Patient Facility Representative (PFR) Alliance Meeting

March 7th, 2024
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 Andiappan, MSW
Patient Services Speaker

Yvonne Heavner, RN, RNBS
Quality Improvement Speaker
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!

- 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
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.
Mental Health

Shezeena Andiappan, MSW
Patient Services Specialist
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
# Peer Mentor Programs

<table>
<thead>
<tr>
<th>Program</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>IPRO's Peer Mentoring Program</td>
<td><a href="https://esrd.ipro.org/patients-family/pfe/peer-mentoring/">https://esrd.ipro.org/patients-family/pfe/peer-mentoring/</a></td>
</tr>
<tr>
<td>American Association of Kidney Patients</td>
<td><a href="https://aakp.org/center-for-patient-engagement-and-advocacy/support-groups/">https://aakp.org/center-for-patient-engagement-and-advocacy/support-groups/</a></td>
</tr>
<tr>
<td>NKF On-line Communities</td>
<td><a href="https://www.kidney.org/Communities">https://www.kidney.org/Communities</a></td>
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<tr>
<td>Renal Support Network</td>
<td><a href="https://www.rsnhope.org/">https://www.rsnhope.org/</a></td>
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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
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](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 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?
https://www.facebook.com/IPRO.ESRDNetworkPgm
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

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

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 #