

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







- <u>Kidney Transplant Interest Form</u>
- <u>Kidney Transplant Lobby Day Ideas</u> and <u>Lobby Day Checklist</u>. These tools have been developed to help clinic staff and FPRs to plan a lobby day with a focus on transplant.
- <u>Medicare</u>, <u>Kidney Transplant and Work</u>. 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>Is Transplant for Me? Know Your Options</u> (brochure)
- Ten Benefits of Kidney Transplant (handout)
- <u>A Transplant Story</u> (podcast) listen to additional patient transplant stories on the <u>Kidney Patient Views</u> podcast.
- Transplant Bulletin Board Kit

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 <u>8.5 x 11/8.5 x 14)</u>
- 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 Facility Peer Representative (FPR) to complete a patient engagement activity.

- Work with your Facility Peer 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 FPR for their feedback and encourage them to attend the next <u>FPR Connection Call</u> (the third Wednesday and Thursday every other month starting Feb. 2020 at 2 pm CT) to share with others!
- Be sure to share your patient engagement activity with the Network. You can send your activities and photos to our Patient Liaison, Quin Taylor.

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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