



End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

March 7th, 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



Shazeena Andiappen, MSW
Patient Services Speaker



Yvonne Heavner, RN, RNBS
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!



- Christopher Stephens
- Bradford Bello
- Nancy Hotaling
- Lynnann Westhoff
- Cassandra Price
- Valerie Peavy
- Destiny Pastore
- Stephen Lewis
- Yvette Mendez
- Hector Mendez
- John Prendergast
- Mary Johnston
- Sandra Ward



NPFE-LAN Members!

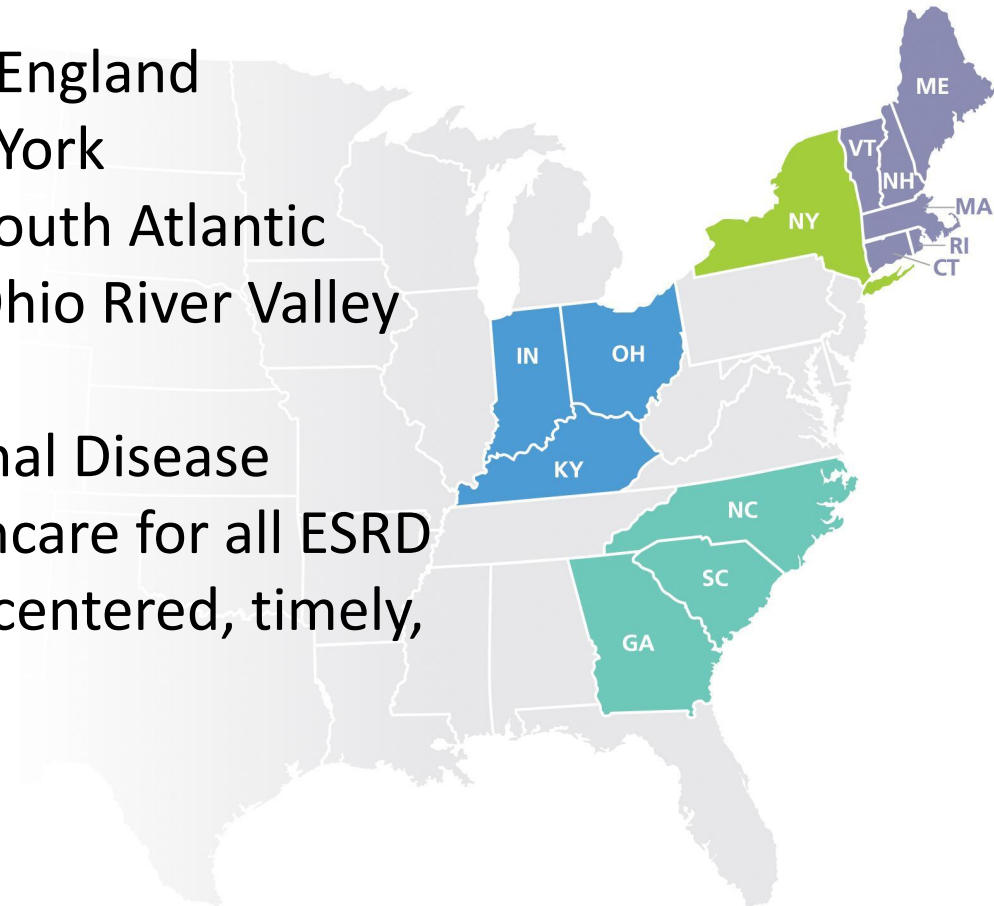
- Patient Safety Affinity Group
- Health Equity Committee
- Transplant AG Group
- Hospitalization Affinity Group
- Vaccinations AG Group

*Thank
you*

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, 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 # F31CMC1100029 Publication # ES01993.GA.MW.0202013.01R 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).

Mental Health



Shezeena Andiappen, MSW
Patient Services Specialist

Network Check-In

Polling Question



Do you believe there is enough awareness and understanding about mental health in your dialysis facility?

- Yes
- No
- Unsure





What is Mental Health?

Definition

[Mental Health](#) includes our emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and how we make healthy choices.



Recognizing Red Flags

Common Warning Signs of Mental Illness



- Feeling very sad or withdrawn
- Trying to harm or end one's life or making plans to do so
- Severe, out-of-control, risk taking behaviors that causes harm to self or others
- Significant weight loss or gain
- Seeing, hearing or believing things aren't real
- Excessive use of alcohol or drugs
- Drastic changes in mood, behavior, personality or sleeping habits
- Extreme difficulty concentrating or staying still
- Intense worries or fears that get in the way of daily activities

Mental Health Effects on Dialysis Patients

Impact on Patients Emotional and Physical Health



- Dealing with life changes, adjustment to new dialysis
- Non adherence to treatments, medication
- Addiction: Misuse of drugs, alcohol
- Aggression: Behavioral outburst (verbal or physical abuse, threatening acts)
- Higher risk for involuntary discharges
- Withdrawal from friends, family

Can Mental Health be Improved?

Tips on Improving Mental Health



- Healthy Lifestyle
- Utilize social Support
- Hobbies and Interest
- Self-Care
- Peer mentoring
- Support Group
- Professional Help: Therapy, Medication

Remember:

"Your mental health is just as important as your physical health"

"It's okay not to be okay"

"Your struggles do not define you"

"There is no shame in seeking help for your mental health"

"You are not alone in your struggles"

"It's okay to ask for support when you need it"

Are there Available Services for Mental Health?

Community Resources



- SAMHSA Substance Abuse and Mental Health Services Administration: [SAMHSA](#)
- Psychology Today: Browse an online directory of mental health professionals in your area. [Find a Therapist](#)
- American Psychological Association (APA) Psychologist Locator: [Psychologist Locator](#)
- Renal Support Network: Hopeline Peer Support Hotline. [Hopeline Peer Support Hotline](#)
- 988 Suicide & Crisis Lifeline: <https://988lifeline.org/>

Depression and Peer Mentorship



Yvonne Heavner, RN, RNBS
Depression and Incident Quality
Improvement Lead

Network Check-In

Polling Question



Does your facility have a patient support group?

- Yes
- No
- Unsure



Increasing Patient Engagement at the Facility Level

How can a facility patient representatives help?



- Studies show that peer support can have a positive impact on patient outcomes.
- The success in peer support comes from building relationships and sharing real life experiences.
- Additional benefits can be gained by the peer mentor. They feel a sense of worth and accomplishment through helping others.






How Can a Patient Facility Representative Help?

Ideas we learned from great PFR's!



- Helped the social worker make a mental health bulletin board in the facility
- Helped with the patient newsletter
- Celebrates special days
- Encourages patients to participate in facility activities



Can Patient Support Groups and Peer Mentoring Help with Depression?

What are the benefits of patient support groups and peer mentoring?

- Studies show that peer support can have a positive impact on patient outcomes.
- The success in peer support comes from building relationships and sharing real life experiences.
- Peer support can help to improve patients' sense of hope
- Peer mentoring and patient support groups allow for patients to learn from one another
- Patients often report feeling less lonely and less isolated when engaging with peers
- Patients who participate in support groups or peer mentorship may experience a decrease in anxiety and depression
- Patients who chose to become a peer mentor often feel a sense of worth and accomplishment through helping others.

Did You Know?

IPRO has a [Peer Mentoring Program](#) that your patient facility representatives can attend? Please click on the link to learn more!

Would you like to learn more about the benefits of patient support groups?

The Mayo Clinic wrote a great article on this topic titled "[Support Groups: Make connections, get help](#)".

(Click the link to be taken to this article)

Check Out Some Other Patient Support Groups or Peer Mentor programs below!

Program	Website
NKF Peers (National Kidney Foundation)	https://www.kidney.org/peers
IPRO's Peer Mentoring Program	https://esrd.ipro.org/patients-family/pfe/peer-mentoring/
American Association of Kidney Patients	https://aakp.org/center-for-patient-engagement-and-advocacy/support-groups/
NKF On-line Communities	https://www.kidney.org/Communities
Renal Support Network	https://www.rsnhope.org/

Does Your Facility Have A Peer Mentor or Patient Support Group?

IPRO, the End-Stage Renal Disease Organization for the Network of New England, Network of New York, Network of the South Atlantic, and Network of the Ohio River Valley, prepared this material under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy. CMS Contract Number: 757CMC19D0029. CMS Task Order Numbers: 757CMC21F0001 (Network 1), 757CMC21F0002 (Network 2),

Peer Mentor Programs



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American Association of Kidney Patients	https://aakp.org/center-for-patient-engagement-and-advocacy/support-groups/
NKF On-line Communities	https://www.kidney.org/Communities
Renal Support Network	https://www.rsnhope.org/

Ideas on how facility staff or the Network can help?



- Do you feel comfortable talking about depression with staff?
 - What would help patients feel more comfortable?
- Any new ideas for depression resources, is anything you would like to learn more about?
- Any input on this topic?



Next Steps



Aisha Edmondson
Patient and Family Engagement



Network Check-In

- Are you interested in participating 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?
 - Yes
 - No
 - Unsure



Next Steps

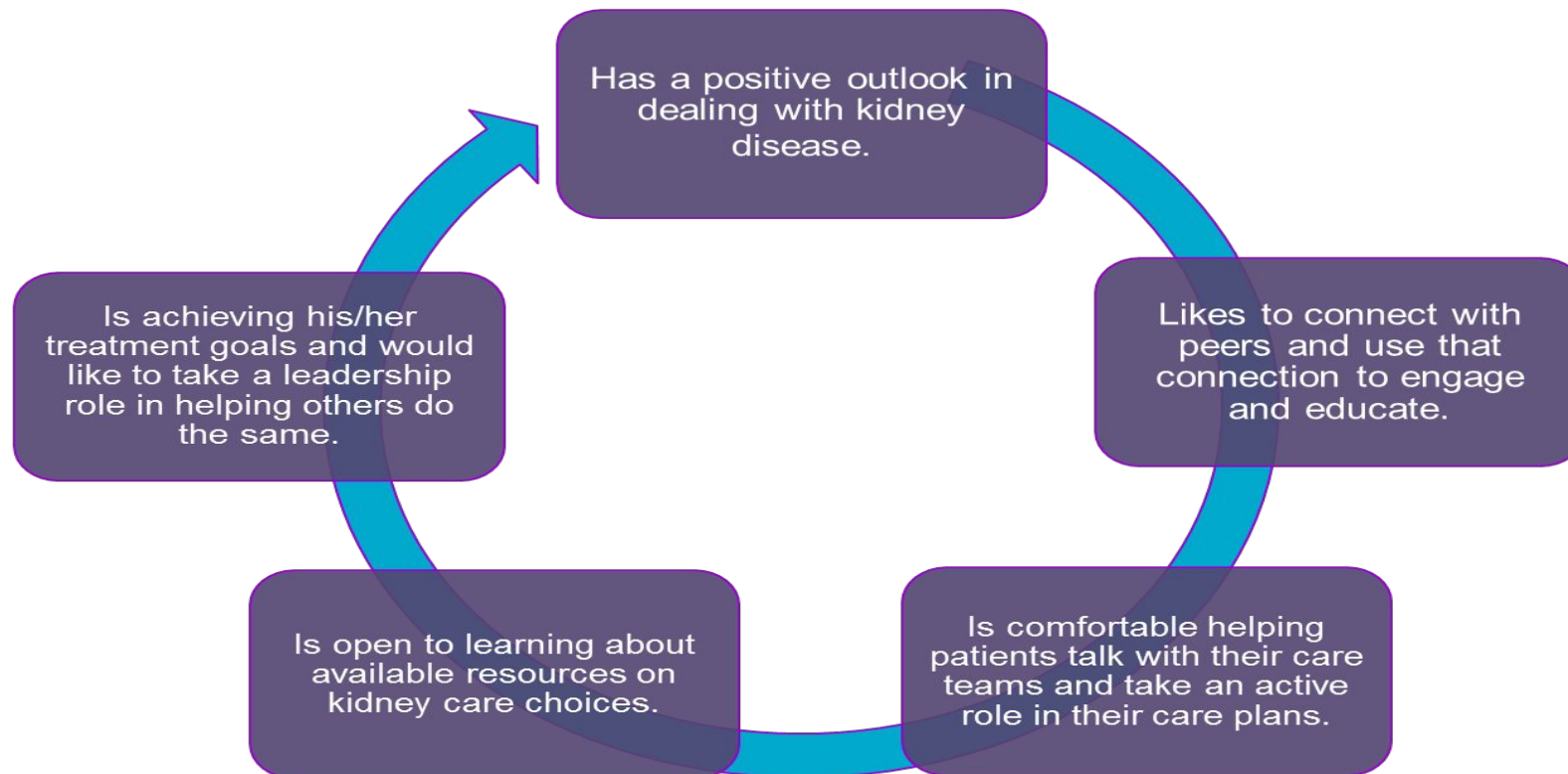


- **Follow** us on social media!
- **Join** the PFR Alliance Facebook Group <https://www.facebook.com/groups/ipropfralliance>
- **Create** your IPRO Learn Account <https://esrd.iprolearn.org/login/index.php/>
- **Participate** in a call with Network staff and CMS to share your experience as a PFR, address 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 that you 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!





Next PRF Meeting - Mark Your Calendar!

Thursday, April 4th 2024 at 5:30pm ET

- Upcoming Topics: Access to Care “Coping” and Transplant
- Things to Think About: What content would you like to see on our social media platforms?

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.

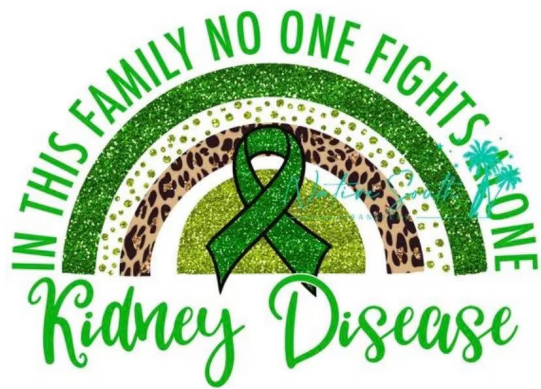
Community Awareness Campaigns

March is National Kidney Month!!



The World Kidney Day Joint Steering Committee has declared 2024 to be the year of “Kidney Health for All – Advancing equitable access to care and optimal medication practice”.

You can show your support by wearing **green** ribbons during the month of March or April as green is the color for both Kidney Disease Awareness and organ donation awareness.



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
Project Manager: Patient and Family Engagement
Tel: 216-755-3066 | E-mail: aedmondson@ipro.org

Stephanie Cole, BA, PSM, QP
Project Manager: Community Outreach Specialist
Tel: (919) 928-6042 | E-mail: scole@ipro.org



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