This was the start of the Maher family’s 15-year journey with the hospital that would inspire them to create a lasting legacy (see story on page 6).

Biliary atresia is a rare, life-threatening congenital problem that damages the liver. With the condition, the bile ducts from the liver to the gallbladder are blocked, which leads to scarring and loss of liver tissue. Biliary atresia is the most common reason for liver transplants in children in the United States.

The first treatment for JD was a Kasai procedure that essentially reroutes the bile ducts from the liver. However, this procedure is often just a stop-gap because children usually still need a liver transplant within the first year or two of life.

“The Kasai procedure helped for a while, but we knew we were facing a liver transplant,” Jenny says. “While we were waiting, I always felt at ease to call the nurses at St. Louis Children’s Hospital and ask questions about caring for JD. They became part of our family.”

The Mahers realized the chances of JD receiving a cadaver liver donation were slim because of United Network of Organ Sharing (UNOS) rules for transplant. Another option for JD was a living donor transplant. At the time in 1996, living donor transplants for livers had just begun. The first two in the world were performed in 1989 and doctors only had early statistics about success rates.

To save their son’s life, the Mahers pursued the living donor option. And Jim was a match to donate a portion of his liver to JD.

Since St. Louis Children’s Hospital surgeons had not yet performed an adult to infant living donor liver transplant at that time, the Mahers went to a Chicago hospital for the procedure when JD was 9 months old.

“The Children’s Hospital doctors worked so well with the doctors in Chicago,” Jim says. “Locally, they did all the evaluations for the transplant and cared for us all the way up to the day we left for Chicago, and then again post-

continued on page 8
Ben Gives Back for Breakthroughs in Brain Tumors

When 7-year-old Ben Robinson had a headache, fatigue and vomiting, his mom, Shelly, thought he had the flu. He stayed home from school, skipped baseball practice and soon felt better.

But a week later, the symptoms hit again so Shelly took Ben to a hospital emergency room near their southern Illinois home. A CT scan showed a tumor on the back of Ben's brain. Ben was immediately sent by ambulance to St. Louis Children's Hospital, a two-hour trip.

“I was in shock,” Shelly says. “It was surreal—everything moved so fast. But we are fortunate to live so close to a top-notch hospital.”

Ben had an MRI at St. Louis Children's Hospital to confirm the diagnosis. “Everyone at the hospital was considerate, understanding and answered every question I had,” Shelly says. “They bend over backwards for kids and families. I knew Children's Hospital was the right place for Ben to have surgery.”

Jeff Leonard, MD, a Washington University pediatric neurosurgeon at St. Louis Children's Hospital, removed a golf-ball size tumor from Ben's brain. The tumor was a medulloblastoma, one of the most common types of brain tumors in children. Yet each tumor is unique and doctors still are learning about how different tumors respond to various treatments.

To address this, Dr. Leonard and his colleague, Joshua Rubin, MD, PhD, a Washington University pediatric oncologist, created a pediatric brain tumor bank to collect and study brain tumors, with support from the Children's Discovery Institute. This large tumor bank is helping researchers worldwide conduct a variety of breakthrough brain tumor studies.

Shelly, an occupational therapist, didn’t hesitate to donate Ben's tumor tissue to the pediatric brain tumor research bank. Ben’s unique tumor created a new segment of tissue samples. “Maybe Ben's tumor tissue will help researchers develop a new treatment or even find a cure for brain tumors.”

After Ben’s surgery, the boy who loved to sing and dance had to relearn to walk and feed himself. While in the hospital for nearly two months, he was busy in the playroom, the library and on the rooftop Olson Family Garden painting and planting. “He also loved the Clown Docs and Touch Dogs—they really brightened his day,” Shelly says.

Today this outgoing 10-year-old is back to singing and dancing, swimming, and practicing Tae Kwon Do. “He's back to being a normal kid,” Shelly says. “I can't say enough about St. Louis Children's Hospital. You get spoiled and then you can't go anywhere else.”

Ben Robinson’s tissue is being used in a brain tumor data bank funded by the Children’s Discovery Institute.

Ride for a Child at Pedal the Cause

On Sunday, October 7, a unique group of cyclists will gather at Soldier's Memorial in Downtown St. Louis for a shared goal—supporting cancer research. The 3rd Annual Pedal the Cause bike challenge will raise money for cancer research through the Children's Discovery Institute and the Cancer Frontier Fund, an initiative of the Foundation for Barnes-Jewish Hospital that benefits the Siteman Cancer Center. 100% of the proceeds raised stay in St. Louis to fund these efforts.

Founded by the president of the Koman Group and cancer survivor, Bill Koman, Pedal the Cause has seen great success in its first two years. In 2011, more than 1,300 cyclists participated and raised $1.325 million to support cancer research.

Each year, St. Louis Children’s Hospital gives its Pedal the Cause teams the opportunity to “Ride for a Child” in honor of a pediatric patient, who is currently undergoing cancer treatment or celebrating survival after receiving treatment. In addition, the hospital names an “ambassador” for its official team—this year, that ambassador is 12-year-old Noah O’Neal.

Noah has been fighting cancer for most of his life after being diagnosed with a brain tumor at 3 months old. Despite many health challenges, including loss of eyesight due to treatment, Noah loves to sing, dance and has a zest for life that has made him somewhat of a celebrity around Children's Hospital.

For more information on becoming part of St. Louis Children's Hospital Team Noah or creating your own Children's Hospital team, contact Kimber Wilcox at 314.286.0976 or kwilcox@bjc.org. More information on Pedal the Cause can be found at PedalTheCause.org.

Scan this with your smartphone to watch a special video about Noah.

DID YOU KNOW? St. Louis Children’s Hospital is the first pediatric hospital in Missouri to acquire a new technology designed to make CT scans safer for children by cutting the amount of radiation emitted. See story on page 4 to learn more.
Team Up for Kids this Fall!

Local Businesses Join Forces for Pin-Up Promotion

This September, various retailers in Missouri and Illinois will be “Team Up for Kids!” Retail partners will be selling paper pin-ups to customers to raise money for St. Louis Children’s Hospital and Cardinals Care, the community foundation of the St. Louis Cardinals.

The pin-ups will be sold for just $1 each. Customers will sign the top portion to be displayed in the store. Each pin-up also includes a tear-off entry form that customers will mail to enter a prize drawing for the “Ultimate Game Day Experience.”

The “Ultimate Game Day Experience” grand prize includes the following:

- Tickets to a St. Louis Cardinals game in an all-inclusive area for four people during the first homestand of the 2013 season
- Visit to the field for four people to watch practice before the game and a photo opportunity with one or more players
- Visit to the Fox Sports Midwest broadcast booth during the game
- Appearance on Fox Sports Midwest Cardinals Live pre-game show
- Overnight hotel stay in Downtown St. Louis (includes two rooms)
- Dinner for four at Joe Buck’s restaurant
- Limo transportation to and from the game

Proceeds from the “Team Up for Kids” pin-ups will help fund programs and services at St. Louis Children’s Hospital such as music therapy, surgical research and the Healthy Kids Express mobile health program.

Pin-ups will be sold from September 1-30, 2012 at the following retail locations:

- Walgreens
- Jack in the Box
- Slackers

Thanks to our promotional partners, The St. Louis Cardinals, Fox Sports Midwest and Cfx Advertising for their support. Please visit StLouisChildrens.org/TeamingUpforKids for official rules and more information.

Children’s Holiday Festival

Event Brightens the Holidays for Both Guests and Patients

It’s not too early to start thinking about the holidays! Planning is currently underway for the Children’s Holiday Festival, a bi-annual event to benefit St. Louis Children’s Hospital. On Saturday, December 8 at the Renaissance St. Louis Grand Hotel, guests will enjoy an exciting evening with plenty of cheer, festive entertainment, holiday treats and more.

The highlights of the Holiday Festival are Honorary Patient Trees, which will be decorated in honor of patients at St. Louis Children’s Hospital and displayed at the event. The trees will be presented to the honorary patients at the Patient Tree Reveal Breakfast and on display at the Children’s Holiday Festival Gala that evening. Following the event, the trees will be delivered to the patients’ homes to brighten their holiday season.

Elaborately decorated trees, holiday decorations and wreaths will also be available for purchase at the event with all proceeds benefitting St. Louis Children’s Hospital.

Tickets to the Children’s Holiday Festival will be available for purchase in mid-October. For more information or if you are interested in sponsoring an Honorary Patient Tree or donating a decorated tree, wreath or other holiday decoration, please contact Kimber Wilcox at 314.286.0976 or kwilcox@bjc.org.

Discover the Answers with the Children’s Discovery Institute

Mark your calendars to attend the 5th Annual Children’s Discovery Institute Symposium on Wednesday, November 14, from 6:30 –8:30 p.m. The event, titled “Up Close and Personal: The DNA of Discovery,” will be held at the Charles F. Knight Executive Education and Conference Center at the Washington University Danforth Campus.

At the symposium, guests are invited to get ‘up close and personal’ with Children’s Discovery Institute scientists and their research. Attendees are also able to ask questions and enjoy hands-on, interactive experiences to learn how investments in the Children’s Discovery Institute are accelerating discoveries for children. Cocktails and hors d’oeuvres will be served.

If you are interested in attending, please contact Erin Taake at 314.286.1573 or erin.taake@bjc.org.
New “Safest Imaging” Marketing Campaign Unveiled

St. Louis Children’s Hospital is promoting the importance of safe imaging through a popular character known among generations of parents and kids—Mr. Potato Head. The campaign centers on Mr. Potato Head and the theme, “The safest imaging for kids. And their buddies.” The headline accompanies a visual of a Mr. Potato Head scan.

“This commitment to low-dose imaging is a tremendous advantage of our hospital for families,” says Steve Kutheis, director of marketing. “We want parents to learn more about the importance of their child receiving the safest imaging possible. Radiation safety can be a scary thing, so our challenge was to create a fun and informative campaign that attracts a parent’s attention.”

The Children’s Hospital pediatric radiology team in the Joe Buck Imaging Center provides safe care by using the lowest amount of radiation necessary to obtain effective images, and customizes scans based on the weight and age of each child. In early Fall, the Center will begin using a Flash CT scanner that images more quickly and uses up to 75% less radiation than a standard adult CT.

The Mr. Potato Head safe imaging campaign features billboards, direct mail and magazine ads. In addition, a special safe imaging section on the hospital’s PursueKnowing.com website features more information, videos and fun activities such as “virtually” building your own Mr. Potato Head. Visit PursueKnowing.com/SafestImaging to see more.

Dana Brown Charitable Trust to Support New Surgical Suite

A new surgical suite at St. Louis Children’s Hospital will soon become a reality, thanks to a $1 million commitment from the Dana Brown Charitable Trust.

The new Dana Brown Surgical Suite will be located on the 6th floor of the hospital. This addition, which is currently in the planning stages, will allow the hospital to dedicate an operating room that will provide immediate access for trauma patients needing surgery. As a result, Children’s Hospital will meet the standards necessary to maintain the country’s highest level of trauma designation as Missouri’s only American College of Surgeons (ACS) Trauma Center for pediatrics.

“Designed as a state-of-the-art, minimally invasive operating room, the Dana Brown Surgical Suite will feature robotic surgical instruments along with other capabilities to enable the hospital to meet the growing surgical needs of its patient population.”

“We’re extremely grateful for the continued support of the Dana Brown Charitable Trust,” says Lee Fetter, president of St. Louis Children’s Hospital. “Dana Brown’s generosity has had a tremendous impact on the hospital.”

Children’s Earns Elite ACS Trauma Verification

The American College of Surgeons (ACS) has formally verified St. Louis Children’s Hospital as a Level 1 Pediatric Trauma Center, elevating its already premier status in trauma care.

St. Louis Children’s Hospital is the only pediatric hospital in Missouri and Illinois to receive this national verification.

“Receiving ACS trauma verification means that St. Louis Children’s Hospital has met the highest standards set for a Level 1 Pediatric Trauma Center,” says Trauma Manager Diana Kraus, RN, BSN. “This verification has really taken the hospital to another level of expertise and the highest level of preparation to care for injured children.”

Joe Buck Classic Golf Tournament Success

On May 21, more than 100 golfers gathered at Old Warson Country Club for the 12th Annual Joe Buck Classic, one of the nation’s leading charity golf tournaments. A long-time supporter of St. Louis Children’s Hospital, Joe Buck annually hosts the event to support efforts at Children’s Hospital and help fund cutting edge equipment for the Joe Buck Imaging Center.

Thanks to the generosity of players and sponsors like the Albrecht Family Foundation and Michelob Ultra, the 2012 Joe Buck Classic Golf Tournament raised more than $410,000. Since its inception, the prestigious event has raised more than $5.5 million to benefit St. Louis Children’s Hospital.
Sell-Out Crowd Enjoys St. Louis Children’s Hospital Day at Six Flags

The 29th Annual St. Louis Children’s Hospital Day at Six Flags on Friday, June 1 was an event to remember. A beautiful and unseasonably cool Friday night brought a sell-out crowd to Six Flags St. Louis for an evening of food, family and lots of fun. Nearly 3,600 guests enjoyed a complimentary dinner catered by J. Buck’s and a Parent Patio featuring drinks and music. At 7:45, only Children’s Hospital guests remained in the park to indulge in complimentary popcorn, pretzels, ice cream and other food, free arcade games and no lines for the more than 35 rides around the park.

Development Board member Rich Ledbetter with his family at the 2012 Six Flags event.

“Better understanding of the disease process is a critical first step to a cure,” says Dr. Bednarski. “Hyundai Hope On Wheels is making an investment in a better future for our children.”

Thanks to the generosity of individuals, families, corporations and many event sponsors, including presenting sponsor MPM, MPMKS & The Timothy H. Trout Family, St. Louis Children’s Hospital Day at Six Flags raised more than $500,000.

Members of the newly-formed Children’s Hospital Youth Council attended the Six Flags event to have fun and recruit new members.

Hyundai Awards $75,000 to St. Louis Children’s Hospital for Cancer Research

On June 26, St. Louis Hyundai Dealers joined Hyundai Motor America in awards St. Louis Children’s Hospital Foundation with a Hyundai Scholar Grant in the amount of $75,000. The funds will support Dr. Jeffrey Bednarski’s work on understanding the cellular mechanisms that prevent leukemia. “Better understanding of the disease process is a critical first step to a cure,” says Dr. Bednarski.

“The grant was officially presented during a Hope on Wheels Handprint Ceremony at St. Louis Children’s Hospital where area children affected by cancer placed their handprints in colorful paint on a new Hyundai Tucson—the official vehicle of the program—to commemorate their brave battles with cancer. Since 2004, St. Louis Children’s Hospital Foundation has received $570,000 from the Hyundai Hope on Wheels program.

Children’s Hospital patient, Hannah Smith and her doctor, Hyundai Scholar Dr. Jeff Bednarski, attended the Hyundai Hope on Wheels press conference.

Local Tradespersons Come Together for KIDstruction Week

Construction companies throughout the region recently united in support of KIDstruction Week, an innovative fundraising initiative for St. Louis Children’s Hospital.

Participating companies offered their tradespersons the opportunity to contribute $1, or more, for each hour they worked during “St. Louis Children’s Hospital’s KIDstruction Week” at the end of July. Companies were also encouraged to match their employees’ gifts at a percentage of their choosing, or to make a lump sum donation, to demonstrate their commitment to the cause.

Nearly 40 companies participated in the 2012 KIDstruction Week and more funds were raised to support St. Louis Children’s Hospital thanks to the following sponsors: Kwame Building Group, Inc.; Lakenan Insurance; Cross Rhodes Reprographics, Inc.; Erb Equipment Co.; KA Pazdera Hauling and Excavating, LLC; and Rebar Specialist, Inc.

Stay tuned for event results! For more information on KIDstruction Week, visit KIDstructionWeek.com.
Maher Family Passes the Value of Giving to the Next Generation

After JD Maher (featured on cover) was born with biliary atresia and treated at St. Louis Children's Hospital, his parents Jim and Jenny knew they wanted to give back to the hospital in some way. In addition, the Mahers wanted to leave a lasting legacy of giving with their four boys, whose ages range from 6 to 15.

Two years ago, they established the Maher Family Endowment Fund at St. Louis Children's Hospital Foundation. This fund is intended to provide comfort, support and encouragement for patients and families at St. Louis Children's Hospital. The fund provides activities and events for patients, meals and comfort items to families, gifts to uplift children and families, and support for special wishes and requests.

“St. Louis Children's Hospital Foundation is a great partner and helped us create a customized fund so children in the hospital having procedures receive prizes for being so brave,” says JD’s father Jim. “I know from JD’s experience that kids really look forward to those little things as a reward. These kind of things made our experience at the hospital much better, yet they’re not line item in the budget.”

JD’s mom Jenny says her oldest son was thrilled when the family set up the fund. “He said that’s exactly what the kids need. One of the highlights for JD was when he received a prize. Kids in the hospital are so innocent and have to go through major ordeals. The little things bring them joy. We’re trying to teach our kids to give back and we hope other kids benefit from this fund.”

A managing partner of “The Maher Group” at Merrill Lynch, Jim has served on the St. Louis Children’s Hospital Foundation Board for two years and formerly chaired the Children’s Legacy Advisors Board. “All parents who walk through the hospital doors seek hope and health for their child,” he says. “The Foundation helped us structure something meaningful through our endowment. To us, this endowment is about passing on our values and beliefs to our children. Through our endowment, we’ve created a tool so our kids can continue to give back in the future.”

Because of the Maher’s passion for soccer, Jim arranged for the Kick It 3v3 national soccer tour tournaments that played in St. Louis and Alton this summer to donate a portion of each team’s entry fee to the Maher’s endowment fund. The Mahers then matched the contributions.

“In life, there are both wants and needs,” Jim says. “Giving falls under the ‘needs’ category. We need to do this—to help St. Louis Children’s Hospital and families by investing in a world-class, top-10 hospital right in our backyard.”

—Jim Maher

“Endowed Funds: The Gift that Keeps Giving

Looking to make a long-term difference for the kids at St. Louis Children’s Hospital? Consider establishing an endowed fund, which will provide the hospital with a long-term financial resource.

An endowed fund is the “gift that keeps giving” because it generates annual income for the hospital. Endowment funds are invested and each year, a portion of the fund’s income is used for the hospital program or service designated by the donor, while the rest of the return is re-invested to preserve and grow the original gift.

While the Maher Family Endowment at St. Louis Children’s Hospital is being used to provide patient and family care, there are many other areas of the hospital that endowment funds may support. These include community outreach, pediatric research and the establishment of an Endowed Chair at St. Louis Children’s Hospital.

St. Louis Children’s Hospital Foundation recently received a very generous and impactful gift from the estate of Lois Tuttle—thanks to this gift, the hospital will establish a new Endowed Chair (name yet to be announced). Lois formed a connection to Children’s Hospital many years ago after her sister Jean was treated and cured of a stomach ailment that threatened her life.

If you would like to learn more about how you can positively change children’s lives through an endowment or other gift planning, please contact Jan Rogers at 314.268.0981 or jbrogers@bjc.org.

DID YOU KNOW? Because of donor support, 92 medical research projects in serious childhood diseases and disorders have been initiated through the Children’s Discovery Institute since it was launched in 2008.
On March 1-4, Mark Harrell Horse Shows hosted March to the Arch at the National Equestrian Center in Lake St. Louis. For the third year, St. Louis Children’s Hospital has been the recipient of the funds raised through an evening of entertainment, including dinner and a silent and live auction. The $75,000 in proceeds will support the March to the Arch Endowment Fund for cancer research through the Children’s Discovery Institute at St. Louis Children’s Hospital.

Beads of Hope was the brainchild of friends Louise Starek and Emmi Windes who thought of creating beaded jewelry to benefit the kids at Children’s Hospital. Both girls have a special place in their heart the hospital—Louise had cranial surgery here when she was 7 months old and Emmi has seen both her sister and brother treated at Children’s Hospital. After inviting their friends Kallia and Keena Williams to also participate in selling jewelry, the girls raised $200 for St. Louis Children’s Hospital and plan to raise more.

Through Kids Helping Kids Fix Broken Hearts, the Klader family has donated $5,500 to provide funding for lodging, food and transportation expenses for heart patient families through the Family Care Fund. The three oldest of the five Klader kids designed and printed their organization logo on dishtowels which are sold to raise funds. Their organization has sold more than 6,000 dishtowels to help heart patient families at St. Louis Children’s Hospital and across the United States.

The Sansone Sports Camp started 13 years ago when the three oldest of the ten Sansone kids wanted to share their love of sports by teaching other kids soccer, basketball, volleyball and more. Each year, the Sansone siblings donate half of the camp’s fees to a different charity. A record 50 kids attended the sports camp in May and $1,000 was donated to St. Louis Children’s Hospital’s Hematology/Oncology program.

Attention Fundraisers!

St. Louis Children’s Hospital is always grateful for fundraising efforts by area organizations and individuals. Still, it is important to remember that Children’s Hospital must approve all events that use the St. Louis Children’s Hospital name and logo. If your group would like to organize a fundraising effort to benefit Children’s Hospital, please contact Kimber Wilcox at kwilcox@bjc.org or 314.286.0976. Thanks for helping do what’s right for kids!

Thanks to You!

The following is a list of some of the recent fundraisers held by various organizations, businesses and individuals to support Children’s Hospital’s mission.

Friends PICU Service Project

On June 16, several members of the Friends of St. Louis Children’s Hospital gathered in the Pediatric Intensive Care Unit (PICU) at the hospital to assemble family care bags. These bags are given to families that may arrive at the PICU in the middle of the night with no personal care items. For more information on the Friends of St. Louis Children’s Hospital and the group’s many efforts to support hospital programs, contact Abby Edwards at 314.286.1549 or aedwards@bjc.org.

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Meet JD

transplant. St. Louis Children's Hospital is the reason we have a freshman in high school today.”

Jim says donating part of his liver to his young son was an overwhelming experience. “JD and I have such a special bond,” he says. “We both share the same scars that we call our tattoos. When JD was a little fella, he was like a little hero to me. Even after the tough things he went through, he had amazing resiliency. Today, he is such a special person. He conveys a warmth to everyone he meets—he’s very genuine.”

JD did well with his liver transplant until he was in first grade. Scar tissue began building up in the vessels where his new liver had been connected. This blockage was affecting his liver function. Soon, he had another liver transplant—this time from a cadaver.

“We couldn’t have done it without St. Louis Children’s Hospital,” Jenny says. “I can’t imagine not having a hospital like this close to home. To have the support of family and this hospital was a Godsend. We always took the hospital for granted until we needed it. It was an eye-opening experience.”

Jim says his family, who added three more sons to the crew since JD was born, has “hopped from miracle to miracle.”

Today, at age 15, JD plays golf and tennis, and is involved in many activities (he isn’t allowed to play contact sports). The immunosuppressant medications he took as a baby damaged his kidneys, so he may face a kidney transplant as he gets older. But the Mahers are confident as they look to the future.

“St. Louis Children’s Hospital will walk us through it if he needs a kidney transplant,” Jim says. “The hospital has always been home and has always been there for us. We know we’re in good hands there.”

Follow Us!

We’re on Twitter, Facebook and many more! Share your love and enthusiasm for St. Louis Children’s Hospital by joining us on our official social networking and media sites. Become our friend, hang out with other supporters, get health tips, news, videos and updates from St. Louis Children’s Hospital. Just visit StLouisChildrens.org for links and stay connected!

Holiday Gifts to Remember

If you are interested in making the holidays brighter for the kids at St. Louis Children’s Hospital, consider purchasing an item from the patient Wish List. The most requested items include:

• Laundered, fleece tie-blankets
• Teddy bears
• Current DVDs for teens
• Light-up or educational toys for toddlers
• Hard baby dolls (no cloth)
• Teen items, such as cologne, perfume, wallets, purses, watches, journals, make-up and pajama pants
• Sports items, such as team hats, jerseys, sport balls
• Action figures and toys such as fire trucks, police cars, Hot Wheels cars, ambulances, etc.

Please contact Karen Rieker at 314.286.0995 or krieker@bjc.org to coordinate the donation of your purchased gift. If you are too busy to shop, monetary donations and gift cards are always welcome and most appreciated. Visit StLouisChildrens.org/Giving to donate online or use the enclosed envelope to mail in your monetary donation.

DID YOU KNOW? St. Louis Children’s Hospital is the only pediatric hospital in St. Louis and one of only two in Missouri accredited by the American Diabetes Association.