

INTRODUCING THE DONATE LIFE REGISTRY ... New York's Registry of Consent Is Legally Binding

To boost the desperately needed number of organ, eye and tissue donors in New York, the state now has a new donor registry: The New York State Donate Life Registry. The legally binding registry that records an individual's consent to be a donor was launched on July 23.

The previous registry had indicated intent only, and required legal consent from next of kin, even if someone had registered to be a donor.

The Donate Life Registry of consent was approved by the New York State Legislature in 2006, following a massive grassroots effort to establish First-Person Consent (switching from "intent" to "consent.")

New York is the 44th state to establish a registry of consent.

With the introduction of the Donate Life Registry, next of kin will be informed of their loved one's decision to donate, and they will be given information regarding the donation process. But family members will no longer be able to veto the decision of a designated

donor.

"It's a very substantial change, legally," Elaine Berg, the president and CEO of the New York Organ Donor Network, told the *New York Daily News*.

"So many times people have said to us, 'What? My family, my parents, my husband can say no after I signed on?' and until now the answer to that was yes, unfortunately," Ms. Berg said.

"We hope the new concept will make people secure that, if they register to donate, their wishes will be respected."

Those in New York State's original registry of intent will remain in that database. If they wish to register their legal consent to be a donor, they will need to re-enroll to be in the new Donate Life Registry.

New Yorkers can enroll in the Donate Life Registry when they apply for, or renew, their driver's license or non-driver's identification card.

They can also enroll at www.donatelifeny.org or sign a donor enrollment card provided by one of New York's organ, eye and tissue procurement organizations, including the New York Organ Donor Network.



BY THE NUMBERS

- For the first time, the number of people on the national organ transplant waiting list exceeds 100,000, of which approximately 7,500 are in the greater New York metropolitan area.
- Thousands more need corneas and eyes, and tissue such as skin, bone and heart valves.
- 90 percent of Americans say they support organ donation, but only 35 percent of licensed drivers or ID card holders nationwide have enrolled in a state donor registry.



Photo: Beth English

Seen Around the World, High-Profile Kidney Recipients Visit Wall Street — A Symbol of Resilience

New York Organ Donor Network board member Richard Roth, a CNN correspondent and kidney transplant recipient, conducted a "live" interview on CNN International in early October with another prominent kidney recipient: seven-time NBA All-Star, Alonzo Mourning.

The interview took place on Wall Street a few days after the world's economy underwent seismic changes.

The discussion focused primarily on Mourning's new autobiography *Resilience: Faith, Focus, Triumph*. The notion of resilience was linked by Mourning to how people could survive the waves of uncertainty that were set off by the Wall Street tumble.

In his book, Mourning — in conjunction with Dan Wetzel — reveals that it was his inner strength that allowed him to petition himself into foster care as an 11-year-old.

Similarly, it was his faith and determination that enabled him to study his way onto the dean's list at Georgetown University and helped him to return to peak performance after his transplant surgery.

Roth received his new kidney on March 14, 1998; Mourning was transplanted on December 19, 2003.



**New York
Organ Donor
Network**

INSIDE THIS ISSUE

**MARKING THE NEW YORK
ORGAN DONOR NETWORK'S
30TH ANNIVERSARY**

Coverage begins on page 5

Regina Did Not Tell Her Family That She Wanted to Be an Organ Donor; Her Loved Ones Only Found Written Proof After She Had Given the Gift of Life

At the age of 55, Regina Collins returned to Valley Stream, NY last year after briefly living in Charlotte, NC. She had missed her four sons, their families including two grandchildren, and her aging mother.

Back home, Regina went about her daily routine as she had for ten years, as a director of customer service for United Airlines at JFK Airport.

But tragically, just one month after re-joining her family, Regina was involved in a car accident, and she was taken to Mary Immaculate Hospital in Queens. On July 2, after languishing for four days, Regina was declared brain dead.

When her sons Gary, Rich, Steven and Bryan Fischer were approached

by the New York Organ Donor Network, they agreed to donation even though they did not have any form of prior documentation from Regina.

"We looked at each other in shock but without hesitation said yes," Rich remembers, "because this is what we believed our mom was all about — giving to others her whole life."

As a result, a 24-year-old woman received a kidney; a 49-year-old man received the other kidney; and her liver was given to a 53-year-old woman.

A few days after their mother's passing, Rich and his brothers came upon Regina's New York driver's license. When she had returned home from Charlotte, Regina had applied for a new license and enrolled in the Donor Registry. And there it was, staring back at them, the words "ORGAN DONOR."



REGINA COLLINS with grandchildren Lily (2 at the time; now 4) and Julia (6-months-old then; now 2), and sons (from left) Gary, Rich, Bryan and Steven.

Now, there was written proof of her wishes, especially important for Regina's 86-year-old mother. This afforded the family a greater level of comfort despite the deep loss.

"My brothers and I are very lucky to have Nanny in our lives," said Rich. "She means everything to us. The only thing that keeps her going these days is the knowledge that her daughter gave the gift of life to others."



THE DRIVER'S LICENSE with the printed words "ORGAN DONOR" in red lettering that confirms Regina Collins had enrolled in New York's Donor Registry.

In a Profoundly Moving Ceremony, Those Who Gave the Gift of Life Are Remembered



Recognition Program and Luncheon on October 19.

The program, which honors the memory of New York's organ, eye and tissue donors, took place at the Roosevelt Hotel in Midtown Manhattan. New York State Gift of Life Medals of Honor were presented to each donor family.

Invited transplant recipients introduced themselves and expressed their deep gratitude to donor families.

The day's proceedings were organized by the department of

hospital and family services, led by its director Linda Bowes and manager Arlene Barnett.

Shown in the photo below are, from left, Linda Bowes, who delivered the welcoming remarks; Richard Roth, senior CNN correspondent, Donor Network board member, and kidney

recipient; Pat-ti, Joey and Victor DiS-anto — Joey is a heart recipient and U.S. Transplant Games athlete; and Elena Dinn, a cornea recipient.



Double-Lung Recipient Andrea Eisenman, Who Was Once at the Top of the Transplant Waiting List for 14 Months, Now Knows the Joys of Love and Marriage

There are weddings, and then there are weddings. Surrounded by relatives and friends, Andrea Eisenman married Stephen Downey in Manhattan on September 13.

What made this celebration even more joyous was the fact that for Andrea, a double-lung transplant recipient, marriage was once highly unlikely. Staying alive was all that mattered.

When Andrea was 9 months old, she was diagnosed with cystic fibrosis (CF).

At age 29, she was informed that she needed new lungs to survive. What followed was an agonizing and frightening wait of 5½ years before a suitable donor was found for her.

"During the last 14 months, I was at the top of the waiting list," Andrea says. "I was living with a portable oxygen tank, and maintained on intravenous antibiotics to battle pneumonia."

Andrea finally received a life-saving bilateral lung transplant on April 25, 2000, at NewYork-Presbyterian Hospital/Columbia University Medical Center. Thanks to her donor, Andrea now leads a full life.

"I'm only alive today because a generous family donated their loved one's organs," she says.

Now fast-forward to September this year. Family members of Andrea's donor were among the wedding guests. For both families, it was an opportunity filled with powerful emotion to celebrate the lives of the donor and recipient.

So how did Andrea meet Stephen, a former Peace Corps volunteer who owns a newspaper distribution business?

It was their canines that did it. In the summer of 2006, Andrea's Ernie, a purebred Boston terrier, met Stephen's

Scuffy, a pound-ad-
opted terrier mix, in a dog run at Riverside Park. The dogs bonded instantly.

Andrea and Stephen began dating in March 2007,

and marriage would follow roughly 18 months later.



AT THEIR WEDDING, Stephen and Andrea displayed their Donate Life wristbands. RIGHT: The wedding cake with sculptures of Scuffy and Ernie, the dogs that played the role of matchmakers.



At the Donor Network, where she volunteers, Andrea Eisenman draws upon her professional designing skills to create graphic designs for many of the agency's invitations, posters and other materials.

She also brings her artistic talents to the *CF Roundtable*, a newsletter for adults with CF.

Not to be outdone in more taxing ways, Andrea has won medals for running and biking at the U.S. Transplant Games.

Photo credits: National Kidney Foundation



Team Liberty Takes Home 24 Medals at 2008 NKF Transplant Games

Members of Team Liberty from New York and New Jersey won 24 medals, including 11 gold medals, at the National Kidney Foundation's 2008 U.S. Transplant Games in Pittsburgh, PA from July 11-16.

The Games are Olympic-style sporting events for organ, tissue and bone marrow transplant recipients. It is also an opportunity for recipients to meet donor family members and living donors. The next Games are scheduled to take place in Madison, Wisconsin in 2010.

We congratulate these 2008 Team Liberty athletes:

Alison Cain: Gold, 100-Meter Breaststroke, and Bronze, 50 Meter-Backstroke; **Ruben Caseiro:** Gold, 1500-Meter Racewalk; **Julianne Culhane:** Gold, 50-Meter Backstroke, and Silver, 50-Meter Freestyle; **Michele Dabal:** Gold, Table Tennis, and Bronze, Tennis Singles; **Rich DeRocher:** Gold, Racquetball, and Bronze, Long Jump; **Emily DiMartino:** Gold, 1500-Meter Racewalk; **Mike DiPiano:** Bronze, Discus; **Joseph DiSanto:** Silver, Golf; **Howard Fields:** Gold, Tennis Doubles, and Bronze, Badminton; **Muthuswamy Govindarajan:** Gold, Badminton and Bronze, Table Tennis; **Debbie Greenberg:** Gold, 200-Meter Dash, and Gold, 400-Meter Dash; **Gretchen Hagerty:** Silver, 5K Race for Organ and Tissue Donation; **Bob Pathak:** Silver, Badminton; **Scott Smolka:** Silver, Tennis Singles; **Harvey Weinberg:** Gold, Tennis Doubles; Bronze, Tennis Singles, and Silver, Table Tennis.



RUBEN DARIO CASEIRO, the men's 1500-Meter Racewalk Gold-Medal Winner at the Games, received a kidney 18 years ago from his mother in Argentina. Ruben, who lives in the Queens neighborhood of South Ozone Park, co-founded

the Association of Transplanted Sportspeople of Argentina (ADETRA). Affiliated with the World Transplant Games Federation, its purpose is to demonstrate the transplant recipients' improved quality of life through their sports activities.



**New York
Organ Donor
Network**

During Her All-Too-Short Life, Taisha Constantly Beat the Odds, and Her Lasting Legacy Is What She Longed For...The Gift of Life and Sight to Others

At the time that Brooklyn resident Taisha Rodriguez-Galloway was born with serious birth defects in 1992, doctors told her mother, Judith, that she wasn't expected to survive. But Taisha did far more than that. She overcame one obstacle after another, including 52 operations, to become a loving, caring daughter.

When, finally, Taisha did succumb on July 8, 2005 at the age of 12 years 7 months at New York Methodist Hospital, it came as a great shock to Judith. But even then, Taisha would triumph by ensuring that her life would be shared with others.

When asked to authorize donation, Judith's decision to give consent was influenced, in part, by a television movie she and Taisha had once seen about a girl struggling to find a heart donor. After viewing the movie, Taisha was so affected, she firmly instructed her mom that if the opportunity ever arose, she wanted to be a donor.

Judith did not forget Taisha's wishes. And she remains extremely grateful that at that difficult time her goddaughters — Niurka Flores, Yovanka Serrano, Elizabeth Alvez, and Belinda Vega — supported her decision to honor Taisha's desire to give the gift of life.

As a result, Taisha saved the lives of no less than three people. Her heart went to a 13-year-old boy; her liver to a 44-year-old man, and her left kidney to a 66-year-old man. In addition, a 40-year-old woman received a cornea, as did a 27-year-old man.

Judith takes comfort knowing that Taisha's life has taken on extra meaning. And she is blessed with countless memories of her feisty daughter.



JUDITH RODRIGUEZ, Taisha's mom, received a New York State Gift of Life Medal of Honor when she visited the New York Organ Donor Network headquarters in Manhattan. Welcoming her, from left, are Marie Colon, a Donor Network family services coordinator; Dinah Hoke, family services administrative assistant; Kathryn Dwyer, the Donor Network's manager of volunteers, and Ronnie Schwartz, the Donor Network's assistant Memory Quilt coordinator.

"The first time we went to church, she ran to the altar and began to sing in front of everyone," Judith recalls.

"Although she was generally quiet in school, she became concerned and very vocal when another kid needed help from the nurse."

Perhaps most telling about Taisha's extraordinary personal strength is the fact that, just two months before her passing, Judith suffered a stroke that left her blind.

Despite the terrible setback for both mother and daughter, Judith recalls with a sense of fondness and immense awe how Taisha reversed roles this time by helping *her* to cope with life's difficulties. That was just one way in which Taisha celebrated her life. Giving life to others would be another, very special, meaningful way.

That is Taisha's final legacy.

A QUILT SQUARE TO REMEMBER TAISHA, FROM SUNRISE TO SUNSET

Judith was determined not to allow her blindness to hinder her ability to honor Taisha. Belinda Lee, one of Judith's goddaughters, meticulously followed her directions to create the New York Organ Donor Network Memory Quilt square shown here.



In one of the photos, Taisha is shown striking a Marilyn Monroe pose.

Surrounding the red heart are musical notes, reflecting Taisha's love of music, and drawings of birds and clouds, which were her favorite subjects when doodling in her school notebooks.

"I instructed Belinda to note the dates of Taisha's birth and death as sunrise and sunset," Judith explained. "That's how I view her life. I believe God healed her so that she could give her organs so that someone else could live."

Memory Quilt Panels 11 and 12 Are Unveiled

Panels 11 and 12 of the Donor Network's Memory Quilt have been completed. The quilt squares are created by donor families to honor the lives of their loved ones. The volunteer quilter for Panel 11 was Justine Schembri, the wife of a donor, Anthony Schembri. Judith Honohan was our volunteer quilter for Panel 12.



Panel 11



Panel 12

Anniversary Greetings

Elaine Berg, President and CEO of the New York Organ Donor Network



This special edition of *On the Beat*, with several pages devoted to celebrating our 30th anniversary, includes a double-page spread capturing some of the highlights of our history over three decades.

From our 30 memories over 30 years, we get a sense of our early leadership, and how medical, scientific and legislative advances impacted our efforts.

In the shorter term, since our last major chronological milestone — our 25th anniversary — we have accomplished many of the goals we had set for our organization. This is true even though we continue to face a variety of challenges as we seek to increase organ, eye and tissue donation.

Over the past five years, I am most proud of the fact that we have developed into a much more professional organization. We moved toward a community-oriented board of directors and a more representative governance structure. This represents a huge change in the way we perceive ourselves and the way we are perceived by our communities, who are among the most diverse in terms of race, ethnicity, religion, culture and beliefs anywhere in the nation.

Although awareness of organ donation is widespread, many people tell us they don't know how to record their

"We have developed into a much more professional organization."

wishes to be donors. So, in addition to providing the public and health care professionals with the facts about donation, we now focus on eliciting action—by encouraging enrollment in the New York State Donate Life Registry. This computerized database of legal consent was rolled out in July; the previous registry indicated an intent to donate.

On another level, the Donor Network has become a more clinically-oriented operation. It can be seen with the professionalism of a fulltime medical director, the implementation of a research program, the launch of our in-house Donor Center and kidney preservation unit, our expansion into skin recovery, and in our use of a sophisticated computerized system that tracks each donor case from first referral to allocation.

As we move onto the next chapter of our organization's existence, I wish to thank our staff, board of directors, members of our medical advisory board, committees and volunteers for all that they do. We are an organization that saves lives in an amazing way — we draw from the best of humanity, our donors and their families.

And it is fitting that the legacy of our donors is not only the revitalization of thousands of transplant recipients but also a constant renewal of faith in the power of the human spirit.

Peter Hutchings, Chairperson of the New York Organ Donor Network



Every single time somebody receives a transplant, no matter how "un-newsworthy" it might be, I think it is a tremendous accomplishment. I have not lost my sense of wonder that we know how to save these lives.

As we mark our 30th anniversary, we must acknowledge the generosity of the donors and their incredible families. Thanks to them, lives are saved every day and in the most extraordinary ways.

All of us here at the New York Organ Donor Network are in awe of the science of donation and transplantation, and of those remarkable individuals who celebrate life by giving life.

Mr. Hutchings retired as Guardian Life's Chief Financial Officer in 2001.

Lloyd E. Ratner, MD, Chairperson of the Donor Network's Medical Advisory Board



In 1988, I completed my general surgical training, by which time the New York Organ Donor Network was already celebrating its 10th anniversary.

Twenty years on, I can report comprehensive progress in the degree of regulation and professionalism in the areas of donation and transplantation.

Yet, as has always been the case, the shortage of donors continues to pose the greatest challenge. For this reason, the Medical Advisory Board is firmly resolved to do all we can to improve our clinical practices so that one day, as the agency's vision statement states, "the urgent demand for organs and tissues will be met."

Lloyd E. Ratner, MD is professor of surgery and director of renal and pancreatic transplantation at the College of Physicians and Surgeons/Columbia University.

30 Years . . . 30 Memories

Now that the **New York Organ Donor Network** is 30 years old, we identify 30 "firsts," facts and other assorted memories. For instance, did you now that for the first nine years of our existence, our name was the **New York Regional Transplant Program (NYRTP)?**



1 From 1973, before the establishment of a centralized organ procurement organization in the greater New York metropolitan area, The Community Blood Council operates a combined New York-New Jersey transplant program. ABOVE: The cover of a brochure from August 1976, announces the first-ever Transplant Coordinators Workshop.

2 New York Regional Transplant Program, Inc. (NYRTP) breaks away from the Community Blood Council and is incorporated on May 15, 1978. It opens its doors on June 1, as the centralized organ procurement organization serving the greater New York metropolitan area.



3 The first home of NYRTP in 1978 is the New York Academy of Medicine located at 103rd Street and Fifth Avenue in Manhattan. In 1988, NYRTP would move a little further uptown to 475 Riverside Drive. Later, as is shown above, the agency's original logo would undergo at least one modification.

4 In 1978, from our inception, Dr. Khalid Butt is the first president to serve on the board of NYRTP. Decades later, as the century draws to a close, he will serve a second term from 1995 to 1996.



5 Dr. Mark Hardy is the agency's first vice-president and becomes president in 1979. He serves two more two-year terms, beginning in 1985 and then in 1997.



6 In its first years of operation, Geraldine (Gary) Rasmussen oversees NYRTP's central coordinative functions. (Later, she is assisted by Larry Shapiro.)

7 In 1980, the Uniform Determination of Death Act is adopted by 43 states as a legal definition of brain death.

8 William Stubenbord, MD, is NYRTP board president in 1981, and he will serve additional terms from 1997 and 1999.

10 The U.S. Congress establishes the National Organ Transplant Act (NOTA) in 1984, prohibiting the selling of organs and tissues.

11 In 1985, New York and Oregon pass the Required Request Laws that mandates all potential organ and tissue donors be approached for donation.

12 1986 — What a Year!

On September 30, the United Network for Organ Sharing (UNOS) receives the federal contract to operate the Organ Procurement and Transplant Network (OPTN), a computer network linking all organ procurement organizations and transplant centers.

On November 1, organ and tissue procurement for more than 70 greater New York metro area hospitals is integrated under the leadership of NYRTP.



13 After 10 years of operation, the NYRTP hires its first executive director, Faye Davis, RN, in 1988.

14 The first NYRTP newsletter, *The Review*, begins publication in the spring of 1989. Also during this year, Vivian Tellis begins his term as NYRTP's president. The first successful small intestine transplant takes place; so does the first split-liver transplant.



9 Transplantation moves to another level in 1983 when Cyclosporine, used to suppress the immune system to prevent the rejection of transplanted organs, is approved for commercial use.



15 In 1991, at a "Children's Successful Transplantation Reunion," Joyce Dinkins, wife of New York City Mayor David Dinkins, signs a donor card. NYRTP board member Dr. Vivian Tellis looks on. Behind Mrs. Dinkins is Tyrone Howard, a kidney recipient, and NYRTP's Faye Davis. In the same year, Richard Weil, III, MD, becomes NYRTP president.

16 In 1993, a cinema advertising campaign promotes donation in New York City, the same year that Dr. Charles Miller (The Mount Sinai Hospital) becomes president of NYRTP.



17 NYRTP expands its service area in 1996 to include Long Island.

18 MAY 6, 1997 ... A NEW NAME!

On this day, the New York Regional Transplant Program (NYRTP) legally changes its name to the **New York Organ Donor Network, Inc.**



19 New York enacts a Routine Referral Law in 1998, mandating that hospital staff notify an organ procurement organization of every death.

20 The Dar Vida Hispanic outreach program (shown here) begins in 1998. Also in 1998, the Donor Network receives accreditation from the Association of Organ Procurement Organizations (AOPPO). Pike County, PA is added to our service area.



Erica Miller, wife of transplant surgeon Charles Miller, MD, and their daughters. In November, Elaine Berg becomes Donor Network executive director.

22 On June 1, 2000, the New York State Organ and Tissue Donor Registry is launched. In the same year, the Donor Network adopts an Internet-based system for organ allocation.

23 In 2001, our board of directors ratifies by-law and board structure changes. Dr. Lewis Teperman (NYU Medical Center) is named chairperson, (he had begun his term as president). Executive director Elaine Berg is named president and chief executive officer.

24 On April 23, 2002, New York Mayor Michael Bloomberg holds up his driver's license at a news conference at Bellevue Hospital to show he has consented to be an organ, eye and tissue donor. The Donor Network's Elaine Berg is at his side.



25 On June 11, 2003, our new Web site, www.donatelifeny.org is launched.

26 In 2004, the Donor Network joins the nation's other organ procurement organizations in adopting a single brand identifier, "DONATE LIFE." We become "A Donate Life Organization," and our logo is adapted to reflect this change. Also in 2004: Rocco Andriola, Esq. serves as our first non-surgeon chairperson; and we move on November 19 from 475 Riverside Drive to 132 West 31st Street.



27 On January 26, 2005, the New York Donor Network, announces a formal partnership with the National Minority Organ and Tissue Transplant Education Program (MOT-TEP). It is designed to empower African-Americans to develop education programs that get them involved in addressing the organ, eye and tissue donor shortage. In the same year, the Donor Network opens its own kidney preservation unit.



28 CELEBRATE DONATION AND LIFE

The Donor Network launches a groundbreaking series of hospital-centered regional campaigns in 2006. Donation and the Donor Registry is promoted among clinical and non-clinical hospital employees. The campaign theme is: "I donate life because I celebrate it." Also in 2006, Dr. Dale Distant, (SUNY Downstate Medical Center) is our chairperson.



29 Our 24/7 Donor Center opens June 1, 2007. The in-house communications operation fields all donor referrals from more than 100 hospitals. In the same year, the Donor Network begins to recover skin.

30 The New York State Donate Life Registry of legal consent is launched on July 23, 2008, following far-reaching legislation in Albany two years earlier. Peter Hutchings, a former chief financial officer of Guardian Life, is the Donor Network's chairperson.

A CONVERSATION WITH THOMAS RUSSELL, MD, FACS, EXECUTIVE DIRECTOR OF THE AMERICAN COLLEGE OF SURGEONS

To obtain a broader perspective about organ donation and transplantation as the New York Organ Donor Network marks its 30th Anniversary, *Martin Woolf* interviewed Dr. Russell.



DONATION AND TRANSPLANTATION: AN ASSESSMENT OF PAST SUCCESSES AND FUTURE CHALLENGES

When The New York Times asked you last year whether there is any operation now being performed that 40 years ago you never guessed could be done, why did you select transplantation?

Clearly, transplantation has got to be one of the huge areas of advancement. It was significant that Dr. Joseph Murray received a Nobel Prize for the first kidney transplants, initially in identical twins. Think about what we are doing today. It's an amazing field that not only affects the surgical workforce but also has tremendously influenced the whole area of immunology and the medical disciplines that revolve around transplantation.

You wrote a letter on behalf of the American College of Surgeons in support of the Living Kidney Organ Donation Clarification Act, which amended the National Organ Transplant Act to clarify that paired kidney exchange donation does not violate the prohibition of organ purchases. What, specifically, are ACS's thoughts on the value of this type of donation?

"Anything we can do to increase the pool of donors ... is a step in the right direction."

We think that it is ethical and are delighted that it became the law. Anything we can

do to increase the pool of donors and make a donor who is incompatible for one patient compatible with someone

else is a step in the right direction. As you know, there are other things that we don't think are ethical and we will, of course, weigh in on those issues as they are brought to the forefront.

Would you like to mention one or two that come to mind?

The selling of organs is something that we are very much troubled about. The commercialization of this part of surgery is something that we would be very concerned about. We also want to make sure that organs are appropriately distributed to people who need them. Should they be just used regionally or should they be distributed to those who need the organs the most?

Oftentimes at hospitals, medical staff feel uncomfortable with donation because they see the death of a patient as a loss — without acknowledging that an inevitable loss can have a positive impact in terms of saving the lives of others. How would you suggest we can more effectively get this message across?

That is a great question. I think what we have to do is to better educate the medical staff. It is important to have a champion in the hospital, someone with experience in donation who is committed to reminding the medical staff about the shortages and the need to identify a potential donor. When you have a patient who dies, it's emotional not only for the family but also for the caretakers. This situation adds to the complexity, and that is why you have to be educated and be supported with a team or the champion

in the hospital who does this kind of work on a regular basis.

You've said medical facilities should be graded on quality and accountability. How would you relate the question of transparency and trustworthiness to the organ donation and transplant field?

First of all, transplant is to be commended because there is a lot of transparency, much more than in other fields of surgery today.

The transplant centers have been mandated to keep track of their outcomes, and I think they've done a fine job in doing it. It's about keeping track of outcomes. To that end, the College is trying to get the public to understand what the whole surgical process is about, and I wrote a little book on this experience entitled *I Need an Operation, Now What?*

Actually, you state in your book that patients should feel free to ask their surgeons anything they want answered.

Yes. Although we may wear masks and work behind closed doors, it's not a secretive process. We do it with dignity and respect. And we do it with the idea of trying to help patients and maybe, for instance, allowing a patient to get off dialysis and have better kidney function because of an organ donation.

"Transplant is to be commended, because ... there is a lot of transparency."

These Transplant Recipients, Leaders of New York's Transplant Support Groups, Explain Why They Give Back and Send 30th Anniversary Greetings

The New York Organ Donor Network is able to accomplish its life-saving work in large measure because of the dedication of our many partners.

For example, it is the transplant support groups that help us on a consistent basis to get the word out about donation to every corner, every county of the greater New York metropolitan area—a region of 13 million people. We couldn't do it without the commitment of these volunteers, transplant recipients who are giving back by supporting the Donor Network and our life-saving mission.

Of course, they support donation while offering essential and invaluable support and resources for transplant recipients and those on the waiting list, as well as their families.

On the Beat is pleased to share with our readers these 30th anniversary messages from the presidents of the support groups, on behalf of their members. It is also an ideal opportunity for you to get to know who these dedicated people are.

Rudy MASRY

President of Transplant Support Organization (TSO), Westchester Chapter



“My lovely wife Ally gave me one of her kidneys on January 15th, 2003. I had been on dialysis for 18 months when I finally said yes to her testing. It means no more dialysis, the freedom to travel when-

ever and wherever we want without making arrangements for dialysis. It is very liberating. Ally and I plunged into working with the New York Organ Donor Network and made it our mission to register as many people as possible to be organ donors. To the Donor Network, from TSO, our heartfelt congratulations on your anniversary. Keep plugging.”

Joan GOTTESMAN

President of Transplant Support Organization (TSO), Staten Island Chapter



“I am a liver recipient who would have died seven years ago without a transplant. I was told there were tumors on my liver, and there was no way to control them. My twin sister, Helene Werger, donated part of her liver. I

was so lucky, and that's why I support the Donor Network's mission to save lives. Donation is such a simple thing to do, and it's maddening that people needlessly die. I have a wonderful life, and I can't believe the work the Donor Network is doing, what you have achieved and what you're aiming for. It's so life-changing.”

Sue NEGRIN

Co-President of Transplants Save Lives, Inc. (TSL), Rockland and Orange Counties



“In June, 2003, after surviving a major heart attack, I received the heart of a 14-year-old girl, thanks to the generosity of her family. My children, who were 3, 6, and 9 then, are now magnifi-

cent young adults whose lives, along with my wonderful husband's, I have been blessed to be a part of! My personal mission, along with the Donor Network, is to increase organ donor awareness and show people that transplantation works. Mazel Tov! to the Donor Network for 30 years of educating and servicing the Greater New York community.”

Mike SOSNA

President of Transplant Recipients International Organization (TRIO), Long Island Chapter; Chairman, Public Policy, TRIO International

“I was very lucky to receive the generous 'Gift of Life' on July 18, 1995. My father was a perfect match and gave me one of his kidneys. He saved my life. I am deeply grateful for this gift and I'm so pleased to offer peer support to hundreds of Long Island TRIO members. We partner with the Donor Network during events throughout the year to promote the "Donate Life" organ donor registry. I send my best wishes and sincere thanks on this special anniversary. Here's to the next 30 years saving many, many more lives. Keep up the great work.”



Lorraine DEPASQUALE

President of Transplant Recipients International Organization (TRIO), Manhattan



“I received a life-saving liver transplant on June 26, 1989 thanks to the generosity of a 28-year-old man whose choice to become an organ donor saved my life. Nineteen wonderful years have passed since my transplant, and I have become

an advocate for organ and tissue donation as a volunteer with the Donor Network since then and through my volunteer efforts as the president of TRIO Manhattan, a support group for transplant patients. I congratulate the Donor Network on their 30th Anniversary and their ongoing commitment to saving lives through education and awareness to increase donation.”

Debbie DELGADO-VEGA

Founder and CEO of Latino Organization for Liver Awareness (LOLA)



“We congratulate the Donor Network on its 30th Anniversary. As a former member of your board of directors, a liver transplant recipient and a volunteer, I take great pride in being a part of such an elite life-saving program. Our collaborative efforts throughout the many years meant reaching out to the general public, particularly the Latino community, and proved to be a huge success. Many lives have been saved, which includes several LOLA members and humbly my very own. In this spirit, we extend our deepest gratitude to the entire Donor Network team, its Board of Directors and most especially Elaine Berg, for her leadership and expertise. LOLA salutes the Donor Network for 30 years of excellence.”

La Presencia Latina Es Clave...

Durante los últimos 30 años, la Red de Donación de Órganos de Nueva York se ha destacado de manera significativa tanto en los sistemas clínicos como en la enseñanza pública. Al mismo tiempo, se ha avanzado la diversidad de sus empleados para reflejar la diversidad de las comunidades que servimos. Al comienzo de la organización, se empleaban solo 3 hispanos. Hoy contamos con 31 profesionales de origen hispanos o 17% de nuestro equipo.

Además la presencia de los hispanos se hace real tanto en la colaboración con las organizaciones Latinas como en la participación de los hispanos en los cuerpos administrativos y en la junta de directores.

El Sr. Rafael Paniagua, padre de una recipiente de corazón y anterior, el editor del periódico Viva del Daily News, fue uno de nuestros primeros miembros Hispanos en la junta de directores de la Red de Donación. Hoy contamos con el Dr. Manual Davalos-Rodriguez, cirujano del trasplante del hígado en el centro médico de Westchester quien a pesar de su horario ocupado, participa activamente en la junta de directores además de dar la mano en los esfuerzos de la educación de la comunidad.



Hemos tenido muchos socios - organizaciones hispanas que nos ayudan a promover la donación de órganos y tejidos en nuestra comunidad, inclusivo: The Hispanic Nurses Association, Association of Hispanic and Healthcare Executives, Hispanic Chamber of Commerce, The Hispanic Federation, Latino Organization for Liver Awareness, the Puerto Rican Institute for the Elderly, Asociacion Hispana de Profesionales de la Salud Inc, NY, Allianca Dominicana, 100 Hispanic Women y muchos más.

Además de nuestras propias campañas, participamos activamente en la campaña nacional llamada DONE VIDA según lo ven en esta [página]. Esta campaña simboliza un mensaje uniforme de la donación para todos los hispanos en la nación.

Con la ayuda de todas las organizaciones y los líderes hispanos en el área metropolitano de nueva york y por ser una cultura generosa, de todos los donantes, los hispanos forman el grupo más alto en donar órganos y tejidos de todos los grupos étnicos. Estamos muy orgullosos de las muchas contribuciones de nuestra comunidad hispana, en particular porque los hispanos si donan y no solamente reciben el regalo de vida.

Author Gretchen Rubin, a Prominent Lawyer, Joins the Donor Network Board of Directors



Gretchen Rubin has been appointed to the board of directors of the New York Organ Donor Network.

A lawyer who turned to writing, Ms. Rubin is currently working on *The Happiness Project* (forthcoming HarperCollins 2009) and has a popular daily blog, also called The Happiness Project (www.happiness-project.com).

Her previous books include the bestselling *Forty Ways to Look at Winston Churchill*; *Forty Ways to Look at JFK*; *Power Money*

Fame Sex, and *Profane Waste* (in collaboration with the artist Dana Hoey.)

Ms. Rubin received her undergraduate and law degrees from Yale and was editor-in-chief of the *Yale Law Journal*. She clerked for Justice Sandra Day O'Connor on the U.S. Supreme Court and served as a top adviser to Federal Communications Commissions Chairman Reed Hundt. For many years, she taught a seminar at Yale Law School and Yale School of Management.

Ms. Rubin lives in New York City with her husband, Jamie Rubin, and their two young daughters.

Transplant Surgeon David Leeser, MD, a Decorated Lieutenant Colonel, Is a Member of the Donor Network's Medical Advisory Board



David B. Leeser, MD, an assistant professor of surgery at NewYork-Presbyterian Hospital/Weill Cornell, has joined the New York Organ Donor Network's medical advisory board. A nationally renowned board certified transplant surgeon who specializes in pancreas and kidney transplantation, Dr. Leeser also performs islet cell transplantation.

Earlier this year, Dr. Leeser was part of the Weill Cornell transplant team that performed the nation's first three-way living-donor kidney transplant surgery chain that may revolutionize the organ transplant process in the United States and dramatically improve the opportunity for patients in need of kidney

transplants to find a compatible donor.

Dr. Leeser was previously the chief of kidney and pancreas transplantation at Walter Reed Army Medical Center. He is a Lieutenant Colonel (retired) from the US Army Medical Corps, and he was deployed in support of Operation Iraqi Freedom on two separate occasions. Lt. Colonel Leeser was decorated with the Bronze Star Medal and the Meritorious Service Medal.

Dr. Leeser received his medical degree from Temple University School of Medicine. He completed his internship in General Surgery at Walter Reed Army Medical Center in Washington DC and his residency training at Temple University Hospital. Dr. Leeser completed his training in Abdominal Organ Transplantation at the University of Maryland in 2004.

SUPPORTING PUBLIC EDUCATION ABOUT DONATION IN CELEBRATION OF A HEART RECIPIENT'S NEW LIFE

After staring death in the face not that long ago, and now brimming with energy and good health, heart transplant recipient John Acquaro has presented the New York Organ Donor Network with a check for more than \$16,500.

The money was raised to benefit the

Donor Network at a summer fundraiser hosted by The Friends of Watch Hill on the Sunset Deck at the Watch Hill Marina, Fire Island, NY.

The fundraiser, which included a silent auction, celebrated the first anniversary of Acquaro's heart transplant, and to help support much-

needed public education about organ, eye and tissue donation.

Acquaro, a Donor Network volunteer, certainly confirmed his return to good health as a Team Liberty athlete at the NKF Transplant Games in Pittsburgh, PA in July.



HANDING OVER THE CONTRIBUTION: From left, Elaine Berg, Donor Network president and CEO; John Acquaro and his wife, Karen; Donor Network manager of volunteers, Kathryn Dwyer, and Julia Rivera, director of communications.



TO MARK his life altering event—his heart transplant on April 1 last year—John Acquaro renamed his boat “Time Bomb Defused 4-1-2007.”

Financial Contributions Received by the New York Organ Donor Network

The New York Organ Donor Network gratefully accepts financial contributions via credit card or personal check. These funds are used for organ, eye and and tissue donation public education initiatives. You can make your financial contribution directly online at www.donatelifeny.org. For more information, call Ameeta Bahia at 646-291-4457. We wish to thank the following for their support:

In Memory of James T. McGovern: Doris McGovern

In Memory of Sarah Lynn Plunkett: Mr. and Mrs. Timothy J. Plunkett

In Memory of Geraldine Smalls: Mary DeLeonardis and the Wyandanch Teachers Association

In Memory of Vincent Crimini: Mr. and Mrs. Louis Ruggiero; Mr. and Mrs. Joseph Kressaty (Ruggiero); Steve Belich

In Memory of Laura Kantakis: Mary K. Patterson and Family; Doreen Moses, Ann Marie Moses, Cornelia Sera, and Rosemarie Johnson

In Memory of Robert G. Richardson: Andy Spitz; Christine Cahill; Katina Goldman; Mr. and Mrs. Duane S. Oetjen; Lawrence Lissauer; Mr. and Mrs. August A. Oetjen, Jr.; Susan A. Rinaldi; Patty Chin and Dorothy Chin; Mr. and Mrs. Thomas Tallman; Mary Randall; Mr. and Mrs. Alton Riley; Mr. and Mrs. Robert T. Buzga; George M. Levy, Esq.; Finkelstein & Partners, LLP, Jacoby & Meyers, and Fine, Olin & Anderman; Nancy Morgan; Lynn Eberle and the Hopevale Teacher's Association; Anna Griffin

In Memory of Richard Mullane Jr.: Tom Vicale

In Memory of Rocco Vito Cea: Mr. and Mrs. Jason Cea

In Memory of Paul Ornstein: Sheila L. Ornstein

In Memory of Arlene Salvador: Mr. and Mrs. Joseph Delloiacovo; Diane Molleur; Ceal Sweeney; Susan Rourke; Jennifer Soodek; Mr. and Mrs. Ron L. Manske; Mr. and Mrs. Thomas W. Giard, Jr.; Judy, Dawn, Lisa, Peggy and Karen at GES

In Memory of Pasquale Andriola: Sally J. Rogers; Mr. and Mrs. Jacques Dufour; Leslie T. Giglio; Joan Ditur; Mr. and Mrs. Michael Rufrano; Barbara Vargas; Anne Pellett; Mark D. Marcellus; Steve Bibas; John Ng; Bonnie Lane; Phyllis K. Wendelboe; Port Washington School District's Association of Principals and School Administrators; Kim Kirzner, Esq.; Kevin Natale, David Klein, Brian Moody, Deborah Dyckman, Ken Reiser, John Aquaro, Steven Horowitz and Scott Singer; Denise F. Attonito; Christopher T. McKinney; Port Washinton Association of Educational Secretaries-Sunshine Fund (PWAES); Robert T. McManus Jr. and Family; Mr. and Mrs. Robert J. Delapina; Don Leavy; Mr. and Mrs. Martin D. Polevoy; Mr. and Mrs. George Karman; Marianne Evangelou; Mr. and Mrs. Christian Matthews; Sigrid M. Stabenow; Mr. and Mrs. Dominick Rutigliano and Family; Pasquale Cestaro III and Family; Mark Bevilacqua and Ann Mathisen; The Paul D. Schreiber High School English Department; L'Abbate, Balkan, Colavita & Contini, LLP; Patricia M. De Respino and Lisa M. Bennett; Mr. and Mrs. Jesse L. Smith, Jr.; Mr. and Mrs. Steven M. Schlusell

In Memory of Frank Dellino: The Employees of the City Waste Services of New York

In Memory of Anthony J. Garrison: Mr. and Mrs. Bill Garrison

In Memory of Kevin Doyle: Kathleen Brandt

In Memory of Ila Ozero: Mr. and Mrs. Edward Los and Mr. and Mrs. Stan Kwiatkoski; Kathleen Warrenchuk+

In Memory of Sylvio Marceda: Mr. and Mrs. John Slapp and Family; Marion Galla; Edward R. Mulato; Mr. and Mrs. John Datre; Mr. and Mrs. James Travers; Judge and Mrs. Gregory W. Carman; Mr. and Mrs. Michael Borut; C. Francis Cotter, MD; Mr. and Mrs. Vincent F. Accardi; Mr. and Mrs. Michael V. Accardi; B. Suzy Diggle-Fox; Scott Drayer

In Memory of Mary Jean Wilkinson: Howard W. Jaffie; Mr. and Mrs. Paul Schwartz; Patricia L. Falco; Mr. and Mrs. Joe Iannuzzi; Mrs. Thomas A. LaPanne, Jr.; Mary C. Moore; Marie Ferrigno

In Memory of Derek Duane Koncelik: Karen Phua

In Memory of Alan Salko: Marilyn Yablon

In Memory of Paul Turco: Rose Marie Turco

In Memory of Maria Vasquez: Julia E. Rivera

In Honor of Philip Bekerman: Mr. and Mrs. Philip Bekerman; Mr. and Mrs. Allen Resnick; Mr. and Mrs. Erik Weinstein and Family.

In Honor of John Acquaro: Gino Cella and Jazz Audio, Inc.; Mr. and Mrs. Frank Sconzo; Dr. Paul C. Carey, DDS; Mr. and Mrs. Joseph Pennisi; Mr. and Mrs. Michael Ambuske; Eileen Schooley; Mr. and Mrs. Kenneth Scheriff; Charles A. Szeglin; John L. Szeglin; Mr. and Mrs. Raymond McCarthy; Anthony Mauro and the Friends of Watch Hill at Fire Island, Inc.

In Honor of Frank Stankiewicz: Mr. and Mrs. Jennifer Marconti; Rick Coronato; Jane Zemba; David and Margaret Tuthill; Jeff Hoogsteden and Marissa Shultz; The Velocci Family; Mr. and Mrs. M. Zawlocki; Mr. and Mrs. Richard Boyle

We also wish to thank the following for their contributions: Grand News Marketing, Inc.; Colin Campbell and the Orange and Rockland Funeral Director's Association; Diabetes Transplant Fund, Inc.; Bethany Mathewson and Merrill Lynch (Garden City Office) Employees; Kerri Kleiner; Michael and Hanneke Enthoven; Employees of East Side Custom Choppers.



**New York
Organ Donor
Network**

On the Beat is published by the New York Organ Donor Network, the federally designated nonprofit organ procurement organization in the greater New York metropolitan area. The Donor Network is responsible for the recovery of organs, eyes and tissues for transplantation, and the education of health care professionals and the general public.

Chairman, Board of Directors:
Peter Hutchings
President/CEO:
Elaine R. Berg
Chairman, Medical Advisory Board:
Lloyd E. Ratner, MD
Director of Communications:
Julia E. Rivera
Communications Manager/On The Beat Editor:
Martin J. Woolf
132 West 31st Street, 11th Floor,
New York, NY 10001
Phone: 646-291-4444
24-Hour Donor Center: 800-GIFT-4-NY
Fax: 646-291-4600
E-mail: Communications@nyodon.org
www.donatelifeny.org

Non Profit Org.
US Postage
PAID
Hamburg, NY
Permit No. 159

132 WEST 31ST STREET
11TH FLOOR
NEW YORK, NY 10001-3406
www.donatelifeny.org



ALL 5 NEW YORK CITY BOROUGH PRESIDENTS BACK DONOR NETWORK'S REGISTRY DRIVE FOR MINORITY AWARENESS DAY

This year's National Minority Awareness Day for organ, eye and tissue donation came with an extra punch in New York City: All of the city's borough presidents pledged their support for the New York Organ Donor Network's campaign that calls upon all people of color to save lives by enrolling in the New York State Donate Life Registry.

At ceremonies across the city, timed to impact the August 1 day of awareness, the borough presidents met with Donor Network employees, donor family members, and transplant recipients who repre-

sent many of New York's racial and ethnic communities.

Karen Cummings, the Donor Network educational specialist who arranged the meetings, said, "Of the more than 100,000 individuals awaiting organ transplants nationwide, over 53,000 are people of color. That's why it was so heartening to hear the borough presidents say that awareness is just the first step. Awareness needs to be followed by action—the act of enrolling in the registry—because so many lives are at stake."



MANHATTAN: From left, Elaine Berg, Donor Network president and CEO; Manhattan Borough President Scott Stringer; Sau Hwang, a liver recipient; and John Morais, a kidney recipient.



QUEENS: From left, Joseph DiMartino, a liver recipient; Queens Borough President Helen Marshall; Grace DiMartino, Joseph's wife; Karen Cummings, a Donor Network public and professional educational specialist; and Mark LaRose, a kidney and pancreas recipient.

Check out
www.donatelifeny.org

☐ **NEW YORK CITY BOROUGH PRESIDENTS SUPPORT DONATION**

Full story and photos

☐ **CALENDAR OF EVENTS**

Including National Donor Sabbath in November 2008 and National Donate Life Month in April 2009

☐ **ENROLL IN THE NEW YORK STATE DONATE LIFE REGISTRY**

