

ETCLC Patient and Donor Family Representatives: Sharing Invaluable Lived Experience to Increase Organ Donation & Kidney Transplantation

Overview

Patient and Donor Family Representatives (PFRs) continue to play an integral role in ESRD Treatment Choices Learning Collaborative (ETCLC) quality improvement activities. Their engagement informs transplant programs, organ procurement organizations, and donor hospitals about the needs, expectations, and recommendations of transplant candidates, recipients, and donor families.

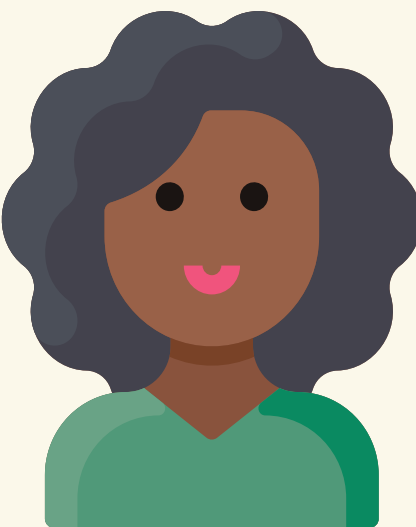
Purpose

Use the PFRs’ lived experiences to implement innovative strategies to increase the number of:


- Patients who seek placement on the kidney transplant waitlist.
- Patients that stay active and ready to receive a kidney transplant.
- Transplant centers using high Kidney Donor Profile Index kidneys.

Who’s Involved

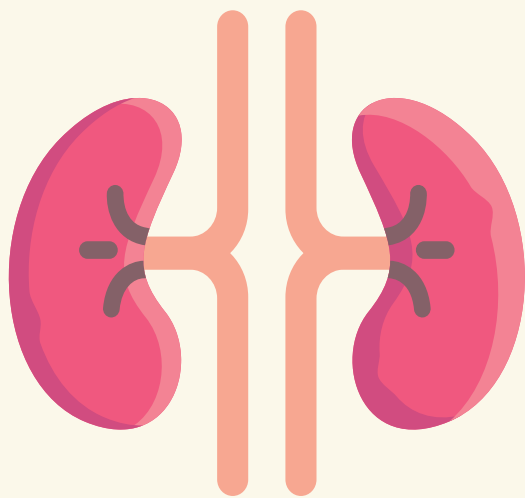
These individuals make up the ETCLC PFRs:



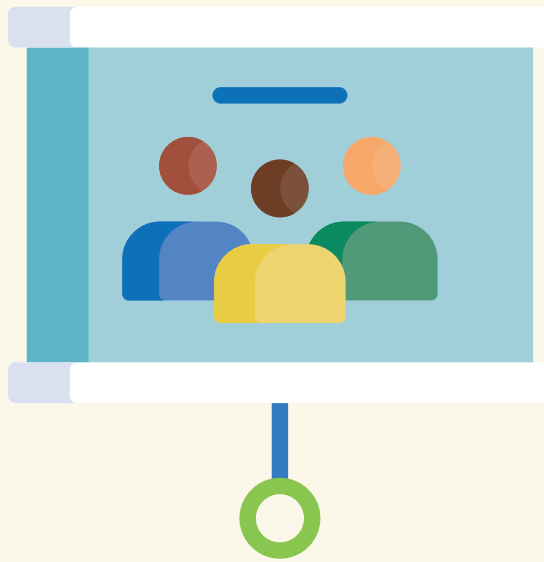
Dialysis Patients on the Kidney Transplant Waitlist



Kidney Donor Family Members



Kidney Transplant Recipients



ETCLC Patient National Faculty Members

PFR Engagement

- Participated in monthly transplant and donor-centric Quality Improvement Team meetings and pacing events to share insights and perspectives.
- Shared successful initiatives (e.g., waitlisting) of the ETCLC with the End Stage Renal Disease (ESRD) Networks and with the Centers for Medicare & Medicaid Services (CMS) during Quality Conference.
- Worked to develop educational resources designed to reach people where they are in their transplant journey, including partnering with the ESRD National Coordinating Center’s Patient Health Equity Workgroup and the CMS Office of Minority Health.

PFR-Developed Resources



What I Need to Know About Donating My Loved Ones’ Organs

Is your loved one registered as an organ donor? Or have they talked about their interest in their organs? Having a conversation about their wish for donation is extremely important for you to understand that organ donation from your loved one only happens after they have died or suffered an irreversible injury where there is no opportunity for recovery. This resource will help you discuss the choice for organ donation and loved ones’ wish, or choice, to be an organ donor.

Discuss The Choice of Donation	Honoring Your Loved Ones’ Wishes
<ul style="list-style-type: none">• Know your loved ones’ wishes and ask if they are a registered organ donor.<ul style="list-style-type: none">▪ Support them in registering at RegisterMe.org• Be clear about organ donation details and minimize “what if” circumstances.• Discuss what organ donation means to you and your loved one.• It is more than one conversation.<ul style="list-style-type: none">▪ As we age, or our life circumstances change, it is important to discuss end-of-life choices, and document them through a living will or the Five Wishes.• Speak to your loved ones often about their wishes and choices for end-of-life services.	<ul style="list-style-type: none">• Listen to and ask questions of your loved one’s care team.• Accept when your loved one has irreversible damage.<ul style="list-style-type: none">▪ What are their wishes in this circumstance?▪ Are they a registered organ donor?• Partner with the hospital during the time as they contact the local organ donation organization. They will support your loved one’s donation.• Grieve your loss and celebrate the life of another.• Learn from others who have experienced loss and organ donation.

Understanding and Agreeing to Better Than Dialysis Kidneys

Better Than Dialysis Kidneys can be a good option for you if you are older, have other medical conditions in addition to kidney disease, or if you have been on dialysis for several years.

Considering and accepting a *Better Than Dialysis* kidney can also shorten your time on the transplant waitlist. These kidneys may also be called expanded criteria or high KDPI kidneys.

Expanded Criteria Kidneys	High Kidney Donor Profile Index (KDPI)
<p>Expanded criteria kidney donors have the following risk factors:</p> <ul style="list-style-type: none">• Donor age is over 60, or over age 50 with these risk factors:<ul style="list-style-type: none">▪ History of high blood pressure,▪ Stroke as the cause of death,▪ Serum creatinine level over 1.5 mg/dL before the kidney is removed (this shows the level of kidney damage). <p>Accepting one of these kidneys can improve your quality of life while also providing rest from dialysis.</p> <p>Your transplant center must get your written permission to consider one of these kidneys for you. The kidney may not be perfect but could be a great option for you. These kidneys may require some dialysis after the transplant to “kick start” the function of the kidney, but your transplant team will have a plan for that.</p>	<p>KDPI is used to provide each kidney with a score to help transplant professionals match the right kidney for you. KDPI scores are based on characteristics of the individual donating the kidney. A high KDPI kidney score may be based on a kidney donor’s:</p> <ul style="list-style-type: none">• Age, height, and weight,• Race/ethnicity,• History of high blood pressure and diabetes,• Cause of death,• Serum creatinine level, and• Presence of hepatitis C. <p>All or any of these characteristics can help determine how long the kidney will function for you.</p> <p>Higher KDPI scores are expected to function for a shorter amount of time and every transplant and recipient’s experience will vary. These kidneys may be a good option if you do not want to stay on dialysis for a long time.</p>