American Kidney Fund®

Stepping up to the plate: what it means to be a living kidney donor

Speakers: **Steve and Heather Winfree**

Macey L. Henderson, JD, PhD

Meet our speakers!

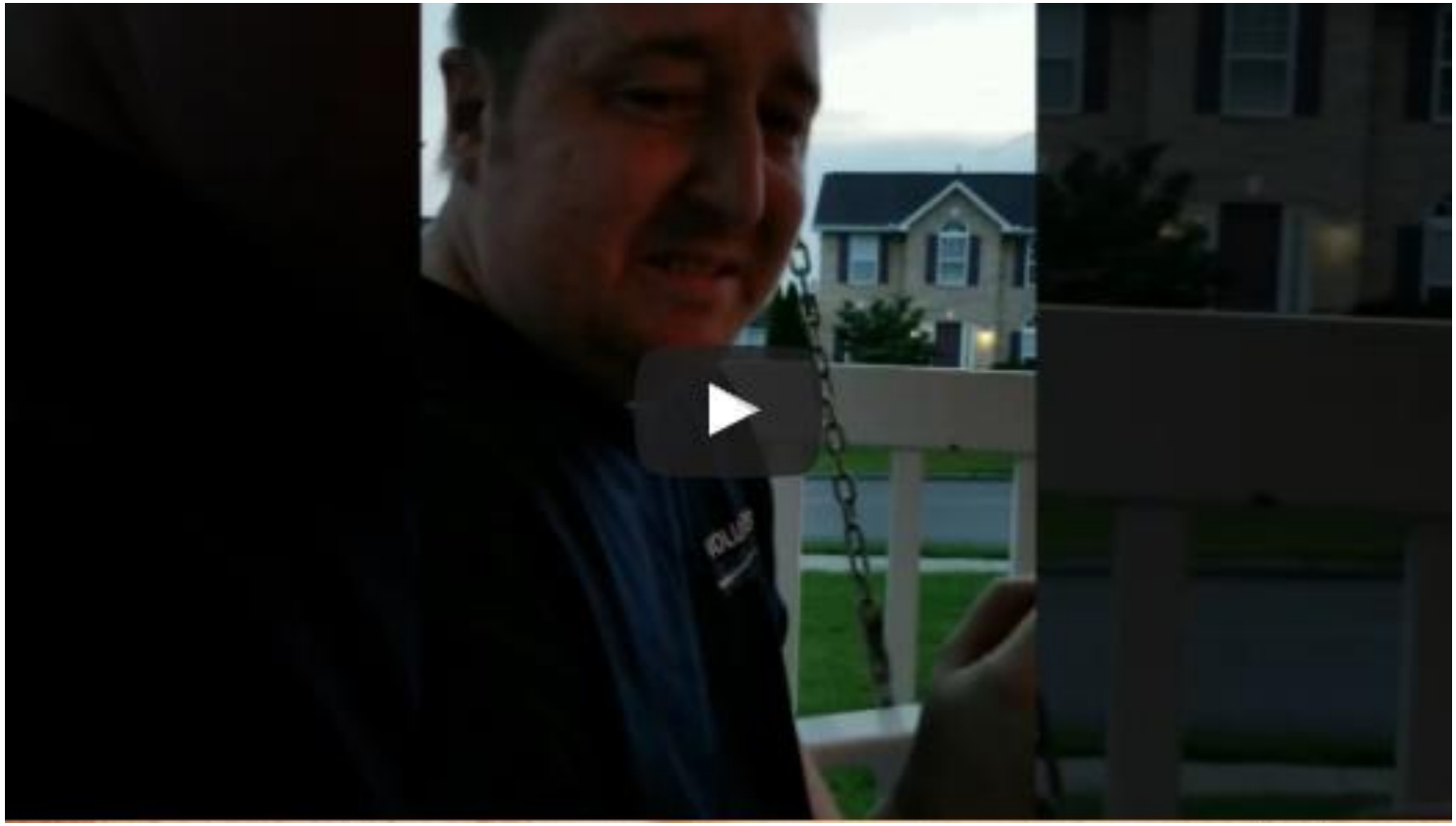
- Heather and Steve Winfree
  - Kidney patient advocates
  - Recently garnered media attention from viral video Heather recorded to surprise Steve with the news she is a kidney match
  - They are awaiting the kidney transplant surgery

- Macey Henderson, JD, PhD
  - Assistant Professor of Surgery and Nursing at Johns Hopkins University
  - Her background in law, ethics, health policy and management support her research into the health outcomes of living kidney donors and transplant patients.

Question 1: Steve

- Would you start by providing a brief overview of your journey with kidney disease, and what led you to become a patient advocate?

Video



Question 2: Steve

- Steve, what were you feeling in the moment that Heather revealed the news that she was a match?

Question 3: Heather

- How did you make the decision to donate one of your kidneys to Steve?

Question 4: Heather

- What has the process been like so far, what stage of the process are you in now?

Question 5: Heather

- Is there anything you would like to tell others who are considering being organ donors?

Question 6: Steve

- What does it mean to you to be receiving a kidney from your wife?

Question 7: Steve

- What advice can you give someone who is just starting out on dialysis and someone who is waiting for a transplant?

Question 8: Steve

- What are your plans for life post-transplant?

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Living Kidney Donation: Understanding the Risks, Benefits, and Process

Macey L. Henderson, JD, PhD

Department of Surgery, Division of Transplant Surgery

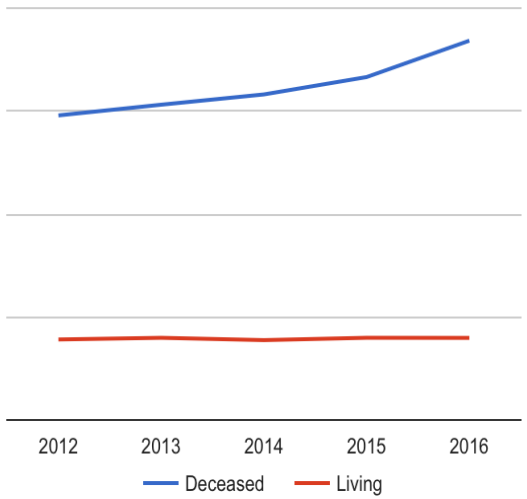
Johns Hopkins School of Medicine

Transplants By Donor Type - All Organs

January 1, 2012 - December 31, 2016

Based on OPTN data as of August 10, 2017

Year	Deceased Donor Transplants	Living Donor Transplants
2012	22,187	5,866
2013	22,967	5,987
2014	23,715	5,818
2015	24,980	5,989
2016	27,630	5,981
Total	**121,479**	**29,641**



Data subject to change based on future data submission or correction.

Types of living donor transplants

- Directed donation
- Non-directed donation
- Paired donation

Directed donation

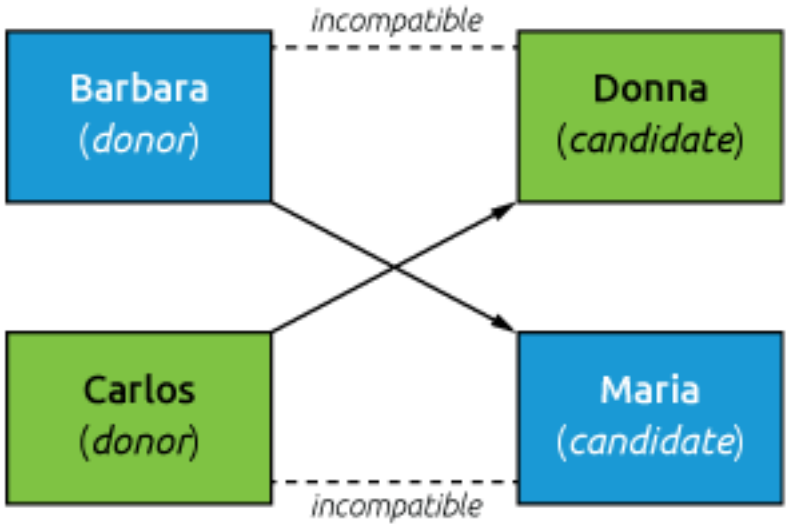
- Most common type of living donation
- The donor names the specific person to receive the transplant who may be:
  - **a biological relative**, such as a parent, brother, sister, or adult child,
  - **a biologically unrelated person** who has a personal or social connection with the transplant candidate, such as a spouse or significant other, a friend or a coworker, or
  - a biologically unrelated person who has heard about the transplant candidate's need

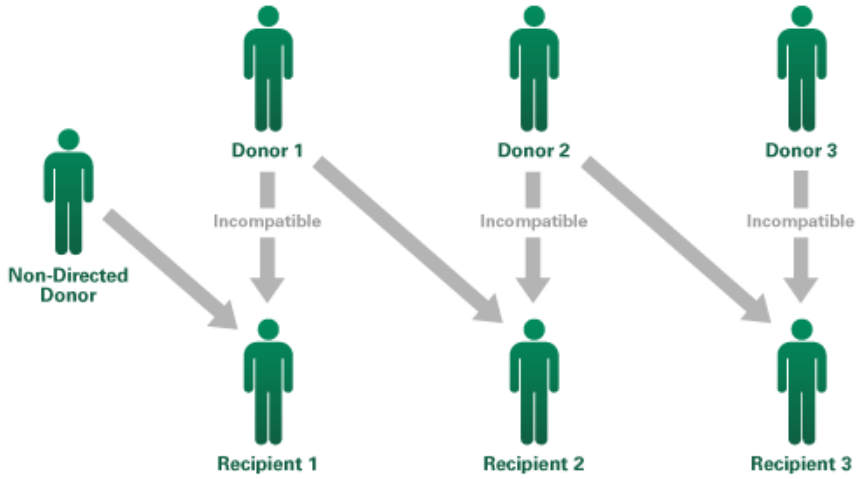
Non-directed donation

- The donor does not name the specific person to get the transplant
- The match is arranged based on medical compatibility with a patient in need
- Some non-directed donors choose never to meet their recipient
- In other cases, the donor and recipient may meet at some time, if they both agree, and if the transplant center policy permits it

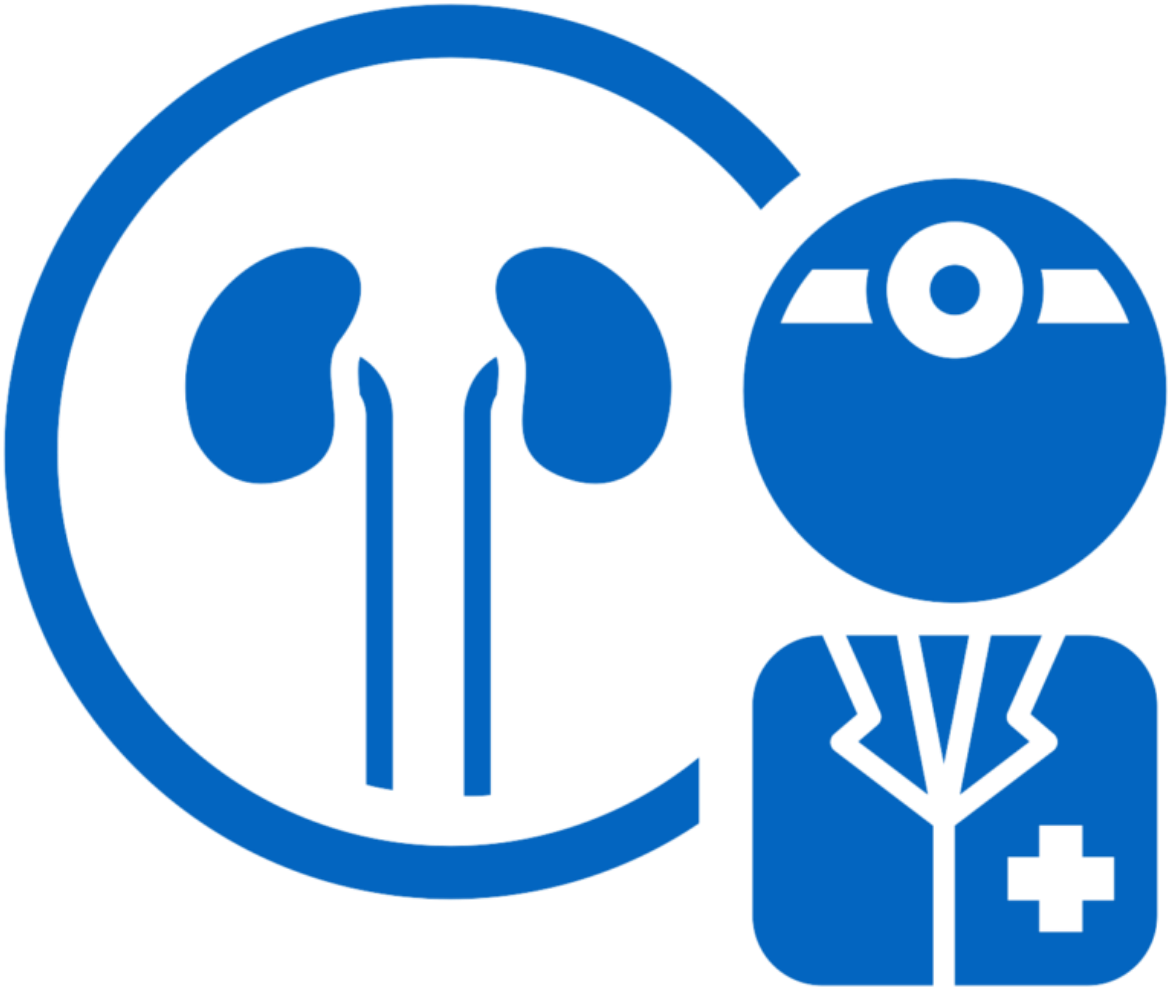
Paired Donation (kidney exchange, swaps, chains)

- Involves pairs of living kidney donors and transplant candidates who do no not have matching blood types
- The two candidates "trade" donors so that each candidate receives a kidney from a donor with a compatible blood type





Risks and Benefits



Informed Consent: A Donor Must Be Able to Say

- You want to donate
- No one forced you to donate
- No one said they would give you something of value for donating
- You know that you can decide not to donate at any time

Advantages for the Living Donor

- There **are no medical benefits to the donor**
- Some donors have felt that there are benefits including:[1-2]
  - Receiving an **extensive medical workup** that may help identify known medical problems
  - Receiving **a boost in self-esteem** or **an increased sense of well-being**
  - Developing an **improved relationship** with the recipient

[1]Johnson EM AJ, Jacobs C, Suh G, Humar A, Suhr B, Kerr SR, Matas AJ. Long-Term Follow-Up of Living Kidney Donors: Quality of Life After Donation. Transplantation. 1999;65(5):717-721.
[2]Jacobs CL, Gross CR, Messersmith EE, et al. Emotional and Financial Experiences of Kidney Donors over the Past 50 Years: The RELIVE Study. Clinical Journal of the American Society of Nephrology. 2015;10(12):2221-2231.

Advantages of Kidney Transplantation to the Recipient

- Better quality of life
- More free time (no more dialysis!)
- More stable blood pressure and electrolyte levels than on dialysis
- Higher rates of employment among adults for those who receive kidney transplant than those who stay on dialysis

Advantages of Living Kidney Donor Transplant for the Recipient

- On average, kidneys from living donors last longer
  - Fiver years after receiving a kidney transplant, 86% of living donor kidney transplant recipients had a working kidney, versus 74% of deceased donor transplant recipients[3]
- "Pre-emptive" transplant
- Planned surgery

[3]Hart A, Smith JM, Skeans MA, et al. Kidney. American Journal of Transplantation. 2016;16(S2):11-46.

What to Expect as a Living Donor

1. Screening and Evaluation
2. Surgery
3. Recovery
4. Long-term follow-up

Stage 1: Screening and Evaluation

- You'll undergo tissue typing and lab screenings to check for ABO blood type and HLA (tissue type) compatibility with your recipient and how well the kidney will be accepted by the recipient
  - **There are options for incompatible living donors and recipients**

Options for Incompatible Donors and Recipients

- Paired kidney exchange
- Blood type-incompatible transplants
- Sensitized and positive crossmatch transplants

Comprehensive lab testing

- Blood tests
- Urine tests
- Pap smear/ gynecological exam
- Colonoscopy (if over age 50)
- Cancer screening
- Antibody screen

Screening and evaluation

- If your labs are satisfactory, you will meet with a transplant clinician to **discuss the procedure and risks associated with evaluation/kidney donation**
- You will then have more medical testing and work-ups, if you agree

Potential medical events that could happen during the evaluation:

- Being allergic to a test and having a bad reaction
- Discovery of an infection the hospital staff need to report
- Discovery of a serious medical condition that could require more medical tests or treatment that you will have to pay for
- Discovery of a genetic health risk factor or issue that you did not know about

Additional testing

- A full day of appointments and diagnostic testing is usually required
  - X-rays
  - Electrocardiograms (EKG)
  - Radiologic testing
- You will also meet with a psychologist, donor advocate (called an Independent Living Donor Advocate), and nurse coordinator
- Further testing may also be required

Potential surgical or medical risks that could happen if you donate:

- Death or disease
- Scars, hernia, infection, blood clots, pneumonia, nerve injury, pain, tiredness, and other symptoms that are common when people have surgery
- Abdominal symptoms like bloating, nausea, or having a bowel obstruction

Potential mental or social risks *after* donating:

- Problems with how you feel about your body or what it looks like
- Problems with depression or fear and stress
- Feeling sad if the transplant recipient becomes ill or dies
- Changes in your lifestyle because you donated an organ

Potential money problems after donating:

- Paying for travel, short-term housing, and child care, and not being paid while you were away or recovering from surgery
- Having to pay for costs of lifelong follow-up visits
- Losing your job or your income/ Having a hard time finding a job in the future
- Having a hard time getting, keeping, or paying for health insurance, disability insurance, and life insurance.
- Future health problems that may not be covered by the transplant recipient's insurance

Things to Know

- On average, you will permanently lose 25-35% of your kidney function after donating
- Your risk of having kidney failure later in your life is not any higher than it is for someone in the general population of a similar age, sex or race
- **However, you are more likely to have kidney failure than healthy people who are not donors**

Risk: Chronic Kidney Disease

- Chronic kidney disease most often starts in the middle of your life (40-50 years old). **Kidney failure most often starts after age 60**
- If you get tested when you are young, doctors cannot predict how likely you are to have chronic kidney disease or kidney failure later in life
- If you damage your other kidney (the one you did not donate), you may have a higher chance of having chronic kidney disease, which could go on to become kidney failure

Risk: kidney failure and need for a transplant

- You will need medical treatment (dialysis or transplantation) if you start to have kidney failure
- Current policy gives living donors priority on the national waiting list if they need to get a kidney transplant in the future

These events and others could happen *during or after* surgery, and they could be *short-term or permanent*:

- You will lose some of your kidney function
- You could have kidney failure and need dialysis
- If you become pregnant after donating, you are more likely to have high blood pressure during pregnancy called “preeclampsia”

Stage 2: Surgery

Stage 2: Surgery

- Most donor surgery is laparoscopic (laparoscopic donor nephrectomy) with the possibility of conversion to an open procedure
- Surgery is usually scheduled 4-6 weeks in advance (this varies!)
- Donor nephrectomy takes about 2-3 hours
- Donors usually spend 2-3 days in the hospital

Stage 3: Recovery

- You might have a patient controlled anesthesia device and/or oral medication to control pain after surgery
- Getting up and around will help you recover—listen to your nurses!

Stage 3: Recovery

- Recovery can take from 2-12 weeks
- No lifting more than 10 lbs. for 6 weeks to prevent hernia
- Most doctors say not to drive for 2 weeks after donation
- If you have children, you might need help with childcare
- Depending on your job, you may need 2-8 weeks off from work

Stage 4: Long-term follow-up

- International guidelines recommend **annual post-donation follow-up care** including:
  - Blood pressure measurement
  - Body mass index (BMI) measurement
  - Serum creatinine with estimation of eGFR (kidney function→ blood test)
  - Albuminuria measurement (urine test)

Stage 4: Long-term follow-up

- U.S. transplant hospitals **must** follow-up with living kidney donors at 6-months, 1-year, and 2-years after donation
- Keep your remaining kidney healthy!
  - Exercise regularly
  - Have a healthy and balanced diet
  - Abstain from smoking tobacco
  - Support your psychosocial well-being

Learn More

- United Network for Organ Sharing https://www.unos.org/donation/living-donation/
- Living Donor Facts www.livingdonorfacts.org
- The National Kidney Foundation https://www.kidney.org/transplantation/livingdonors#livingdonation

Questions?

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Join us for next month's webinar!

Tuesday, September 19, 2-3 p.m. (ET)

Dr. Elaine Ku
University of California San Francisco

Hepatitis C and kidney disease – what you need to know

Nephrologist, Dr. Elaine Ku, will join us to discuss:

- The relationship between hepatitis C and kidney disease.
- The treatment options for hepatitis C in kidney disease patients who are both on, and not on dialysis.
- How the new medicines that cure hepatitis C have expanded options for patients needing a kidney transplant.

Visit www.KidneyFund.org/webinars to learn more and register!