carlson. It is very special for the patient families to see their doctor on his motorcycle and their nurses serving coffee and volunteering at the registration table. It makes the families feel supported by their medical team on this special day of fun and celebration.

Asked about her favorite part of the Ride for Kids®, Carlson recalled the start of each ride. “We stand back and watch all of the bikes leave with our kids and families to go on the Ride. The smiles on their faces, as they wave to us when they leave, make it all worthwhile.” □



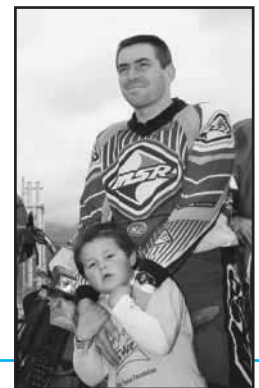
Kathy Carlson

2004 Southern California Dual Sport Ride® Rescheduled

The Southern California Dual Sport Ride for Kids® originally scheduled for Sunday, March 21st has been rescheduled to Sunday, June 13, 2004 due to the massive snowfall and trail closures in the Hungry Valley area. Since many participants have already collected donations in preparation of this event, we encourage them to send the funds to the Pediatric Brain Tumor Foundation (PBTF), indicating that they will participate in the Southern California

Dual Sport Ride for Kids®. We will return a ride receipt that they will need to bring to registration on the day of the event (Sunday, June 13, 2004). We apologize for any inconvenience to our participants. For more information please visit our website, www.rideforkids.org, or give us a call at (800) 253-6530. □

Brandon and his dad Paul enjoy the 2003 San Bernardino Ride for Kids®.



Date: Sunday, June 13

Start Location: Hungry Valley State Vehicle Recreation Area
(60 miles north of Los Angeles)

Directions: Take I-5 (North) to Smokey Bear Road Exit,
(go West) to Pyramid Lake Road,
(South) to dirt Hungry Valley Road,
(West) to Ride Start Point @ 4 1/2 miles

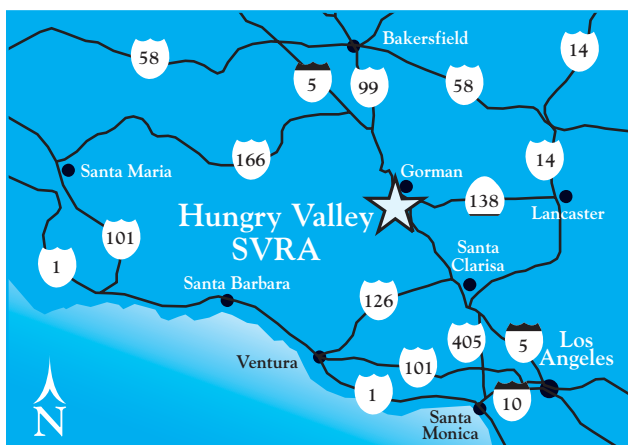
Registration Open: 7:00 a.m.

Registration Close: 8:30 a.m.

Ride's Meetings
& Awards: 8:45 a.m.

Ride starts and finishes
at Hungry Valley SVRA.
(see map to left)

Free breakfast!



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Dear Valued Supporters:

Thank you. The Pediatric Brain Tumor Foundation is deeply grateful for all gifts received in support of finding the cause and cure of childhood brain tumors. Every dollar makes a difference.

We have made every effort to provide a complete and accurate listing. If you have a correction, call us at (800) 253-6530. Listings are for donations received January 1, 2003 through December 31, 2003.

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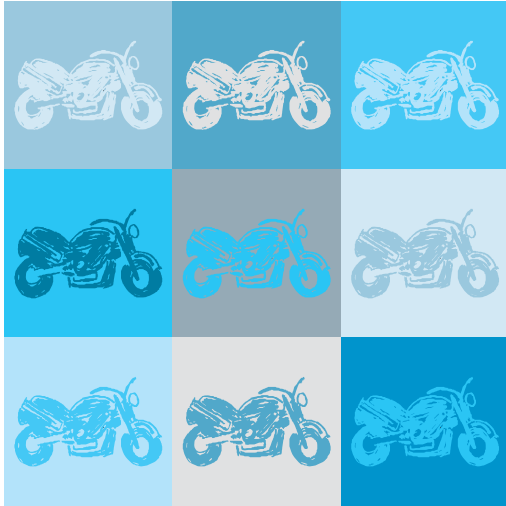
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 James Zabler

Mitchel Zalewski
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Frank Zupcic
 GWRRA PA Chapter I

Event Schedule

*Ride for Kids
2004*



- | | |
|---------------------------------------------------------------------------|----------------------------------------------------------------------|
| Houston, TX Ride for Kids®
<i>April 25</i> | Hudson Valley Ride for Kids®
(Harriman, NY)
<i>August 1</i> |
| Pittsburgh, PA Ride for Kids®
<i>May 2</i> | Madison, WI Ride for Kids®
<i>August 8</i> |
| Triangle Area (NC) Ride for Kids®
(Raleigh-Durham, NC)
<i>May 2</i> | New England Ride for Kids®
(North Oxford, MA)
<i>August 15</i> |
| Torrance, CA Ride for Kids®
<i>May 16</i> | Ann Arbor, MI Ride for Kids®
<i>August 29</i> |
| Atlanta, GA Ride for Kids®
<i>June 6</i> | Asheville, NC Ride for Kids®
<i>August 29</i> |
| Richmond, VA Ride for Kids®
<i>June 6</i> | Puget Sound (WA) Ride for Kids®
<i>September 12</i> |
| Kansas City, MO Ride for Kids®
<i>June 13</i> | Columbia, MD Ride for Kids®
<i>September 19</i> |
| Southern California Dual Sport
Ride for Kids®
<i>June 13</i> | St. Louis, MO Ride for Kids®
<i>September 19</i> |
| Knoxville, TN Ride for Kids®
<i>June 26</i> | Birmingham, AL Ride for Kids®
<i>September 26</i> |
| Colorado Ride for Kids®
(Golden, CO)
<i>June 27</i> | Sacramento, CA Ride for Kids®
<i>October 3</i> |
| Indianapolis, IN Ride for Kids®
<i>July 11</i> | Dallas-Ft. Worth, TX Ride for Kids®
<i>October 10</i> |
| Chicagoland (IL) Ride for Kids®
<i>July 18</i> | Phoenix, AZ Ride for Kids®
<i>October 17</i> |
| Utica, NY Ride for Kids®
<i>July 18</i> | Louisiana Ride for Kids®
(Lafayette, LA)
<i>October 24</i> |
| Minnesota Ride for Kids®
(White Bear Lake, MN)
<i>July 25</i> | Dunnellon, FL Ride for Kids®
<i>November 7</i> |
| Marysville, OH Ride for Kids®
<i>July 31</i> | |

✎ *New Event!*

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