☐ NewYork-Presbyterian
☐ Weill Cornell Medical Center

Living Donor Kidney Center

# The Gift of Life

MAKING AN INFORMED CHOICE

### KNOWING YOU MADE A POSITIVE IMPACT ON SOMEONE'S LIFE **IS SIMPLY AMAZING**

Cover photo: Both altruistic kidney donors, Sharon was inspired to donate by a friend, while Ann participated in a 15-person Kidney Paired Donation chain. Ken donated a kidney to his sister-in-law, describing it as a privilege.

### The mission of the Living Donor Kidney Center at

NewYork-Presbyterian Hospital/Weill Cornell Medical

Center is to empower people to make an informed

choice regarding living kidney donation, and to

educate potential donors, past donors, healthcare

professionals and the public about living donation.

### Expanding Opportunities...Changing Lives.

For countless people throughout the region and the nation, a kidney transplant holds the only hope for a second chance at life. When this powerful "gift of life" is offered by another living person, lives are transformed in an amazing way.

At NewYork-Presbyterian/Weill Cornell Medical Center, we are fully committed to providing every possible opportunity for transplantation, and to advancing the science of donation for the benefit of both donors and recipients. The Transplant Program at NYP/Weill Cornell is among the largest in the country, and it is the only center in our area that features a combination of low waiting time, high numbers of transplants and excellent survival rates.

In harmony with our transplant program, our Living Donor Kidney Center practices living donation in a comprehensive, multidisciplinary way for the donor. Our kidney donor team is one of the most experienced in the United States. At our center, living donation is done whenever possible, enabling greater numbers of patients to receive kidneys that function better and last longer. The process begins with fully educating our potential donors about the physical and emotional aspects of donation, and continues by guiding those who wish to donate through every step of the process.

We work in cooperation with the Rogosin Institute, one of the top comprehensive renal centers in the nation, to provide access to the best in medical and surgical expertise. As a national leader in expanding opportunities for transplantation, we've developed technologies and approaches that are changing patient care in the transplant field. And at the heart of it all, we maintain an unwavering focus on the health and well-being of our donors and recipients while embracing the remarkable journey that living donation enables. NYP has the longest history of kidney transplantation in New York. For three years running, our kidney transplant program was one of a handful in the country and the only program in our region to receive the Kidney **Transplant Excellence** Award from Health-Grades in recognition of our excellent outcomes.

The Rogosin Institute

### **Historical Steps in the Transplant Program**

1963:
Our first living donor kidn
transplant – also the first
New York State

1984:

We begin to offer hand-assisted, minimally invasive donor nephrectomy (kidney removal) as an alternative to traditional, open surgery Our 1000th kidney transplant

Our 2000th kidney transplant We begin a purely minimally invasive approach for donor nephrectomy

#### 2001: We introduce steroid-free

maintenance immunosuppression regimens and molecular monitoring tools

2005 Our 1000th donor nephrectomy

### Our 3000th kidney transplant

2008: We participate in our first kidney paired donation experience as a founding member center of the National **Kidney Registry** 

The first single-site donor nephrectomy is performed at

Our living donor kidney transplant program is now the second largest in the U.S.

our center

2010: Our 1500th living donor transplant

#### 2012: Our 4000th kidney transplant

2011: We celebrate the foundation and launch of the Living Donor **Kidney Center** 

### I'VE NEVER HAD ANY DOUBT IN MY MIND About Donating

After seeing her friend on dialysis, Diane was moved to make a difference by becoming her kidney donor.

### Why Living Donation?

Living donation has had a major impact on the kidney transplant field, expanding hope for those awaiting a life-saving transplant, and creating an enormous opportunity for others to give the gift of life to a friend, loved one or even someone they don't know.

An increase in living donor kidney transplants holds the only hope for survival in many cases. More than 90,000 people are currently on the waiting list for kidney transplantation. At the same time, the availability of deceased donor organs has remained stagnant over the past few years, a trend that will likely continue.



Living donation not only increases the number of kidney transplants and saves more lives, but it also provides the following benefits:

- A life-saving transplant can take place much sooner than waiting for a deceased donor organ.
- Living donor organs function better and longer than deceased donor organs.
- Recipients generally recover more quickly with a living donor organ.
- The transplant can be scheduled at a convenient time for the donor and recipient.
- Often, transplants can be scheduled before dialysis is required (pre-emptive transplantation), which means better outcomes for the recipient.
- Patients on dialysis are off sooner than those on the waiting list, so they often receive a transplant when they are less ill.
- Being off the waiting list sooner can potentially shorten the time for those still waiting.

In the United States today, approximately 550,000 people have reached end stage kidney failure and require dialysis to survive or have received a kidney transplant. By 2020, this number is expected to increase to 750,000.

### Graft Half-Life\*

Kidney transplants from living donors last much longer than those from deceased donors.

**Source:** 2010 OPTN/SRTR Annual Data Report, Published in American Journal of Transplantation 2012 12 (Suppl 1)

\*For transplants that survive for the first year after transplant (in 2007)



NewYork-Presbyterian has more Top Doctors than any hospital in the U.S., according to the America's Top Doctors survey by Castle Connolly. We also rank among America's Best Hospitals by *U.S. News and World Report* and are the #1 hospital in New York.



At NYP/Weill Cornell, we are proud to offer skilled living donor and transplant teams with surgeons who remain on the cutting edge of surgical technology. In fact, our surgeons have pioneered the introduction of new technologies in our region, including the removal of a donor kidney using only one incision in the navel (belly button). We offer progressive therapeutic options not generally available through other transplantation programs, with lower rejection rates and excellent survival rates compared to national standards. In addition, our Transplant Research Program ranks among the best in the world, allowing us to integrate clinical research with basic science and bring those innovations directly to our patients' bedsides.

As a national leader in experience with living donor kidney transplantation, we have a dedicated team of specialists whose sole function is to care for the living donor and ensure that the donor's best interests are protected. This multidisciplinary team includes surgeons, nephrologists, transplant coordinators, nurses, social workers, nutritionists, financial coordinators and donor advocates who work with potential donors throughout the process. Kidney donors are cared for by the same group of professionals from the moment they step forward as a potential donor through the follow-up that occurs long after donation.

Education and support are important components of our program, and a multitude of resources are available to both donors and recipients before, during and post-care. We fully understand and appreciate the complexities of the donation process, and we approach each potential donor and recipient with compassion and understanding, every step of the way.

### **Pre-Emptive Transplantation**

We're committed to enabling pre-emptive transplantation (transplant before a patient needs dialysis) to further improve patient outcomes. In fact, we perform about 48 percent more pre-emptive transplants than the national average.

**Source:** Internal Data for 2011 Transplants; 2010 OPTN/SRTR Annual Data Report



### SAVING LIVES COME IN MORE WAYS THAN YOUGAN IMAGINE



his childhood friend Joseph, a Suffolk County police officer.

### THE LIVING DONOR KIDNEY CENTER MADE A DIFFERENCE FOR OUR FAMILY

Living donation is a family affair for Brian and his wife Evette, who each donated a kidney to twin sons Alan and Brian.

### The Choice of Becoming a Donor

#### Who Can Donate?

Most people over age 21 (in some cases, over age 18) who are healthy and have normal kidney function and anatomy can become kidney donors. A donor does not necessarily have to be a family member of the recipient. Thanks to advances in surgical techniques that enable minimally invasive surgery for donors as well as improvements in anti-rejection medications, both related and unrelated people can now donate.

Generally, unrelated donors have some emotional relationship with the recipient. However, altruistic donors – people who wish to donate a kidney but do not have a specific recipient in mind – now represent an increasing proportion of living donors. In addition, due to the availability of groundbreaking Kidney Paired Donation programs, donor and recipient pairs that are incompatible can "swap" with other donors and recipients with whom they match. At the Living Donor Kidney Center, we provide more opportunities for patients that come forward with incompatible donors than other hospitals in the region.

A good living donor is one who is motivated

To donate a kidney, potential donors must be free of major diseases, such as diabetes, severe heart disease and certain forms of high blood pressure. They should not have recent cancer, a history of certain cancers like breast cancer or melanoma, liver disease or a history of multiple kidney stones. In addition, they should be living in a stable environment with social supports and have medical insurance before donation. one who is motivated to donate, is free of coercion, is healthy and has normal kidney function. The person must be both medically and psychosocially fit, and must understand the donation process.

Living Unrelated Donor Transplants

At NYP/Weill Cornell, we perform about 35 percent more living unrelated donor transplants than other centers in our region or nationally.

Source: SRTR Report, January 2012



#### **The Donor Evaluation Process**

At the Living Donor Kidney Center, the health and emotional wellbeing of the living donor is our first priority. While an ultimate goal is, of course, to help the intended recipient, we don't want to negatively impact the health of another individual during the process.

In general, people are born with more kidney function than they need to be healthy. Even when a kidney is donated, otherwise healthy individuals usually have more than enough kidney function they need to remain healthy, since the remaining kidney is able to compensate.

Our living donor team, which includes a nephrologist, surgeon, transplant coordinator and social worker, evaluates a potential donor independently of the transplant candidate's team. Each potential donor works with a donor advocate who serves as an advisor and liaison throughout the process.

Potential donors receive what is probably the best medical evaluation of their lives, assessing both short-term and long-term medical risk. This process ensures that the potential donor is healthy enough to donate and is not at high risk for developing diseases that could impact the function of their remaining kidney. Components of the medical evaluation include general medical history, social history, a physical exam, a kidney-focused exam, general laboratory tests, kidney-focused laboratory tests, immunological testing (blood type and crossmatch compatibility), metabolic-focused testing (to look for issues such as diabetes or high cholesterol), anatomic assessment of the kidneys and their blood flow, screening for transmissible diseases (such as HIV and hepatitis) and cancer screening.

We also conduct a comprehensive social evaluation to address all questions and concerns and be certain that donation fits well within a potential donor's lifestyle and preferences. The psychosocial evaluation is performed by a social worker, with consultation from a psychiatrist if indicated. It addresses issues such as motivation guiding the decision to donate, the ability to understand the risks of donation, the availability of support during the recovery period after donation, the financial impact of donation, the impact of donation on insurability and other important issues. In summary, our living donor team ensures that the potential donor:

- Is not at risk for developing kidney disease
- Has adequate kidney function to have a healthy life with one kidney
- Fully understands the donation process and is not taking on psychosocial, emotional or socioeconomic risk by donating
- Does not feel coerced into donating

## BEING A LIVING DONOR MADE THIS A PROUD MOMENT IN MY LIFE

Ariel donated his kidney to his cousin-in-law, Roberto, creating a bond that connected them like brothers.

## THE "GREATEST TEAM IN THE WORLD" TOOK GOOD CARE OF ME

After receiving a kidney through a kidney exchange, Evan gives his experience with the team two thumbs up.

### **Surgery and Recovery**

#### **Advances in Surgery**

Over the past 50 years, there have been great advances in the types of surgery available to kidney donors. Until the mid-1990s, kidney removal was performed with traditional, open surgery under general anesthesia and with a large incision. This type of "open nephrectomy" is now quite rare.

Today, most donor kidneys are removed in a procedure called **laparoscopic donor nephrectomy.** This minimally invasive surgery uses a tiny camera and instruments to remove the kidney through three or four small incisions in the abdomen. A variation of this procedure is hand-assisted laparoscopic nephrectomy, in which one of the incisions is slightly larger to accommodate the surgeon's hand. Compared to traditional surgery, laparoscopic nephrectomy results in a faster recovery time, a shorter hospital stay, less pain and minimal scarring.



The Weill Cornell

Our latest surgical advance is **laparoendoscopic single-site donor nephrectomy,** in which only a single incision is made through the navel. With minimal risk and excellent outcomes, this type of nephrectomy results in an even quicker recovery and an improved cosmetic result.

#### **The Recovery Period**

After donating a kidney, most living donors remain in the hospital for just one to two days after their surgery. The most common issue experienced by donors is tenderness, itching or pain at the site of the surgical incision. Donors may also experience gastrointestinal upset. Donors should avoid heavy lifting (greater than 10 pounds) for about four weeks after the surgery.

Most donors who work in an office setting can return to work within two to three weeks of their surgery. For donors with more physically demanding professions, the time frame may be four to six weeks.

#### **Follow-Up Health Assessments**

Transplant centers are required to follow living kidney donors for at least two years following the donation surgery. Donors should be seen by their surgeon at some point between two to six weeks after the surgery, and then at six, 12 and 24 months by the donor team. If donors cannot visit our center, they may see their own primary care physician, who can then forward the pertinent information. In the longer term, donors should have annual checkups with their primary care physicians. Transplant Program was the first center in New York to perform laparoendoscopic single-site donor nephrectomy for a living donor in 2009, and has quickly become a national leader in this approach.

### Making an Informed Decision

People who are considering becoming a kidney donor must carefully weigh the potential risks and benefits of being a donor when making their decision. Although the surgery itself is a major consideration, other factors such as medical risks, the cosmetic result and socioeconomic and emotional factors also play an important role in the decision-making process.



When a potential donor fully understands the donation process, undergoes a thorough evaluation and makes a decision to move forward, it is truly one of the most amazing gifts a person can give to another human being. As with any surgery, donor nephrectomy carries a small amount of risk. For example, donors could experience pain, infection, a blood clot or a reaction to anesthesia. We fully review potential risks and important considerations to ensure that donors are comfortable with their decision to give the gift of life, and our team members provide support throughout the process.

On the financial front, there are many costs covered by the recipient's insurance. There also are some non-covered expenses, some of which may be tax-deductible. These include hotel and travel expenses, lost wages and child care. Our financial coordinators help donors know exactly what to expect in this area.

#### **Life-Changing Benefits**

Many studies have been performed to assess the risks of kidney donation on the people who made the choice to become a donor, leading the medical community to believe that:

- The risk to a donor's physical health is minimal in both the short term and long term, in terms of kidney function, blood pressure and the donor's lifespan.
- Compared to the general population, kidney donors tend to have higher quality of life scores after donation.
- Donors have similar or improved psychosocial health after donation.
- The overwhelming majority of donors would choose to donate again.

Donation is a tremendous, life-changing event for both the donor and the recipient. The benefit derived from donating a kidney to someone in need is a very personal insight that is only known by the living donor. Each donor has a unique experience as they go through the incredible journey of donating a kidney.

# THANKS TO A VERY Special Person, My **Life back again**

Andreia feels amazing and is back to doing the things she loves thanks to her husband Marc's donation to a kidney exchange.

### A FAMILY EXCHANGE PROGRAM PROVIDED A PERFECT MATCH

Corrie donated a kidney through a kidney exchange, enabling his mother Margot to receive one.

### Maximizing Opportunities Through Kidney Paired Donation

Cluster #1 Cluster #2 Cluster #2 Cluster #2 Cluster #3 Cluster #3 Cluster #3 Cluster #3 Cluster #3 Cluster

### Donor Chain

KPD opens new doors to kidney transplantation. In fact, if compatible donor-recipient pairs were to routinely enter the KPD database, the possibilities of better-matched kidney transplantation nationwide would be endless. At the Living Donor Kidney Center, we continually seek innovative ways to break down barriers and increase access to transplantation. One of the shining examples of this commitment is our use of Kidney Paired Donation (KPD).

About one-third of patients needing a kidney transplant who come forward with potential donors are incompatible with their donors due to blood type or immune system reactivity. KPD uses a sophisticated registry to assist these pairs in finding another donor and recipient with whom they can "exchange" kidneys, allowing a transplant to take place. Compatible donor and recipient pairs can also participate in this program to help improve the match for themselves and another pair.

The concept of KPD is not limited to two pairs. It has progressed over the past several years from simple donor and recipient swaps at one transplant center to complex, cross-country kidney paired donations, called kidney chains. In fact, at the Living Donor Kidney Center, we recently participated in an extremely complex kidney chain involving 11 donor/recipient pairs. The process was an incredible effort among the transplant teams, the recipients and the donors who looked beyond their own personal situations to save the lives of 11 others.

Since 2008, we have performed numerous KPD transplants by working with the National Kidney Registry (NKR), which was founded by the father of one of our young transplant candidates at NYP/Weill Cornell. In addition to being a founding member center, we have been the most active transplant center within NKR. We are also one of a few transplant centers to be selected to participate in the KPD Pilot Program of the United Network for Organ Sharing, whose goal is to develop a national matching program.

### Kidney Paired Donation (KPD) by Year at NYP/ Weill Cornell

Since the origin of KPD in 2008, we've performed increasing numbers of living donor KPD transplants each year, enabling greater numbers of patients to receive life-saving transplants.

Source: Internal Data



### **Further Advances in Care**

Just as living donation has made an enormous difference for kidney transplant recipients, we continue to extend the lives of these patients by advancing the science of transplantation and developing cutting-edge approaches to care.



since the inception of

our program, and are

comparing traditional

versus single site

laparoscopic donor

nephrectomy. Moving

forward, more prospective

clinical trials and donor

follow-up registries are

being developed.

completing a clinical trial

For example, in our core transplant immunobiology lab, we've developed novel molecular techniques for diagnosing rejection in our transplant recipients. Biomarkers provide an index of any rejection activity via the urine or blood, providing real-time information in a convenient, non-invasive way – which will hopefully replace the need for a kidney biopsy.

Thanks to these molecular tools, we can now individualize each our research also extends to living donors. Currently, we are retrospectively reviewing the outcomes experienced by donors

Amazingly, about 80 percent of our kidney transplant recipients now go home off of steroids. Since 2001, more than 1,500 patients have received our steroid-sparing medication regimen. The acute rejection rate seen in our patients is less than 8 percent, which is below national standards. Even patients who are considered high-risk for rejection due to their ethnic background or the type of kidney they receive have done well with this regimen. Benefits to our patients also include better lipid profiles and lower rates of diabetes after transplant, which may help to reduce cardiac disease risk factors after transplant.

In addition to these efforts, we're conducting research on various other topics, including clinical trials of new medications that suppress the immune system. We are also better enabling kidney transplantation for patients with HIV, hepatitis C and/or hepatitis B infection, as well as kidney transplantation for older adults.

### **Next Steps**



If you wish to talk to a team member about living donation, schedule a transplant evaluation or be evaluated as a kidney donor, please call us at 212-746-3099.

As part of our robust support system, our website offers extensive information about the kidney donation and transplant process, including a Living Donation Resource Center. Please visit us online at: **cornellsurgery.org/transplant**. NewYork-Presbyterian Hospital, based in New York City, is the nation's largest not-for-profit, non-sectarian hospital, with 2,353 beds. The hospital has nearly 2 million inpatient and outpatient visits in a year, including more than 220,000 visits to its emergency departments — more than any other area hospital. NewYork-Presbyterian provides state-of-the-art inpatient, ambulatory and preventive care in all areas of medicine at five major centers: NewYork-Presbyterian Hospital/Weill Cornell Medical Center, NewYork-Presbyterian Hospital/Columbia University Medical Center, NewYork-Presbyterian/Morgan Stanley Children's Hospital, NewYork-Presbyterian/The Allen Hospital and NewYork-Presbyterian Hospital/Westchester Division.

One of the most comprehensive health care institutions in the world, the hospital is committed to excellence in patient care, research, education and community service. NewYork-Presbyterian is the #1 hospital in the New York metropolitan area and is consistently ranked among the best academic medical institutions in the nation, according to U.S. News & World Report. The hospital has academic affiliations with two of the nation's leading medical colleges: Weill Cornell Medical College and Columbia University College of Physicians and Surgeons.



NewYork-Presbyterian/ Weill Cornell Medical Center 525 East 68th Street New York, NY 10065

cornellsurgery.org/transplant









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