Patient Facility Representative (PFR)
Alliance Meeting

January 4th 2024
Patient and Family Engagement Facilitators

Aisha Edmondson
Patient Family Engagement Lead
Patient and Family Engagement Facilitators

Stephanie Cole, BA, PSM, QP
Community Outreach Specialist

Julia Gesick, BSW
Emergency Management Speaker

Name & Credentials
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!

- Jo Long
- Dessia Smith
- Laurence Sawyer
- Cathy Longo
- Jakarta Bentley
- Yvette Eades
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.
Home Modalities

Michelle Prager, MSW, LSW
Home Modalities and Telemedicine
Network Check-In
Polling Question

Are you currently sharing any information on home dialysis in your facility?
• Yes
• No
• Unsure
New Resource
How Old Is Too Old For Home Dialysis?

Some people feel overwhelmed by the technology and amount of training needed to conduct dialysis at home. This is often the case for older adults, but the benefits an older person can experience with home therapy are a great reason to reconsider this option.

Benefits of home dialysis:
- People on home dialysis have treatments more frequently than those who receive their treatments in a dialysis clinic. Because treatments are done more frequently, they are gentler on your body. This can result in:
  - less choice of your blood pressure dropping;
  - better control of swelling (edema) and your blood pressure being too high;
  - increased energy level;
  - feeling better after dialysis;
  - fewer restrictions on your diet and fluid intake;
  - reduction in the amount of medications you have to take.
- Doing your dialysis at home will mean that you no longer have to travel three times a week to your dialysis facility, saving you time, travel costs, and stress in dealing with traffic and/or bad weather.
- You also have the flexibility to travel, do your hobbies, and schedule your treatments around your social life and activities.
- You and your doctor can choose a home modality that best fits your lifestyle.
- Home hemodialysis is done via needles into your access site or through your venous central line. Peritoneal dialysis is done using a surgically placed catheter in your abdomen, so no needles are necessary. Either treatment can be done on your own, without assistance.

While home therapy may seem like a lot to consider, these benefits can make a difference in your quality of life. Talk to someone on your dialysis home care team about any concerns you may have.

Tips to help make starting home therapy more successful:

Some additional suggestions for getting the most out of your home dialysis training:
- Repeat training sessions until you master each step; this might include having you demonstrate the step you have learned.
- Have family members/roommates be a part of the training process to help support you.
- Educate yourself about all home machines to find the best fit for your lifestyle.
- Partner with your in-center team, ask them to show you the equipment you’ll be using for home dialysis. It may be helpful to observe a machine setup.
- There are many different types of machines available for peritoneal dialysis or home hemodialysis. Ask your care team to show you options that would work best for you.
- If you decide to do home hemodialysis, start your self-education/education in-center before the transition to home hemodialysis, so that you feel very confident in your ability to conduct your treatment.

Resources, support, and aids are available to help you with your home dialysis treatments. Ask your team about:
- How available they are to answer questions for you once you are home.
- Equipment that can help you connect and disconnect from the peritoneal dialysis or home hemodialysis. If you have problems with your hand strength.
- Magnifying glasses for sight issues during connections and disconnections.
- Pictures and visual aids to help you remember the steps you learned during your training once you are home.
- Emergency support through an on-call nurse 24/7 from your dialysis company as well remote monitoring systems for home hemodialysis.
- Creative strategies for storing supplies if your space is limited.
- How to use smart devices like Alexa or Google Home to call 911 if you cannot get in your phone in the event of an emergency.
- You can also make arrangements with your local fire department to allow them access to your home via a lock box should you have an emergency.

To file a grievance with the Network, please contact:
IPRO End-Stage Renal Disease Network Program Corporate Office:
3750 Main Street, Lake Success, NY 11050-1872
Patient Toll-Free: (800) 238-3773 • Main: (516) 233-9767
Email: esrdnprogram@ipro.org • Web: esrd.ipro.org

Better healthcare. Real time.
Resource

Seeing Yourself In A Positive Light with A Peritoneal Dialysis Catheter

What body image issues do people on peritoneal dialysis experience?

- Weight gain. Some patients experience weight gain due to the sugars that are in the solution used in dialysis treatments. Talk with your doctor and dietitian to help balance your prescription and your diet.
- Blowing and feeling full. The extra fluids in your stomach make you feel this way. Some people find it easier to make them less hungry or able to eat. Often these feelings become less noticeable as your body adjusts. To help with meals, you can try to do your treatments after meals.
- Permits. The insertion of the catheter can weaken the stomach muscles; the fluid puts pressure on the weakened muscles and can cause a tear (hermit), depending on how fast the hermit is and how you can have surgery to repair it.
- The catheter looks and hangs off of your stomach. In fact, the catheter tube is very small, however, if you are uncomfortable with how it looks, you can use a peritoneal dialysis catheter cloak. Cadaver BT/IVs help keep your peritoneal catheter hanging in place and make it less noticeable when wearing different types of clothing or bathing suits. They come in different types to suit all clothing options.

What are other ways to help you cope with peritoneal dialysis?

Consider the benefits of peritoneal dialysis over the changes to your body image. List ways you can work through the changes you’ll be dealing with when you start dialysis. The best way to keep your treatment is to talk to your friends and family about how you feel. And, possibly you may want to talk with someone who is currently on peritoneal dialysis.

Remember you are the person you were prior to being diagnosed with kidney disease. You will be the same person while on dialysis.

When you have a negative thought about your self-images, pay and identify that thought. You can write it down if you would like. This thought helpful or harmful? If this thought is hurtful, replace that thought with something that is positive.

If you have not considered peritoneal dialysis due to some of these concerns, please talk with a member of your dialysis team who can help you find the right resource to answer your questions.

To file a grievance, please contact us:

IPRO End Stage Renal Disease Network Program
Corporate Office: 1077 Marcus Ave, Lake Success, NY 11042-2172
- Patient Services: (516) 231-0767 • Toll-Free: (800) 238-3773
- Email: PatientServices@iprony.org • Web: iprony.org

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continued on next page
Emergency Management

Julia Gesick, BSW
Patient Service and Emergency Management Specialist
Network Check-In
Polling Question

Do you travel independently to and from dialysis?

• Yes
• No
• Unsure
How to Prepare for Winter Weather

• Ask your care team about emergency plans if inclement weather were to occur.
• If possible, stock up on extra supplies, food and medications to minimize trips to the community.
• When traveling to and from dialysis, dress appropriately for the weather.
• If you are staying with a friend or loved one during an emergency, keep your dialysis facility informed of how they can contact you.
• If possible, have a backup transportation plan.
Winter Weather and Transportation
How to Travel Safely Before, During or After an Emergency

• If you know your transportation may be affected by an emergency, communicate with your care team to form a backup plan.
• Make sure you have contact information for your transportation provider and your dialysis clinic saved in your cell phone or address book.
• If you are concerned about a possible emergency situation that would delay your travel home, make sure you leave your home with an emergency go-bag and an external battery charger for your mobile device.
Feedback Requested
Is this resource helpful?

Emergency Preparedness Checklist for Patient

An emergency can happen at a moment’s notice. This checklist will help you get started. You’re not prepared if you cannot check off these items in your emergency plan:

☐ My dialysis facility has the current street address and phone number(s) that they need to contact me and/or household member(s) or care partner(s).

☐ I have discussed my emergency plan with my dialysis facility and my household members.
   Dialysis facility name: __________________________
   Dialysis facility address: __________________________
   Dialysis facility telephone number: __________________________

You will be getting a phone call from a facility staff member after the emergency, make sure to answer the phone so the facility can check on your safety.

☐ I have a back-up plan to get dialysis treatments if my dialysis facility is closed.
   Alternative dialysis facility name: __________________________
   Alternative dialysis facility address: __________________________
   Alternative dialysis facility telephone number: __________________________

☐ I have been notified of a shelter that I can evacuate to, which will provide me with transportation to a dialysis facility for treatments. My Shelter location is:
   Shelter name: __________________________
   Shelter address: __________________________
   Shelter telephone number: __________________________

☐ I have been notified that transportation will be provided for me from the shelter to the dialysis facility on the following days/times:
   Day: __________________________ Time: __________________________
   Day: __________________________ Time: __________________________
   Day: __________________________ Time: __________________________

☐ My facility has provided me with my patient evacuation packet, which includes information on my health status such as treatment run time, medication list, last lab results, hepatitis status, insurance information and the 3-Day Emergency Diet.
Healthy Living BINGO Game!!

Tiffany Reese-Arrington, CCHT
Healthy Lifestyles
Resource Highlights

BINGO

Healthy Living Bingo

Introduction

The objective of this game is to help patients identify important terms related to end stage renal disease (ESRD) and to increase their understanding in an informal and non-threatening way.

Prepare to Play:

- Distribute the set of Bingo cards and the Bingo Glossary Key to the game participants prior to the session.
- You can ask the facility’s social worker to print copies of the cards for the participants, or you could send the documents electronically if you and the participants have exchanged email addresses.
- Make sure that each participant knows which card they will use. If there are more than one card, they can use the identical card to play with them.
- If the participant has more than ten participants, please be aware that you may have more than one winner in one round.
- Advise the participants to have hand bins/cups, coins, or a marker that can be used to mark their card after definitions have been read.
- Schedule a virtual meeting on a platform that allows you to share content on a computer or laptop screen (e.g., Zoom, Google Hangout, WebEx, or Skype). Share the meeting information with your participants via email or text. To further promote the game, you could also ask your facility’s social worker to help you create and distribute a flyer.
- Before you host the meeting, be sure to review the PowerPoint presentation and test it out in advance. On the very last slide, you have the option to add your contact information: your name and phone number (optional) in the PowerPoint presentation.
- In the last slide (slide 9), you will be able to decide what type of bingo combinations you will accept.
- Options include: verbal, horizontal, diagonal, or all card combinations.

Instructions:

1. When you host the virtual Bingo game, make sure that you have a set of Bingo cards and a set of Bingo cards on your screen in “Full Screen” mode so that the buttons work.
2. You may set the numbers 1 through 20 at random to identify a definition by clicking the blue/underlined number on each ball. Once you have called that ball’s number, the number will turn pink to indicate that the definition associated with that number has been used.
3. Each card has a definition with a blank button that you will click after reading the definition. This will allow you to show the corresponding image and key word to match the Bingo Card. Once you show your participants the response, you can use the button.
4. If your participants have challenges identifying the key word associated with a definition, take time to explain the terminology or acronym. You may also guide your participants to the Bingo Glossary Key if anyone needs assistance with the definitions or numbers that have been called.
5. Once a winner has been identified, click the BINGO button on the bottom right of the “Let’s PLAY!” slide. This will take you to a “Congratulations!” slide to celebrate the winner.
6. Play as many rounds as you like. (You may want to suggest to participants who they should have more than one copy of the card if they anticipate playing more than one round of Bingo).

Note: The purple IPRO logo in the center of the card serves as a “free space.”

To file a grievance, please contact us:
IPRO End-Stage Renal Disease Network Program Corporate Office
1979 Marcus Avenue, Lake Success, NY 11042-5072
Phone Toll-free: 888-236-3737 • Main: 516-386-7607
E-mail: endstagerenal@ipro.org • Web: endpro.org

https://ipro.org/
Let’s PLAY!
This is a vibration felt over the fistula. Check morning and night using two fingers over your fistula to feel the motion of the blood flowing through it. This shows that your access is working. Report any changes to your dialysis team.

Click here to reveal answer
This is a vibration felt over the fistula. Check morning and night using two fingers over your fistula to feel the motion of the blood flowing through it. This shows that your access is working. Report any changes to your dialysis team.
A focused approach to improve quality and safety for all patients in your clinic. It brings together members of the dialysis team in monthly meetings to work together to find creative solutions to quality and safety issues. These meetings include all members of your clinic’s professional dialysis team (dietitians, social workers, nurses, physicians); clinic management; and patient representatives.
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This provides a number of health benefits, both physical and emotional. Benefits include improved heart function, stronger bones and muscles, improvement in doing everyday activities and improvement in your emotional state.
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If there is a life-threatening emergency while you are on the dialysis machine, you should learn this procedure to safely disconnect yourself from the machine. This procedure should be used only if you have a fistula. If you have a catheter wait for a member of the healthcare team to disconnect you from the machine.
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A trained professional who provides support to patients and their families, discusses treatment goals and goals for life outside of dialysis. Talk to them if you are feeling depressed or having a hard time adjusting to life with dialysis.
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A written, verbal, or electronic request for a formal investigation of a concern or complaint about your dialysis facility. If possible, this should first be discussed with a member of your facility’s management team. If that approach is not comfortable or successful, you should contact your ESRD Network or your state’s survey agency.
A written, verbal, or electronic request for a formal investigation of a concern or complaint about your dialysis facility. If possible, this should first be discussed with a member of your facility’s management team. If that approach is not comfortable or successful, you should contact your ESRD Network or your state’s survey agency.
A treatment option in which an organ is replaced with a healthy organ from a living or deceased donor.
A treatment option in which an organ is replaced with a healthy organ from a living or deceased donor.
A common and treatable condition in which your red blood cell levels are low. If you have this, your body does not get enough oxygen-rich blood, and you may feel tired, weak, and short of breath.
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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
Next PRF Meeting - Mark Your Calendar!
Thursday, February 1st  2024 at 5:30pm ET

- Upcoming Topics: Support Groups

- Things to Think About: Your PFR Work, Focusing on your impact to your facility!
https://www.facebook.com/IPRO.ESRDNetworkPgm
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
Stephanie Cole, BA, PSM, QP
Community Outreach Specialist

Thank you all for making these meetings such a pleasure!

I will be going on maternity leave sometime in the next couple of weeks, so this will be the last meeting I will be a part of for the next few months.

In the meantime, Aisha will be the point of contact for anything PFR related.

I thank you all for your understanding!

Contact Aisha Edmondson at (216)755-3056
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 #