

Patient Facility Representative (PFR) Alliance Meeting

09/07/2023

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



Stephanie Cole, BA, PSM, QP Community Outreach Specialist



Julia Gesick
Emergency Management
Speaker

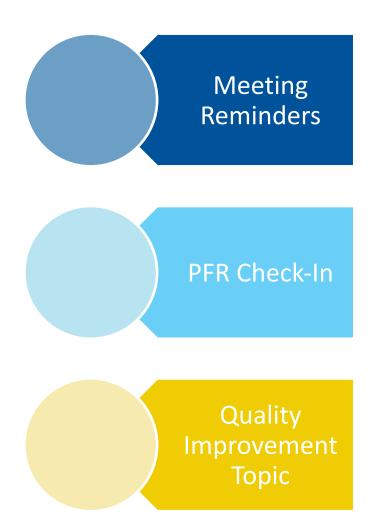


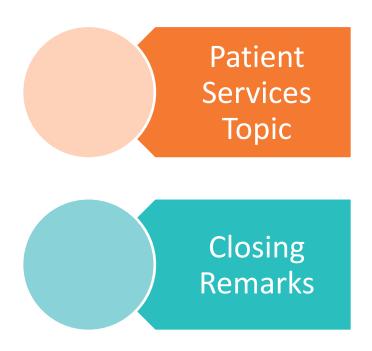
Yvonne Heavner
Quality Improvement Speaker

Today's Agenda

Topics for Review/Discussion







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



IPRO ESRD Network Program



The IPRO End-Stage Renal Disease Network Program includes four ESRD Networks:

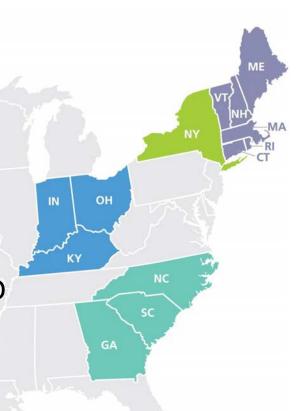
Network 1: ESRD Network of New England

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)



August Follow Up

Kidney Transplant Compare

Kidney Transplant Compare



August Action Item Follow Up

Last month the PFRs were asked to:

- Work with your facility staff to PRINT and POST the patient flyer for Kidney
 Transplant Compare
- 2. Gather feedback from a patient on their use of the application be ready to share!

Action Item



Polling Question

Did you print and post the Kidney Transplant Compare flyer in your facility?

- 1. Yes
- 2. No



Action Item



Polling Question

Please share any patient feedback you gathered from sharing the application last month:

1. free type in the text box



Network Check-In

Polling Question

SHEWI & FAMILIE

Do you feel prepared for an emergency situation?

- Yes
- No
- Unsure



What Do Dialysis Patients Need to Know About Emergency Preparedness?



Julia Gesick BSW
Emergency Management Specialist

Objectives



- Emergency preparedness is essential for patients to ensure continuity of care. It is important for people on dialysis to plan ahead for emergencies and disasters in order to stay safe. This webinar provides information that will help understand:
- Types of emergencies
- How travel can impact your care
- What to ask your team
- What supplies may be needed

What is the Network's Role in an Emergency?

Preparedness, Mitigation & Response



- Networks monitor conditions that impact a facility's ability to to provide service to dialysis patients
- Establish relationships with state emergency management officials and healthcare coalitions
- Work to identify challenges and barriers impacting patients and their facilities
- Communicate barriers, needs and outcomes to CMS

What is an Emergency?

Emergencies can be Local, State Level, Regional or National

ANGA GENERI

- Weather Event
- Facility Closed/Altered (Water, Power, Structural)
- Public Health Issues (COVID-19)
- Man Made Event (Terrorism, Supply Shortage)
- Transportation Event (Weather, Bridge Collapse)
- Communications Event (Phone/Internet Outage)

Basic Requirements for Dialysis



- **Space** to do the treatment
- **Electrical Power** to run the equipment
- Dialysis Machines
- Portable Water for use in the treatment (each treatment requires a minimum of about 100 gallons of treated, pressurized water)
- Supplies such as dialyzers, blood lines, saline, medications, etc.
- Personnel qualified to perform dialysis
- A physician's prescription for dialysis and medical records to support the treatment
- A **hospital** or other similarly equipped system and means to transport a patient if complications occur during treatment
- Transportation to and from dialysis

What to Ask Your Team



- What is my facility's emergency plan?
- How will my facility contact me if there is an emergency?
- How will I receive dialysis if my facility is unable to open?
- How can I best prepare my home for an emergency?
- What should I do if an emergency happens during treatment?
- Where is my closest medical needs shelter?



Resources and Supplies Needed



Have a "to-go" bag ready with essentials such as:

- Water and food
- Health Documents
- Emergency Tools
- Clothes and Toiletries



Feedback Requested

Please Provide Your Answer in the Chat



- December 2022, a large snow storm impacted Buffalo, NY
- Patients and staff were forced to spend the night at their clinic due to lack of transportation/rapid rate of snowfall

What are TWO items you would feel are a **need** for staying overnight in an emergency at your dialysis facility?

Depression - How can we better approach this topic with patients?



Yvonne Heavner RN, RNBS

Why is it important to address depression with patients?



- •Studies show that patients on dialysis with a diagnosis of depression have a decreased quality of life.
- •Depression may lead to missed treatments/medications which can lead to decreased physical health as well.

How can depression be better addressed in facilities?

Common Barriers



- Stigma
- Appointment fatigue
- Patients aren't interested
- Mental health professional shortages
- Lack of support



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.





- •Do you feel comfortable as a PFR talking about depression?
- •Any ideas for additional resources?
- •What do you feel would be good information for patients to learn about depression/mental health treatments
- •Working on a new handout "What to expect during your first therapy appointment"?
- •Any input on this topic?

Recently Released Handout



You have a chronic illness...

You have a lot of questions about how your life will change ...



Often when people are diagnosed with a chronic illness they feel a sense of loss and sadness. They don't know the answers to many questions.

But help is available to address these feelings.

Working Through Feelings

For many people, change is not easy. When newly diagnosed with a chronic illness, people often are forced to deal with necessary changes in lifestyle, lower energy levels, increased responsibility, threats to financial security and other concerns. These changes often cause feelings of sadness, grief, loss, or anger that can negatively affect the way people think and act and may lead to depression for some.

After speaking with kidney patients, we have learned that many do not seek treatment for these difficult and painful feelings due to fear of being seen in a negative light (stigma) and shame. It is important to know that while kidney disease affects everyone differently, many people have feelings of loss and sadness as they face the realities of a chronic illness such as kidney disease.

If you are experiencing overwhelming feelings, it's important to know you're not alone. Many react the same way to changes in their lives. It's important to remember that talking to professionals and getting support can help you move through these feelings and remind you that your feelings are normal and you are not alone!

A Process

In 1969, a Swiss psychiatrist, Elizabeth Kubler-Ross, introduced a five-stage model that describes what people often experience (in part or in total) as they deal with grief or loss. The five stages of grief/loss are:

- Denial withdrawing, avoidance, forgetfulness, anxiety, difficulty focusing, missing treatments
- Anger irritability, easily frustrated, anger outbursts, short temper
- Bargaining feeling guilty, overthinking, feelings of "What-if"
- Depression feeling sad, withdrawing from family and friends, lack of motivation, decreased energy, hopelessness, sleep disturbances, anxiety
- Acceptance hopeful, coping, and learning to adapt

continued on next page

Network Check-In

Polling Question



Do you feel this idea for a new handout will be helpful to patients hesitant to go to therapy for depression?

- Yes
- No
- Unsure



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/
 - Register online: https://redcap.ipro.org/surveys/?s=CJMXNF9DNR
 - Our 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

Next PRF Meeting - Mark Your Calendar!

Thursday, October 5th 2023 at 5:30pm ET

Upcoming Topics:
 Reducing Hospitalizations, providing patients on knowledge on where to go.

 Things to Think About: Should you always go straight to the ER if you need care?



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-ofcare 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.



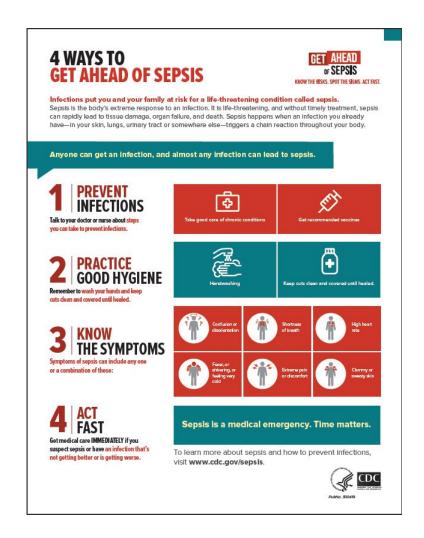
To file a grievance, please contact us: IPRO End-Stage Renal Disease Network Program Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072 Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773

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

Community Awareness Campaigns

Sepsis Awareness Month ***Get Ready Day-9/19/2023







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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Engagement

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End-Stage Renal Disease Network Program

IPRO End-Stage Renal Disease

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