

REACHING OUT

BRIGHTER TOMORROWS FOR CHILDREN WITH BRAIN TUMORS



Event attendees dance and sing on stage with Max Weinberg and The Weeklings.
(Pictured left to right): Rachel Stein, Mindy Deutsch, Mark Stein



(Pictured at top): Max Weinberg and The Weeklings.
(Pictured at bottom): Max Weinberg, Reggi and Roxie Deutsch.

ROCKIN' FOR RORY EVENT RAISES MORE THAN \$100,000 FOR FOUNDATION

AN INCREDIBLE EVENING OF DANCING, music and friendship culminated in raising \$114,000 for The Rory David Deutsch Foundation. Rockin' For Rory was held at the 210 Restaurant & Live Music Lounge in Highwood, Illinois. Attendees rocked to the tunes of Rock & Roll Hall of Fame recent inductee, Max Weinberg, legendary drummer of Bruce Springsteen's E Street Band. The Weeklings joined Max Weinberg for the evening's festivities.

Mark Stein, Weinberg's manager of sixteen years, is a friend of Ross and Mindy Deutsch. Mark has been involved with past Foundation events, and he thought it would be "really cool" to have this event for the Foundation.

"Ross is a huge Bruce Springsteen and the E Street Band fan, and I thought this would be a great event," Stein said. "I found a venue that would be big enough to be able to host a nice party. It was basically Max and three musicians

who know every rock tune from the sixties to the eighties — The Beatles and Bruce and the Stones and Elvis Costello and Tom Petty — all these great tunes."

Ticket prices were \$200 per person and \$350 per couple, all proceeds went to The Rory David Deutsch Foundation. Beer, wine and dessert were anonymously donated. Rick and Marc Malnati, owners of Northbrook, Illinois based Lou Malnati's, were among the evening's attendees. As a special treat, they had their pizza brought in for everyone in attendance.

Weinberg and the Weeklings played for the duration of the over three-hour event, during which a live auction took place. Included in this auction were Northwestern University basketball tickets and locker room passes donated by Chris Collins, Northwestern University Basketball Coach, and autographed drum heads donated by Max Weinberg.

(Continued on Page 3)



LETTER FROM THE FOUNDERS

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

It has been more than nineteen 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. The Foundation's 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 benefiting The Rory David Deutsch Foundation, "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 twentieth 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

J.A.B. Produce Continues Annual Giving Tradition

DURING THE TIME AMERICANS IN THE Chicagoland area are getting ready for the Fourth of July holiday, it is only natural to need fresh produce for their backyard barbeques. Synonymous with this tradition is J.A.B. Produce's Rory Day, held annually since 2008.

Each year, J.A.B. Produce President Steve Serck picks three days surrounding this holiday. The day with the largest sales is chosen to benefit The Rory David Deutsch Foundation. Five percent of that day's proceeds are donated, and this year's donation amounted to \$9,120. Serck, who also is a board member of The Rory Foundation, said that each year usually sees between \$9,000 and \$12,000 in the donated amount.

Even though the J.A.B. Produce Rory Day is technically just one day, Serck said that it is always the same, always an ongoing thought.

We keep doing it year in and year out to keep the cause in everyone's mind.

"We never put Rory's memory to rest. Pediatric brain tumors — as much research as they've done it's still a problem out there, and we try and pick causes that are important to us," he said. "It touches a lot of people down here because a lot of people have kids, and the relationship goes back a long way. We keep doing it year in and year out to keep the cause in everyone's mind."



J.A.B. Produce Rory Day.

Serck's friendship with Ross and Mindy Deutsch began almost twenty years ago. In college he was also friends with Ross's brother, Jay. In the late 1980s Serck was a trader at the Chicago Mercantile Exchange along with Ross and Jay. Additionally he and Ross played basketball in friendly pickup games. The friendship grew even further when their wives met at Mom and Tot classes. Robbie Deutsch and Serck's oldest son, Jacob, were in the same class.

"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 and J.A.B. employees place banners throughout the establishment about four to five days prior to Rory Day to publicize the event, reminding customers to try to make the bulk of their purchases on Rory Day.

We've been doing this for a long time, so everyone knows what it is and they are happy to help out. They know Rory's story.

"[We hope] customers can try and save as much of their purchases for that day, and we have a lot of the same customers over the years," Serck said. "We've been doing this for a long time, so everyone knows what it is and they are happy to help out. They know Rory's story."

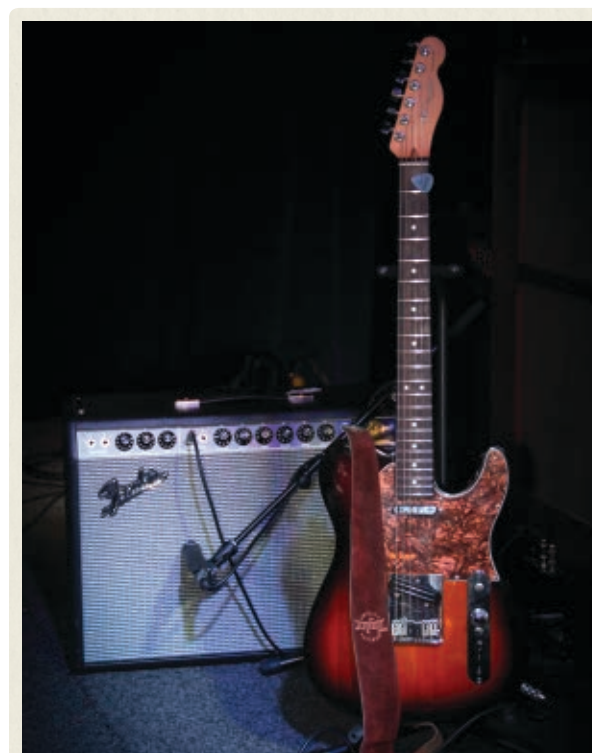
J.A.B. Produce is located in the Chicago International Produce Market, at 2404 South Wolcott in Chicago. For more information, call (312) 226-7805. *R*



PLEASE VISIT OUR WEBSITE FOR MORE
INFORMATION ABOUT OUR FOUNDATION,
AND TO MAKE A DONATION: WWW.RORYD.ORG

(Continued)

ROCKIN' FOR RORY EVENT RAISES MORE THAN \$100,000 FOR FOUNDATION



Event attendees enjoyed live music, and a live auction.

All pictured "Rockin' for Rory" event photos were provided by Kirsten Kuhlmann Photography. Thanks, Kirsten!

The dedication and devotion to turn this extreme tragedy into something that is helping so many others is inspirational, and it makes you want to help in any way possible.



"People donated money to come up and play with the band and sing — that's been a big part of what we do when we do charity events," Stein said. "We will raise money during the show and be interactive while Max is playing, and it's a thrill for somebody to be on the same stage as somebody who is in the Rock & Roll Hall of Fame."

Enid Deutsch, Rory's grandmother, said "The evening's setting was similar to a living room. There were couches and tables, and an area in front by the band for dancing. The music was very contemporary; everybody who was there knew the songs; they sang along and danced with the band. Everyone was happy to be there; it was a very congenial crowd, whether you knew somebody or not, everybody was very social. Max Weinberg was unbelievably personable and the band, The Weeklings, was wonderful." Ross Deutsch, Rory's father, who echoed these sentiments, extended a special "thank you" to Mark Stein for arranging Max Weinberg to play.

Stein said that the Foundation is "an incredible organization."

"What Ross and Mindy and their friends and family have done over the years is nothing less than remarkable," he said. "The dedication and devotion to turn this extreme tragedy into something that is helping so many others is inspirational, and it makes you want to help in any way possible. From day one I've done everything possible to use my connections in the sports and entertainment industry, which I'm a part of, to raise dollars for the Foundation, which in turn leads to research to cure this insidious disease."

Enid Deutsch said that as the years pass, the events continue to grow, which is incredibly meaningful to the family and Rory's legacy.

"The people who were involved nineteen years ago are still involved. We started out initially having family events. This was the first time that we have had an event for adults, as Rory's contemporaries are now twenty-six years old, and we have to find a new avenue for events," she said. "Friends who have started with us are still very much involved. People have a tendency to lose interest, and that interest is still present. We have people who donate monthly from their salary checks and people who every year will make a donation in honor of a child's birthday — it is incredibly heartwarming." *R*

PAULINA COOPER DOT-TO-DOT RUN/WALK SHINES AFTER MORE THAN A DECADE



Dot-to-Dot race volunteers

AFTER MORE THAN A DECADE OF RUNNING and walking, the Paulina Cooper Dot-to-Dot 10K and 5K is still connecting the community in support of pediatric brain tumor research. The one-day event was held on Sept. 17 as the middle of three races in the Heartland 10K series in Kansas City, Missouri. The first race was the Plaza 10K and the last was the Broadway Bridge 10K. Although this year's overall numbers were a little bit lower than normal, Ann Todd-Cooper said that 750 runners turned out despite the inclement weather. This is the eleventh year for the Dot-to-Dot and the fourth year of the partnership with the Heartland 10K series.

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. At six years of age, this little girl, who had an innate ability to connect with people, passed away on Sept. 21, 2004. The event's main purpose is to raise money for researching and developing effective treatments for children with aggressive brain tumors.

Many runners enter the event without the background knowledge of the basis for the race. The Cooper family's fifteen-minute presentation at the beginning of the day informs the participants on how and why the race got started. Todd-Cooper introduces herself and her family during the opening ceremonies, and at this time she shares where the money is going and then introduces the Pegasus Award winner.

Looking back on the beginnings of the Dot-to-Dot, Todd-Cooper, who owns Blue Valley Physical Therapy which organizes and plans the Dot-to-Dot race, said that in the beginning people at Blue Valley Physical Therapy wanted

to do something. Working with many sports injuries, it was yet another connection to an event they could host in their field. In addition, it was a way honoring 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. This year the race raised approximately \$44,500, and Todd-Cooper said that at least eighty percent of the sponsors have been sponsors since the first year's race — a testament to their loyalty and reliability.

"Blue Valley Physical Therapy does all of the organization and planning of the race. We have three race directors, and we all have our own paths that we do and we all work well together," Todd-Cooper said. "Melissa Church and Sara Bandy, those two girls and myself are the ones that basically get everything together. The first year we had no idea what we were doing. By the third year we figured it out and now we can all do each other's jobs."

Additionally, one of Blue Valley's physical therapists, Shawn Stockwell, is also a DJ. He served as the emcee of this year's event.

"He made the announcements before the race, and this year I asked him, 'Would you be the emcee that's in between each of the segments of things that we do?' He was kind of that in-between person, and I think that helped out quite a bit," Todd-Cooper said. "He does a great job; he's really been in front of people and he can talk really well. He's awesome when he comes to talking and has lots of good energy."

Both Paulina and Rory's doctor was Dr. Stewart Goldman. These two children 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, Alexis Ashmore. Todd-Cooper reaches out to the Children's Mercy Hospital in Kansas City each year, and a social worker nominates individuals who may be interested in coming to the race and receiving the award. Ashmore's name came up this year, and her family said absolutely.

"Her family came and brought probably six to seven people to support — her aunt came from New Mexico and ran in the race," Todd-Cooper said. "Of course every year the Pegasus Award is probably the highlight. Alexis was there, and she's not old enough to talk very much, and I think people go through their day-to-day lives not thinking about children and cancer, and it gives everybody a moment to pause and to think about it."

A huge sigh of relief that day was the end of the torrential downpour, right in time for the start of the opening ceremonies.

"We woke up at four a.m. to get there by five, and it was just coming down in sheets. We're all standing around thinking, 'Are we going to be able to do this?' About seven fifteen, right when we were supposed to start the opening ceremony, it just stopped, and that was the end of it," Todd-Cooper said. "You would hate for this Pegasus award winner and her family come in and not be able to put the race on for them. Mindy and Ross flew in that night and you would have hated for them to come all the way and not have the event. It just worked out really nice. I guess the rain just cleaned the streets off for us and we had nice weather."

Todd-Cooper listed numerous highlights of the eleventh Dot-to-Dot, including Ross and Mindy's plaque presentation, a letter that Dr. Goldman sent, Shawn's emceeing abilities, and connecting with participants that she has not seen in a year.



Mindy Deutsch presenting Ann Todd-Cooper with the plaque

(Continued on Page 5)

(Continued)

...we need to continue to fight and keep doing these things, because little by little the small differences that we make eventually over time will add up and make a bigger impact at some point.

"Having Ross and Mindy there was amazing. That whole presentation to me was very meaningful, very important and very uplifting," she said. "I think you just keep the tenacity of continuing to do the race every year. It's what these kids have to have, that strength and that tenacity to stick with it. Unfortunately anybody today who is diagnosed with the same brain tumor that Rory had, or Paulina had, the prognosis continues to be poor, but it doesn't mean we should stop the fight, and we need to continue to fight and keep doing these things, because little by little the small differences that we make eventually over time will add up and make a bigger impact at some point."

For more information, visit www.dottodotrun.org.



Ross and Mindy Deutsch with Ann Todd-Cooper, Dot to Dot race medals, 2017 Dot to Dot Race start



Treasurer's Report By Ellyn Samsky & Enid Deutsch



THE GROSS PROCEEDS OF THE RORY DAVID Deutsch Foundation for the period November 1, 2015 to October 1, 2017 are close to \$410,000.00. This raised the total fundraising dollars, since our inception, to approximately \$8,000,000.

Max Weinberg, of Bruce Springsteen's E Street Band, preformed at our recent fundraiser "Rockin' for Rory". This event, which was held at 210 Restaurant & Live Music Lounge in Highwood, Illinois on April 8, 2017, generated close to \$114,000. A heartfelt thanks goes to Mark Stein, Judy Shatkin, Steve Goldstein, the restaurant staff, and to all those who participated in the event.

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.

From their races in the fall of 2016 and 2017, The Paulina Cooper Dot-to-Dot Race in Overland Park, Kansas has made The Rory David Deutsch Foundation the beneficiary of \$74,500.00. J.A.B. Produce's annual "Rory Day" continues to reap benefits by raising nearly \$19,000.00 over the past two years. Former Highland Park High School basketball players, Chris Wroblewski and Zack Meuser, planned a basketball camp for future players. Their time and effort generated \$7,800 for our cause. General donations to the Foundation have accounted to close to \$51,000.00. 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 can be purchased for \$5.00 each. For a more generous donation personal letters of Happy Day events or letters in memory of, can be sent. The cards and letters can be purchased by calling our office at 1(888) 919-RORY or by visiting our website at www.roryd.org.

Investment income earned from our endowed funds are in excess of \$115,000.00.

We have pledged up to \$450,000 payable to Duke University over the next five years helping to secure the hiring of Dr. David Ashley.

Dr. Ashley will serve as Director of Pediatric Neuro Oncology at the Preston Robert Tisch Brain Tumor Center. In addition, The Foundation has pledged \$200,000, over a five-year period, to the Robert & Ann Lurie Children's Hospital in Chicago, Illinois. This pledge will be commemorated with a plaque in Paulina Cooper's memory. It can be viewed in the Family Visitation Room on the oncology floor of the hospital.



Thanks to this overwhelming generosity The Rory David Deutsch Foundation will go on in perpetuity and make our dream closer to a reality—a cure for the devastating disease that took our beloved Rory much too soon.

FORMER HPHS BASKETBALL PLAYERS ORGANIZE CAMP



North Shore Elite Basketball Clinic middle school participants and coaches (coaches pictured from left to right): Sean Wallis, Zack Meuser and Chris Wroblewski.

FORMER HIGHLAND PARK HIGH SCHOOL varsity basketball players, Zack Meuser and Chris Wroblewski, organized a basketball camp for young players. The idea was fantastic but something was lacking. They wanted to give back, but what? The answer to the question became immediately clear. The proceeds of the North Shore Elite Basketball Camp would benefit The Rory David Deutsch Foundation. Zack and Chris know Ross Deutsch,

Rory's father. Both men attended Highland Park High School, and Ross was their assistant varsity basketball coach. Neither Zack nor Chris knew Rory but the special relationship between these three men began several years ago and continues today. Zack Meuser was a four-year varsity point guard at Highland Park High School graduating in 2007 and a University of Michigan graduate in 2011. Chris Wroblewski was a four-year shooting guard

for the Highland Park Giants who graduated in 2008. He graduated from Cornell University in 2012 where he continued his basketball career. During his sophomore season, Chris helped the basketball team reach the NCAA Tournament in 2010. "Coach Deutsch attended that game and my final game in Ithaca, New York as well which meant a great deal to me." Chris continued, "Ross is a father figure to many of his players. I have been very fortunate to know him since elementary school".

Coach Deutsch was one of our greatest mentors who made us the individuals we are today. We wanted to raise awareness for something that was near and dear to him and therefore near and dear to us.

Zack said "The reason we chose the Foundation was because the individual most affected was Ross Deutsch. Coach Deutsch was one of our greatest mentors who made us the individuals we are today. We wanted to raise awareness for something that was near and dear to him and therefore near and dear to us. In addition to the money raised we wanted to keep Rory's name alive".

(Continued on Page 11)

Children's Theatre Company Keeps Kids' Sense of Community Alive

EACH YEAR THE CHILDREN'S THEATRE Company, headed by director and founder, Margo Proeh, expands in growth and development. And, that is a great thing for The Rory David Deutsch Foundation, as a portion of the theater's ticket sales proceeds benefit the Foundation.

The ties between the Foundation and the theater have been established since the Foundation's inception. This year, for the fourth time, there are plans in the works to partner with the Chicago Youth Dance Exhibition in December, where the Foundation will be honored. Proeh said to check the website for more information.

Meanwhile, the Children's Theatre Company still presents two musicals per year. This encompasses a twelve-week rehearsal schedule, including invitations for children, ages five to thirteen, to attend. The theater just finished Camp Rock, and up next is Aladdin Jr. with cast members participating in stage direction, set design and lighting.

The Proeh family lived on the same block with Ross and Mindy Deutsch, and the families planned a trip to Disney World. However, the

day they were scheduled to leave, Rory became ill. Proeh saw the pain the family went through, and she thinks the Foundation is a great cause.

"They were my good friends and neighbors and community members. It happened so close to home that it was really shocking," she said.


Proeh said that she tries to pick out musicals that are timely, cute for kids and what is in their realm of interest. She said that theater is "crucial" in this day and age because of the onset of technology.

"You're slouched, you're looking at your phone, you're not making contact, and what happens is kids lose a sense of community," Proeh said. "[Theater] brings kids together for one goal. They connect their heads to their heart, and self expression is very important. It allows them to express themselves, and it allows children in a very comfortable setting to take chances and do things they would have a hard time doing on their own."

The safe environment of a theater class and the production also helps the children work

together and to explore becoming someone else, an aspect of acting. Proeh said, possibly creating a more empathetic child who is learning as he or she moves forward. When Proeh started the theater in 1993, she remembers watching children seeing other individuals their age performing and realized that they can accomplish the same. Proeh also remembers the Deutsch family attending the shows — a bittersweet memory.

"Ross and Mindy have done such a wonderful job in perpetuating Rory, and there is a place to go if someone's child needs assistance or help, to be supported," Proeh said. "Just like Ross and Mindy empower others going through a hard time — they are very strong people who are fighters and fight for this cause. They work with other people; it's something that Ross and Mindy stand for and they are creating a community to help others."

For more information, visit www.thechildrenstheatreco.com, www.youthtalentnetwork.com and www.youthdanceexhibitor.info. 

Greater > Than Team Shares a Toast to Family Togetherness

GREATER THAN, A CLEAN, HYDRATING sports drink, is made with a base of coconut water, juice and electrolytes. No added sugar and is non-GMO project verified.

The Highland Park basketball program includes a fall conditioning plan that Jon Sider and Craig Samsky, Ross's nephew, participated in when they were in high school. This was Jon's first meeting with Ross. When Greater Than first started, Jon 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, Jon wrote a check to the Foundation on behalf of Greater Than, which was the onset of support. Once Craig, Rory's cousin, came on board, the relationship between The Rory David Deutsch Foundation and the company continued to grow.

Craig said, "I work with two of the most unselfish people I could ever ask for. Mark and Jon Sider treat me as a brother. They always attend the Foundation events and support my family as if it is their own family foundation. I could not ask for anything more. It means a lot not only to me but to the rest of my family."

The Chicago-based company currently is focusing on gyms, yoga studios and CrossFit, a very niche driven industry that will help build a strong foundation.

"Business is growing; We are working extremely hard and we're growing in a different way than

most people would be accustomed to," Craig said. "We're trying to grow in a niche-centered market; it's a different type of growth and way of doing business."

Greater Than will continue to support and promote The Rory David Deutsch Foundation until we find a cure for pediatric brain tumors.

For more information, visit <https://drinkgt.com/>.

As the relationship between Greater Than and the Foundation continues to grow, the bond between the Deutsch and Samsky families has never been stronger.

"Obviously Rory was our cousin, and we were very close growing up. My brother, Marc, and I have an extremely close relationship with our aunt, uncle and cousins," Craig said. Although many years have passed, Craig said that nothing has changed in the family's lives in terms of staying in touch. No matter how busy things get, staying connected is extremely important to everyone.


"We don't do it because it makes our grandparents and our parents happy, it's because we want to — and we value our relationships with one another," he said. "We look at Robbie and Rickey as younger brothers and Reggi and Roxie as younger sisters; there's never a time where you can't call or text Marc or me. That relationship is extremely valuable and you can't put into words how important that is."

Craig and Marc attribute praise to their aunt, uncle, parents and grandparents, who they said work "so hard" to make it all work on both a family and Foundation level. They said that it is amazing how family and friends come together, sometimes on short notice, and work hard to make an event happen.

... it is amazing how family and friends come together, sometimes on short notice, and work hard to make an event happen.

"People do it in their own busy lives and take time away from their own family to help us. My brother and I have a sincere appreciation for people willing to help," Craig said.

Craig and Marc were nine and eleven years old, respectively, when Rory passed, away, almost twenty years ago. Craig commented how incredible it is that supportive people are still involved in raising awareness and money.

"Obviously we are doing things that we never wanted to do, and we're doing it under sad circumstances. It's bittersweet in that you see my parents, grandparents and our aunt and uncle happy that we're raising money, but it still brings sadness to our family," Craig said. 

HIGHLAND PARK HIGH SCHOOL GIRLS' TENNIS TEAM SERVES UP FUNDRAISING ACE

TWO YEARS AGO, THE GIRLS OF THE Highland Park Varsity Tennis Team had an idea. They came to Head Coach Steve Rudman with a proposal to raise money for both the tennis team and a charitable organization. Rudman has known Ross and Mindy Deutsch for years, and Reggi Deutsch, their daughter, was on the tennis team. So, it was only natural that the inaugural year's charitable recipient was The Rory David Deutsch Foundation.

"We wanted to do it [the fundraiser] in the sense where we would get little kids involved, and families, and make it a couple of hours on a Sunday afternoon," Rudman, who has coached the girls' team for nineteen years, said. "Ross, who also coaches at the school, is very visible and even though Reggi has graduated, she still comes by once a week. It's good seeing them still being involved and being around."

The inaugural fundraiser was held at Danny Cuniff Park on September 25, 2016, highlighting the Highland Park Tennis Team. About forty five girls on both the varsity and junior varsity teams were involved in coordinating the process of running the event. Prior to the event the girls were involved in securing local businesses to donate to a silent auction and to spread awareness of the future function. On September 25 the team members were visible on the courts, running drills with



both children and parents. Rudman estimates that two to three courts had the parents participating in drills with the team, and five to eight courts designated for the children.

"We had music blasting, and there was food there and it was a fun couple of hours," Rudman said. "We were lucky to have a nice day where people could just go out and play. And in the meantime we raised some money, so it was great."


Fundraising items included an entry fee for the event, the silent auction items and baked goods that were for sale. The Rory David Deutsch Foundation received \$1,250 of the proceeds.

Rudman said that the turnout was so great that he knew the inaugural year was just the beginning of something the team wanted to

do every year. In fact, the team just finished the 2017 event for a child who passed away recently, the daughter of a friend of Rudman.

"It's a continuous thing every year; we are looking at who we know and where we can help and we'll go from there," he said. "When the girls came to me two years ago and said 'Is there something that we could do?' we thought about what would be different; what would be unique?"

Now that the fundraiser has two years of experience, Rudman thinks they have the basis for an event that can continue to grow each year.

"That's our hope — that we can continue to do this and continue to raise whatever we can to give to a charity every year." 



Members of 2016 Highland Park Varsity Girls Tennis Team

Indian Trail School Remembers Rory Through Citizenship Award, Rory Room



First grader Eve Johnson pictured with Ross and Mindy Deutsch, Barry Bakal.



Fifth grader Parker Feder pictured with Ross and Mindy Deutsch, Barry Bakal.

THE NINETEENTH ANNUAL RORY AWARD for Citizenship at Indian Trail School winners have been announced. This year’s first grader, Eve Johnson, and fifth grader, Parker Feder, will have their names emblazoned on the plaque outside of the school’s Rory Room.

All students, grades one through five, have the opportunity to describe what constitutes a good citizen. Younger students may draw a picture, and older students write an essay. Then classroom teachers submit student work to two judges (classroom teachers) who choose a primary student (grades one through three) and an intermediate student (grades four through five). The winners are recognized by their ability to describe the attributes of good citizenship.

Barry Bakal, a friend of the Deutsch family, created the award in 1999 as a way to honor Rory and his sense of community and good citizenship.

Barry Bakal, a friend of the Deutsch family, created the award in 1999 as a way to honor Rory and his sense of community and good citizenship. Each year the award recognizes students whose writing or artwork best reflects the caring and generosity Rory exhibited in life. Additionally, Bakal presents a \$200 donation to the Foundation in the award winners’ names. Since inception, Bakal has donated more than \$8,000 in forty different students’ names.

When Bakal started the award, he said that his thought was to keep an ongoing memory for Rory.

“It’s been nineteen years — he would be twenty-six, or twenty-seven by now, and Indian Trail is the only school he went to, so his memory in

that school is a lasting memory, which is sort of what I was hoping for,” Bakal said. “I did it because Ross and Mindy were suffering so much, and it was so hard, and I thought that it could help. It definitely has to the extent that it can. My son is a year older than Rory, and he’s twenty-eight, and you see the changes. So, it’s unbelievable. I’m glad I’m able to do it, but I wish it never would have happened.”

Jackie Jacobs, a reading specialist at Indian Trail, has been at Indian Trail since 1993. She now teaches in the Rory Room, housed inside the Library Learning Center. The room was created in Rory’s memory. Directly outside of Rory’s Room there is a plaque composed of Rory’s picture and the names of the winners.

Each year the plaque is removed, so the names of the winners can be inscribed on gold nameplates. These nameplates are then added to the plaque.

“The kids of course don’t know Rory, and some of the kids pass by [the room] and they ask questions about who Rory was,” Jacobs said. “In their minds he is still a little boy; these are K5 students, so it’s hard for them to conceptualize that he was a little boy, and today would be a man. It’s really beautiful. Kids will question why is there a room for him and what happened, so I think even in that way it’s incredibly special for me because I love his family. There weren’t a lot of teachers who were there when Rory was there, so I feel honored that I was in that space and that I have some depth to share with the kids.”

Jacobs said that she is aware that when Rory’s parents come to the school along with Bakal to present the award, they also visit the Rory Room, look at the plaque, comment and share a moment. It is a time when Rory’s name is said aloud, something that Jacobs said keeps his name alive.

“I always think back to Jon Edwards, who was a presidential candidate. His wife Elizabeth spoke in her book about their son, Wade, who was killed in a car crash,” Jacobs said. “She talked about the need to hear people speak her son’s name, to see his name printed — that is what gave her peace and comfort. Although no one should ever have this tragedy, it’s a time when Rory’s name is spoken so highly and can just bring a moment of, if anything, a time of reflecting on this beautiful boy and his goodness and his childhood.”



Mindy and Ross Deutsch and Barry Bakal pose with the 2016 Rory Award winners. (Recipients pictured from top to bottom) Vivika Walter, and Elijah Davis.

RESEARCH UPDATE

DUKE UNIVERSITY’S NEW PEDIATRIC NEURO-ONCOLOGY DIRECTOR SHARES RESEARCH GOALS, UPDATE



THE PRESTON ROBERT TISCH BRAIN TUMOR CENTER

DAVID ASHLEY, MBBS, FRACP, PH.D., has been named director of Pediatric Neuro-Oncology for The Preston Robert Tisch Brain Tumor Center (PRTBTC) at Duke. Ashley previously served as Professor and chair of medicine and director of the Andrew Love Cancer Center at Deakin University in Australia and Professor and Director of the Children’s Cancer Centre in Melbourne.

Ashley, who is internationally considered a top figure in pediatric brain tumor research, has contributed hundreds of diverse publications to the academic arena, received numerous highly sought-after grants and awards, and held several distinguished leadership appointments. He completed his fellowship and postdoctoral scholarship at Duke University Medical Center more than two decades ago and has now returned.

“In choosing to accept a position at The Preston Robert Tisch Brain Tumor Center at Duke, I have made a deliberate and considered move to embed myself in an environment where I believe we can make the largest contribution to the field of pediatric neuro-oncology,” Ashley said regarding his decision to take this next step in his career.

At Duke, Ashley hopes to enhance the infrastructure of pediatric brain tumor research and develop more effective approaches that will lead to improved clinical outcomes

At Duke, Ashley hopes to enhance the infrastructure of pediatric brain tumor research and develop more effective approaches that will lead to improved clinical outcomes, as brain cancer now kills more children than any other disease, including leukemia. He is excited to extend the already successful research platforms on the adult side of the PRTBTC to the pediatric

side and will be responsible for transitioning the recombinant poliovirus, or PVSRIPO, into the pediatric neuro-oncology program.

“I have been doing children’s brain tumor research for twenty-five years and I believe outcomes in pediatric brain tumors have come to sort of an impasse in terms of making progress,” Ashley said. “We’ve made huge insights into the molecular biology and genetics, but it doesn’t seem to be translating into meaningful changes in patient outcomes yet. We’ve really have to start taking some of these insights and translate them into more meaningful outcomes for the children and their families.”

Ashley’s expertise on epigenetic targets within pediatric brain tumors will also be instrumental to the program. Epigenetic changes can inhibit tumor suppressors and induce oncogenes – genes capable of transforming a normal cell into a cancer cell. Ashley will continue to investigate how epigenetic manipulation of tumors can restore cell processes that cause cancerous cells to move back to a normal state.

“In addition to epigenetic manipulation I really do believe that immune based therapy is one thing that could make a difference,” Ashley said. “We’ve been doing a lot of vaccine development and targeting the brain tumor cells and the polio treatment trial in children will be a great step forward. Children have different immune systems, and we have to apply the technology in a different way. However, we do have reason to believe from the data that we have so far that the children may do better with the polio virus than adults, so fingers crossed.”

As for Ashley’s theory on why brain cancer now kills more children than any other disease, he said there has been no significant improvement in pediatric brain tumors, while there has been improvement in other cancers.

“Children with other types of cancers .. there have been improvements in outcomes. We’ve made enormous gains in our understanding of some of the genetic mutations and molecular biology in the last decade, and that’s fantastic, but that has not translated into making a meaningful impact,

and that is tough — it’s not an easy thing,” Ashley said. “A lot of drugs that have been found for adult cancers are just not applicable to children, and particularly to children with brain tumors. It’s a completely different disease, the drivers, the things that make brain tumors in children are unique to children, and therefore we have to invent approaches.”

Innovation is key to finding a cure, and Ashley said that one of the reasons he came to Duke are the platform technologies and the ability to work with like-minded people.

Innovation is key to finding a cure, and Ashley said that one of the reasons he came to Duke are the platform technologies and the ability to work with like-minded people.

“A lot of the innovative things that we do, you have to have a kernel of an idea of meaningful applications before the major government based funding organizations will invest,” he said. “A lot of that innovation comes out of philanthropy because it allows us to see innovative things that may not be supported by other foundations, and I think that’s critically important. In brain tumors there must be some really innovative thinking and approaches to make the next steps. So the Deutsch Foundation is critically important.”

In brain tumors there must be some really innovative thinking and approaches to make the next steps. So the Deutsch Foundation is critically important.

ANN & ROBERT H. LURIE CHILDREN'S HOSPITAL OF CHICAGO FURTHERS RESEARCH

OREN BECHER, M.D., ALSO TO BE NAMED THE RORY DAVID DEUTSCH SCHOLAR AT LURIE CHILDREN'S

THE BRAIN TUMOR TEAM AT ANN & ROBERT H. Lurie Children's Hospital of Chicago continues to provide innovative, high quality care to improve outcomes for children and to help them become strong and healthy cancer survivors.

Jason Fangusaro, M.D., head, section of neuro-oncology, and Stewart Goldman, M.D., head, division of hematology, oncology, neuro-oncology and stem cell transplantation, are leading a team at Lurie Children's pursuing all aspects of pediatric brain tumor care and research — from novel diagnostics, early stage clinical trials and innovative treatment technology — to unique services focused on the special needs of brain tumor survivors.

CLINICAL CARE

Lurie Children's Pediatric Brain Tumor Program is one of the largest pediatric neuro-oncology programs in the country, seeing more than 160 patients (both new and second opinion) each year. This hospital is one of the few institutions nationally to offer advanced training to physicians who wish to specialize in pediatric neuro-oncology and has trained six fellows in ten years.

Lurie Children's continues to invest in new initiatives, including:

Neuropsychology Service to provide early recognition of cognitive deficits children may experience as a result of aggressive treatments or the location of the tumor itself, which can impact learning and their ability to complete daily tasks.

Psychology Support to provide both emotional and psychosocial support to patients and their families as they cope with the stress and difficulty of a new diagnosis and throughout treatment and follow-up.

School Liaison works in tandem with the hospital's neuropsychologist to support patients' educational needs as they transition back to the classroom. The liaison helps patient families understand their child's rights and effectively advocate for his or her special education needs. She also educates teachers and other school personnel about the child's particular medical condition, its side effects and how this might impact neurocognitive function. This unique service helps children integrate back into school with great success.

Social Work Services to provide comprehensive social, emotional and financial guidance, support and resources to patients and their families.

Brain Tumor Survivorship Clinic, BrainSTAR, which provides medical expertise, educational resources and support to help patients manage the long-term effects of surviving a childhood brain or spinal cord tumor. Lurie Children's also works in partnership with experts from the Northwestern Brain Tumor Institute to develop a transition plan for survivors as they reach adulthood.

Lurie Children's program has become one of the nation's most active sites for early phase clinical trials that offer patients access to new treatments and hope for improved survival.

CLINICAL TRIAL UPDATE

Thanks to its commitment to innovation, quality and patient safety, Lurie Children's program has become one of the nation's most active sites for early phase clinical trials that offer patients access to new treatments and hope for improved survival.

Through the hospital's collaboration with the nation's major clinical research groups, such as Children's Oncology Group (COG) and the COG Phase I Consortium, Collaborative Ependymoma Research Network, Pediatric Brain Tumor Consortium (PBTC) and the newly formed Pacific Pediatric Neuro-Oncology Consortium, Lurie Children's is involved in more than fifty studies, the majority of which are phase I and phase II studies in the earliest stages of testing.

Collaborations undertaken with world renowned scientists and clinicians at Northwestern University Feinberg School of Medicine have been especially fruitful. Researchers have developed a combined Molecular Tumor Board; are collaborating with adult providers, including specially-trained immunologists; and drawing on cutting-edge technology and research expertise of our campus partners to pursue innovative avenues of research.

PROJECTS UNDERWAY

Lurie Children's has launched the first vaccine trial for pediatric patients diagnosed with high-grade glioma and ependymoma tumors. The vaccine is produced individually for each patient using his/her own resected tumor tissue with the hope that it will activate the body's immune system to fight against tumor growth or recurrence. Patients have been accrued and treatment has begun.

A team of neuro-oncologists, neurosurgeons and basic researchers from Lurie Children's and Feinberg School of Medicine are pursuing new treatment approaches for highly aggressive pediatric brain tumors, particularly high grade gliomas and diffuse intrinsic pontine gliomas (DIPG). They seek to understand how chromatin modifications promote the development of pediatric central nervous system tumors and use this insight to evaluate new therapeutics that target chromatin modifiers.

To improve outcomes for children with brainstem tumors, researchers are evaluating novel approaches to enhance drug delivery to the tumor site. One laboratory study seeks to determine whether delivering chemotherapy intranasally is more effective than traditional methods. Intranasal delivery represents an innovative new approach to treat particularly aggressive tumors such as DIPG.

Recent scientific advances have provided the means to understand the distinctive behavior of central nervous system tumors at the molecular and genetic level. Lurie Children's Precision Medicine in Oncology program is applying this knowledge to develop more targeted diagnostic approaches and highly tailored treatments based on the biological characterization of each patient's cancer. Precision Medicine in Oncology will expand the technology and expertise to accelerate the development of precisely targeted, and, in turn, more effective cancer therapies. This program aligns with a major institution-wide Precision Medicine initiative that seeks to translate new scientific understanding in this emerging field into individualized treatment and prevention approaches for a wide range of childhood diseases.

OREN BECHER, M.D., JOINS LURIE CHILDREN'S



The Rory David Deutsch Scholar at Lurie Children's Hospital, Dr. Oren Becher

In January 2017, Oren Becher, M.D., from Duke University School of Medicine, joined the program at this hospital. Dr. Becher has extensive experience developing mouse models of pediatric brain tumors, particularly DIPG, to support the study of genes and mutations that influence the development of these tumors and evaluate novel therapies that could translate into new clinical trials for children. One of his goals is to develop a strategy to overcome the blood-brain barrier, which is a significant obstacle in delivering drugs to DIPG tumors.

Additionally, toward the end of 2017, in a formal ceremony at Lurie Children's, Dr. Becher will be named the Rory David Deutsch Scholar. Maeve Sheahan, individual giving officer, major gifts at the hospital, said that he held that title when he was at Duke University. Dr. Becher was actively recruited by Dr. Goldman.

"Dr. Goldman knew he wanted to build our basic science program. Dr. Becher is world renowned for his research in DIPG tumors specifically, so he was a great fit to build upon our basic science program," Sheahan said. "I think that Dr. Goldman was thrilled when Dr. Becher was ready to make the move to Lurie Children's, and it's obviously an important development for our program."

Dr. Becher said, "I am honored to be the Rory David Deutsch Scholar and dedicate my work to finding better treatments for children with brain tumors. The work that I do is inspired by children like Rory and sustained by the generosity of organizations like The Rory David Deutsch Foundation. I am grateful for their support and partnership."



PHILANTHROPIC GIVING

Philanthropic investments enable Lurie Children's Pediatric Brain Tumor Program to offer the latest treatment protocols, pursue scientific innovation and sustain indispensable family-centered support programs. Sheahan said that the hospital is very grateful for The Rory David Deutsch Foundation's partnership and its ongoing support.

"They made a very generous commitment to the hospital last year to name a consultation room to honor the relationship with Paulina Cooper's family," Sheahan said. "It was really such a wonderful gift, and that gift is going to grow the endowment that they had established in 2005, which is really remarkable to think about. Researchers like Dr. Becher can continue their great work with the hope of finding better treatments for this devastating disease, and it's been my honor to work with the family. The Foundation has been around for a long time, and I think it's a true testament to Rory and his impact. It's just amazing that they have continued to raise money for brain cancer research and support so many families."

For more information, visit facebook.com/luriechildrensbraintumor and luriechildrens.org.



Paulina Cooper Family Consultation Room

(Continued)

FORMER HPHS BASKETBALL PLAYERS ORGANIZE CAMP



Chris Wroblewski and Zack Meuser huddles with Ross and Mindy Deutsch. Photography By Joel Lerner

Their basketball camp was designed for high school and middle school aged boys and girls. An entrance fee was charged for the prospective hoopsters who were taught basic skills, ball handling, and how to be a contributing member of a team. The participants were given tee shirts and instructional tapes for additional guidance. The camp's debut in September of 2016 was held at the Recreational Center of Highland Park. The proceeds from this inaugural event were over \$7,500. As part of its community involvement, Mesirow Financial, Zack's employer was a major sponsor. It is the hope of these two young men that the camp will become an annual occurrence, continuing beyond their years of involvement.

"I am incredibly proud of Zack and Chris" Ross said. "I am humbled and honored by their efforts and thankful for their friendship."



DONATION CARDS

The Rory David Deutsch Foundation is offering donation cards at a minimum of \$5 per card. The cards serve a dual purpose. In addition to sending messages of congratulations or condolences, your donations will help further pediatric brain tumor research. The cards can be purchased by emailing enid@roryd.org or by calling The Foundation office at 1(888) 919-RORY.

The RORY David Deutsch Foundation

REACHING OUT

BRIGHTER TOMORROWS FOR CHILDREN WITH BRAIN TUMORS



WINTER 2017

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.

The RORY David Deutsch
FOUNDATION
Brighter Tomorrows for Children
With Brain Tumors



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

Presorted
Standard
U.S. Postage
PAID
Permit No. 26
Highland Park, IL