Patient Facility Representative (PFR) Alliance Meeting

10/05/2023
Patient and Family Engagement Facilitators

Aisha Edmondson
Patient Family Engagement Lead
Patient and Family Engagement Facilitators

Stephanie Cole, BA, PSM, QP
Community Outreach Specialist

Liz Lehnes, MSW, LCSW
Patient Services Specialist

Katie Chorba, MSN, RN
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
Please Welcome Our Newest Members!

- Sean Quinn
- Lyndon Spleen
- Elizabeth Desmonies
- Kwaku Ayisi
- Tina James
- Emily Locey
- Janice Kowalski
- Kayla St. Pierre
- Anthony Paratore
- Charles Easley
- Rita Normandeeau
- Jack Hearns
- Lula Crayon
- Vincent Pike
- Diane Grant
- Laura Wilcox
- Ozzie Walter
- Marsha Parker
- Walter Meader
- Joseph Memmo
- Douglas Lilly
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)
October Debrief with Patient Services

Liz Lehnes, MSW, LCSW
Patient Services Specialist
Network Check-In
Polling Question

When you first started dialysis, do you think you adjusted well to the transition?

• Yes
• No
• Unsure
Adjusting to Dialysis
Changes to everyday life

You may notice as seasons are changing, you feel some struggle with:
● your dialysis adjustment
● grief and coping
● observing others going through this as well

Think to yourself a moment:
● What are some hobbies that I did prior to starting dialysis?
● What are some things that I heard about that I want to try?
● What did it take/ Will it take for me to get started?
Adjusting to Dialysis
Checkpoint

Think to yourself a moment:

• What are some ways YOU have/can see yourself helping someone like this?

• What are some ways you were helped?

• Imagine a treatment floor where YOU had a YOU helping with your adjustment to dialysis…
Healthy Boundaries
Should feel like:

- Accepting when others say no
- Saying no without guilt
- Communicating and discussing wants and needs
- Not anticipating needs of others
- Acting in alignment of your beliefs and values
- Feeling safe to express self
- Respect towards other patients and staff
- Encouraging and supporting one another

Boundary Violations:

- Comments or remarks that others may find offensive or threatening, including comments regarding people’s culture or ethnicity
- Sexual comments or touching, including sexual activity or exposure
- Stalking, following, or uninvited involvement in someone’s personal life
- Offering gifts that could be perceived as bribery
- Personal relationships, such as dating or social activities
- Buying or selling goods of any kind
- Offers of employment
- Giving, receiving or loaning money
When a patient comes to you first

Do:

- Please remember that you have to be in a good space to be able to help so if you notice yourself struggling consider your current habits:

And how they can look different for you, even if it is changing up your routine for a day. If you don’t know how to get started, tap into your clinic Social Worker or take a look online searching “PDF Self Care Assessments”!
Network Resources

**Decreasing Patient - Provider Conflict Manual**

- “Six Steps To Resolving Conflict”
- “Tips for Defusing Anger”

**Helpful Website Links**

- Important Information for Kidney Patients About Substance Use Disorders Handout: [Network 1](#) | [Network 2](#) | [Network 6](#) | [Network 9](#)
- Depression and Dialysis - My Story: [Read It!](#)
- Support Groups - Creating Community: [Read It!](#)
- Alternative Approaches to Peer Mentoring Handout: [Network 1](#) | [Network 2](#) | [Network 6](#) | [Network 9](#)
- Support Group Tips: [Network 1](#) | [Network 2](#) | [Network 6](#) | [Network 9](#)
- Talking To Your Doctor About Mental Health: [Worksheet](#)
- Stop the Stigma Surrounding Depression: [Provider Resource](#)
- Shatter the Stigma: Flipping the Facility Culture: [Frequently Asked Questions](#)
Network Resources Cont
Outside Resources

- National Kidney Foundation: A “New Normal”: Life on Dialysis - The First 90 Days
- American Kidney Fund: 6 Tips to Help You Adjust to Dialysis
- Take Care of Your Behavioral Health: Tips for Social Distancing, Quarantine, and Isolation During an Infectious Disease Outbreak: Guide
- Coping with Stress During Infectious Disease Outbreaks: Guide
- Coping with Infectious Disease Outbreaks in the Dialysis Setting for Healthcare Workers: Flyer
- NAMI COVID-19 Resource and Information: Guide
- Grief Management for the ESRD Healthcare Provider: Slides
- Taking Care of Your Mental Health in the Face of Uncertainty: Article
- National Kidney Foundation: CNSW Care Planning Resource Toolkit (PDF)
Where Can a Patient Facility Rep Help?
Observation> Intervention> Reaction

• You observe a patient has been missing quite a few treatments. When they do come, they are dressed in their pajamas. > You wonder if they can benefit from Patient Facility Rep support; You greet them one time, introduce yourself and check in to get to know them. > They say hello back each morning and begin to be more talkative. They miss treatment less because they get to go out and see a friend.

• You see a person get upset with a staff member. > You let them cool down and another day ask if they want to talk about any topics or resources. You help explain this topic (for example: fluid) how it relates to your life and experience and give them space to talk and connect the dots. > You’ve made a friend. They understand better because of YOU.
Where Can a Patient Facility Rep Help?
Observation> Intervention> Reaction

Would anyone like to share a time they have had a similar experience?
Reducing Hospitalizations

Katie Chorba, MSN, RN
Assistant Director; Project Lead
Hospitalizations, Nursing Home
Network Check-In
Polling Question

Should you always go straight to the ER if you need care or is it dependent on what you may be experiencing?

• Yes
• No
• Unsure
What Type of Care Do I Need?
Patient-Facing Resource

- Often, patients face critical decisions about their medical care.
- Introducing "What Type of Care Do I Need?"
- A patient-facing resource designed by the Network to aid in decision-making.
- Key Features:
  - Provides a comprehensive list of signs, symptoms, and conditions.
  - Guides patients on whether to seek care from their primary doctor, visit urgent care, or head to the ER.
  - Offers reassurance: Patients uncertain about their next steps can call the dialysis center during operational hours.
  - In cases of doubt or emergency, it emphasizes the importance of calling 911 for immediate assistance.
- The Network’s goal is to empower patients with knowledge for better healthcare decisions.
**WHAT TYPE OF CARE DO I NEED?**

Sometimes you need to make a quick decision about where you should go to seek medical attention. Here’s a guide to help you get the care you need when you need it!

If you need assistance contact your dialysis unit during operation hours. When in doubt, dial 911.

<table>
<thead>
<tr>
<th>Condition, Signs, Symptoms</th>
<th>Primary Care Doctor</th>
<th>Urgent Care Facility</th>
<th>Hospital Emergency Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abscess that needs to be drained (painful sore with pus)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Allergic reaction (sudden swelling of face or neck, having trouble breathing)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Allergies (seasonal)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Asthma attack</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Bleeding that will not stop</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Broken bone</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Broken bone (bone sticking out of the skin)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Burn (minor)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Burn (white or charred – severe)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Cast problem (wet or soiled)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Chest pain</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Cold</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Cough</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Cut (skin surface – minor)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Cut (deep cut, needing stitches – severe)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Dehydration (weak, dizzy, fever, headache, unable to keep fluids or foods down)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Dizziness (falling, unable to stand)</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Dog bite</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Earache</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>

End-Stage Renal Disease Network Program

For more information or to file a grievance, please contact us:

IPRO End-Stage Renal Disease Network Program
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11043-1072
Patient Services: (888) 221-8787 • Toll-Free: (800) 238-3773
Email: esrdnetworkprogram@ipro.org • Web: esrd.ipro.org

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, incorporated. This material is 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: 576585-DR. This document is part of an integrated program that includes materials produced by: 758542-001, Network 1; 758542-010, Network 2; 758542-002, Network 3; 758542-003, Network 4; 758542-004, Network 5; 758542-005, Network 6. Distribution of this material is not authorized by CMS. No CMS approval. 4/2020.
The resource provided by the Network on "What Type of Care Do I Need?" will be distributed to both staff and patients by the Facilities department.

Facilities will provide staff with cut-out flashcards, each representing a different condition, sign, or symptom from the resource.

During or before treatment, staff will offer patients one of these flashcards, initiating a conversation about the patient's potential care path based on the selected flashcard.

Staff will also use the resource to assess if the patient's chosen path aligns with the recommendations.

If the patient's choice does not align, this presents an opportunity for an educational session with the relevant staff member.

This process aims to promote communication and address any potential barriers patients may encounter in accessing the appropriate care they need.
Interactive Facility Activity/Resource Feedback

- Does this resource seem like it would be helpful?
- Would you be willing to participate in the interactive activity in your facility?
- What do you see in your facilities that is driving increased hospitalizations?
  - Missed treatments
  - Fluid Management
  - Access issues
  - Other
- What type of patient-facing resource would you like to see next?
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?

• **Review** the Frequently Asked Questions resource
  [https://esrdncc.org/globalassets/peer-mentoring-operational-toolkit/14pmlmsfaq508 .pdf](https://esrdncc.org/globalassets/peer-mentoring-operational-toolkit/14pmlmsfaq508 .pdf)

• **Contact** Aisha Edmondson at (216)755-3056 or Stephanie Cole (919) 928-6042
Next PRF Meeting - Mark Your Calendar!
Thursday, November 2nd 2023 at 5:30pm ET

• Upcoming Topics: Access to Care & Health Equity

• Things to Think About: As a patient, do you know about Health Equity and Culturally and Linguistically Appropriate Services (CLAS)?
Community Awareness Campaigns

World Mental Health Day!! October 10, 2023

Every year we celebrate World Mental Health Day on the 10th of October. The theme for 2023, set by the World Foundation of Mental Health, is 'Mental health is a universal human right'. World Mental Health Day is about raising awareness of mental health and driving positive change for everyone's mental health.

Practice Self-Care

Care for your mental health as much as you can. Promoting healthy behaviors may help you support others. Rely on yourself or your support system for care. Some positive coping mechanisms you might use include:

- Journaling about your feelings
- Exercising
- Practicing sleep hygiene
- Playing with your pets or children
- Spending time with someone you love
- Meditating or practicing mindfulness
- Yoga
- Spending time in nature
- Swimming
- Singing or playing an instrument
- Listening to music
- Cooking or baking
- Taking a class
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:

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Stephanie Cole, BA, PSM, QP
Project Manager: Community Outreach Specialist
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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 #