

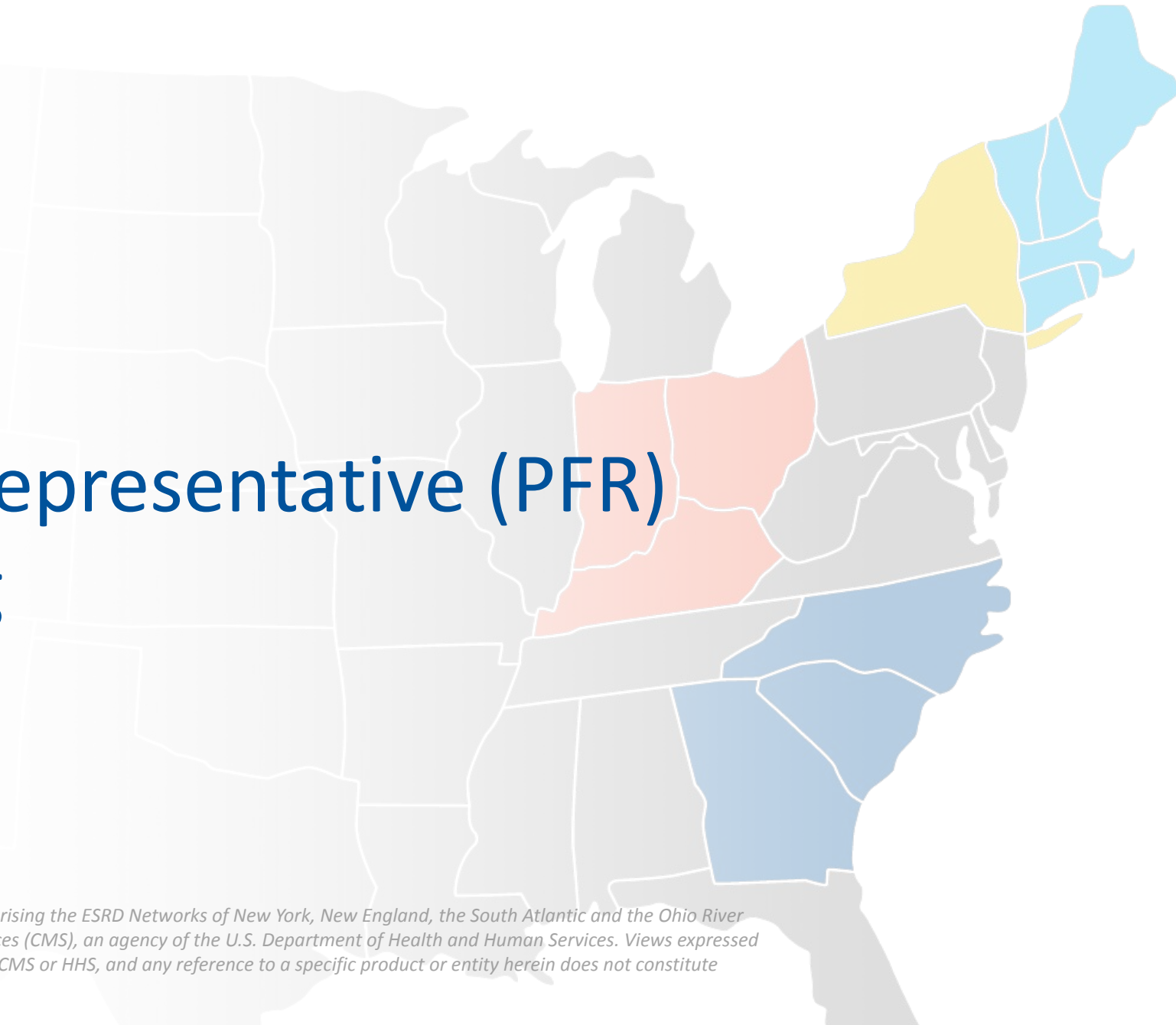


End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

February 1st, 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



Liz Lehnes, MSW, LCSW
Patient Services Specialist



Stephanie Roy, MPH
Health Equity Specialist

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



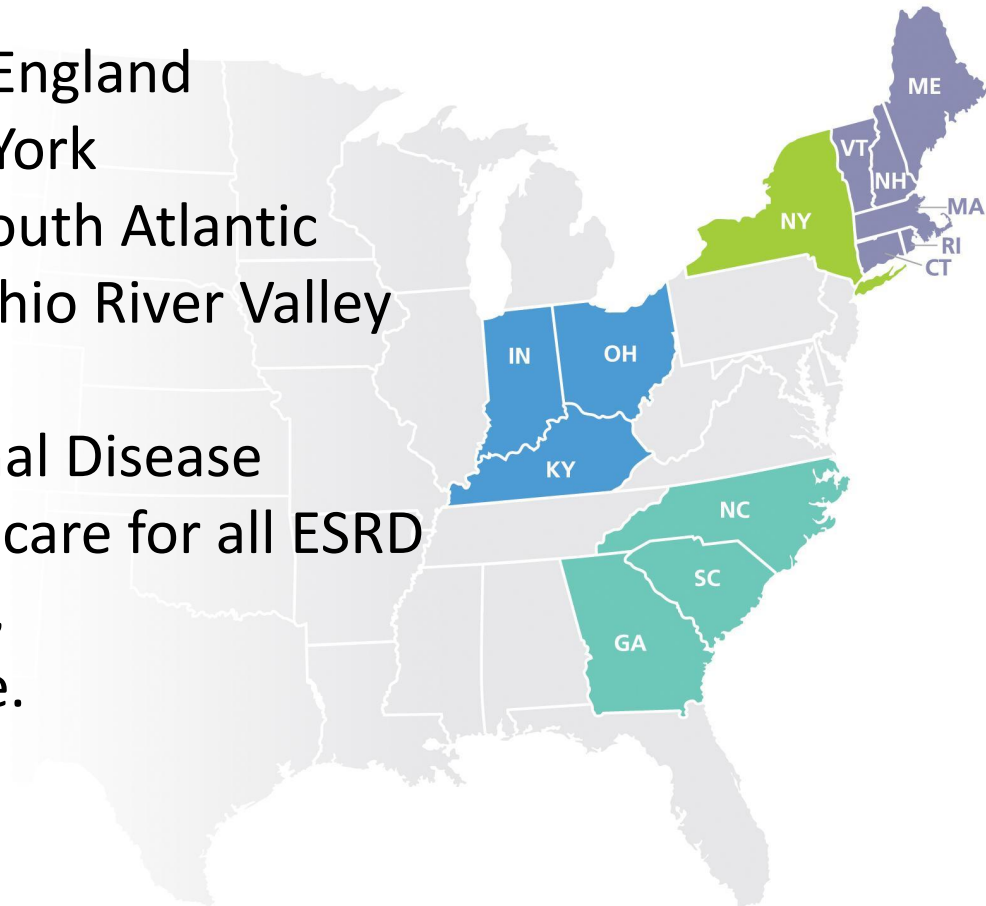
Welcome Our New PFRs!

- James Blanks
- Michele Pecora
- Mary House
- Mehmet Kara
- Diane Burnett
- Jacqueline
- Sandra Ward
- Eddie Hoover

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.

IPRO 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 # F31CMC1100029 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: F31CMC1100029. CMS Task Order Number: F31CMC1100029 (Network 1), F31CMC1100029 (Network 2), F31CMC1100029 (Network 3), F31CMC1100029 (Network 4), F31CMC1100029 (Network 5)

Social Determinants of Health



Stephanie Roy, MPH
Health Equity Specialist

What are Social Determinants of Health (SDoH)?



- Education
- Healthcare
- Physical infrastructure
- Social factors
- Economic factors



Network Check-In

Polling Question



Does your facility screen for SDoH?

- Yes
- No
- Unsure



Why are facilities screening for SDoH?



CMS has asked facilities to screen for social determinants of health (SDoH) to help improve health equity.

- What is health equity?
- How will this improve care?

What to look for/expect?



Living Situation

1. What is your living situation today?³

- I have a steady place to live
- I have a place to live today, but **I am worried** about losing it in the future
- I do not have a steady place to live (I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, on a beach, in a car, abandoned building, bus or train station, or in a park)

Food

Some people have made the following statements about their food situation. Please answer whether the statements were **OFTEN**, **SOMETIMES**, or **NEVER** true for you and your household in the last 12 months.⁵

- ### 3. Within the past 12 months, you worried that your food would run out before you got money to buy more.
- Often true
 - Sometimes true
 - Never true

Financial Strain

11. How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is:⁹

- Very hard
- Somewhat hard
- Not hard at all

Network Check-In

Polling Question



Are there any concerns/hesitancy about the new screening questions?

- Yes
- No



Support Groups



Liz Lehnes,MSW,LCSW
Patient Services Specialist

Network Check-In

Polling Question



Have you ever been a part of a Support Group?

- Yes
- No
- Unsure



Support Groups

How Can These Help You as Patients and Family Members?



- You will find strength in sharing common experiences
- You will develop a sense of empowerment and control over the circumstances
- You will gain insight by discussing challenges and successes of others facing similar circumstances
- You will have a positive outlet to help reduce stress, allowing for more mindful care
- You will better be able to identify needs where focused staff and patient education would be helpful
- You will share experiences you've talked about with your support group with your team to better understand the "why" with treatment recommendations
- You will captain the ship of your care by being empowered with education
- Your participation will help improve all patients' overall experience of care

Tips for Getting Started

Building and Sustaining A Support Group



- **Be Persistent** - It takes a time to be known in your area and for people to see your group as a resource.
- **Don't be Discouraged** - The first few sessions may have very limited attendance
- **Identify your core group** and learn about each other, identify **commonalities**. An effective support group will build relationships inside and outside of the topic of kidney disease
- **Don't overcomplicate** the design of the support group, a few basic ground rules will help your group stay organized but keeping it simple will allow you flexibility.
- **Be consistent**. Holding your meeting at the same place and time will allow people to come as they are able and not be confusing.

Topic Ideas

For Newly formed ESRD Support Groups



- Topics should engage, build your growing Support Group Community, and possibly be educational
- Lobby Game Day
- Lobby Day with a transplanted patient
- Treatment options talk Day (have a home program staff speaker do a Q&A)
- Recipe Swap Day
- New Activities, Hobbies and/or Maintaining Balance Day
- [IPRO Bingo Card Day](#)
- Holiday centric Events
- Pen pals

Additional Resources

Support Groups



[Renal Support Network \(RSN\) Online Kidney Disease Support Groups](#)

[Support Groups](#)

[You are Not Alone](#)

[Utilize PFR Resource Toolkit](#)

[Patient Portal](#)

Next Steps



Aisha Edmondson
Patient 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

What's New!



- If you are a PFR who has stated they want to be a Peer Mentor, Please join us for our upcoming and monthly Peer Mentoring training modules Part 1 and 2 every 25th-27th of the Month!

More ways to join:

Need help? Go to <https://help.webex.com>

Join from the meeting link

<https://ipro.webex.com/ipro/j.php?MTID=m66ce26946b8715ce82cffa2fa9bc56aa>

Join by meeting number

Meeting number (access code): 2422 510 7328

Meeting password: pyXdmWjN497

Tap to join from a mobile device (attendees only)

+1-855-797-9485,,24225107328## US Toll free

+1-415-655-0002,,24225107328## US Toll

Join by phone

+1-855-797-9485 US Toll free

+1-415-655-0002 US Toll

Toll-free calling restrictions



Next PRF Meeting - Mark Your Calendar!

Thursday, March 7th 2024 at 5:30pm ET

- Upcoming Topics: Mental Health, Depression Resources
- Things to Think About: Would you like to be featured on a upcoming call?

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



<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 blue and yellow truck moving to the right. The side of the truck has a large white Facebook 'f' logo and a QR code. A white cloud with motion lines is behind the truck, suggesting movement.

Community Awareness Campaigns

February 2024



- Share with your friends on Social Media about National Donor Day. Let's help people register to be an Organ Donor!



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](#)



**Questions?
Comments?**



Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

Aisha Edmondson
Patient and Family Engagement Lead
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Stephanie Cole, BA, PSM, QP
Project Manager: Community Outreach Specialist
Tel: (919) 928-6042 | E-mail: scole@ipro.org



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