Patient Facility Representative (PFR) Alliance Meeting

February 1st, 2024
Patient and Family Engagement Facilitators

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Patient and Family Engagement
Lead
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Health Equity Specialist

Liz Lehnes, MSW, LCSW
Patient Services Specialist
Today’s Agenda
Topics for Review/Discussion

Meeting Reminders

PFR Check-In

Quality Improvement Topic

Patient Services Topic

Closing Remarks
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
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, 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.
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?¹
   - [ ] 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.⁶

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:³
   - [ ] 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
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](https://www.facebook.com/groups/ipropfralliance)
- **Create** your IPRO Learn Account [https://esrd.iprolearn.org/login/index.php/](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/](https://esrd.ipro.org/patients-family/pfe/peer-mentoring/)
  - Sign up to become a peer mentor!
  - Have questions?
- **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=m86ce26946b8715ce82cfa2fa9bc56a

Join by meeting number
Meeting number (access code): 2422 510 7328
Meeting password: pyXdmVjN497

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?
https://www.facebook.com/IPRO.ESRDNetworkPgm
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
Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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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 #