Living Kidney Donation Curriculum

Donate Life Northwest is expanding its public education to include living donation, in particular, living kidney donation. The goal of this education is awareness of and information about living donation. Recruiting living donors is not a goal.

Beginning fall 2012, all Donate Life Northwest volunteers will learn basic information about living kidney donation. This information should be incorporated consistently into any discussion of donation and transplantation whether the volunteer is staffing an information or registration table, working in the canteen of a blood drive, or giving a presentation.

Donate Life Northwest is conducting a series of update trainings and also providing hard-copy and web-accessible content.

Information about living donation is divided into 3 tiers:

- All volunteers ➔ Need-to-know Basic Information
- All volunteers ➔ + Talking Points
- Volunteers with a living donation connection ➔ + Personal Talking Points

Adapted from the National Kidney Registry, the American Association of Kidney Patients, UNOS, Legacy Transplant Services, Oregon Health and Science University, University of Washington Transplant Services
Living Kidney Donation

I. All Volunteers: Need-to-know Information

- **Living kidney donation, like all donation, is a personal decision** that should be made only after you are fully informed about the possible risks and benefits.
- **A living donor transplant can impact two lives** by making one more deceased donor kidney available for a person on the waiting list

A. **Current statistics and facts**
   1. 80% of people needing an organ transplant in the U.S. are waiting for a kidney; about 19 die every day while awaiting a kidney transplant
   2. The number of transplantable deceased donor kidneys continues to decline due to advances in trauma care and safety education (hooray!) and with an increase in co-morbidities like hypertension and Type II diabetes (boo!)
   3. In Oregon and Washington, the wait for a deceased kidney is about 2 years
   4. The average person with end-stage renal disease will live 10 years longer if they receive a kidney transplant vs. staying on dialysis
   5. During each of the last five years, more than 6,200 transplants were made possible by living donors.
   6. 97% of living donor kidneys are functioning one year after transplantation; 80% after 5 years; 50% of these kidneys will work for about 18 years, considerably longer than the 11 years of a typical deceased donor kidney

B. **Advantages for the Recipient of a Living Donor Kidney**
   1. Better preparation: the surgery can be planned and scheduled
   2. Shorter Wait: it is possible to receive a kidney in a few months and sometimes without being on the transplant waiting list or on dialysis
   3. Potential for closer genetic match when the donor is a blood relative
   4. A kidney from a living donor usually starts working in the recipient immediately after surgery.
   5. A kidney from a living donor typically lasts longer than one from a deceased donor
   6. Allows the donor the potential benefits associated with giving a kidney

C. **Who Can Be a Living Donor**
   1. Potential donors must be in excellent health and want to donate. Minimum age is specific to the transplant center. OHSU = 21 years; Legacy Good Samaritan = 18 years.
   2. A donor does not need to be a blood relative
   3. All donor/recipient matches require a healthy donor, blood type compatibility and tissue type compatibility
D. Three Types of Living Kidney Donation

- Some options may not be available at all transplant centers

1. Directed Donation = giving to someone you know – a friend, relative, coworker, neighbor

2. Non-directed donation/anonymous donation = giving to a non-specified recipient; donor and recipient remain anonymous to each other.
   a. Some donors may eventually meet the transplant recipients, but only if both parties agree.
   b. Pacific Northwest Transplant Bank and the local transplant centers - Oregon Health & Science University and Legacy Transplant Services - have partnered to create the Anonymous Living Donor Program.

3. Paired Donation = when the donor and recipient do not match blood or tissue types, they agree to “swap” with another donor/recipient pair with whom they are compatible.
   a. The transplant program finds the match. Many participate in the Alliance for Paired Donation, a non-profit organization that provides a nationwide computer kidney matching program.
   b. Paired donation increases the chance that an individual will receive a living donor kidney transplant and reduces the length of time waiting, often resulting in healthier transplant patients and better outcomes.

4. Donor Chains = normally begin with an anonymous donor and end when the last paired donor in the chain donates to an unpaired recipient on the deceased donor waiting list.
E. What Is the Process to Become a Potential Living Kidney Donor?
1. The potential donor must contact the transplant center where the intended transplant candidate is being followed or the local transplant center to ask if they have an anonymous donation program.
2. The transplant center staff will ask for a brief medical history to screen for conditions that may prevent donation and will inform the potential donor of possible risks and benefits involved in being a donor. All information is kept confidential.
3. Further screening includes but is not limited to blood and urine tests, X-rays, EKG, CAT scan, MRI, psychosocial and/or psychological evaluation, gynecological exam and cancer screening.
4. Making an informed decision is critical! Ask questions, ask more, ask even more!
   a. Each transplant center must have a written living donation informed consent process.
   b. Each transplant center must have written protocols for all phases of the living donation process.
   c. Be honest about all concerns, feelings and fears.
   d. Talk in detail with your loved ones, such as family members and friends, as well as other living donors.
   e. Fully consider medical, psychological, financial, insurance and family life impacts.

F. How Long Is the Donor in the Hospital?
1. The average stay in the hospital is 2-4 days after surgery.
2. Most kidney donors return to normal activities after 4-6 weeks. Driving may be prohibited up to 2 weeks. The newer, laparoscopic kidney donation surgery is less invasive and involves smaller incisions, which can help decrease recovery time for the donor.
3. Transplant centers are required to have a written protocol for the living donor follow-up process and report data for 2 years after donation.
4. Living kidney transplants are done in Oregon by Oregon Health & Science University (OHSU), Legacy Good Samaritan Hospital and Veterans Administration Medical Center. There are 4 living donor transplant programs in Washington in Seattle and Spokane.

G. What Are the Financial Costs for the Donor?
1. The recipient’s insurance covers the cost of the donor’s evaluation, hospitalization and limited follow-up visits and tests.
2. The recipient’s insurance may not cover follow-up services for the donor if medical problems occur from the donation. The donor’s insurance may not cover these expenses either.
3. The recipient’s insurance typically does not cover the donor’s transportation, lodging and meals, phone expenses, childcare and lost wages during the evaluation, surgery and follow-up services.
4. The donor social worker assists in planning and finding resources to provide financial help.

An interesting point:
A recent NPR-Thomson Reuters Health Poll found that 60% of Americans support some kind of financial incentive to organ donors. However, researchers have looked at what happened in the years before and after tax incentives offered by 17 states and found no increase in organ
donation rates. Possible causes include: organ donors will commit regardless of cost, especially if they know the recipient; tax breaks may be too small; tax deductions are less effective than tax credits in reducing the donor’s tax bill; people may not know about organ donor tax incentives.

H. Common Myths About Living Kidney Donation

1. Myth: My health and life span will be compromised if I donate a kidney.
   Fact: Overall risks of donating a kidney are considered very low and properly evaluated donors can live healthy lives with just one kidney. Potential living donors have the opportunity to discuss all concerns and risks with the surgical team before the surgery takes place. Donation does not affect your life expectancy.

2. Myth: I can donate a kidney only to a blood relative.
   Fact: While the best tissue match often is someone of the same ethnic background as the recipient, an organ donor does not need to be biologically related to the recipient.

3. Myth: The medical costs prevent most people from being a living kidney donor.
   Fact: The recipient’s insurance or medicare pays for all medical costs for the living donor’s medical evaluation, surgery, hospitalization, anesthesia, doctor’s fees and limited follow-up care. The recipient’s insurance typically does not cover the donor’s transportation, lodging and meals, phone expenses, childcare and lost wages during the evaluation, surgery and follow-up services. Assistance with these costs may be available for low-income donors.

4. Myth: The need for kidney donation isn’t as critical as for other organs because people needing a kidney have dialysis to keep them alive.
   Fact: While dialysis can sustain life for some patients, the average patient with end stage renal disease will live 10 years longer if they receive a kidney transplant versus staying on dialysis. Dialysis is a lengthy, regular, exhausting procedure that can drastically reduce one’s ability to work and quality of life.

5. Myth: Once I commit to being a living donor, there is no backing out.
   Fact: At any time in the process, the donor has the option to decide against donating.

I. Where to Get More Information

1. www.transplantliving.org or 1-888-894-6361
4. www.paireddonation.org or 877-APD-4All
5. www.lodap.com
6. www.livingdonorassistance.org
7. www.livingdonors.org
All Speakers: Talking Points

- **Living kidney donation, like all donation, is a personal decision** that should be made only after you are fully informed about the possible risks and benefits.

- The goal of this information is **awareness** about living kidney donation; recruiting living donors is NOT the goal.

- **A living donor transplant can impact two lives** by making a deceased donor kidney available for another person on the waiting list.

- About 80% of people needing an organ transplant in the U.S. are waiting for a kidney; about 19 die every day while awaiting a kidney transplant.

- Common causes of kidney failure include: diabetes, high blood pressure, and genetic diseases such as polycystic kidney disease.

- The average person with end-stage renal disease will live 10 years longer if they receive a kidney transplant vs. staying on dialysis.

- Potential living donors must be in excellent health and want to donate. Minimum age for donors is 18 years old at Legacy Good Samaritan Medical Center and 21 years old at Oregon Health and Science University (OHSU).

- **Myth:** I can donate a kidney only to a blood relative.
  **Fact:** While the best tissue match often is someone of the same ethnic background as the recipient, an organ donor does not need to be biologically related to the recipient.

- **Myth:** My health and life span will be compromised if I donate a kidney.
  **Fact:** Overall risks of donating a kidney are considered very low, and properly screened donors can live healthy lives with just one kidney. Potential living donors have the opportunity to discuss all concerns and risks with the surgical team before the surgery takes place. Donation does not affect your life expectancy.

- **Myth:** The medical costs prevent most people from being a living kidney donor.
  **Fact:** The recipient’s insurance or medicare pays for all medical costs for the living donor’s medical evaluation, surgery, hospitalization, anesthesia, doctor’s fees and limited follow-up care. The recipient’s insurance typically does not cover the donor’s transportation, lodging and meals, phone expenses, childcare and lost wages during the evaluation, surgery and follow-up services. Assistance with these costs may be available for low-income donors.
II. Volunteers with a Living Donation Connection: Personal Talking Points

1. When you received your transplant
2. Why you needed a kidney transplant
3. If you were on dialysis, how long? What was the Impact on your life?
4. How you found your living donor
5. How your life has changed since your transplant
6. If you know your donor, how their life is today?