

LIVING DONOR GUIDE

THE
Ernie
BOMBECK
PROJECT

A GUIDE TO BECOMING A LIVING KIDNEY DONOR



Save a life
It's in you



THE ERMA BOMBECK PROJECT

The life force of Erma was always optimism and hope. It sustained her throughout her family life and her career – and drove Erma in her later years when she was ill. She was convinced that out there, somewhere, were people so selfless and families so compassionate they would commit to the ultimate act of love – a gift of life.

Her words were, “The real life heroes and heroines are the patients who are hanging tough and the donors who are faced with the hard decisions and give humanity a good name. We are about preserving life. It is indeed a gift.”

The Erma Bombeck Project carries Erma’s vision forward. While non-living donors are the mainstay for the majority of organ transplants, The Erma Bombeck Project’s goal is to also raise awareness and increase the number of living donors.

It is a tall order to be sure. But so is the need. We urge you to register to be an organ donor, and share the message of living donation. Save A life. It’s in you.

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THE BENEFITS OF LIVING DONATION

It takes a special person to serve as a kidney donor for a family member or friend – they are truly heroes. Living donation offers significant advantages, including improved transplant-kidney and patient survival rates (compared with kidneys from deceased donors) and shorter waiting time to transplantation for the recipient. However, it's important that you fully understand the process and the potential risks involved. This information booklet will provide you with an overview of the evaluation process and the donor procedure. It will also address frequently asked questions, including questions about recovery, medical costs, and follow-up care. We hope that this is just the first step in your journey of kidney donor education, and that regardless of your personal choice at the end of the learning process, that you share the experience and knowledge with others.

THE GIFT OF LIFE,
IT'S IN YOU

Donating a kidney is a completely voluntary decision. It is your right to withdraw from this process at any time.



KIDNEY

URETER

BLADDER

Living Kidney Donation Makes a Difference

A kidney received from a living donor really is a gift of life. Research has shown that, overall, both the lifespan of a kidney and a patient's survival rate are greater when a donation is from a living donor (vs. from a non-living donor).

Dialysis

Dialysis is a procedure that removes waste products from your body that are normally eliminated by the kidneys. There are two types of dialysis: hemodialysis and peritoneal dialysis. Hemodialysis is performed multiple times a week and takes three to five hours each session, while peritoneal dialysis must be done daily. People on dialysis may experience discomfort, fatigue, and other complications of kidney failure and dialysis.

Transplant

A kidney transplant is a surgical procedure performed to replace the diseased kidneys with a healthy kidney from another person. While transplant may provide better quality of life and greater life expectancy for a recipient (compared to dialysis), it's essential that both donors and recipients understand the procedure and are aware of the risks.

Remember: dialysis and transplant are treatment options for kidney failure, not cures.

Region	Donor Type	Years Post Transplant	Survival Rate of Kidney
U.S.	Non-Living	1 Year	89.0
U.S.	Living	1 Year	95.1
U.S.	Non-Living	3 Years	77.8
U.S.	Living	3 Year	87.8
U.S.	Non-Living	5 Year	66.6
U.S.	Living	5 Year	79.8

Organ Procurement and Transplantation Network

Kidney Kaplan-Meier Graft Survival Rates For Transplants Performed : 1997 – 2004

Based on OPTN data as of March 8, 2013

<http://optn.transplant.hrsa.gov/latestData/rptStrat.asp>

CONSIDERING LIVING KIDNEY DONATION

Ernie THE

B O M B E C K
P R O J E C T

Unfortunately, there are not enough organs to meet the increasing demand. As of January 2014, more than 99,000 people were on the waiting list for a kidney in the US, and that number increases every year. In 2013, over 15,400 kidney transplants were performed in this country; over 10,000 kidney transplants were from deceased donors, while more than 5,000 were from living donors. As the waiting list and the waiting game – grows, more people are exploring the option of living donation. A living donor transplant can shorten the wait time from years to months.

REGISTERING SAVES LIVES

Whether you decide that living kidney donation is right for you, registering to be a non-living donor can save a life, changing the life of not only the patient, but that of their family and loved ones. Visit donatelife.net today for more information and to register.

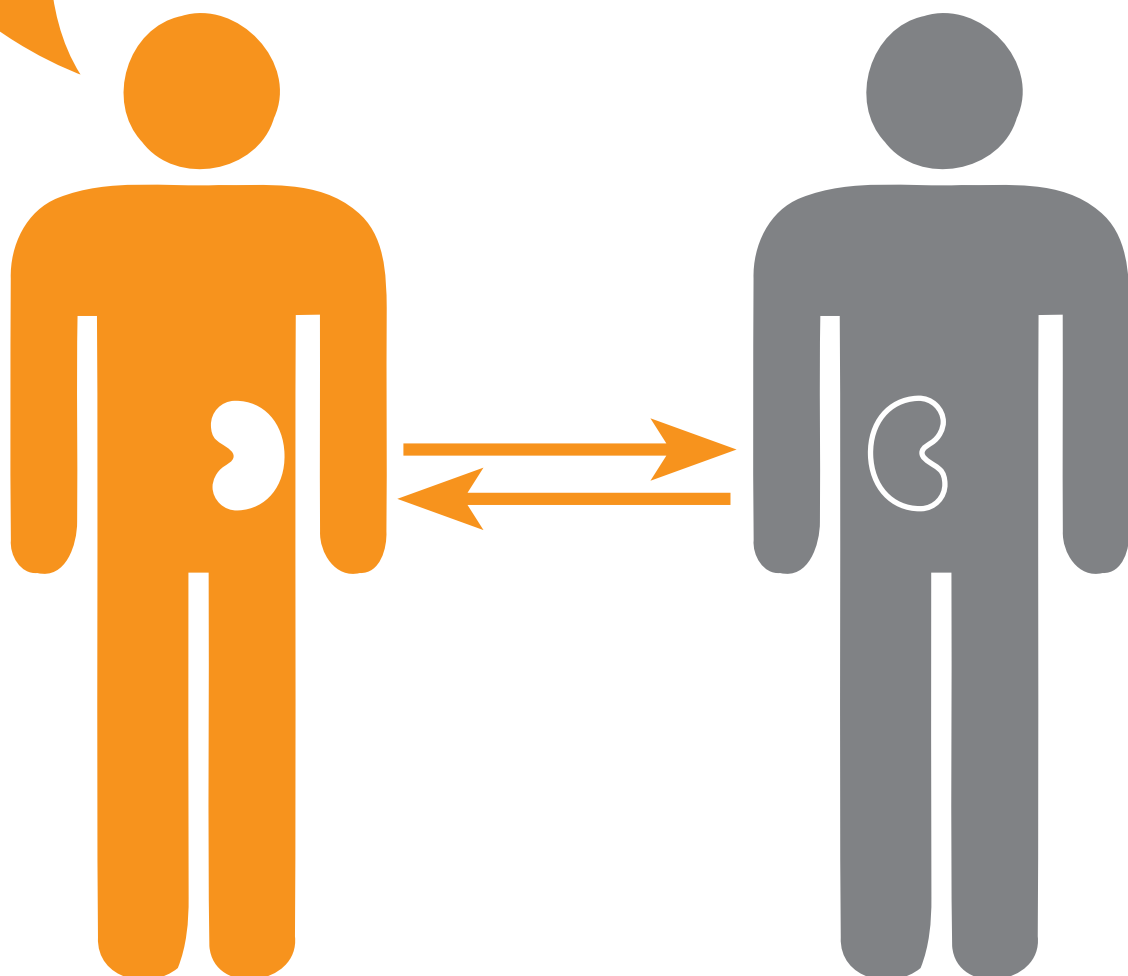
Arizonans can visit DNAZ.org directly for local events, registration and resources.



CROSSMATCH

As part of your screening, the transplant center may conduct a blood test that determines compatibility between donor and recipient. A positive crossmatch indicates incompatibility. A negative crossmatch indicates compatibility.

"We are rarely presented with an opportunity to make such a tremendous difference in someone's life."
—Gary, Living Kidney Donor



THE EVALUATION PROCESS

In order to be considered as a living donor, an evaluation process must be completed to ensure both your health and safety. The following information is an overview of the steps that may be required prior to becoming a living donor: *Please note: This is an overview of the evaluation process, testing varies from center to center.*

PHONE SCREENING

You, as the potential donor, are responsible for initiating a phone call to the transplant coordinator to express your interest. During this phone screening, the coordinator will obtain your demographic information and a brief medical history. They may also ask you to supply results of past lab tests, procedures or physician visits.

MEDICAL/SURGICAL EVALUATION

The medical evaluation is comprised of several phases of testing. Some centers may perform outside testing while other centers may complete all testing in-house. A complete medical history is required. Testing may include the following:

- **Urinalysis**
- **Blood tests**
- **EKG**
- **Chest X-ray**
- **CT/Ultrasound of the abdomen**
- **Recent age-appropriate screenings such as pap smear, mammogram, and colonoscopy may also be required**

Once the evaluation process is complete, you will meet with the surgeon to discuss any questions you may have regarding your surgery.

PSYCHOSOCIAL EVALUATION

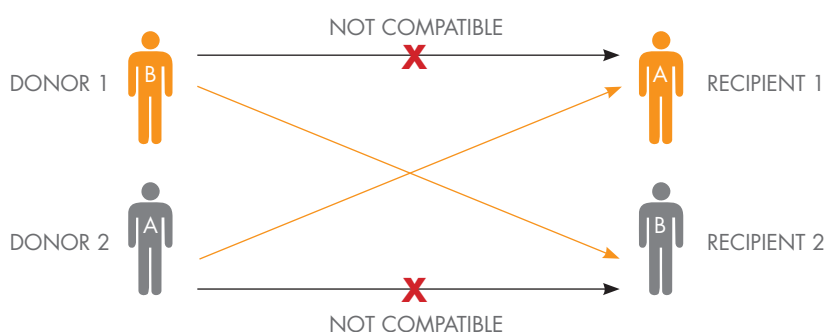
The next step to completing the evaluation process is the psychosocial evaluation to be performed by a Licensed Social Worker. The purpose of this meeting is to ensure emotional and physical wellness and financial ability to become a living donor. You may also be asked to complete an evaluation with a transplant psychiatrist/psychologist.

APPROVAL PROCESS

Because each transplant center has independent testing requirements and criteria, you may consider applying with another transplant center should you not be approved.

OPTIONS FOR INCOMPATIBLE DONORS

If you and your intended recipient are not compatible, there may be additional programs available. In the case of paired exchange or chain transplant programs, your donation can still help your intended recipient, and potentially many others.



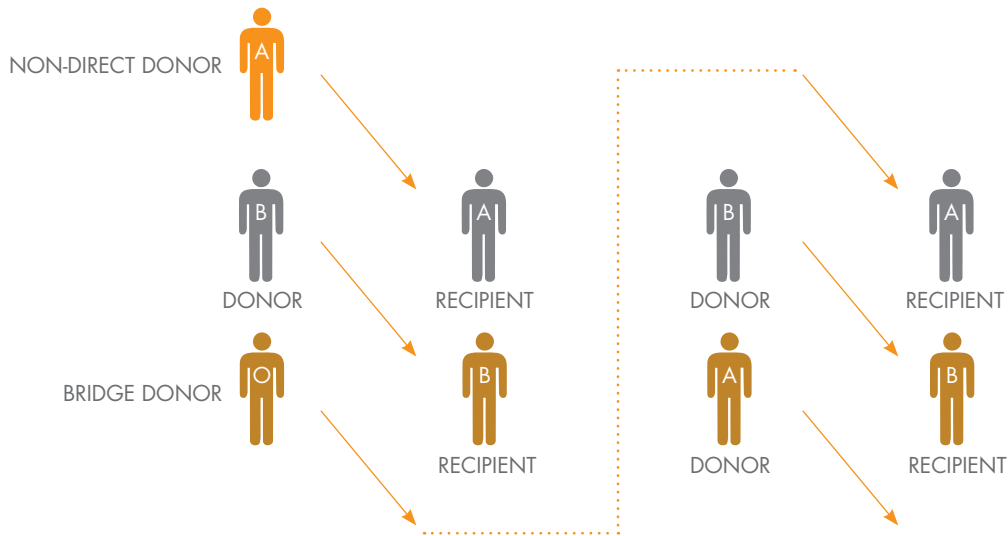
Paired Exchange

With paired-organ donation, a donor exchanges his or her kidney with the living donor from another incompatible donor/recipient pair to create two compatible pairs. While it's true that the donor will not directly donate his or her kidney to the intended recipient, exchanging with another incompatible pair will allow for two compatible transplants.



Chain Transplants

Donor chains work similarly to paired kidney donations in that they take advantage of healthy and willing—but incompatible—donors. The chain is initiated by what is called a non-directed donor. A non-directed donor is someone who offers to donate a kidney without a designated recipient, but with the explicit wish to donate to someone in need of a transplant.



“Paired donation is the ultimate way to pay it forward. One donated kidney can produce a limitless positive chain reaction for those in need of a kidney transplant.”

—Michelle, Paired Living Kidney Donor

LOOKING FOR MORE SPECIFIC ANSWERS?

The next step will be to contact your nearest transplant center to communicate with their staff, who will be happy to assist you in any questions or concerns you have before moving forward with the next steps of evaluation.

10 THE INDEPENDENT LIVING DONOR ADVOCATE

Every living donor transplant program in the United States must provide an Independent Donor Advocate (ILDA) whose responsibilities include but are not limited to the following:

Promoting the best interest of the potential living donor

Advocating for the rights of the potential living donor


Assisting the potential living donor in obtaining and understanding information about the:

- Consent process
- Evaluation process
- Surgical procedure
- Medical and psychosocial risks and benefits
- Benefit and need for follow-up
- Alternative options available to potential recipients
- The option to “opt-out” in a protected and confidential manner

Your ILDA will assist you as you learn about donation and transplantation and if being a donor is a right decision for you.



The ILDA ensures that your rights as a potential organ donor are fully represented. The ILDA serves as your living donor advocate from the time you contact the transplant program, as well as after donation. Your current and future safety is their number-one concern.



Keep in mind that at any point in the donor evaluation process, you have the right to change your mind. We will respect your decision whether you decide to move forward or if you would like to stop the process.

"Seek the answers. Don't ever discount your feelings of doubt...There's no shame in asking questions"

—Michelle, Paired Living Kidney Donor

"I've never had to stare in the face of death before and to know that I'm averting it for someone else.. .it's really worth it."

—Karny, Altruistic Living Kidney Donor

THE LAPAROSCOPIC SURGERY PROCESS & RECOVERY

The laparoscopic donor nephrectomy is a minimally invasive surgical procedure for obtaining a kidney from a living donor that can make the surgery and recovery easier.

In this procedure, the surgeon makes two or three small incisions (about the size of a dime) in your lower abdomen. Through one of the other openings, a special camera called a laparoscope is used to produce an inside view of the abdominal cavity. Surgeons use the laparoscope which transmits a real-life picture of the internal organs to a video monitor, to guide them through the surgical procedure. Your kidney is then removed through a three- to four-inch central incision below your belly button.



The donor surgery can take up to four hours. The surgical pain is managed with medications during the hospital stay and prescriptions are provided at the time of discharge.

In comparison to the standard operation, the laparoscopic donor nephrectomy results in a smaller incision, reduces recuperation time and usually shortens the hospital stay. Hospital stays vary and depend upon your recovery. In general, most donors can plan to return to work in four to six weeks. Hospital discharge instructions including restrictions will be provided by your transplant center.

FOLLOW-UP CARE

Upon discharge from the hospital you will be scheduled for a post-donation appointment to evaluate your recovery and progress.

You will also need to schedule follow-up appointments at six months, one year, and two years after kidney donation. These post-donation follow-up appointments are not only important for your well-being but also important for the transplant community.



DONOR MEDICAL COSTS

The Transplant Financial Counselor at your chosen transplant center will review the transplant costs and considerations for living kidney donation with you.

Evaluation

- Medical expenses associated with living donor evaluation are covered by the recipient's insurance. The living donor should not incur any expenses for the evaluation.
- However, expenses related to another health concern that may be identified during the evaluation process will not be covered by the recipient's insurance.

Donation

- The actual donation surgery expense is covered by the recipient's insurance.
- Not all insurance companies provide coverage for living donation.
- The Transplant Financial Counselor will explain what is covered and the length of time coverage is provided after the surgery and for your follow-up care.

Other Considerations

- We recommend that all Living Kidney Donors have their own medical insurance plan.
- Anything that falls outside of the transplant center's donor evaluation is not covered. These costs could include annual physicals, travel, lodging, lost wages and other non-medical expenses.
- Although it is against the law to pay a living donor for the organ, these costs may be covered by the recipient.
- You may also want to learn more about the National Living Donor Assistance Center www.livingdonorassistance.org which provides financial assistance to those who want to donate an organ.

Insurance Coverage after Donation

- After the organ donation, private health insurance companies may consider you to have a pre-existing condition.
- You may be unable to get insurance.
- You may have a waiting period of 12 months.
- Future life, health, and disability insurance companies could refuse to insure you due to the organ donation.

LIVING KIDNEY DONOR CAREGIVER ASSISTANCE

Following your surgery, you will need a caregiver to assist you in your recovery. Your caregiver is an important part of your “donation team”, both during and after your hospitalization.

- Your caregiver can be any willing family member or friend.
- Your caregiver should be with you the first week after you are discharged from the hospital.
- You should plan to have them stay with you or you stay with them to ensure your needs are being met.

The following are the responsibilities of your caregiver:

During your hospital stay:

- Learn about your discharge medications
- What you are taking
- Why you are taking it
- When do you need to take it
- Learn about your nutritional needs after donor surgery
- Teach who to call for help after your discharge from the hospital

After your hospital stay:

- Assist with transportation to follow-up medical appointments and lab work
- Assist with household duties such as meals, light housekeeping, shopping and errands
- Contact the transplant center or surgeon for problems or concerns.

RESOURCES

The Erma Bombeck Project

ErmaBombeckProject.org

The National Kidney Foundation of Arizona

azkidney.org

Banner Health Transplant Center

bannerhealth.com

Mayo Clinic Transplant Center

mayoclinic.org/kidney-transplant

University of Arizona Medical Center

umcarizona.org

National Kidney Foundation – Living Donation Site

www.livingdonors.org

National Living Donor Assistance Center

livingdonorassistance.org

Organ Procurement and Transplantation Network

UNOS.org



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fifty years of kidney success