

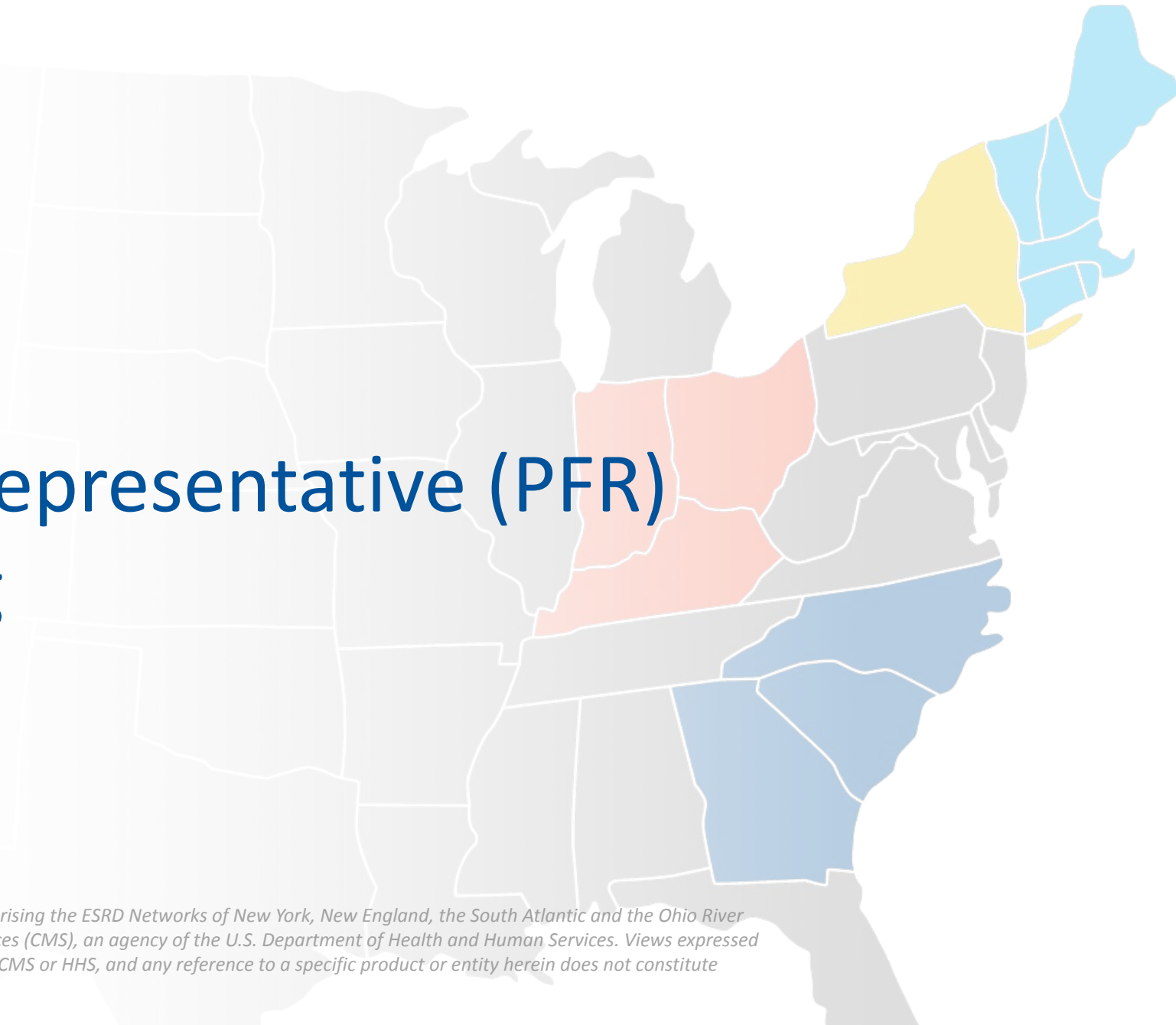


End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

April 4th 2024

This material was prepared by the IPRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic and the Ohio River Valley, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication #



Patient and Family Engagement Facilitators



Aisha Edmondson
Patient and Family Engagement
Lead

Patient and Family Engagement Facilitators



Stephanie Cole, BA, PSM, QP
Community Outreach Specialist



Brooke Andrews, MSW
Patient Services Speaker



Caroline Sanner, MSN, RN-BC,CPHQ
Quality Improvement Speaker

Today's Agenda

Topics for Review/Discussion



Meeting
Reminders

Patient
Services
Topic

PFR Check-In

Closing
Remarks

Quality
Improvement
Topic



Meeting Reminders



- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



Welcome Our New PFRs!

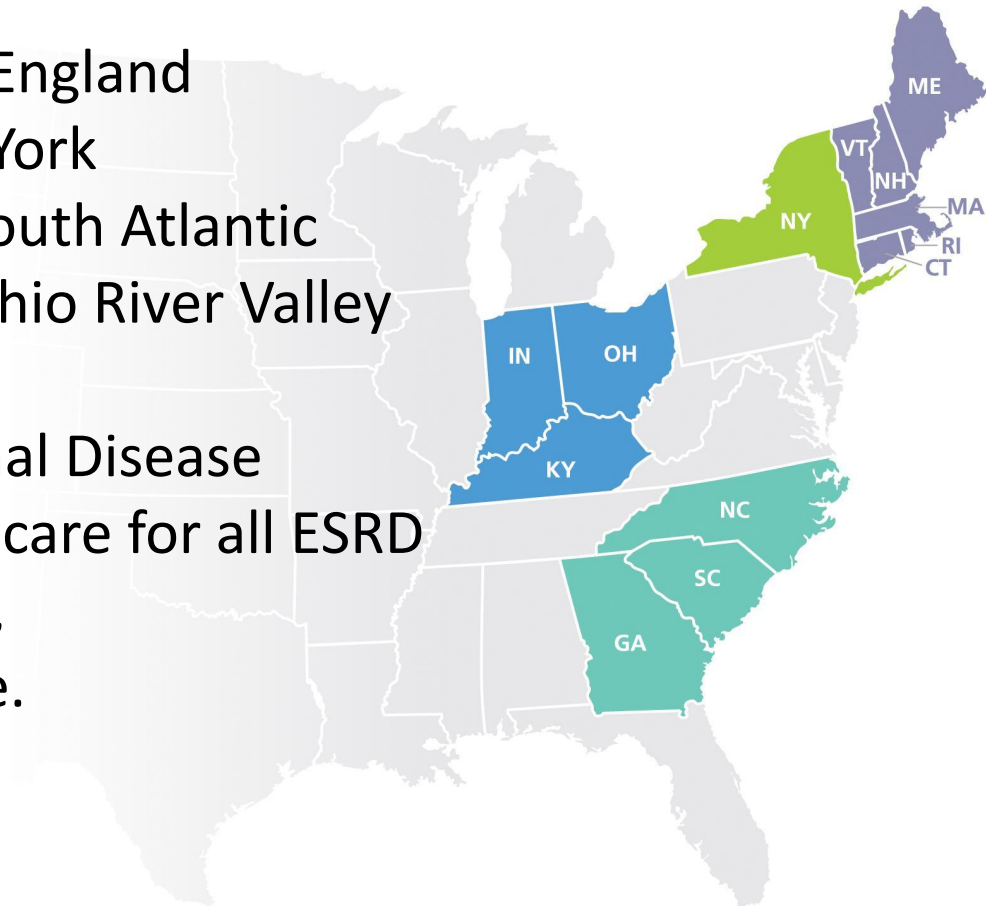


- Tashawn Owens
- Michelle Morris
- JaKarta Bentley
- Lorita Washington
- Yolanda Arlee-Scott
- Keyon Bounds
- Brenda Paneto
- April Snell
- Karen Harvey
- Cinthia Velez
- Fitzroy Jackson
- Stephanie Taylor
- Lynnann Westhoff
- Portia Bibbs

IPRO ESRD Network Program



- The IPRO End-Stage Renal Disease Network Program includes four ESRD Networks:
 - Network 1: ESRD Network of New England
 - Network 2: ESRD Network of New York
 - Network 6: ESRD Network of the South Atlantic
 - Network 9: ESRD Network of the Ohio River Valley
- The mission of the IPRO End-Stage Renal Disease Network Program is to promote healthcare for all ESRD patients that is safe, efficient, efficient, patient-centered, timely, and equitable.



Network Check-In

Polling Question



Which Network are you from?

- Network 1 (Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont)
- Network 2 (New York)
- Network 6 (North Carolina, South Carolina, Georgia)
- Network 9 (Indiana, Kentucky, Ohio)



The Network's Role

What the Network's staff CAN and CANNOT do




Network staff CAN...

- Advocate for patients' rights, depending on the situation.
- Provide information and educational resources.
- Investigate concerns about issues related to quality of care.
- Help patients understand their rights and help them navigate the ESRD care delivery system.

Network staff CANNOT...

- Force a facility to accept a patient.
- Close a dialysis facility.
- Go onsite to investigate a facility's clinical procedures, witness interactions between staff and patients, or view a videotape of incidents (HIPAA violation).
- Add a patient to the transplant list.
- Recommend a lawyer and assist with a lawsuit.
- Get staff members fired or arrange for staff to have their pay docked.
- Force a facility to change its admissions policy regarding catheters.
- Verify Medicare coverage or give out Medicare cards.
- Interfere with facility surveys.
- Hide a patient's involuntary discharge (IVD) history.

The IPRO ESRD Network Program can help resolve many concerns you may have about the care you receive as a dialysis patient.



The mission of the IPRO End Stage Renal Disease (ESRD) Network Program is to promote health care for all ESRD patients that is safe, effective, efficient, patient-centered, timely, and equitable.

Network staff CAN...	
Advocate for patients' rights, depending on the situation.	~ Example: "My unit is too cold" With your permission, a Network staff member can contact your facility to find out if the temperature can be controlled.
Provide information and educational resources.	~ Example: "I need a fourth shift, and my facility does not offer one" The Network can provide you with a list of facilities in your area that offer a fourth shift (Dialysis Facility Compare tool available on www.medicare.gov)
Investigate concerns about issues related to quality of care.	~ Example: "I am upset about the care I am receiving at my facility" The Network can conduct a review of your medical record to evaluate the quality of care you are receiving.
Help patients understand their rights and help them navigate the ESRD care delivery system.	~ Example: "I don't agree with a policy at my facility" The Network can advocate on your behalf and could help you work with facility staff to find a compromise that would work for you and the facility.

However, some concerns may be beyond the Network's scope. Network staff CANNOT...

✘ Force a facility to accept a patient.	✘ Get staff members fired or arrange for staff to have their pay docked.
✘ Close a dialysis facility.	✘ Force a facility to change its admissions policy regarding catheters.
✘ Go onsite to investigate a facility's clinical procedures, witness interactions between staff and patients, or view a videotape of incidents (HIPAA violation).	✘ Verify Medicare coverage or give out Medicare cards.
✘ Add a patient to the transplant list.	✘ Interfere with facility surveys.
✘ Recommend a lawyer and assist with a lawsuit.	✘ Hide a patient's involuntary discharge (IVD) history.

The Network collaborates with the State Department of Health to advocate for individuals and help resolve concerns about care received at dialysis facilities.



Better healthcare, realized.

To file a grievance, please contact us:
IPRO End-Stage Renal Disease Network Program Corporate Office:
 1979 Marcus Avenue, Lake Success, NY 11042-1072
Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
E-mail: esrdnetworkprogram@ipro.us • **Web:** esrd.ipro.org

Developed by the IPRO ESRD Network Program while under contract with the Centers for Medicare & Medicaid Services. Contract # F31CMC100029 Publication # ES01993.GA.MW.020209.3.01 v4 02/2022 IPRO, the End Stage Renal Disease Network Program, the Network of New England, Network of New York, Network of the South Atlantic, and Network of the Ohio River Valley, prepared the material under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. CMS Contract Number: F31CMC100029. CMS Task Order Number: F31CMC210001 (Network 1), F31CMC210002 (Network 2), F31CMC210003 (Network 3), F31CMC210004 (Network 4)

Living Your Best Life on Dialysis!! Save the Date NW1



SAVE THE DATE

Living Your Best Life on Dialysis

You're Invited to attend a FREE Kidney Patient Educational Event

Saturday, April 27, 2024 • 8:00 AM – 3:15 PM

La Quinta Inn Springfield 100 Congress Street, Springfield, MA 01104

The day will include:

- Patient presentations
- Expert Panels
- Modality educators whose goal is to support, educate, and help patients thrive—not just survive—with kidney disease

We will address common misconceptions about dialysis treatment options, health equity, and patient concerns.

Free food, fun, and giveaways for all registered guests.



All attendees and sponsors register here:

<https://redcap.ipro.org/surveys/?s=LPPDHJLY87M8YMX9>

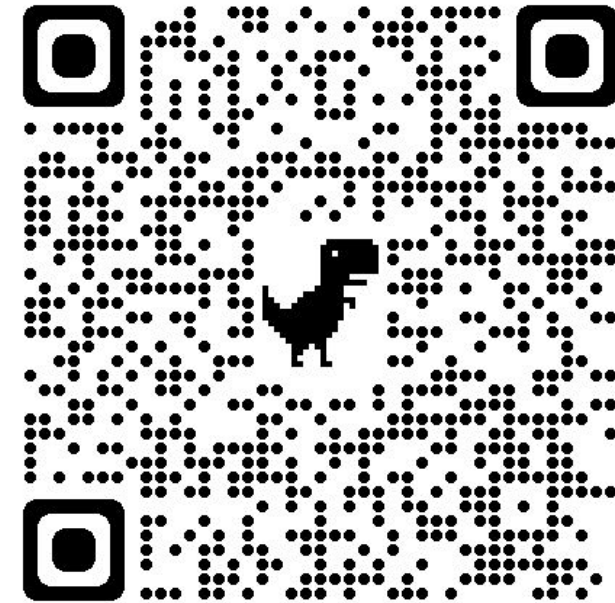
Presented by:



End-Stage Renal Disease
Network of New England

This material was prepared by the IPRO ESRD Network of New York/New England/the Ohio River Valley/the South Atlantic, an End Stage Renal Disease Network Organization, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services (HHS). Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication # ESRD.IPRO-GA-NW1-20240131-276 v.3 2/14/2024 -VB

Join us



Access to Care

Coping



Brooke Andrews, MSW
Patient Services Specialist

It's Okay not to be Okay



The stages of grief



Reality



Network Check-In

Polling Question

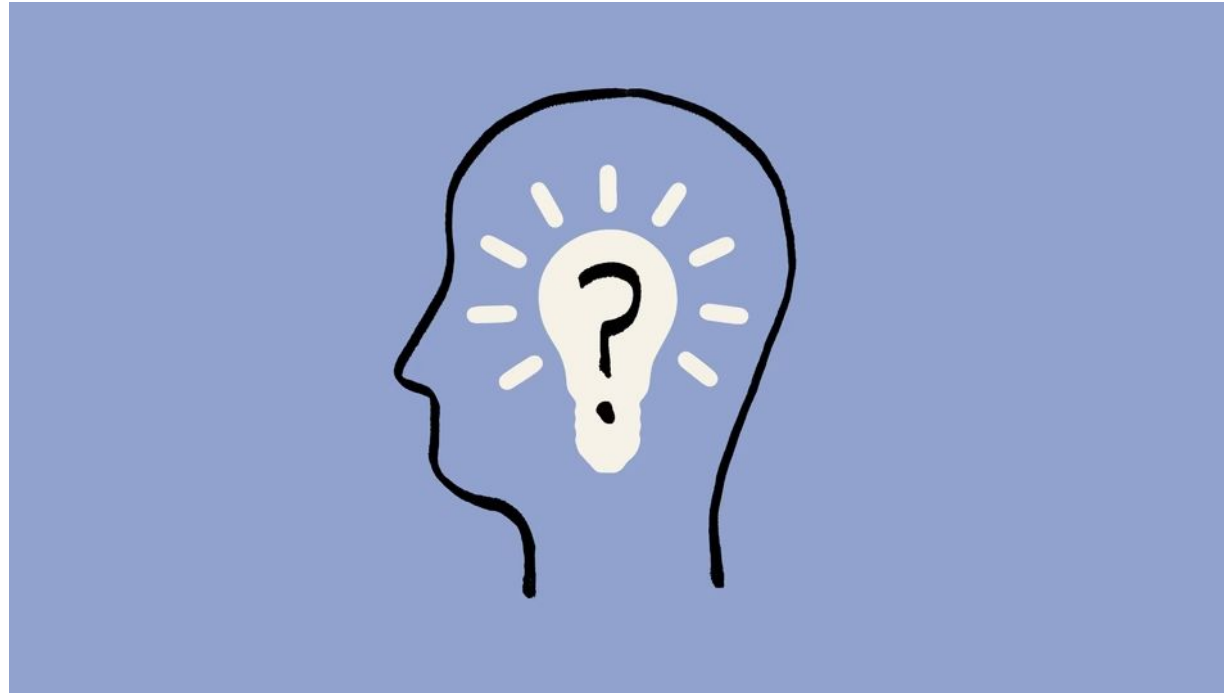


Do you feel like you have healthy coping skills?

- Yes
- No
- Unsure



Open Discussion : How do you cope?



Coping Strategies



9 WAYS TO MANAGE STRESS



Self-Care



talkspace

SELF-CARE VS. COPING SKILLS: HOW ARE THEY DIFFERENT?

Self-Care

- A preventative measure
- Acts attending to your emotional, mental, spiritual, & physical health
- Decrease extreme distress and burnout
- Can decrease the need for coping skills in the future

Coping Skills

- Used to get you through the tough times
- Activities or tactics you use when you're in a stressful situation
- Strategies you can use when you need to buy a bit more energy or time, like hitting the "pause button" when stressed

Ask for support



- Clinic Social Worker or other staff members
- Clergy
- Friend
- Family
- Each other

Resources



- **American Association of Kidney Patients (AAKP) Community:** AAKP recognizes the value of local patient support groups. Through its website and various publications, the AAKP Community provides a centralized resource to locate ESRD support groups within patients' communities.
- **Helparound Phone App:** Helparound assists chronic kidney disease patients and their support systems, overwhelmed by a life-changing condition, to simplify the day-to-day management of dialysis treatment. NxStage delivers information and support resources as needed, when needed, via smartphone.
- **Home Dialysis Central Forums:** Home Dialysis Central is an online discussion forum and a one-stop resource for patients and professionals who want to learn more about home dialysis options—what they are, where they can be found, and why someone might want to choose one over another. Patients, family members, and caregivers can get advice from experts or other members of the home dialysis community, or they can share their knowledge with others.
- **Nephkids Cyber-Support Group:** This resource is a cyber-support group for parents of children with CKD. It offers an interactive email group (listserv) for parents of children with many types of chronic kidney disease.
- **National Kidney Foundation (NKF) Peers Lending Support:** 1-855-653-7337 (1-855-NKF-PEER) This NKF website is specifically for new patients who need support and want to connect with peers who “have been there.”
- **Renal Support Network (RSN) HOPEline Peer Support:** 1.800.579.1970 The RSN website empowers people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future, and to make friends through informative, patient-directed programs.

Increasing Education and Access to Transplant



Caroline Sanner
Transplant Project Lead



What is my role?

I work to:

1. increase the number of patients who get added to the transplant waiting list
2. increase the number of patients who get a kidney transplant

How?

1. Work directly with transplant centers and dialysis facility staff to provide education, resources, and help to improve their approaches to waitlist/transplant
2. Work directly with patients (**YOU!**) to learn what challenges you face in getting waitlisted and transplanted
3. Take everything we learn and put forward actionable items to make an impact in the community

Network Check-In

Polling Question



Have you used Kidney Transplant Compare?

- Yes
- No



Network Check-In

Time to Unmute!

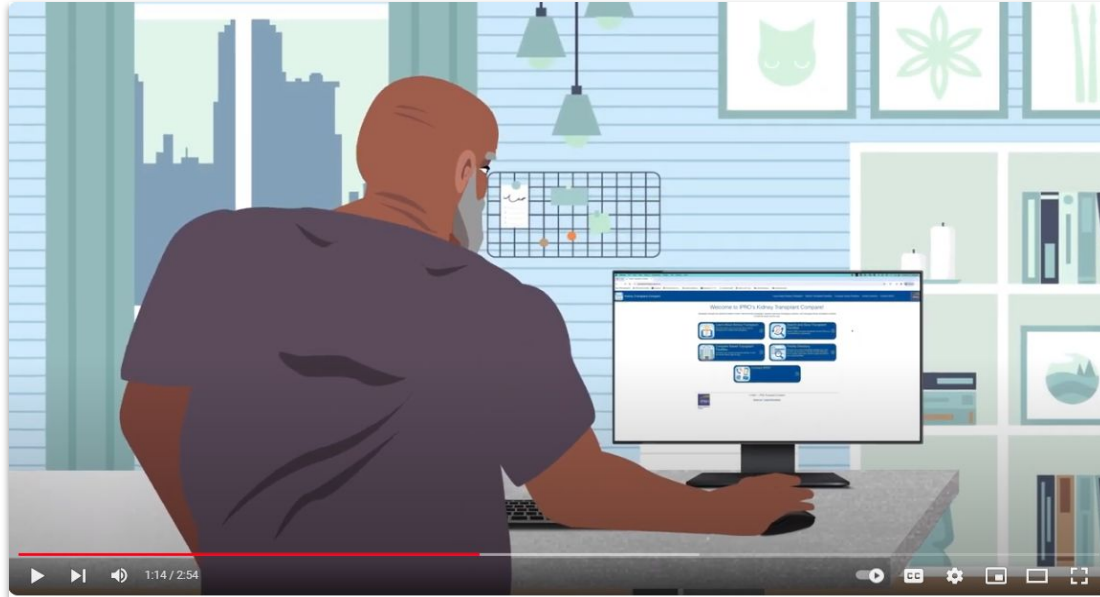


Please share your experience with Kidney Transplant Compare



Kidney Transplant Compare

Commercial



https://youtu.be/VpPyKJ_26o0?si=HRIDd_ta7oUyTaoX



Kidney Transplant Compare

41/48 Transplant Centers Represented (85%)

Patient and Provider Feedback

- Encourages multi listing
- Allowed patients to choose a center with a shorter wait time
- Reduces “trial and error” of finding a center that will accept patients of older age and higher body weight



Kidney Transplant Compare

Action Items



1. Talk about this tool with patients and providers at your facility
 - Patient Flyer:
https://esrd.ipro.org/wp-content/uploads/2023/06/TranspCompare-Flyer-Patients_v5-508c-3.pdf
2. If your transplant center is not listed, connect with the Network to help advocate for that center to get involved!

Introducing... Kidney Transplant Compare
transplantcompare.org

Putting patients and family members in the driver's seat of their transplant journey

DOWNLOAD FOR IPHONE | DOWNLOAD FOR ANDROID | USE YOUR WEB BROWSER

Welcome to IPRO's Kidney Transplant Compare!

Navigate through the sections below to learn about kidney transplant, search and save transplant centers, and compare those transplant centers to find the best one for you!

- Learn About Kidney Transplant >
- Search and Save Transplant Facilities >
- Compare Saved Transplant Facilities >
- Facility Directory >
- Contact IPRO >

Choose the Best Transplant Center For YOU.

1. Learn the basics of kidney transplant and find FREE patient resources. Consider your life plan and decide if kidney transplant is the best treatment option for you.
2. Search, filter, and save transplant centers that you are interested in based on their location, patient selection criteria, support services, and results.
3. Compare the transplant centers you are interested in to choose the best option for you!

Use the camera on your mobile phone or tablet to scan this image code to learn more about Kidney Transplant Compare or visit esrd.ipro.org

Better Than Dialysis Kidneys

New Resource!




These kidneys may shorten your wait time!

a GREAT option for older patients!

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>

Ask your nephrologist or transplant team about Expanded Criteria and High KDPI kidneys - they are *Better Than Dialysis*.



This material was adapted from the ESRD National Coordinating Center and prepared by the Technical Assistance, Quality Improvement and Learning Contractor under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services (HHS). Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. PI-TAGI-11286D-07202023-02

EC/KDPI are fancy ways to explain the kidneys condition

Accepting any kidney is better than staying on dialysis!

<https://files.constantcontact.com/3c70eff001/423e2d1f-f354-4d3c-ad8a-b888e10baba3.pdf>

Network Check-In

Polling Question



Do you think education about Expanded Criteria (EC) or High Kidney Donor Profile Index (KDPI) Kidneys is too advanced for most patients at your facility?

- Yes
- No
- Unsure



Network Check-In

Time to Unmute!



Being knowledgeable about these kidneys and choosing to accept one of these kidneys is important for a patient's quality of life off of dialysis.

Share how you think we can work to inform more patients about Better Than Dialysis Kidneys?



How to Access Resources?



1. <https://esrd.ipro.org/>



End-Stage Renal Disease Network Program

IPRO

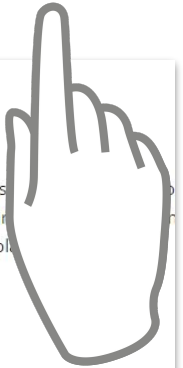
Home About Patients & Family Providers Emergency Management **Quality Improvement** Events

- Behavioral Health
- Bloodstream Infections
- Health Equity
- Home Dialysis
- Hospitalization Reduction
- Long-Term Catheter
- Nursing Home Dialysis
- Telehealth
- Transplant**
- Vaccinations

PROMOTING SAFE, EFFECTIVE, PAT



Scroll Down



Tools & Resources for Patients

A kidney transplant is a type of surgery where you (the recipient) gets a kidney that was donated by someone else. It can improve your quality of life and increased health compared to other treatment options. Below are tools and resources to help you access to kidney transplant. The resources are listed based on the Five Steps Towards Kidney Transplant.

FIVE STEPS TOWARDS TRANSPLANT

- Interest in Transplantation
 - What is a Kidney Transplant: [English](#) | [Spanish](#) | [Video](#)
 - Get the Facts: Kidney Transplantation: [English](#) | [Spanish](#)
 - Do You Know Your Treatment Options Brochure: [English](#) | [Spanish](#)
 - How Much Does a Kidney Transplant Cost: [English](#) | [Spanish](#)
 - Planning for a Kidney Transplant: [English](#) | [Spanish](#)
 - Turning Negatives into Positives: Why transplant is a good idea for me! [English](#) | [Spanish](#)
 - Patient Stories
 - [Your Life, Your Choice](#)
 - [Motivational Patient Stories](#)
 - [Is a Kidney Transplant Right for Me?](#)
- Referral to Transplant

Next Steps



Aisha Edmondson
Patient and Family Engagement

Next Steps



- **Follow** us on social media!
- **Join** the PFR Alliance Facebook Group <https://www.facebook.com/groups/ipropfralliance>
- **Create** your IPRO Learn Account <https://esrd.iprolearn.org/login/index.php/>
- **Participate** in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care - volunteers needed each month!
- **Become** a Peer Mentor:
 - Understand the steps <https://esrd.ipro.org/patients-family/pfe/peer-mentoring/>
 - Sign up to become a peer mentor!
 - Have questions?
- **Review** the Frequently Asked Questions resource <https://esrdncc.org/globalassets/peer-mentoring-operational-toolkit/14pmlmsfaq508.pdf>
- **Contact** Aisha Edmondson at (216)755-3056 or Stephanie Cole (919) 928-6042



<https://www.facebook.com/IPRO.ESRDNetworkPgm>

IPRO End-Stage Renal Disease Network Program

We're on the move...
Follow us to our new Facebook page.
<https://www.facebook.com/IPRO.ESRDNetworkPgm>

The graphic features a light blue background. On the left is the IPRO logo. To its right is the text "End-Stage Renal Disease Network Program". Below this is the phrase "We're on the move..." in italics, followed by "Follow us to our new Facebook page." and the Facebook URL. A white cloud with motion lines is positioned between the text and a stylized truck. The truck is blue and yellow, with a white Facebook 'f' logo on its side and a QR code on its cargo area.

Social Media

Follow Us!



- [IPRO ESRD Network Program's Facebook Page](#)
- [IPRO ESRD Patient Facility Representative \(PFR\) Alliance Group](#)



- [IPRO ESRD Network Program's Twitter Page](#)



- [IPRO ESRD Network Program's LinkedIn Page](#)



- [IPRO ESRD Network Program's Instagram](#)



Next PRF Meeting - Mark Your Calendar!

Thursday, May 2nd 2024 at 5:30pm ET

- Upcoming Topics: Patient Spotlights!!!
- Things to Think About: How will you use the information shared on these calls?

Please join us each month for an IPRO ESRD Network Program hosted **webinar for patients!**

Patient Facility Representative (PFR) Alliance Conference Call
First Thursday of Each Month • 5:30 PM–6:30 PM EST

Please join us in our informative monthly webinars hosted by the Network to help understand quality-of-care expectations for dialysis facilities. Learn about new goals and priorities and how they will affect ESRD patient care.

Scan the QR Code to log onto the meeting!

Topics include:

- Patient and Family Engagement
- Emergency Preparedness
- Health Equity
- Behavioral Health
- Hospitalizations
- Healthy Lifestyles
- Transplant Coordination
- Home Therapies Utilization
- Peer Mentoring

Webinar Access: <https://tinyurl.com/PFRAllianceMeeting>

Meeting ID: 2426 823 7622

Toll-Free Dial-In: 1-855-797-9485

Password: IPROPFR

For more information, please contact the Network at 516-686-9790.

To file a grievance, please contact us:
IPRO End-Stage Renal Disease Network Program
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072
Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
Data Management: (516) 268-6426 • Administration: (516) 686-9790
Support Portal: help.esrd.ipro.org/support/home • Website: esrd.ipro.org/

Developed by the IPRO ESRD Network Program while under contract with Centers for Medicare & Medicaid Services. Contract # 75FCMC19D0029

Community Awareness Campaigns

National Donate Life Month!



Questions? Comments?



Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

Aisha Edmondson
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Tel: 216-755-3056 | E-mail: aedmondson@ipro.org

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Project Manager: Community Outreach Specialist
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**End-Stage Renal Disease
Network Program**

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