End-Stage Renal Disease Network of New York

# IPRO

# HELP YOUR PATIENTS REDUCE THE WAIT FOR A KIDNEY TRANSPLANT

## **LIVING DONATION**

Patients living with end stage renal disease face life-changing treatment regimens and uncertain wait-times for a kidney transplant. There is much patients can do, with the help and support of their care providers, to reduce the time they wait for a transplant. A companion handout that will help you educate your patients about some of their options is available. This flyer includes nationally supported references for the strategies described in the handout. Increasing your understanding of these strategies by reviewing this resource will help you to be the best advocate possible for anyone waiting for a transplant.



#### **MAKING THE ASK EASIER**

Living Donation is the fastest way to receive a kidney transplant. Many patients will not consider this option for a variety of reasons, but chief among them is their concern about asking someone for a donor kidney. Many transplant centers can assist by creating a social media campaign, which is easy to set up, reaches a large number of people, and has been proven to help patients successfully find a donor, faster. The patient or significant other has to supply the information to share with family, friends and the community, but they will not have to do the direct "ask" for a kidney. Learn here how a social media campaign increased living donor registration.

John Hopkins Medicine: https://bit.ly/2NS6e4L.

#### **TRANSPLANT CHAMPIONS**

Some transplant centers will offer to train someone who has been designated by the patient to act on their behalf as their "Champion." This person shares the patient's story and helps connect folks in the community with the opportunity to become a living donor. Through training, the Champion will know what to discuss and how to answer many of the questions that someone who is considering donating their kidney might ask. Talking with someone



network2.esrd.ipro.org

other than the person who needs the organ helps to ease the discomfort of saying no.

#### POTENTIAL DONOR NOT A MATCH? TRY PAIRED DONATION

If a willing living donor is not a match for the patient, or if the patient is worried that the person they are considering will not be a match, the patient and their donor could be considered for paired donation.

Many transplant centers participate in a paired donation program, in which the patient and their donor are matched with another patient-donor pair. The result is that both recipients (one from each pair) receives a compatible living donation. This ensures that the patient receives the best matching kidney for the patient from a living donor, when an identified potential donor is not a match to them. Make sure you direct someone who has these concerns to a center that offers assistance through this program. See the attached reference from the National Institutes of Health (NIH) on paired donation, as well the Living Kidney Donors network. NIH Link: <u>https://bit.ly/37kkmeU</u> Living Kidney Donors: <u>https://bit.ly/38wWIBr</u>

# DECEASED DONATION THE ONLY OPTION? THERE IS STILL HOPE

When non-living donation is the only option for your patient, there are still several suggestions you can share to help shorten the patient's wait time. Knowing about all the options available allows patients to advocate for themselves and may help them to receive an offer sooner. A recent study published in Science Daily focuses on patients who die while waiting for a kidney, having missed multiple offers. https://www.sciencedaily.com/releases/2019/08/190830112807.htm

#### **PROMOTE MULTIPLE LISTINGS**

If there are transplant centers the patient can travel to within a four hour drive, you may want to suggest that they list themselves at multiple transplant centers. If the Transplant Center has a different organ procurement organization (OPO) supplying their kidneys, the patient's opportunities for a potential match will increase. The patient may not need to go through a full work-up since many results can be transferred from their first listing, but they will need to keep lab results and other information up to date at every center where they decide to list. Increasing the chance of a transplant is worth the extra effort! For more information about multiple listings, click here: National Kidney Foundation (NKF) <u>https://bit.ly/2sQPjZb</u>

#### CONSIDER A KIDNEY WITH A HIGHER KIDNEY DONOR PROFILE INDEX (KDPI) NUMBER

Every organ donated is given a KDPI, or risk score. The lower the score, the longer the organ is expected to last (lower score=lower risk).

The higher the KDPI score, the higher the risk the organ may not last as long (higher score=higher risk). These scores, however, are predictions and are not a guarantee. Accepting a KDPI kidney of >85% is associated with significantly better health outcomes than waiting on the transplant waiting list.

Even if the patient agrees to consider an organ with a higher score, they can always say no to the offer at the time the kidney becomes available. Willingness to accept an organ with a higher KDPI score may shorten a patient's time on the waitlist. For additional information on KDPI, see this Health and Human Services resource: <u>https://bit.ly/2GgeN59</u> and the Scientific Registry of Transplant Recipients (SRTR) study on high KDPI graph survival: <u>https://bit.ly/2NUdxcb</u>

#### DON'T RULE OUT KIDNEYS AT RISK FOR INFECTION

A kidney may become available from a donor who participated in risky behaviors, i.e. IV drug use or sex with multiple partners. While these behaviors might have exposed this person to an infection, the chance of that infection being transmitted to the patient through the transplant is less than one percent. The patient is more likely to catch an infection due to poorly prepared food or unsanitary conditions. If a patient does get an infection from a donated kidney, it can be treated with minimal side effects. The patient can always refuse a kidney with higher risk at the time it is offered. See the NIH conclusion on use of organs from donors with hepatitis C and HIV. Click here: https://bit.ly/2GjB1U1

Waiting for a kidney from a deceased donor can take anywhere from3-5 years or longer. It is important to educate your patients on all the options to consider that would reduce or shorten their wait time.



### Want to Learn More?

Review these websites Scientific Registry of Transplant Recipients (SRTR) Features Transplant Compare which compares transplant centers by wait time to transplant and organ survival. A great source of transplant data! https://www.srtr.org/

#### United Network of Organ Sharing (UNOS) Contains national transplant data and resources for education. <u>https://unos.org/</u> Organ Procurement and Transplant Network (OPTN) Data, education, and resources on transplant and the matching process. <u>https://optn.transplant.hrsa.gov/</u>



#### To file a grievance, please contact us: IPRO End-Stage Renal Disease Network of New York 1979 Marcus Avenue, Lake Success, NY 11042-1072

Patient Toll-Free: (800) 238-3773 • Main: (516) 209-5578 • Fax: (516) 326-8929 E-mail: esrdnetwork2@ipro.us • Web: network2.esrd.ipro.org Developed by IPRO ESRD letwork of New York while Inder contract with Centers or Medicare & Medicaid ervices. Contract IHSM-500-2016-00020C

05/11/20 Version