



Ride for Kids

EDITION

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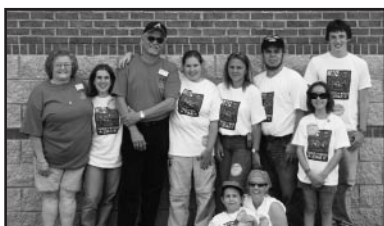
Ride for Kids® Heroes Task Force Leaders Show the Way

At the heart of every Ride for Kids® are the Task Force Leaders, the people responsible for organizing the activities and recruiting the volunteers necessary to conduct a Ride for Kids® event. It is an awesome responsibility for those who take on the job – and every one of them is a volunteer.

Just who are these “Superpeople” and why do they dedicate themselves to this seemingly enormous task? Jim and Nona Unversaw are entering their ninth season as Co-Task Force Leaders of the Atlanta Ride for Kids®. “When I think back and remember why Nona and I took on this job, and why we continue to do it today, it’s the same answer – we do it for the kids,” said Jim. “Deep down, we all want to help these children in their battle with brain tumors and no task is too great for us. What makes it all possible is that the PBTF is such an organized organization – literally – and they give us the tools to do the job.”

One reason that every Ride for Kids® is a well-oiled event is that the PBTF provides tremendous support for Task Force Leaders. Easily-understood procedures and the guidance of a dedicated Ride for Kids® Manager are two valuable resources upon which all Task Force Leaders draw. Perhaps the best tool available to both new and experienced Task Force Leaders alike is the annual meeting where Task Force Leaders from around the country gather for three days of seminars and workshops. This gathering not only provides them with a template for how to conduct a Ride for Kids® event, but, just as importantly, enables Task Force Leaders to share their experiences and learn from one another.

Vicky Harding organized the first Kansas City Ride for Kids® in 2004. “Unlike a lot of other Task Force Leaders, I had never been to a Ride for Kids before our event. So our first national Task Force Leader meeting was a real eye-opener. The foundation’s procedures were so complete and comprehensive that we knew exactly what we needed to do. And we received so much encouragement and support from the other Task Force Leaders, that by the time our Ride for Kids was about to occur, we felt prepared.” Thanks to the organization and dedication of Harding and her volunteers, the first Kansas City Ride for Kids® was a success despite the devastating tornadoes and torrential rains



Atlanta Ride for Kids® Co-Task Force Leaders Jim and Nona Unversaw with a few of their very important friends.

that ravaged the area the night before. At the next annual Task Force Leader meeting, Harding was paired with the new Task Force Leaders from Salt Lake City; now they talk regularly about their experiences and successes.

Every Task Force Leader is quick to credit their volunteers. Prominent among them are a core group of lieutenants recruited by each Task Force Leader to plan the route, organize the start and end points of the ride, arrange for food donations and media support and recruit scores of day-of-event volunteers. Rhonda and David Friedenberg are Co-Task Force Leaders for the South Florida Ride for Kids®, which just completed its first event in February of this year. “We got out early and recruited the movers and shakers from the riding clubs throughout our area,” said Rhonda. “They became the backbone of our event. One of our greatest accomplishments was our visitation to local riding clubs and dealers. This success was the result of our broad reach to riding clubs

of all brands.” Indeed, the proof was in the pudding – the first South Florida Ride for Kids® raised \$59,491, the most funds ever announced from the stage of a first-year Ride for Kids® event.

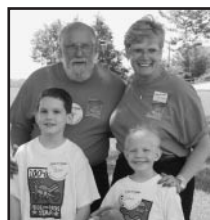
If one message is clear from all of the Task Force Leaders, it is that every Ride for Kids® must stand on its own. “If we have learned one thing after doing this for nearly nine years, it’s that you can never take anything for granted,” said Unversaw. “We still check everything three times. And even though we have very little turnover on our task force, we

have backup for the backups.” This kind of planning creates success, which in turn breeds excellence. During the Unversaws’ tenure as Task Force Leaders, the Atlanta Ride for Kids® has raised more than \$2 million.

Whether it’s a new event or an established one, in a big market or a small one, every Task Force Leader shares an untiring and selfless commitment to working as a team with the PBTF and their local volunteers. Their very example exemplifies leadership and inspires their task force to get the job done. When it comes to helping little kids with brain tumors, they expect nothing less from themselves. ■



South Florida Ride for Kids® Co-Task Force Leaders Rhonda and David Friedenberg share a moment with the “Stars” of their day.



Kansas City Ride for Kids® Task Force Leader Vicky Harding and husband Lou with the “Stars” from 2004

FROM THE PRESIDENT'S DESK

...by Mike Traynor



We launched the 2005 Ride for Kids® season in February with a tremendous success at our first-ever South Florida Ride for Kids® event. While the rest of the nation was blanketed in snow, Kyle Clack and the rest of the Pediatric Brain Tumor Foundation's Ride for Kids® team joined the southern Floridians as they raised nearly \$60,000 for childhood brain tumor research. On this historic day, new awareness about pediatric brain tumors was brought to this populous part of the Sunshine State.

This was not only a great financial success, giving us precious new funding for the Pediatric Brain Tumor Foundation's programs, but it also brought hope to each of the families who brought their young brain tumor patient children to the day's festivities. Thanks to media coverage, it also demonstrated to the whole community that motorcyclists are caring, responsible individuals who, once aware of a valid need, will go out of their way to benefit those needing assistance.

While the day was a brilliant success, the real story lay behind the scenes where Ride for Kids® Task Force Leader Rhonda Friedenber and over 100 volunteers from the local motorcycling community brought their months of preparation to fruition in a highly efficient, smooth-running day of fulfillment for everyone present. It was a true day of ecumenical sharing for all kinds of people on all kinds of bikes; Harley-Davidson riders rode alongside their Honda brethren and Beemer pilots rode in pairs with the riders of KTMs, Yamahas, Suzukis, Kawasakis, Ducatis and others. They all had one goal in mind, to help the kids with brain tumors.

The motorcycle dealers were there as well, joining Rick Case Honda and numerous others who made special donations to make sure the day went well.

If you have been coming to the Ride for Kids® for several years in another city, you know how true this story is. You have experienced all of this and more. If you have yet to sample your first Ride for Kids®, be prepared for one of the best days you have ever had on your motorcycle. And get ready to let a tear of joy trickle from behind your sunglasses as you meet some of the bravest young boys and girls you have ever seen.

We thank everyone for working so well together to ensure that the first South Florida Ride for Kids® was a tremendous success. And we look forward to seeing all the rest of you at one or more of the remaining 35 Ride for Kids® events in 2005, each of which will offer similar tugs at your heart strings and a whole lot of success, thanks to the Task Force Leaders and their many well-organized volunteers.

Let's ride for the kids,
Mike Traynor □

New Ride for Kids® Record Set in South Florida

Although much of the country was in the deep freeze in mid-February, the weather could not have been more perfect for the first annual Ride for Kids® event in Sunrise, Florida on February 20. The sunny, 80-degree day provided an ideal setting for the kickoff of the 22nd season of Ride for Kids® events. Since 1984, the Ride for Kids® program has raised over \$3.8 million to support the research and family support programs of the Pediatric Brain Tumor Foundation.

Over 600 motorcyclists on every make and model of bike were escorted on the early morning ride by an outstanding team of police officers from the Broward County Sheriff's Department and Coral Springs Police Department. Immediately afterwards, riders, volunteers and patient families joined together under a big-top tent for a Celebration of Life Program that featured interviews with several "stars" - young brain tumor survivors whose mere presence both delighted and inspired the crowd.

As wonderful as the event seemed, no one - not even Task Force Leader extraordinaire Rhonda Friedenber herself - knew that history was in the making. As it turned out, this was the most successful first-time event in Ride for Kids® history, raising an astounding \$59,491. Special congratulations go to Rick and Rita Case as Top Individual Fund Raisers with \$5,000 in donations, the HRCA Florida Sports Red Riders as the Top Chapter with \$19,683 in contributions and Florida Sports Cycles as the Top Dealer with donations of \$20,253. A new Honda motorcycle, donated by American Honda Motorcycle, was won by an ecstatic Maree Moscati of Pompano Beach.

Sincere thanks go out to Rhonda Friedenber and her amazing volunteer corps, as well as to Allstate Insurance Company and the numerous South Florida companies who supported this event. □



Ride for Kids® "Star" Justin relaxing with friends at the South Florida Ride for Kids®



Travis, South Florida Ride for Kids® "Star," enjoying the event

PICTURES OF HOPE



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

WHERE HOPE SPRINGS ETERNAL

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

Lending Support Across The Miles

In many ways, Jodi Domsky is a typical 13-year-old. But the Jackson Hole, Wyoming, teen has also worked hard to touch the life of Tyler, a young Pennsylvania boy she has never even met. "My dad grew up with Tyler's dad in Elkins Park, Pennsylvania. I don't actually know Tyler, but we found out at my cousin's Bat Mitzvah, in October, that he was diagnosed with a malignant brain tumor. They were supposed to be at her Bat Mitzvah, but they couldn't come because of the sudden bad news," she said.

In preparation for her own Bat Mitzvah on March 19, Jodi needed to choose a mitzvah – a good deed that is required to be performed in the year of the Bat Mitzvah. Although she originally collected recycled cell phones for use by less fortunate members of her community, Jodi – who is talented with beaded creations – wanted to do something in support of Tyler and his family. So, she began making beaded book thongs (bookmarks) and earrings and forwarding the proceeds to the Pediatric Brain Tumor Foundation. "I chose to make book thongs and earrings because I love to bead and it would honor my friend Tyler," she said.

And honor him it did. Despite a slow start, once the news was listed in the Jewish Community Center's newspaper, the offers to buy Jodi's crafts began to roll in. But Jodi did not stop there. She approached some of the most popular stores in town, who readily agreed to display her wares. At the same time, she was donated the use of a booth at the town's annual Christmas Bazaar, a not-to-be-missed event that brings out most of the community. "We sold out of the book thongs and earrings in the first four hours," she said.

When all was said and done, Jodi had raised \$1,066 for the Pediatric Brain Tumor Foundation in Tyler's honor. "I am very glad that I could do something that would benefit other people less fortunate than me," Jodi said. Her Mom, Lisa, put it all in perspective. "The torah portion of Jodi's Bat Mitzvah is about sacrifice. She has to write a speech about this theme and how it relates to her now. This project reinforces the idea of sacrifice. It's important for her to recognize the value of doing something for others without expecting anything in return," she said.

These days, Jodi and her family are completing the preparations for her Bat Mitzvah, which will take place in a few weeks. There is even talk that Tyler may come for a visit so that the two will finally meet. No doubt he will be taken with her broad, unforgettable smile – a warm, infectious grin that travels from ear to ear. Yet somehow we know that it pales in comparison to the size of her heart. □



Jodi

FANTASTIC FUNDRAISERS

Racing for the Cure

Denise Mathers always thought motorcyclists were a big-hearted bunch. But the Asheville, North Carolina Ride for Kids® volunteer admits that even she is surprised by their continual generosity. Mathers, who is the National Chief Clerk for the AMA Superbike Race Series, interfaces with team managers, riders and crew chiefs and race technicians when they pick up their track credentials before each event. And this spring marks the fourth year that she will proudly display her Ride for Kids® fundraising plaque for all who visit the registration area to see. That's when the magic begins.

"People are terrific when it comes to donating money. They are touched by a cause that does so much to help kids, and it really shows." Mathers is joined in her fundraising efforts by co-worker and fellow Ride for Kids® volunteer Leah Sherritt, who often accompanies her into the race paddocks to collect donations. While the two walk around and chat with familiar faces, they collect money for the Asheville Ride for Kids®.

"What's amazing is that some people even donate several times over the course of the season," Mathers said. To date, their efforts have raised \$9,815 for the Asheville event. "It's a real testament to the motorcycle industry that so many people are so willing to get behind this cause. Last year I posted a sign in Atlanta after the Asheville Ride for Kids thanking everyone for their support. Someone I did not know saw the sign, and donated \$200, which I sent to the PBTF for the 2005 ride." A good omen, no doubt, for what Mathers and Sherritt will be able to accomplish in 2005. □



Denise Mathers and Leah Sherritt raising funds for the Ride for Kids® during bike week

RESEARCH UPDATE



Pediatric Brain Tumor Foundation Institute Update

The Pediatric Brain Tumor Foundation Institute (PBTFI) at Duke is pleased to report on the success of one of its researchers, Hai Yan, MD, PhD. Dr. Yan, an Assistant Professor of Pathology, Molecular Oncogenomics Lab at the Duke Comprehensive Cancer Center, was recently honored with the Damon Runyon Scholar Award from the Damon Runyon Cancer Research Foundation in recognition for his research in 2004 supported by the PBTFI. The February 1, 2005 issue of *Cancer Research* (Volume 65, Issue 3) included an article reporting on the progress of Dr. Yan and his fellow researchers entitled "Identification of OTX2 as a Medulloblastoma Oncogene Whose Product can be Targeted by All-Trans Retinoic Acid." The following excerpts from the article report on a possible new therapeutic agent against medulloblastomas.

"Primary brain tumors are the leading cause of cancer death in children and medulloblastoma is the most frequent malignant brain tumor in this age group. Despite therapeutic advances, more than one third of children with medulloblastomas die from the disease within 5 years of diagnosis, and the remaining survivors experience significant toxicities from extant therapies. Elucidation of the molecular pathogenesis of medulloblastoma may suggest novel therapeutic targets. Whereas comprehensive screens for activating or inactivating mutations would require sequencing and functional studies of tens of thousands of genes, measurements of the genomic DNA copy number, or gene dosage, of chromosomal segments is far more amenable to analysis. Complete sequencing of the human genome has made possible the development of novel techniques that narrow the resolving power of genome-wide screens to regions covering one or a small handful of genes. With digital karyotyping and gene expression analysis, we identified genomic amplification and overexpression of OTX2 gene in medulloblastomas. Medulloblastoma cell lines overexpressing OTX2 were growth inhibited by pharmacologic doses of all-trans-retinoic acid (ATRA) and knockdown of OTX2 expression by siRNA.

"This study shows the power of digital karyotyping as a high-resolution whole-genome approach for the isolation of individual oncogenes. Through analyses of genomes and transcriptomes, we identified OTX2 as being overexpressed in the majority of medulloblastomas with anaplastic histopathologic features and as being genetically amplified in a subset of them. The genetic alterations of OTX2 provide cogent evidence for a pathogenic role, as tumor expression data alone cannot be interpreted with respect to cause and effect. Further experiments are necessary to investigate the possibility that abnormal OTX2 expression may result in the dysregulation of the developmental programs in cerebellar progenitor cells and cause neoplastic transformation. It is of interest that other developmental regulatory pathways have been shown to be altered by expression or mutation in medulloblastomas. In particular, the hedgehog/patched signaling pathway is required for the proliferation and maintenance of cerebellar progenitor cells, and mutations of the components of this pathway have been identified in medulloblastomas. It will be interesting to determine if OTX2 is part of this signaling network or if it belongs to a parallel/alternate pathway.

"Finally, the prospect for the rational use of a new therapeutic agent against medulloblastomas should be discussed. This study showed that ATRA repressed OTX2-expression and inhibited OTX2-expressing medulloblastomas cell growth. Although ATRA and other retinoids may affect multiple molecular pathways, the connection between OTX2 repression and growth inhibition effect of ATRA suggest that OTX2 expressing medulloblastomas may be amenable to therapy with retinoids. Previous studies have shown that pharmacologically relevant doses of ATRA induce apoptosis in medulloblastomas cells, although a connection with anaplastic histology, or OTX2 expression was not established. ATRA is approved clinically for the treatment of promyelocytic leukemia, a disease in which another nuclear receptor is a predominant determinant of pathogenesis. Our studies of ATRA in medulloblastomas, in conjunction with the studies of others, lay the conceptual framework for clinical trials of retinoids in the treatment of a commonly lethal pediatric brain tumor."

A Phase III study of ATRA for the treatment of medulloblastoma is planned by one of the pediatric cooperative clinical trial groups. The PBTFI is negotiating with the clinical trial organizers to test the medulloblastomas in the trial for OTX2 expression. Such testing of OTX2 expression would determine if medulloblastomas are likely to respond or be resistant to ATRA could be predicted prior to start of treatment. □

MAILBOX

Dear Sir or Madam,

I am a fifth grade student at Sterling Public Schools and my class and I divided into groups and made different projects and sold them. Then the groups chose different companies and donated the money to the companies. That is why the money is in this letter. I chose your company because my cousin had a brain tumor and he is 5 years old. Your company has helped him and I really appreciate it.

Sincerely,
Andrew Daehling

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