

Step 1: Plan Review the following Network and community resources to plan a patient engagement activity that explores transplant as a treatment option.

Network Resources

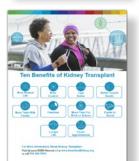
- My Kidney Kit pages. The My Kidney Kit is available in the dialysis clinic and online in English and Spanish at www.mykidneykit.org.
 - The My Choices section includes:
 - Kidney Transplant
 - Talk Transplant-Getting Matched



- Kidney Transplant Center List and Transplant Facts Poster. (English/Spanish). A listing of transplant centers in Iowa, Kansas, Missouri and Nebraska.
- <u>Kidney Transplant Lobby Day Ideas</u> and <u>Lobby Day Checklist</u>. These tools have been developed to help clinic staff and NPRs to plan a lobby day with a focus on transplant.
- Medicare, Kidney Transplant and Work. This handout was developed to assist clinic staff in addressing patient questions regarding how a kidney transplant impacts Medicare and programs available to help coverage continue.



- <u>Patient Engagement Activity Showcase</u> from facilities throughout the Network to get bulletin board and lobby day ideas from the "My Choices" section.
- Talk Transplant: Myths and Facts (handout)
- Ten Benefits of Kidney Transplant (handout)



- <u>Transplant Baseball Playbook</u>. This toolkit was developed to engage patients in learning about transplant and moving them through the steps to transplant listing.
- <u>Very Important Patient Peer Sharing Call Recording</u>. Listen to a conversation with transplant patients sharing and answering questions from peers about their transplant journey.

Resources from the ESRD NCC

The ESRD Network Coordinating Center (NCC) has developed several resources with patient experts from throughout the 18 ESRD Networks.

- <u>Is a Kidney Transplant Right for Me?</u> (booklet)
- Get the Facts: Kidney Transplantation (brochure)
- Partnering Along the Road to Transplant (<u>English/Spanish</u>)—A handout detailing five key steps to effective communication between patients and healthcare professionals. (English/Spanish)
- The Road to Transplant (brochure) includes tips to consider if you are thinking about kidney transplant
- Transplant Celebration Announcements (English <u>8.5 x 11/8.5 x 14)</u> (Spanish 8.5 x 11/8.5 x 14)
- Turning Negatives into Positives "Why Transplant is a Good Idea for Me" (handout)
- Your Life, Your Choice- Stories from Kidney Transplant Patients and Donors (booklet)



- Donate Life website provides information on organ donation.
- My Transplant Coach is an interactive, online, video-based decision aid for patients with kidney failure available through Explore Transplant.
- <u>National Kidney Foundation</u> website has online articles and downloadable resources covering the transplant basics, considering and preparing for transplant, living kidney donation and life after transplant.
- National Living Donor Assistance Center (NLDAC) works to reduce the financial disincentives to living organ donation. The website includes several patient resources including: patient brochures and videos (online and on DVD) created by the American Society of Transplant Surgeons in English & Spanish. Videos include: "Living with Kidney Donation: What You Need to Know" and "Kidney Transplantation: A Guide for Patients and their Families"
- <u>Transplant Living (website)</u> is a service of the United Network for Organ Sharing which includes information to prepare for patients before and after transplant; including information on organ sharing, living donation and cost.
- <u>Transplant Experience</u> (website) provides resources that can help you learn more about transplant, living donation, transplant medications and financial planning. The website includes downloadable <u>Educational Resources</u> including:
 - What Every Patient Needs to Know
 - Sharing Life addresses common questions about living organ donation
 - Starting the Conversation provides tips for talking about living donation
 - What Every Kid Needs to Know and What Every Parent Needs to Know



Explore



Step 2: Act

Team up with your Network Patient Representative (NPR) to complete a patient engagement activity.

- Work with your Network Patient Representative to discuss ideas on what resources and activities they would like to see at the clinic to educate patients on transplant.
- Create a bulletin board sharing:
 - the ten benefits of transplant; or
 - information debunking the myths about kidney transplant; or
 - living donation.
- Play the videos on the lobby and/or patient televisions
- Contact your local transplant center and see if they can come onsite or share resources or invite a patient who's had a transplant to visit and host a lobby day focusing on kidney transplant.
- If your clinic has a tablet, use it to have patients complete the "My Transplant Coach" decision-aide online.
- Share "Donate Life" information with patients and family members. www.donatelife.net/
- Start a support group for patients to provide patients with opportunities to share their stories, struggles and successes. If there is a support group in the area, consider what can be done to encourage and help patients and family members to attend.

Step 3: Share

Share what your clinic has done with the rest of the Network!

- Ask your NPR for their feedback and encourage them to attend the next NPR Connection Call (2nd Thursday and Friday at 1 pm CT) to share with others!
- Take a photo of your activity and report your clinic's patient engagement activities at <u>Patient Engagement Activity Report.</u>

Three Levels of Patient Engagement

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Level 3: Laws and Policy

"Consumers are involved in the decisions that communities make about policies, law and regulations in public health and health care."

Level 2: Organization Design and Governance

"Providers reach out for patient input to ensure they will be responsive to patients' needs."

Level 1: Direct Patient Care

"Patients get information and answer questions about their preferences to help inform their treatment decisions."

For more information or to file a grievance, please contact:

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