

REACHING OUT

BRIGHTER TOMORROWS FOR CHILDREN WITH BRAIN TUMORS

RORY DAVID DEUTSCH PROFESSORSHIP PROVIDES OPPORTUNITY TO MAKE A DIFFERENCE

DUKE MEDICINE'S ENDOWED PROFESSORSHIPS honor exceptional achievement, fuel scientific discovery and invest in teaching and mentoring the next generation of leaders. These permanent partnerships provide an extraordinary opportunity to make a difference. They confer academia's highest honor upon the most accomplished medical scientists, allowing them to pursue research that improves human health and cultivate the bright young minds who will lead future innovations in medicine and health care.

The Rory David Deutsch Foundation has entered into a permanent partnership with Duke Medicine and the Preston Robert Tisch Brain Tumor Center with the establishment of The Rory David Deutsch Professorship. Endowed professorships are Duke Medicine's most prestigious faculty appointments. Because they recognize both exceptional achievement and the potential for future achievement, they are awarded to only the most distinguished physician-scientists and clinicians who have demonstrated extraordinary scholarship in advancing medical science and human health.

The Rory David Deutsch Professorship will be a permanent, self-sustaining source of funding. Distributions from the endowment will be used to support the recipient of The Rory David Deutsch Professorship at Duke University. The

recipient shall be a scholar of true eminence and excellence in the field of Neuro-Oncology. The assets of the professorship are invested and each year, a portion of the value of the fund is paid out to support the fund's purpose, and any earnings in excess of this distribution are used to build the fund's market value. In this way, an endowment fund can grow and provide support for its designated purpose in perpetuity. When you establish an endowment fund, you

create a permanent legacy of support for Duke.

A recipient has not yet been named to The Rory David Deutsch Professorship. Until a recipient is appointed, distributions from the fund may be used to provide research support in basic, pre-clinical translational and clinical investigation of pediatric brain tumors as directed by the chief and associate chiefs of the Preuss Laboratory for Brain Tumor Research. *R*



The Deutsch family at the April 2013 board of directors meeting of the Tisch Brain Tumor Center at Duke presenting the final installment on the \$3.5 million grant to establish the Duke university professorship in Rory's name. (Pictured) Jamie and Chris Spatola, Mike Cragg, Mickie and Mike Krzyzewski, Debbie Savarino, Enid and Ron Deutsch, Mindy and Ross Deutsch, Ellyn and Alan Samsky, Marc and Craig Samsky, Darell Bigner, M.D. and Henry Friedman, M.D..

The Rory David Deutsch Foundation Receives Duke Cancer Institute Shingleton Award

THE DUKE CANCER INSTITUTE (DCI) Shingleton Award is the institute's highest volunteer honor, established in 1987 as a tribute to its founding father and emeritus director, William W. Shingleton, M.D., and his dedication in the field of cancer research and his compassion as a physician. Shingleton was the moving spirit behind the creation of the award, which recognizes those individuals who, through their extraordinary volunteer service and support, build on the achievements of Shingleton and

help sustain an institution that is internationally renowned for its leadership in cancer research and devotion to excellent patient care.

The Shingleton Award recognizes volunteers and donors for their exemplary service to the DCI and their tireless commitment of time, effort and resources to advancing the understanding of cancer and caring for patients with cancer. This year's recipients are the Deutsch and Samsky families, representing The Rory David

Deutsch Foundation, who have demonstrated exceptional service and generosity in furthering the institute's mission to defeat cancer.

Ellen Stainback, director of external relations at the Preston Robert Tisch Brain Tumor Center at Duke, has been at the cancer center since 1989. She said that in looking for award nominations, she and the team look for individuals who have gone above and beyond the call of duty more so than the average volunteer or board member.

(Continued on Page 2)

LETTER FROM THE FOUNDERS

HOPE...DREAM...IMAGINE...

It has been more than seventeen years since we lost Rory, and his legacy remains—The Rory David Deutsch Foundation. Our hope of achieving the Foundation's mission—to eradicate pediatric brain tumors—is the enduring focus of each doctor, researcher and supporter of The Rory David Deutsch Foundation. The dream of realizing the purpose of our mission is reflected throughout this newsletter. We always have maintained that the success of the Foundation cannot be measured solely by the amount of dollars raised. Our success is a result of your participation, devotion and dedication to the cause. Coach Mike Krzyzewski passionately expressed at "An Evening With Coach K" event in 2002, "it's about being on a team, Rory's team. Being part of something bigger than yourself. We, Rory's team, are continuing our own championship quest to go the distance against pediatric brain tumors. Our victory," he said, "will be defined by the energy we bring to that quest, our commitment and the extent of our participation."

As The Rory David Deutsch Foundation moves into its 18th year, our determination is stronger than ever. Rory's warm, sweet nature still inspires and motivates us and so many others to succeed in our mission.

We continue to be overwhelmed by your ongoing show of support, love and passion for Rory's Foundation. From the bottom of our hearts—thank you.

IF A 7-YEAR-OLD BOY
CAN CHANGE THE WAY
THE WORLD SEES PEDIATRIC BRAIN TUMORS
IMAGINE
WHAT WE CAN DO TOGETHER

— Mindy & Ross

(Continued)

The Rory David Deutsch Foundation Receives Duke Cancer Institute Shingleton Award

"You look for people who have extraordinary volunteer service and support, someone who has supported the mission of the Duke Cancer Institute," Stainback said. "It is partially what they contribute financially, but it doesn't necessarily mean that they have personally given it, but they have raised it or helped get money for the institution. It's looking for that one or two individuals who stand out amongst all others."

The Deutsch and Samsky families are part of the Brain Tumor Center family where Stainback worked, and were nominated due to their many years of service on the Duke Brain Tumor Board.

"We're honored to put their names up. They have been extraordinary in giving financially and of their time," Stainback said. "Ross's sister Ellyn and her husband Alan never miss a board meeting. They are just totally devoted to the Brain Tumor Center, and they have been ever since Rory passed away. They've been just incredible to us."

Ross Deutsch said that this award is not just about his family. It is not about fundraising. It is about Rory and the people who cared to attend a recent Monday night foundation board meeting, seventeen years later.

"We've always subscribed to the field of dreams aspect. If you build it, they will come. We still have one hundred people coming to the house when it comes to goodie bags or stuffing invitations," he said. "We've never had a fundraising solicitation campaign—ever. Where the foundation is financially in terms of what we've been able to do is without a doubt what defines The Rory David Deutsch Foundation."

Ross said that he wants everyone to share the Shingleton Award. He cannot emphasize enough that it is about every single person who has attended one of the foundation's events, and or supported or volunteered their time.

"To say we are humbled and honored would be an incredible understatement. To have this professorship in Rory's name—I can't even describe what it means to his legacy as his dad. His name will live on," Ross said. "To be awarded is to kind of let everyone know that our efforts are being recognized. It makes us feel good that our efforts are being honored, but more importantly it gives us credibility. Look at where our money is going—to the best stuff. Look at the work that is being done at Duke in part of our efforts. It's pretty cool."

Part of the awards dinner on Oct. 29 was a video portion, and the members of the Deutsch and Samsky families were interviewed for the video, which Ross said was a beautiful and an emotional moment.

"I love talking about Rory, and I'm not afraid to show my emotions. There's probably not a week or a day where I don't experience emotions. We're incredibly proud about the work that everyone's done, and it's incredibly humbling," Ross said. "At the end of the day there are so many worthwhile causes, and what I've always said about this foundation is that it's not nameless and faceless. This is Rory, this is our son. Foundations like ours are referred to as kitchen table foundations, and the average life expectancy is less than five years. I can tell you, with one hundred percent certainty, the renewed energy that was demonstrated at our Monday night board meeting, this foundation will go on for well after I'm gone."

In addition to the video portion of the awards dinner, there was a panel discussion of doctors from the Duke Cancer Institute. Stainback said this was a new addition to the awards dinner, and that after being in the fundraising business for such a long time, she's learned to appreciate people that when faced with one of the worst things in life, they don't just walk away.

"Even though their loved one is gone, they want to make sure it doesn't happen to someone else's loved one," she said. "That's what you have to love about the Deutsches and the Samskys. Even though Rory was gone, they said, 'We want to do something about this so no other family will have to go through this.'"

View the video at www.roryd.org/shingletonaward.



The Deutsch and the Samsky families receive the Duke Cancer Institute's highest honor at the Shingleton Awards Dinner, held Oct. 29.



The Deutsch and Samsky families at the Tricks + Treats & Stars for Rory event at Fields BMW.

TRICKS + TREATS & STARS FOR RORY RAISES \$205,000 FOR FOUNDATION

RORY'S PASSION WAS THE SOLAR SYSTEM, and stars are in the name for all of the foundation's fund raising events. The Tricks + Treats & Stars Rory event could not help but reach for new heights. The Halloween-themed event, held on Oct. 28, 2012, raised approximately \$205,000 for the foundation. More than 500 people attended the event at Fields BMW Northfield, and half of the attendees were children.

Beth Conen, co-chair of the event, said that for this year's event she and the team wanted to do something slightly different.

"In the past we have done Adler Planetarium, pumpkin farm, sports and carnival themes," she said.

Money was raised via sponsorships, donations, a silent auction and ticket sales. Field's Auto Group, who hosted the event, pledged \$500 to the foundation for any car lease or purchase made in the following six months by anyone who attended. The event, which lasted from 3 to 8 p.m., started with guests receiving T-shirts and goodie bags at check in. Children were asked to dress in costume.

"That was really fun! After check in, they were free to have dinner, play games, face paint, pumpkin decorate, play R-O-R-Y Bingo and go through a haunted maze," Conen said.

One of the highlights of the event was the haunted hayride. The car wash was converted

into a haunted room and kids were then driven around the parking lot in a wagon connected to a tractor trailer. The ride culminated in the haunted room.

"You would never know you were at the car wash," Conen said. "The committee did an amazing job with the transformation with moving objects, fog and music. It looked like it was done by professionals. I love that we had families attend!"

A spring Stars for Rory event is in the planning process, and Conen said it will have a different theme, with a focus on getting younger families involved.

I am so proud of what the family and the foundation has done to help other children through the foundation's research.

"Nobody should have to go through what Rory, so young, went through," she said. "This event makes me feel like I am giving back to the Deutsch family. I am so proud of what the family and the foundation has done to help other children through the foundation's research. The Deutsch's do it for other children with such love and support. The Deutsch family is a great example of how to make a tremendous difference in a child's life."



Attendees of the 2012 event enjoyed a haunted room, pumpkin painting, and a variety of activities.



The Rory David Deutsch Foundation Board of Directors.

PAULINA COOPER DOT-TO-DOT 10K RUN, 5K RUN/WALK CONNECTS POSITIVE MESSAGE WITH PHILANTHROPIC EFFORTS

FOR NINE YEARS, RUNNERS, WALKERS AND children have been connecting in a one-day 10K and 5K run/walk for pediatric brain tumor research. This year's Dot-to-Dot event was held on Aug. 29 as part of the Heartland 10K series in Kansas City. More than 1,000 runners and walkers attended the first leg of the series, whose object was to have three 10k's in three weekends. But, more importantly, Dot-to-Dot was created to honor Paulina Cooper, who, at the age of five in August of 2003, was diagnosed with an intrinsic brainstem glioma. This little girl, who had an innate ability to connect with people, passed away on Sept. 21, 2004 at just six years of age. The event's main purpose now is to raise money for researching and developing effective treatments for children with aggressive brain tumors.

Ann Todd-Cooper said that runners are always looking for something fun and exciting to do, and being a part of the Heartland 10K series draws numbers for their race. While many runners will come out and not really know what they are running for, the Cooper family's fifteen-minute presentation at the beginning of the day helps shed light on how the race got started.

"I introduce myself and my family, and then we talk about where the money is going to and what it's fighting," Todd-Cooper said. "We also do this really cool thing called the Pegasus Award, so that's part of our opening ceremonies, too."

This year's recipient, Teddy Elmer, was greeted with hugs from last year's recipient, which was a highlight for Todd-Cooper.

Looking back on the beginnings of the Dot-to-Dot, Todd-Cooper, who owns Blue Valley Physical Therapy, said that in the beginning people at her work just wanted to do something. Working with a lot of sports injuries, it was yet another connection to an event they could host in their field, and it also was a way to honor Paulina, while raising money for research. She said that brain tumors can affect anybody at any time, and that there needs to be more investigation in this field.

"I think it was kind of the brainchild of a lot of our physical therapists who asked me about it," she said. "There's not a lot of funds that go to aggressive pediatric brain tumors, and the other thing that was interesting is that when we were researching where to give the money to

foundation wise, there was another connection." The Coopers live in Lawrence, Kansas, and Rory's doctor was Dr. Goldman, who was Paulina's doctor. Both Rory and Paulina were diagnosed with the same brain tumor, and Todd-Cooper said that The Rory David Deutsch Foundation was very much aligned with what they wanted to do in terms of where they wanted to send money.

Come race day, a personal highlight for Todd-Cooper was meeting the family of the Pegasus Award winner, and seeing how the event touched lives.

For patients at Blue Valley who couldn't walk or run the Dot-to-Dot, they could donate \$1, and more than \$1,000 was made with those donations. The Blue Valley gym's walls were then lined with recognition papers, getting everyone in the spirit of the race. More than \$46,100 was raised from this year's event.

"Blue Valley Physical Therapy does all of the organization and planning of the race. We have to pay for all of it until we start getting sponsors, volunteers, the day of the race, tear it all down, send out thank you's; it's a good company team building thing that we do. You get your patients involved, and it's really a close knit family," Todd-Cooper said.

Come race day, a personal highlight for Todd-Cooper was meeting the family of the Pegasus Award winner, and seeing how the event touched lives. She also loved the Dot-to-Dot trot, where all of the kids line up and connect one dot to another dot.

Looking ahead to next year, which will mark a decade for the Dot-to-Dot, Todd-Cooper, who admittedly hates to public speak, would love for one of the Deutsch family members to come out and do the opening ceremonies.

"They've heard me talk for nine years; they've got to be tired of me. For year ten we've got to do something big. I don't know what that is, but I'm thinking of reaching out to the Deutsch family and seeing if anybody wanted to come out for race day," she said.



Medals were awarded to the top three finishers in their age category for both the 5K and 10K. All 10K participants received finisher medals.

While raising money for a great cause has not changed, some fundamentals of the Dot-to-Dot have over the past nine years. Todd-Cooper said that the race started with a little more than one hundred participants, and she swears that first year they had no idea what they were getting into.

"That's good because I think if you know too much you wouldn't do it. We had three main people who worked each section, and that first year you only had enough energy and time to figure out what you were doing, let alone what everyone else was doing," she said. "There's a few things that you have to do along the year, but now it's much smoother. It just gets easier."

Now that a few months have passed since the ninth annual Dot-to-Dot, Todd-Cooper said that someone told her that the mother of the son killed in the Jewish Community Center a few years back ran the race and posted about it on her Facebook page. She said that it's nice to see that people validate the race, and having someone like that who wants to participate and spread kindness was nice. It was another way Paulina's gift of connecting to people still shines through.

"Everybody has a little gift, and that was definitely her connection. That's why we named the race Dot-to-Dot. You've gotta connect the dots, and that's a kids' thing that you do. She continues to do that even though she's been gone since 2004, so it's pretty amazing when you step back and take a look at it."

For more information, visit www.dottodotrun.org.

GREATER > THAN SPORTS DRINK ADDS PURPOSE TO FOUNDATION

GREATER THAN, A SPORTS DRINK marketed in the Chicago area, provides a low calorie option for natural hydration. It also provides another avenue for awareness of a great cause—The Rory David Deutsch Foundation.

The Highland Park basketball program includes a fall conditioning plan that Jon Sider and Craig Samsky participated in when they were in high school, where Jon met Ross. When Greater Than first started, Sider chose to take part in a fall conditioning practice to go back in time to relive the wonderful feeling of post practice exhaustion. At the end of the conditioning, Sider wrote a check to the foundation from Greater Than, which began the start of support. Once Samsky, who is Rory's cousin, came on board, the relationship continued to grow.

Mark and Jon Sider both understand the importance of family and giving back. That makes this relationship great.

Greater Than's biggest involvement with the foundation now is attending events, acting as a supporter of the foundation through events participation and the sale of Greater Than.

"As we continue to grow as the premier low-calorie, non-GMO project verified sports drink, we will continue to support the foundation in any way possible," Samsky said.

While Greater Than still is in an early life cycle, the company is beginning to hit its stride with some growth. The Chicago-based company has expanded its distribution in Whole Foods throughout Illinois, as well as Mariano's, Jewel-Osco, Sunset Foods and Treasure Island.

Additionally, expansion is increasing throughout the Midwest and into Heinen's in Ohio. A fifty-store test is in Sam's Club via 12-unit variety pack highlighting its three flavors, Orange Mango, Tropical Infusion and Pomma Berry. The brand is available in Brookshire's and H-E-B in Texas, as well as retailers throughout the New York metropolitan area.

Samsky said that having Greater Than be a part of the foundation is a perfect fit.

"The foundation and my family mean everything to me," he said. "Mark and Jon Sider both understand the importance of family and giving back. That makes this relationship great."

Greater Than is among a flock of new-age sports drinks that seek to move away from artificial ingredients of mainstays Gatorade and Powerade, in this case with a non-GMO formula that includes coconut water, sea salt and natural coloring agents like beta carotene and vegetable juice. Sweetener blend of cane sugar and stevia allows for lower calorie count, sixty calories per sixteen-oz PET bottle. For more information, visit DrinkGT.com.



(From left to right) Jon Sider, Mark Sider, Sanchali Roy and Craig Samsky

Campus Colors Continues Long-Term Support of Rory David Deutsch Foundation



IN 1989, WHILE DRIVING HOME TO HIGHLAND Park from a family vacation, Neil Rubenstein's two sons urged him to stop in Ann Arbor to get official sweatshirts and football jerseys from the University of Michigan. For Rubenstein, an idea came to mind shortly after emptying his wallet and loading his car with sports gear.

Recognizing the inconvenience of having to travel to the actual campus to get college sports apparel, Campus Colors was created in 1990. The goal of Campus Colors was to bring authentic college bookstore merchandise to suburban Chicago. It now is a family-run chain with stores in Highland Park, Water Tower, Kildeer, Hinsdale and Mequon, Wisconsin.

Campus Colors also offers a comprehensive website www.campuscolors.com with an online version of their cool store.

In the years that Campus Colors was establishing its name, it also was building a commitment to The Rory David Deutsch Foundation. The retailer has gone from selling wristbands to organizing other ideas that have generated funds for the foundation. That partnership will carry on this spring.

"Campus Colors is pleased to continue its support of the foundation and looks forward to a spring partnership," co-owner Jon Rubenstein said. "We are big fans of The Rory David Deutsch Foundation and proud to be a supporter."

To learn more about Campus Colors, visit www.campuscolors.com.

North Shore Professionals Golfers Celebrate Final Round

AFTER MORE THAN A DECADE OF GOLFING for a good cause, the North Shore Professionals informal tournament has come to a close. What initially started as a group of friends playing a round of golf at the North Shore Amateur Tournament at Sunset Valley Golf Course in Highland Park ultimately branched off into something much more.

Dubbing their group "The North Shore Professionals," Verne Reich, a friend of Ross's for more than fifteen years, started an informal two-man tournament and began donating a portion of the winning proceeds to The Rory David Deutsch Foundation.

The North Shore Professionals played twice a year, on Labor Day and Memorial Day weekends. Labor Day proceeds are donated to The Rory Foundation, while Memorial Day proceeds are donated to the Vision for Tomorrow Foundation, which is for children who are born with vision problems.

"A bunch of friends would put a little bit of money in the pot, and the one who played the best in the North Shore Amateur each year would take the prize," Reich said. "I nicknamed my event the North Shore Professionals based on the fun we had doing that. I thought a two-man event would be a lot more fun and get more people involved."

At the tournament's peak, twenty two teams signed up, totaling forty four players. The top five teams received payouts, and winners donated a portion of their winnings. Almost \$10,000 has been raised for the foundation. Last year, due to children growing up and having their own sports to play, unfortunately was the last year for the tournament. Reich said that when this tournament started, the guys playing had little kids who are now growing up and competing in sports, so that is where the attention has rightfully turned.

"We had a lot of fun getting a lot of friends together and raised money. We attracted other people from Sunset Valley that I didn't even know. We were really working for these children's charities. I'm sorry that it [canceling the tournament] had to happen, but all good things must come to an end," Reich said. "It wasn't just a charity event. It was getting guys together, but the interest in the two charities that we were donating to—that grew. It became apparent that was very important to our players. Ones that won some cash donated some of it back, so that made it a whole lot of fun."



RORY CARDS, LETTERS SEND GREETINGS THROUGH DONATIONS

A GREETING CARD OR LETTER CAN go a long way in making someone's day. In the case of The Rory David Deutsch Foundation donation cards, your donation, will be devoted to providing funding for pediatric brain tumors and general pediatric research.

When the foundation started, the idea for the cards came from Enid Deutsch, Rory's grandmother. Other organizations she was familiar with had them, and she thought it was a good idea for the foundation. For \$5 a card, you can order in any quantity (minimum of five).

The cards serve a dual purpose, sending congratulations and condolences, and in the giving of a donation. On the front is a picture of Rory along with drawings from one his former first-grade teachers. The card also states that a tax-exempt donation has been made to the foundation.

"You can fill it out for whatever you want. For a memorial donation, the birth of a baby, an anniversary or a new house," Enid said. "On one side it says that The Rory David Deutsch Foundation was established as a living tribute to Rory David Deutsch, a sensitive, bright and warmhearted seven-year-old."

Additionally, for more substantial donations, Happy Day or memorial letters written on foundation stationery are mailed. They notify the recipients that the foundation has received a generous donation. Included are the names and addresses of those making the donation to facilitate easy acknowledgement. These letters are reserved for donations of \$25 and up.

"Many times if people are invited to a special birthday or an anniversary, rather than give a gift, they make a donation and we send a letter," Enid said.

Rory cards have raised \$1,750 since Jan. 1, 2014, and Happy Day donation letters have brought in \$13,000 since that date. Memorial donations have raised more than \$3,000.

To order a Rory card or a Happy Day letter, please call The Rory David Deutsch Foundation at (888) 919-RORY.



Theatre, Dance Company Puts Spotlight On Kids' Value, Talent

SINCE 1992, MARGO PROEH, DIRECTOR and founder of the Children's Theatre Company (formerly the Lake Forest Children's Theatre Company) has had both a commitment to helping children develop character and to The Rory David Deutsch Foundation.

Proeh lived on the same block as Ross and Mindy, and the families were supposed to go to Disney World the day Rory got sick. In knowing what a sweet boy Rory was, Proeh, whose father had been a brain surgeon, wanted to help.

"I saw the pain the family went through, and it was very hard to watch. I thought it [the foundation] was a great cause as well. They were my good friends and neighbors and community members. It happened so close to home that it was really shocking," she said.

So, Proeh buys the rights to two musicals a year for the Children's Theatre Company, with children ages five to thirteen invited to join a twelve-week rehearsal program that culminates in the production. There are young performers who participate in an abridged version, as well as a full musical. Cast members also participate in stage direction, set design and lighting. A portion of the proceeds of the ticket sales is donated to the foundation.

The last production was Willy Wonka Jr., and coming up in December is Wizard of Oz Jr. Proeh said that she tries to pick out musicals that are timely, cute for kids and what is in their realm of interest.

"Theater is a very important thing. It connects your head to your heart. Kids learn to work together as a team; they learn to express themselves," she said. "This day and age a lot of kids' heads are in a screen. So they learn to communicate, they learn to have eye contact and they have fun. They learn to take chances and take risks. The show isn't as important as what goes on in the classroom."



The Chicago Academy for the Arts Repertory Dance Company makes a special appearance Dec. 6 at the Wilmette Regina Dominican High School-based Chicago Youth Dance Exhibition.
(Karie Angell Luc/for Chicago Tribune Media Group)



Steps Dance Center of Aurora company dancers are backstage motivating each other before their second half performance Dec. 6 at the Wilmette Regina Dominican High School-based Chicago Youth Dance Exhibition.
(Karie Angell Luc/for Chicago Tribune Media Group)

Additionally, Proeh, who was a child performer, wanted to teach both her children and others about the arts. A former employee of hers, Dana Rosenthal, was moving to Chicago from Los Angeles and wanted to work with Proeh again. Dana's Dance Catering, a branch of the Children's Theatre, was born. For the second year in a row, the dance company is producing the Chicago Youth Dance Exhibition. Last year thirty youth dance companies in the Chicagoland area were invited to perform at no cost. A portion of ticket sales were donated to the foundation, and Proeh hopes that this year's event, coming up in December, will be even bigger.

"We have had a number of companies that have wanted to join us this year. This year we're planning on having a bigger audience and more people involved. Hopefully we'll be able to donate more to the foundation," she said.

No matter which show Proeh produces, she brings everything back to helping the children overcome something, be it shyness or gaining a sense of purpose or leadership. She said that theater is based on experiences, and in order to show emotion you have to learn and feel. Sharing Rory's memory is one way for the kids to connect to that, even though it's a very hard topic to share.

"When I tell the story about Rory, the kids get really quiet and their faces get sullen. They get sad because it's scary for them," she said. "It's a really good way of communicating their feelings because it's cathartic. If I tell them about Rory they might be scared about other things that's going on in their life. The kids want to have a talk. They automatically want to help and help save someone's life."

For more information, visit www.thechildrenstheatrecocom and www.danasdancecatering.com.

ROBERT CORBETT BIKES ACROSS AMERICA FOR RORY



Rob Corbett (pictured) posing with his bicycle at one of his many stops across the country, biking for charity.

I N 2007, ROBERT CORBETT AND ROBBIE Deutsch, Rory's brother, spent three days canoeing down the Flambeau River in Wisconsin. Corbett worked at Camp Horseshoe in 2006 and 2007, when Robbie and Rickey Deutsch were campers. One of Corbett's jobs at the camp was to organize canoeing trips, and Robbie was chosen to be in the same canoe as Corbett. The pair spent three days in the same boat and became good friends throughout that trip.

However, it was not until three years later that Corbett read Andy Katz's article on ESPN.com and learned about The Rory David Deutsch Foundation. He knew then that he had to do what he could to help the foundation and cancer research.

This summer from May 31 to July 15, Corbett cycled from the east to west coast of America, totaling twelve states, 2,855 miles, forty three days, 107,006 feet of elevation gain and 248 hours of cycling. He only took three complete days off, but had a few forty- to fifty-mile days, most days covering eighty to one hundred miles.

Corbett, who lives in the U.K., had an uncle in the British Army who cycled the length of the U.K. in the 1980s. That 1,000 mile trip, which spanned from John O'Groats in Scotland to Land's End in Cornwall, is about ten miles from where Corbett now resides.

"Growing up hearing about this trip, I knew that I would do it as well," Corbett said. "In 2010, around the same time I found out about the foundation, a friend and I cycled for the Teenage Cancer Trust, a charity with a similar goal as The Rory Foundation."

Four years later, Corbett found the article about the foundation saved on his computer and decided that he would bike a similar trip for both the Teenage Cancer Trust and The Rory David Deutsch Foundation.

Corbett decided in September 2014 that he would make the trek. He joined the local leisure center and swam five days a week over the winter. In February 2015, he braved the cold and began training on the bike. From February to May he cycled about 1,000 miles and lost about forty pounds from the beginning of training to the end of the trip. After cycling in the U.K., America became his next challenge.

Almost 3,000 miles gives one plenty of time to think, and while Corbett never got to meet Rory, he thinks that if he were alive they would have worked together at Camp Horseshoe.

Corbett said that through learning about the foundation and its connection with Duke University, the route planned itself. He started in Wilmington, N.C. and made his way up to Duke. Next he biked across the Appalachian Mountains to Chicago, where he cycled the lakefront trail with Dan Hampson, with whom he worked with at camp. After a rest day at Camp Horseshoe, Corbett headed west through Minnesota, North Dakota and Montana. He crossed the Rocky Mountains and followed the Columbia River and the Lewis and Clark Trail to the Oregon coast. This part of the trip was a highlight for Corbett, as he cycled through the Appalachian and Rocky Mountain ranges, visiting Yellowstone National Park and Mount St. Helens.

"The great thing about America is that each region is different, and cycling through them is one of the best ways to see a country," he said. "Yellowstone National Park on July 4th was special; I really would've loved more than one day there. I cycled around Roosevelt National park in North Dakota, past a herd of buffalo! That was really beautiful."



Scenic views from Rob's trip.

While not a fan of cities, Corbett loved Portland, Oregon. He stayed with a friend there. While in Portland he sold his second-hand bike that he bought in Wilmington. The sale raised £1200 for the Teenage Cancer Trust and \$700 for the foundation.

Apart from the distance, challenges included encountering thunder and lightning everyday through Indiana. He had seven punctures and one broken spoke, and one minor crash when his front wheel caught in a train track across the road on the second to last day. The only damage was a dead leg and a dirty shirt. Most days the temperatures in Montana and North Dakota ranged from 90 to 111 degrees.

"Staying hydrated was really important," Corbett said. "In general the road conditions were brilliant, but a lack of a hard shoulder and the speed of some road made conditions unsafe. Every other car that passed me was a pickup, but went at car speeds. I eventually got used to this."

Corbett did have his mom driving a support vehicle along the way. When bad weather arrived, they was able to avoid it and still progress with the trip.

"Having my mom there with me was really special, and something we could enjoy together," he said. "It was a trip of a lifetime, and she supplied me with lots of chocolate!"

Almost 3,000 miles gives one plenty of time to think, and while Corbett never got to meet Rory, he thinks that if he were alive they would have worked together at Camp Horseshoe.

"Knowing his younger brothers, I'm sure we would have been friends and had some great summers together."

For more information, visit www.facebook.com/USAcoust2coast2015.

JAB PRODUCE HITS ANNUAL RORY DAY RECORD DONATION AMOUNT

STEVE SERCK, PRESIDENT OF JAB PRODUCE, has supported The Rory David Deutsch Foundation for years, not only with the company's annual Rory Day, but also by serving on the Board of Directors.

Serck has been friends with Ross and Mindy Deutsch for almost twenty years. He also was friends with Ross's brother, Jay, in college. In the late 1980s he was a trader at the Chicago Mercantile Exchange at the same time Ross and Jay worked there. He knew Ross from the trading floor and played basketball against him in friendly pickup games after college. The friendship grew even further when their wives met at Mom and Tot classes with Robbie and Serck's oldest son Jacob.

"It was not long after our friendship started that Rory got sick," Serck said. "I have been a close friend to Ross ever since."

Serck got the idea of Rory Day from his business. One of his customers is Whole Foods, which started doing five percent days for local charities.

The work the doctors are doing at Duke is incredible, and I want to make sure they have the funds to keep doing their research."

"It seemed like a great way to provide awareness for the foundation. My employees and some of my customers still wear Rory pins on their jackets every day," he said. "I'm not sure how many years we have been doing this, but it has

been at least since 2008. It will continue to be an annual event."

Serck chose the days before July fourth and Thanksgiving weekend as they are JAB's busiest times of year. JAB places banners throughout his establishment a week before these dates to publicize the future sale. Thus, his customers know to try and make the bulk of their purchases on Rory Day. Since almost every item JAB carries is fresh and perishable, Serck looks at the three days before the holiday and picks the day with the largest sales total. Five percent is given to the foundation based on total sales of everything in the warehouse on that day. This year's Rory Day was July second. The amount donated this year was \$9,921.39, an amount that Serck believes to be the largest amount to date that JAB has donated to the foundation for Rory Day.

Looking back, Serck said that the saddest day of his life was going to Rory's funeral.

"We have been doing this long enough that everyone knows what it is about. No parent ever wants to lose a child," he said. "I take great pride in raising money for the foundation, as I don't want to see any other families go through what Ross and Mindy had to. I have been with Ross on numerous occasions meeting with the doctors who have been doing brain tumor research, and they have a long way to go to find a cure. The work the doctors are doing at Duke is incredible, and I want to make sure they have the funds to keep doing their research."

JAB Produce is located in the Chicago International Produce Market, at 2404 South Wolcott in Chicago. For more information, call (312) 2267805. *R*



JAB Produce Rory Day.

Treasurer's Report By Ellyn Samsky & Enid Deutsch



THE GROSS PROCEEDS OF THE Rory David Deutsch Foundation for the period March 1, 2013 through Oct. 31, 2015 are close to \$230,000. This raised the total fundraising dollars, since our inception, to nearly \$7,600,000.

Once again, The Rory David Deutsch Foundation was the grateful recipient of several

fundraising efforts from various supporters across the nation, city and northern suburbs. The "Running for Rory" race in the summer of 2013 raised close to \$5,000. Since we last reported, three Paulina Cooper Dot-to-Dot races have been held in Overland Park, Kansas, making The Rory David Deutsch Foundation the beneficiary of more than \$91,000. JAB Produce continues to raise funds and has donated more than \$28,000 by sponsoring a "Rory Day" annually in 2013, 2014 and again in 2015.

General donations to the foundation accounted for close to \$115,000. These contributions came from a host of individuals and organizations. Many readers of our previous newsletters, "Reaching Out," responded generously by donating online. Others purchased our all-

occasion donation cards, which raised \$4,000; the cards can be purchased for \$5 each. For a more generous donation, personal letters of Happy Day and Memorial can be sent for the appropriate occasion. These acknowledgements have generated another \$20,000. The cards and letters can be purchased by calling the foundation office at (888) 919-RORY or by visiting our website at www.roryd.org.

In April of 2014, we completed our \$3,000,000 pledge to Duke University. A fully endowed university professorship at Duke now exists in Rory's memory. This milestone guarantees that the foundation will go on in perpetuity and make our dream that much closer to a reality—a cure for the devastating disease that took our beloved Rory much too soon. *R*

Indian Trail Award Keeps Rory's Memory Alive



Mindy and Ross Deutsch pose with the 2015 Rory Award winners. (Recipients pictured from left to right) Apple Wojtowicz, Asher Stern, and Ryan Levin.



THE CARE PROGRAM AT INDIAN TRAIL School in Highland Park has been awarding exceptional students since 1999. The program, a way to nurture responsibility and character, while instilling value and respect in each and every child, was created by Barry Bakal, a friend of the Deutsch family.

Each year the award, which is a tribute to Rory, recognizes students whose writing or artwork best reflects the caring and generosity he exhibited in life. The theme is to define the qualities that describe an exceptional character. Each year the Indian Trail staff participates in the selection process. This past year's award winners were: first-grader Apple Wojtowicz, third-grader Asher Stern and fifth-grader Ryan Levin. Each recipient receives a framed

certificate from Bakal that shows the year he or she was The Rory winner. In addition, their names are engraved on a plaque, and Barry Bakal presents a \$200 donation to the foundation in his or her name.

Bakal said that after sixteen years, it's very important that Rory is remembered.

"The fact that he was a sweet, sensitive person made that part easy early on," he said. "However, his many years later, when none of the kids at Indian Trail were born when Rory was there, his memory is kept alive by all of the things being done by the foundation. The Rory award teaches every student who goes to school there, a little about who Rory was. And, that was my hope sixteen years ago; it is a tribute to the community." *R*

PAST RORY AWARD WINNERS

2012 Sean Kupperman
Hannah Frazer

2013 Natalie Dunlap
Colin Hensler
Eamon Lipka

2014 Leonardo Castrejon
Lindsey Winters
Duncan Drake

SCHOOLS RACE TO FUNDRAISE FOR FOUNDATION

IN 2012 MS. HENKEL AND MR. FUNKE, physical education teachers at Indian Trail School organized "Ragnar Race for Rory". This activity encouraged the students in physical education classes to chart their steps and raise money for The Rory David Deutsch Foundation.

The students in their respective physical education classes exceeded their goal of 400,000 steps, walking and running, to a total of 1,329,646 steps, measuring approximately 670 miles.



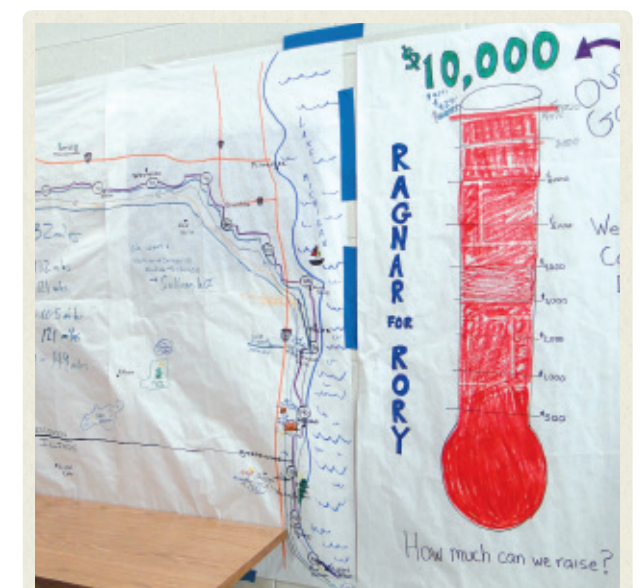
Ms Henkel and Mr. Funke speak at a Ragnar Race for Rory rally.

The following year from May 20, to May 24, 2013 Ms. Zagorski, Mr. Downs and Mr. Kahn, physical education teachers from Elm Place Middle School, partnered with their counterparts at Indian Trail School to create the "Running for Rory Fundraiser".

Students from both schools supported a fundraiser that is near and dear to the community.

According to Mr. Funke, "students from both schools supported a fundraiser that is near and dear to the community. The students from each school worked together and participated in a week long program that fostered the importance of exercise, teamwork and goal setting during physical education classes".

The combined efforts of both activities raised over \$14,000.00. *R*



(top) A chart tracks fundraising progress for Ragnar Race for Rory.

(bottom) Running for Rory, (pictured left to right) Phoebe Rudman, Alexa Golant, Maya Rudman, Roxie Deutsch.

INVESTIGATOR-INITIATED CLINICAL TRIALS DEVELOPED AT THE DUKE CANCER INSTITUTE

RESEARCH AT DUKE INCLUDES IMPORTANT clinical trials. Many of these are investigator-initiated, which means that they have been developed at the Duke Cancer Institute. There are some current top research priorities at Duke:

BRAIN TUMOR TREATMENT VACCINE RESEARCH

One of their novel research endeavors is to create a vaccine against cytomegalovirus, a passenger virus that ninety nine percent of all people carry. It becomes re-expressed in malignant brain tumors. There are several ways of administering the vaccine. The current vaccine program takes white blood cells from an individual patient and pulses their special antigen presenting cells with cytomegalovirus RNA. A new vaccine is in development that is created using a piece of a 4 cytomegalovirus protein, called a peptide, which can be used to pulse those same white blood cells. The vaccine trials are being carried out with agents to reduce T regulatory cells, which may increase the effectiveness of the vaccine.

There are approximately fifty mutations in genes in malignant brain tumors at the time of diagnosis. Many of the mutations contain immunogenic sequences, which means that those mutations are coding for proteins which can be recognized by a person's immune system. Duke is at the beginning of exploring clinical trials which target these immunogenic sequences in patients' tumors. This would be a personalized type of treatment vaccine approach.

Research Abounds at Lurie Children's Hospital

STEWART GOLDMAN, M.D., IS EXCITED about current and future research at the Ann & Robert H. Lurie Children's Hospital in Chicago. As the division head in hematology-oncology, neuro-oncology and stem cell transplantation, Goldman heads a research team that has welcomed two doctors.

With those additions, the team is developing a vaccine trial that will be for high grade myeloma using protein modifiers.

"In the lab we're really excited that we have new doctors in. We've put a whole team together and this is a really exciting venture with us working together," Goldman said. "It's truly a developmental pathway."

A second vaccine trial is underway for the isocitrate dehydrogenase (IDH) mutation. Peptides are being developed to create vaccines that target this common mutation in certain malignant brain tumors. In addition, the genetically modified poliovirus is being tested in animals as a vector to carry the isocitrate dehydrogenase mutation into cells. The theory is that the poliovirus will stimulate immunity against the poliovirus, which will then in turn help trigger immunity against the isocitrate dehydrogenase mutation. A similar approach is being carried out with a histone mutation that is present in the vast majority of a very fatal, rare malignant brain tumor in children called brainstem glioma.

Killing cancer requires not just one weapon, but rather a whole arsenal that can be wielded in combination.

Finally, with all of these immunotherapeutic approaches, Duke is investigating the potential for combination therapies with a group of agents called checkpoint inhibitors, which could enhance significantly the immune response. These checkpoint inhibitors rescue normal immune function from the immune paralysis that occurs with malignant brain tumors. Several of these agents are now available from the major pharmaceutical companies, with whom Duke has close relationships. They have leveraged these relationships to secure

The team is also looking at intranasal delivery for chemotherapy with SM28, which is the active compound. Goldman also is the principal investigator in a multi-institutional trial of thalidomide and carboplatin for children with newly diagnosed and recurrent brain stem gliomas.

"We're looking at an animal model to investigate chemotherapy. We're super excited about that. So, H3K27 mutations, intranasal delivery and vaccine delivery—those are super exciting to us," Goldman said.

Dr. Goldman also shared thoughts about his connection with The Rory David Deutsch foundation.

"Clearly do they not only financially motivate us with their generous contributions to keep

these checkpoint inhibitors and have begun carrying out trials using them. These potential discoveries could represent the next generation of personalized cancer therapy.

GUIDED MISSILE IMMUNOTOXINS FOR TREATMENT OF MALIGNANT BRAIN TUMORS AND MELANOMA

This project is based on a bi-specific guidance protein that targets the most lethal activated genes in glioblastoma multiforme and other malignant brain tumors—genes called EGFRwt and EGFRvIII. In collaboration with Ira Pastan, MD, one of the most eminent scientists at the National Cancer Institute, we have conjugated a very potent bacterial toxin to the guidance protein so that a guided missile-like approach is available to kill malignant brain tumor cells. Duke has just treated their first patient with this immunotoxin. A second immunotoxin targets two of the most important gene products driving malignant melanoma and malignant brain tumors.

Killing cancer requires not just one weapon, but rather a whole arsenal that can be wielded in combination. As one of the original eight NCI designated cancer centers identified in 1972 when President Nixon declared the "War on Cancer," Duke has a long history as a thought leader in cancer research and patient care. Duke is poised to accelerate discoveries and make a dramatic impact on survival rates of patients who are treated at the Duke Cancer Institute and beyond. *R*

it going, it's the passion that Ross, Mindy and the whole foundation has that motivates us to move forward," he said. "It's really making a big difference with kids with brain stem glioma. Our relationship with them keeps us motivated to keep it moving forward and seek other funding, whether it be federal funding or philanthropic."

Dr. Goldman recently had lunch with friends who knew Rory, and they shared thoughts on the kind of young man he would be today and how his bravery still is a motivating factor.

"We talked about how he'd be changing the world. This young man taught me more about the solar system than I knew at that young age. It continues to inspire us to never give up in trying to find the right answers." *R*



From The Lab Of Oren Becher, M.D.,
Rory David Deutsch Scholar

OREN BECHER, M.D., ASSISTANT PROFESSOR of pediatrics in the department of hematology/oncology, has considerable responsibility under his direction. A Rory David Deutsch Scholar in the Preston Robert Tisch Brain Tumor Center at Duke University Medical Center, Becher's interests lie in the areas of the central nervous system tumors in children and teenagers and new treatment regimens for children and young adults with gliomas. Additionally, Dr. Becher is interested in discovering novel, highly-targeted, potent and less-toxic molecular inhibitors to treat brain tumors, testing novel drugs in genetic models of brainstem gliomas or DIPGs.

The Rory David Deutsch Foundation funded Dr. Becher's recruitment to Duke in 2010.

Their support allows my lab to focus exclusively on DIPG, the tumor that took Rory's life.

"Without their willingness to support my recruitment to Duke, I would be at a different institution," Becher said. "The Deutsch family has definitely impacted my career path. Their support allows my lab to focus exclusively on DIPG, the tumor that took Rory's life. We are able to carry out high-risk projects (ones that the NIH would not fund.)"

Dr. Becher's laboratory is studying the genetic alterations that give rise to diffuse intrinsic pontine glioma or DIPG (the type of brain cancer that Rory had). In particular, the lab is investigating the role of a recently discovered abnormality in a histone—a protein that packages our DNA and is abnormal in most human DIPGs. In addition, the lab has recently co-discovered the presence of an overactive cell receptor called ACVR1 in twenty five percent of human DIPGs. Its current efforts are to study how the overactive ACVR1 receptor contributes to DIPG formation using genetic mouse modeling tools and to determine if it can be successfully targeted with drugs. Improved understanding of the mechanisms by which

these abnormalities contribute to DIPG formation will lead to improved therapies against DIPG.

"Although this is a challenging tumor to study due to the its delicate location in the brainstem, we (DIPG researchers as a whole) have made lots of progress over the past five years, and our understanding of DIPG has increased dramatically," Becher said.

In 2010, when Dr. Becher arrived at Duke, he said that the DIPG researchers knew very little about the genetic alterations in DIPG. Through the work of many researchers, the genomic landscape of DIPG slowly is being unraveled.

"It is my belief that there are still important insights to discover about DIPG and that sustained effort on the basic mechanisms that drive DIPG tumor formation will eventually pay off," Becher said. "I could not thank the Deutsch family enough for their continued support over the past five years, and I truly believe that the FDA will approve the first drug for DIPG in the not too distant future." *R*

POLIOVIRUS ACCELERATING BREAKTHROUGH DISCOVERIES IN IMMUNOTHERAPY

THE BODY'S IMMUNE SYSTEM KILLS MANY cancers before they start. But tumors that grow have a way of evading or stopping those mechanisms. Immunotherapy promises to jumpstart the immune system so that it can better recognize and kill cancer cells. Duke has a history of success in developing immunotherapy as a complementary treatment for many types of cancers including melanoma, breast cancer and brain tumors. One of their most promising efforts is using the poliovirus vaccine to effectively treat glioblastoma multiforme, the most aggressive and lethal type of brain cancer.

Dr. Matthias Gromeier has been working at Duke for the last fifteen years to genetically modify the Sabin poliovirus vaccine so that it will not kill nerve cells and cause poliomyelitis,

while it will retain the ability to kill tumor cells. Moreover, this vaccine, when introduced into the tumor tissue, activates the patient's own immune system, providing a secondary means of eliminating tumor cells.

In Phase I clinical trials currently, only available at Duke, the treatment has resulted in complete remission for several patients with glioblastoma.

In Phase I clinical trials currently, only available at Duke, the treatment has resulted in complete remission for several patients with glioblastoma.

This treatment shows promise for treating not just brain tumors, but all systemic solid tumors, e.g. breast, lung, colon, pancreas, and virtually all others also.

As a recent *60 Minutes* program reported, the Phase I clinical trial at the Preston Robert Tisch Brain Tumor Center at Duke has enrolled twenty four patients to date. Twelve of those have survived, with the median survival time overall increased significantly compared to controls. This median survival increase is as great, or greater, than what the FDA required for approval of Avastin in recurrent glioblastoma patients. Patients with the most dramatic positive responses, like Nancy Justice and Stephanie Lipscomb, the young three-year survivor featured in the program, are patients in whom we have witnessed significant clinical responses. There are three very long term survivors. *R*



The RORY David Deutsch Foundation

REACHING OUT

BRIGHTER TOMORROWS FOR CHILDREN WITH BRAIN TUMORS



WINTER 2015

Reaching Out is the newsletter of The Rory David Deutsch Foundation, named in honor of a seven-year-old science buff who lost his life to a brain stem glioma. Rory's Foundation funds research for pediatric brain tumors and other devastating childhood diseases. Please direct your tax-deductible donation or any inquiries to The Rory David Deutsch Foundation.

P.O. Box 547, Highland Park, IL 60035 ★ (888) 919-RORY (7679) ★ www.roryd.org

Drawings created by Rory's friends in Mrs. Baker's 2nd grade class at Indian Trail School.



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