

## Family Waits for the "Gift of Life"

**J**OEY RIELLY was born a beautiful and happy baby on January 4, 1994. By the time he reached the age of 2 months, however, his parents knew something was wrong. He was jaundiced and, at his 8 week check-up, doctors discovered that his liver was enlarged to three times the normal size. Joey was born with biliary atresia, a rare disease of the liver and bile ducts that affects 1 in every 15,000 - 20,000 babies. When a baby has biliary atresia, bile that is normally produced in the liver and travels to the gallbladder is blocked in the liver. This causes cirrhosis of the liver, and finally, liver failure.

On March 8, 1994 Joey and his parents, Shelly and Joe flew to San Diego where Joey underwent an operation known as the Kasai procedure, in which Joey's bile ducts were reconstructed using a portion of his small intestines. Although the surgery was successful, doctors told Shelly and Joe that the disease was more advanced than they expected. "The doctors predicted that Joey would not make it to his first birthday," said Shelly. Throughout the next ten years, Joey was in and out of hospitals. Despite exceeding his doctor's expectations, the Riellys knew that eventually Joey would need a liver transplant to survive. He was officially added to the UNOS waiting list in October of 2002 through Massachusetts General Hospital. His status was upgraded on the list in September of 2003.

Joey's family has received two calls on potential liver transplants. Unfortunately, neither came to

fruition. The first call came when Joey was suffering from a severe head cold, and was medically unable to undergo the surgery. The second donation did not occur due to unsuitability of the organ. "The second call was a real wake up," says Shelly. "We realized we really were not prepared, financially, to spend a long period of time with Joey in Boston." Shelly's friend Kristine Marra organized a fundraiser at Longfellow's Inn in Saratoga Springs to help Joey's parents with medical and living

expenses related to his transplant. Joey's school also hosted a basketball tournament to help the Rielly family with expenses. "The town has been so wonderful," said Shelly, "It's amazing how many people care about Joey and have come forward and offered to help out."

Donation is a subject dear to the Rielly family. Joey's uncles, twin brothers Josh and Joel, were killed in separate accidents 18 months apart, in 1998 and 2000. The brothers were organ and tissue donors. Shelly said, "I will do anything I can in order to get the word out on the importance of donation, not only for the people waiting for a transplant, but to the donor families as well. Donation can really help with the grieving process."

Today, watching Joey do headstands on his family's couch and run around the house with his cousin, it is hard to believe that he and his parents wait on "pins and needles" for the call that will take them to Boston and to a new life for Joey. "We try hard to

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**From Right - Joey Rielly, Shelly Rielly and Joey's cousin Maddison Peluso**

## From the Executive Director Fifty Years of Heroes

Fifty years ago, Dr. Joseph Murray and his team at the Brigham and Women's Hospital in Boston ushered transplantation of organs from dream to reality with the landmark transplantation of a human kidney. This transplant of a man in kidney failure with a kidney from his identical twin brother proved beyond a doubt that transplantation was technically feasible if the body could be prevented from rejecting the organ. Unfortunately, most people who need an organ transplant do not have an identical twin and so the hunt for a means of controlling rejection was on.

Over the last fifty years, many pioneers like Dr. Murray have contributed to the development of transplantation into what is now a highly successful therapy. Surgeons like Drs. Starzl (first liver transplant, Denver, 1963) and Barnard (first heart transplant, South Africa, 1967),

*See Executive Director, page 3*

**N**UMEROUS media outlets in the Capital District Region covered the CDT & Albany Medical Center press conference announcing their participation in the "Organ Donation Breakthrough Collaborative."



**T**HE ASSOCIATION of Organ Procurement Organizations (AOPO) held its annual Professional Education Workshop in Washington D.C. March 8th - 10th. Members met with legislators to discuss the importance of organ and tissue donation and to urge continued support of donation efforts.



**M**ULTIPLE media outlets covered the ceremony at Champlain Valley Physician's Hospital. For more details see page 3.

**C**DT'S PR specialist Lauren Bould, volunteer John Weakley, and Saturn employee Dale Roberts were featured on the "Joe Kelly" show, a half-hour television show featuring current political, social and cultural topics. Saturn's "National Donor Day," the nation's largest one-day donor drive, was discussed. Radio stations broadcast "National Donor Day" events live from the Burlington, Vermont dealership.



## New Faces

**W**ILLIAM YAGER joined CDT as a tissue recovery coordinator in February 2004, after working as an operating room technician II at Albany Medical Center. Previously, William was a paramedic at Mohawk Ambulance Company. He has an associate's degree in occupational studies.



**J**EN SISEMOORE accepted the position of organ procurement coordinator at CDT in February, 2004. She earned her bachelor's degree in chemistry and environmental science from Middlebury College while working as an EMT and an EMT Intermediate on the Vergennes Area Rescue Squad.



**S**TEPHEN BEAULIEU joined CDT as an organ procurement coordinator in January, 2004. Stephen is an LPN who was previously employed at Memorial Hospital and Rubin Dialysis Center. Prior to his LPN certification he worked as both an ICU and ER technician, and spent 14 years in the military.



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keep Joey's life as normal as possible. We do everything we can to make sure he's treated like a regular kid." Joey plays soccer and little league baseball, wearing a stomach guard to protect his liver and spleen. "It can be frustrating, waiting for the call," Shelly admits, "but Joey is remarkable...he is so full of love and happiness that he never seems to care or worry about anything, his smile never fades."

Despite his disease and time spent in hospitals, Joey remains a cheerful and active boy. He enjoys playing with his older sister Brittini 14, and his pets, dog Raider and cat Harley. Joey joins over 17,000 people currently waiting for a liver transplant in the United States. "People don't realize how important donation is until it touches their family," said Shelly. "Hopefully, Joey's story will inspire people to discuss donation with their families."

### Spring 2004

The Legacy is published quarterly by the Center for Donation & Transplant. 218 Great Oaks Boulevard Albany, New York 12203 Phone 518 262-5606 Fax 518 262-5427

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**We  
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**If you are a member of an affiliated hospital who would like to advertise an upcoming event or submit an article to the Legacy, contact Lauren Bould at (800) 256-7811 or via e-mail at lbould@cdtny.org.**

**The Legacy is published on a quarterly basis and covers the health care community that CDT serves in northern and eastern New York, and western Vermont.**

# Debunking the Myth of “Brain Death”

By Dr. Bob Macauley, MD

Clinical Ethicist, Fletcher Allen Health Care

Clinical Assistant Professor of Pediatrics, University of Vermont College of Medicine

**T**HE TRAGIC CASE of Jéssica Santillan, a 17-year-old girl who received an organ transplant of the wrong blood type last year at Duke University Hospital, highlights one of the most stubborn and tragic myths in medical ethics. As the New York Times reported, the patient “died Saturday after doctors declared her brain dead and removed her from life support.” In that one sentence lie grave misstatements.

First and foremost: a person who is brain dead can't be on “life support.” Before ventilators came into use things were simpler: if your brain stopped working, you stopped breathing, causing your heart to stop. But since the 1960's ventilators have been used to keep the lungs working, and the heart continues to beat, and the brain-dead person appears “alive,” especially to their family who are hoping for recovery.

We need to be very clear, though: brain death is death. It is inaccurate to say that Jéssica died “after doctors declared her brain dead.” She actually died before the doctors declared her dead, or else they couldn't have done so.

By speaking gently of “life support” and referring to the patient as “alive” after brain death has been declared, we engender hope where there is none, and we might lead families to wonder if there is some hope of their loved one recovering if they do not remove the ventilator. For the family's sake, especially, we need to be clear: the patient has already died, and the only support we can offer is consolation and companionship and, if they wish, the opportunity to donate organs so that someone else might have the chance to live.

## Birthday Gifts For Awareness

**10** YEAR-OLD Nathan Haber of Plattsburgh decided that his birthday is not just about getting presents and eating birthday cake. After hearing of a classmate's father who has cystic fibrosis and is waiting for a transplant, he decided to celebrate his birthday in a unique way. Instead of presents, Nathan requested that his family and friends donate money to be used for organ and tissue donation awareness. He raised a total of \$100 for the Melissa Lahtinen-Penfield Organ and Donor Fund, which funds public education on donation and assists families with expenses relating to transplantation.

Nathan donated his money at a ceremony held at Champlain Valley Physician's Hospital. CDT coordinator Heidi Pentkowski attended the event and spoke about the importance of donation. “It's wonderful to see how a classmate's story touched Nathan, and that he was willing to give up something of his own in order to help others. Talking about organ and tissue donation is one of the most important things you can do with your family. You can help save lives.”

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and researchers in immunology who gave us new and better immune suppression drugs such as Cyclosporine or FK-506 have had the courage, the vision, and the fortitude to try and try again until levels of success we could only dream of even twenty years ago became commonplace.

When people accomplish these things, it is easy to consider them the heroes of the story. I have had the privilege of meeting both Dr. Starzl and Dr. Murray, of hearing Dr. Starzl and many of the pioneers in transplant immunology lecture, and they are truly great people who have accomplished great things...but they are not the heroes.

The true heroes are the donors, the people who chose to help. Imagine being a living kidney donor and choosing to undergo such an operation to give someone a chance—no guarantee but simply a chance—at a life without dialysis. Imagine losing your child or your spouse or your parent and choosing to donate their organs to give someone you don't know and may never know a chance at life. That willingness to choose, to give, is true heroism. Donation is a selfless, courageous, generous act and one who donates meets the definition of hero no matter how you define the word. At the CDT, we salute all the heroes who've donated over the last fifty years so that others might live.

## "Age is Just a Number"

"OH, YOU WOULDN'T WANT any organs of mine by the time I'm done with them." "I'm way too old to be a donor. What could be used?" These are some responses from people when asked if they would be an organ donor. Unfortunately, many people's perception is that if you're past a certain age, signing up to be a donor is useless since your organs are "older" and not viable for donation.

The medical staff at Ellis Hospital in Schenectady, NY is fighting that perception and opening eyes to the increasing age of donors able to give the gift of life. In the past 10 years, CDT has managed 8 cases involving a donor aged 80 or older. Five of those 8 cases were referred by Ellis Hospital. The ages of those donors ranged from 82 to 85, with an average age of 83 years old. CDT organ procurement coordinator David Bruno gives credit to the staff at Ellis for not only recognizing the potential for donation in older patients, but for adept management of those cases once brain death occurred. "At CDT, we depend on nurses to identify and refer potential donors to us, and to assist us in maintaining the patient's stability. The nurses in the ICU, ER and NeuroCritical Care Unit at Ellis have all been proactive in referring elderly patients that others may not recognize as having the opportunity to donate organs."

Once referred, CDT coordinators rely on nurses to continue management of the case, monitoring the patient's stability and recognizing any potential problems that might arise. Elderly donors can be particularly complicated, given the fact that many donors have had other health issues that may make patient stability more difficult.

When it is time to procure the organs, OR nurses assist throughout the surgery. "Not only do OR nurses deal with what is a major surgery [in procuring organs] but they provide psychological support during surgery. If someone on the team is uncomfortable in dealing with the death, the nurses support them and try to show them that donation is a way for the donor to pass on life," said Carmen

Hercules, RN, Director of Surgical Services at Ellis Hospital.

All donors at Ellis aged 82 and above were able to donate their livers. Five recipients benefited from these life-saving gifts; their ages ranging from 44 to 70 years old. The recipients were critically ill with little time left to wait for transplantation. In every case the recipient had a good prognosis with solid organ function after the transplant. "One of the major challenges that people face as they grow older is coping with a loss of independence. It's wonderful to think that elderly donors are giving back independence to a recipient, who may be weak, confined to a bed or unable to participate in life," stated Mary Beth Bowen, Divisional Director of Patient Care Services.

The staff at Ellis is dedicated to serving as an example to other hospitals that donation from older donors is a possibility. Executive Vice President of Operations Dianne Shugrue said, "The fact that 5 out of 8 of those cases came from Ellis Hospital is a

significant achievement for us. One reason we've had that success is education, the fact that there is no age limit for donation is stressed so heavily here. The nurses keep in mind that every patient counts. We will always call on a potential case."

Another factor in Ellis' success is the enthusiasm and motivation of the nursing staff. "With elderly donors, you know that they have had a long and pro-

ductive life, and with their generosity, we are able to generate more life from their gift. The last thing they are doing in life is being a hero," said Katherine Yawarski, RN, a staff nurse who was involved in 4 of the 5 cases. Joyce McCormack, RN a nursing practice specialist, added, "When the patient dies, I don't think of their death as "the end." I am always thinking about the donor and their family, but my focus expands to the lives that will be saved by that donor's gifts." The open-minded approach that the nurses at Ellis bring to the donation process is critical to saving lives, especially as medical advances open the doors to allow a wider range of donors.



**Ellis Hospital Staff from left (standing) Lisa DeNovio RN, Katharine Yawarski RN, Joyce McCormack RN. From left (sitting) Carmen Hercules RN, Dianne Shugrue, Donna Cafaldo RN and Mary Beth Bowen.**

## Join Us for Donor Day with the Albany Conquest

CDT and the Albany Conquest, the Capital District arena football team, are hosting a "Donor Day" awareness event at the home Conquest game on Saturday, May 8, 2004. Join us as we watch the Conquest battle it out with the Wilkes-Barre/Scranton Pioneers at the Pepsi Arena in Albany, NY.

The festivities will begin at 5:00 pm at the Conquest Tailgate Party on Pearl Street. The Tailgate Party runs from 5:00 - 7:00 pm and includes games, food,

contests, a live band, the Treasures dance team, and much more. There will also be an opportunity for CDT



Come out and show your support for donation

awareness while enjoying a great game. To order tickets please call Lauren Bould at 1-800-256-7811 or (518) 262-5606.

guests to meet the Conquest players and coaches and the Treasures dance team members for a post-game autograph session right on the field.

The Albany Conquest is a member of arenafootball2 (af2) and is looking to win their third consecutive Northeast Division title in the 2004 season. For more information on the team, visit their website at [www.albanyconquest.com](http://www.albanyconquest.com) or call 518-487-2222.

### Guests of CDT will receive the following:

- ◆ Unlimited amount of discounted tickets at the rate of \$10 each (\$2 off box office price)
- ◆ Participation in the Conquest Tailgate Party
- ◆ Free Donor Awareness T-Shirt
- ◆ VIP access to the field for the post-game autograph session with the players, coaches and dance team
- ◆ Continue the fun into the night at the post-game party with the players and dancers (location to be announced)

## CDT is a "Donate Life" Organization Organ Procurement Organizations Join Together to Create a National Identity

FOR THE FIRST TIME ever, organ procurement organizations (OPOs) across America will be associated under a common identity, the "Donate Life" brand. The Association of Organ Procurement Organizations and the Coalition on Donation have announced that all 59 federally designated OPOs will be able to utilize the "Donate

Life" logo to maintain a consistent image and ensure strong visibility for organ and tissue donation awareness throughout the country.

OPOs will continue to utilize their own names and branding in marketing and advertising, but will also have the opportunity to incorporate the "Donate Life" logo into all informational material. This is expected to create a higher profile for donation awareness, with a recognizable and more consistent national image.



A Donate Life Organization

The Coalition on Donation is a non-profit alliance composed of national and local organizations dedicated to organ and tissue donation awareness. The Association of Organ Procurement Organizations is a non-profit organization that is recognized as the national membership association and voice of the nation's 59 OPOs.

## Contact CDT

### if you would like to:

- ENROLL in the New York State Organ and Tissue Registry
- OBTAIN INFORMATION or donor cards
- REQUEST SPEAKERS for schools, civic organizations or health fairs
- BECOME A VOLUNTEER and help raise awareness of donation!

Call or write to:  
The Center for Donation and Transplant  
218 Great Oaks Boulevard  
Albany, New York 12203  
Or visit [www.cdtny.org](http://www.cdtny.org)

**(518) 262-5606**  
**(800) 256-7811**

# A Perfect Match

**T**HIS YEAR marks the fiftieth anniversary of the first successful kidney transplant. In 1954, Dr. Joseph E. Murray and his colleagues at Peter Bent Brigham Hospital in Boston transplanted a kidney from Ronald Herrick to his identical twin brother Richard. This case, in which the donor and recipient were perfect genetic matches, showed that kidney transplantation was surgically feasible in the absence of the body's rejection response system, which recognizes and attacks foreign tissues. This discovery paved the way for suc-

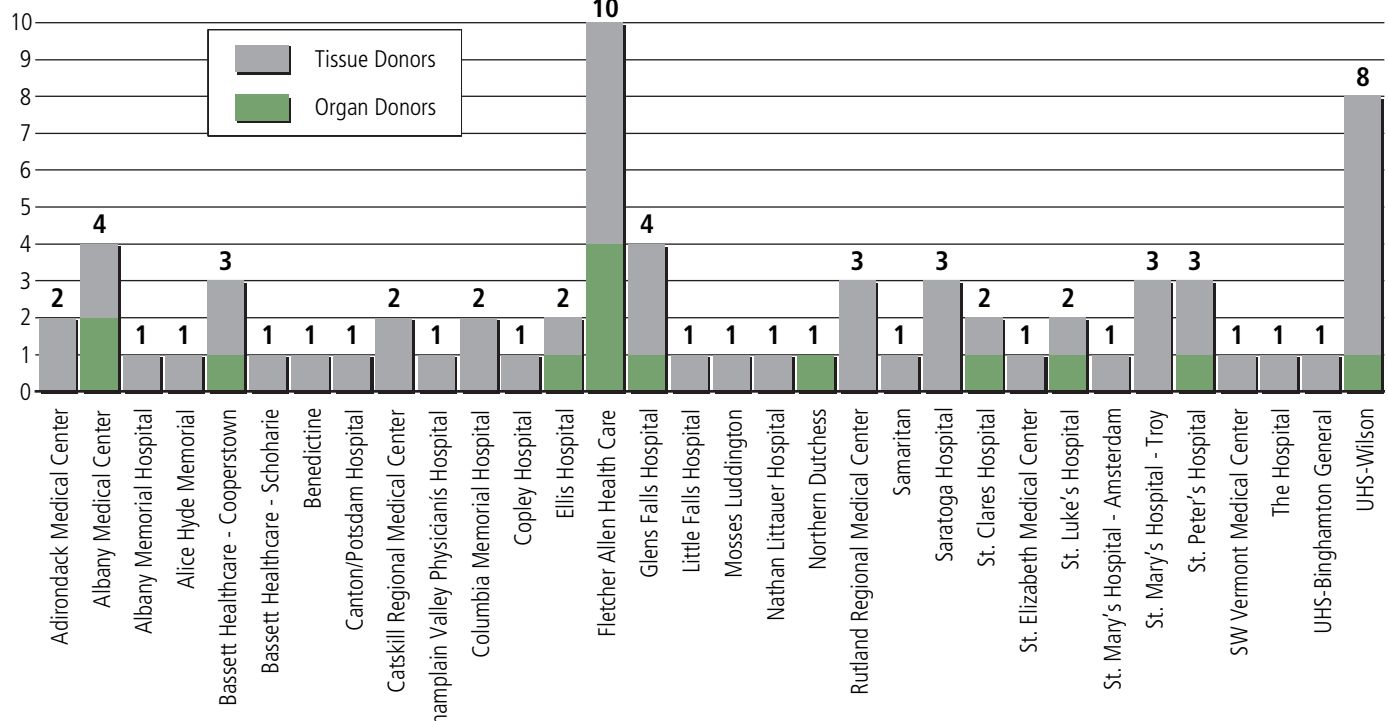
cess in the transplantation of not only kidneys but other organs as well. Today, with subsequent advances in surgical techniques and medication, over 14,000\* kidneys, the vast majority of which are not perfect genetic matches, are transplanted every year. Thanks to the work of Dr. Murray and so many others, organ transplant recipients of all types are able to live long and full lives only fifty years after the first successful organ transplant.

\* Based on average of past three years, excluding kidney-pancreas transplants



**CDT volunteers pose at a training session presented by Transplant Speakers International. TSI offers seminars on sharing personal stories related to donation and transplantation and soliciting speaking engagements from the community.**

**Donor Activity by Hospital - through March 2004** (56 Total tissue donors, 14 Total organ donors)



# Ease of Criteria Makes Transplantation More Equitable for Minorities

**A** CHANGE in UNOS policy regarding “matching” criteria for kidney transplantation has allowed minority groups more access to life-saving kidneys. The change was implemented in May of 2003 and it is expected to increase transplants in minorities by as high a rate as 6 percent.

Minorities are three times more likely to have kidney failure and make up 58%\* of the UNOS waiting list for a kidney or kidney/pancreas transplant. However, in the past, minorities have had less access to transplants due to the number of genetic markers used in tissue typing, which is a factor in the determination of who receives a transplant. The donor organ and potential recipient are checked for matches of three pairs of genetic markers, including HLA-A, HLA-B, and HLA-DR. The more combinations the donor and potential recipient have in common, the more closely matched the donor and recipient from a genetic standpoint. Minorities tend to be more genetically diverse than Caucasians, so they typically have less genetic markers in common with any given donor.

Researchers analyzed the typing criteria and studied a four-year waiting list and the transplantations that occurred during that time in order to determine whether removing one of the genetic markers would affect rates of success in transplantation. They came to the conclusion that removing the HLA-B marker would increase the number of transplants to minorities by a little over 6 percent. The rate of transplant failure is projected to increase by only 2 percent. Top priority will still be given to “perfect match” combinations of genetic markers.

In the first four months following the change in policy, minorities accounted for about 39% of kidney transplants, an increase of close to 7% compared to that period the previous year. “Considering the serious shortage of organs available for transplant, we must do everything we can to ensure an equitable system of distribution, while at the same time keeping patient safety our highest priority,” said CDT Executive Director Jeffrey Orlowski.

\*as of March 2, 2004

## Organ Donation Increased in 2003

**I**N 2003, there was a national total of 6,455 deceased organ donors, a 4.3% increase over the previous year, which is the highest annual rate of increase since 1998. The generosity of these donors, combined with donation from living donors, resulted in a total of 25,448 organ transplants performed in the United States in 2003. In addition, the number of U.S. patients who died in 2003 while waiting for a transplant decreased to 5,968. From 1999 through 2002, over 6,000 patients in the U.S. died annually while waiting for a transplant.

There were 6,808 living donors nation-wide in 2003, representing a 2.9% increase over the previous year. Since 2001, the number of living donors has exceeded deceased donors in the United States, with over 40% of kidney transplants performed in the U.S. originating from living donors.

“We are greatly pleased that the number of organ donors has increased over the past year, allowing more people to receive life-saving transplants. However, we must continue our efforts for the 84,000 people still waiting for the gift of life,” said CDT Executive Director, Jeffrey Orlowski. A new name is added to the UNOS waiting list an average of every 14 minutes.



**Donor family members who contributed a patch view CDT's "Kaleidoscope of Memories" quilt at a reception on March 21st.**



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 P2301



## Upcoming Events

- April 1 .....Beginning of Donate Life Month
- April 14 .....Legislative Education Day
- April 15 .....Winner of Amy Bindelglass Memorial Scholarship Announced
- April 29 .....Eighth Annual Nurse of the Year Award & Appreciation Dinner  
 RNAC Meeting, Century House, Latham, NY
- May 1 .....Albany Medical Center's "Neighborhood Challenge" 5K Race/Walk
- May 8 .....Donor Day with the Albany Conquest
- July 8 .....Donor Memorial Service, Troy, NY
- July 27 .....Donor Memorial Service, Burlington, VT
- August 6-8.....Binghamton SpiedieFest

**If you have any questions about our upcoming events,  
 please contact Lauren Bould at (800) 256-7811.**