

End-Stage Renal Disease Network Program

# Patient Facility Representative (PFR) Alliance Meeting

January 4th 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 Family Engagement Lead

# Patient and Family Engagement Facilitators



Stephanie Cole, BA, PSM, QP Community Outreach Specialist



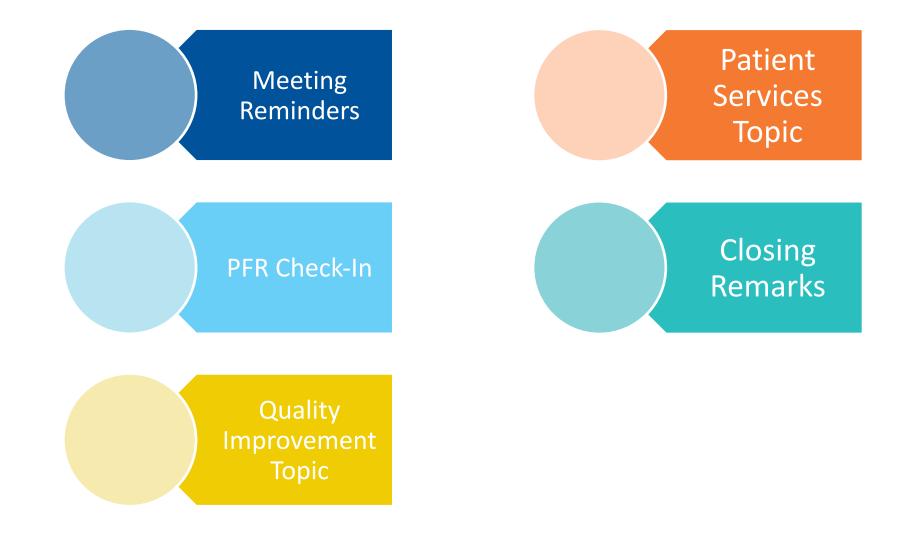
Julia Gesick, BSW Emergency Management Speaker



Name & Credentials Quality Improvement Speaker

## **Today's Agenda** Topics for Review/Discussion





# **Meeting Reminders**



- 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



# **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.



OH

# 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

<ul> <li>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.</li> </ul>
<ul> <li>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)</li> </ul>
<ul> <li>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.</li> </ul>
<ul> <li>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.</li> </ul>

owever, some concerns may be beyond the Network's scope. Network staff CANNOT.

* Force a facility to accept a patient.	<b>X</b> Get staff members fired or arrange for staff to
🗱 Close a dialysis facility.	have their pay docked.
Go onsite to investigate a facility's clinical procedures, witness interactions between staff	Force a facility to change its admissions policy regarding catheters.
and patients, or view a videotape of incidents (HIPAA violation).	Verify Medicare coverage or give out Medicare cards.
X 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.

IPRO	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.jpro.org
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# **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?



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 chance of your blood pressure dropping;
- » better control of swelling (edema) and your blood pressure being too high;
- » increased energy level;
- feeling better after dialysis;
- If 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 though 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

There are many things you and your dialysis team can do to prepare you to feel confident and secure in making the move to home dialysis. You can talk to your dialysis home care team about structuring your training sessions to fit your learning style.

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.
- Invite family members/caregivers to be a part of the training process to help support you.
- Educate yourself about all home modalities 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-cannulation 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 if you have problems with your hand strength.
- Magnifying goggles for sight issues during connects and disconnects.
- · Pictures and visual aids to help you remember the steps you learned during your training once you are home.
- Emergency support through on-call nurses 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 to 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.

### Important to Remember

You are your best advocate! But you are not alone. Your treatment team is available to help and support you. Talk with your dialysis care team to discuss the best home modality for you.

> To file a grievance with the Network, please contact us: 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

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## Resource

### Seeing Yourself In A Positive Light with A Peritoneal Dialysis Catheter



End-Stage Renal Disease Network Program IPR(

### Seeing Yourself in a Positive Light with a Peritoneal Dialysis Catheter



### What is body image?

Body image is how a person perceives, thinks and feels about their body. A person's body image could be positive or negative or both. What's important to remember is that our body image may not be directly related to our actual appearance: we tend to focus on our minor imperfections that others do not even notice.

Having kidney failure is going to make changes to your body. This is partly due to your body's inability to get rid of chemicals that your kidneys are no longer able to remove and also due to the procedures you will undergo to make sure that your body is able to remove those chemicals through other means.

If you and your doctors determine that dialysis is the best treatment for you-whether you are using a catheter, graft, or fistula-you will need to undergo a procedure that will leave a mark on your body. Even receiving a transplant will leave a scar. It is important for you to know about these changes and work on a plan to keep a positive outlook, so you can make the best choices for your care.

Some people worry that doing dialysis at home, which may involve a catheter in the stomach, will affect their body image. However, those concerns may be overcome by learning as much as you can about how this treatment is done and the benefits of this type of dialysis, called peritoneal dialysis.

### Overcoming body image issues.

It is important to consider your concerns about body image and how you can work through them to experience the benefits of peritoneal dialysis.

- Peritoneal dialysis is daily, so you can eat and drink more and may require fewer medications to help you between your dialysis treatments than you would with other treatments.
- The therapy is gentler to your body than other treatments, reducing stress on your heart and blood vessels, which has been shown to reduce hospitalizations for individuals on this treatment.
- It is easier to carry out your daily activities as well as work and travel
- You can swim! Swimming is recommended in either sea water or private swimming pools as long as you follow the recommendations of your home nurse on exit site care.
- . If you get back to these activities, it will help improve your mood and make you feel better overall.



continued on next page

### Seeing Yourself in a Positive Light with a Peritoneal Dialysis Catheter (continued)

### What body image issues do people on peritoneal dialysis experience?

- · Weight gain. Some patients experience weight gain due to the sugar that is in the solution used in dialysis treatments. Talk with your doctor and dietician to help balance your prescription and your diet.
- Bloating and feeling full. The extra fluids in your stomach make you feel this way. Some people find it even makes them less hungry or able to eat. Often these feelings become less noticeable as your body adjusts. To help with mealtime, you can try to do your treatments after meals.
- Hernias. The insertion of the catheter can weaken the stomach muscles: the fluid puts pressure on the weakened muscles and can cause a tear (hernia). Depending on how bad the hernia is you can have surgery to repair it.
- How the catheter looks hanging out 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 belt. Catheter belts help keep your peritoneal catheter tubing 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 and list ways you can work through the changes you'll be dealing with when you start peritoneal dialysis. That may include talking to your partner about your catheter and how you both feel about it. You might also want to talk to your friends and family about how you feel. And, if possible 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 selfimage, stop and identify that thought. You can write it down if you would like. Is this thought helpful or harmful? If this thought is hurtful to you, 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: 1979 Marcus Avenue, Lake Success, NY 11042-1072 Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773 Email: esrdnetworkprogram@ipro.org • Web: esrd.ipro.org

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# **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



		e current street address and phone number(s) that they need
to co	ontact me and/or hou	sehold member(s) or care partner(s).
	ve discussed my emer nbers.	gency plan with my dialysis facility and my household
Dialy	sis facility name:	
Dialy	sis facility address:	
Dialy	sis facility telephone nu	mber:
		call from a facility staff member after the emergency, make sure to illity can check on your safety.
I hav	e a back-up plan to g	et dialysis treatments if my dialysis facility is closed.
Alter	native dialysis facility na	ime:
Alter	native dialysis facility ad	ldress:
Alter	native dialysis facility te	lephone number:
tran	sportation to a dialysi	helter that I can evacuate to, which will provide me with is facility for treatments. My Shelter location is:
Shelt	er address:	
Shelt	er telephone number: _	
	ve been notified that t sis facility on the follo	transportation will be provided for me from the shelter to the owing days/times:
		Time:
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dialy Day:		Time:

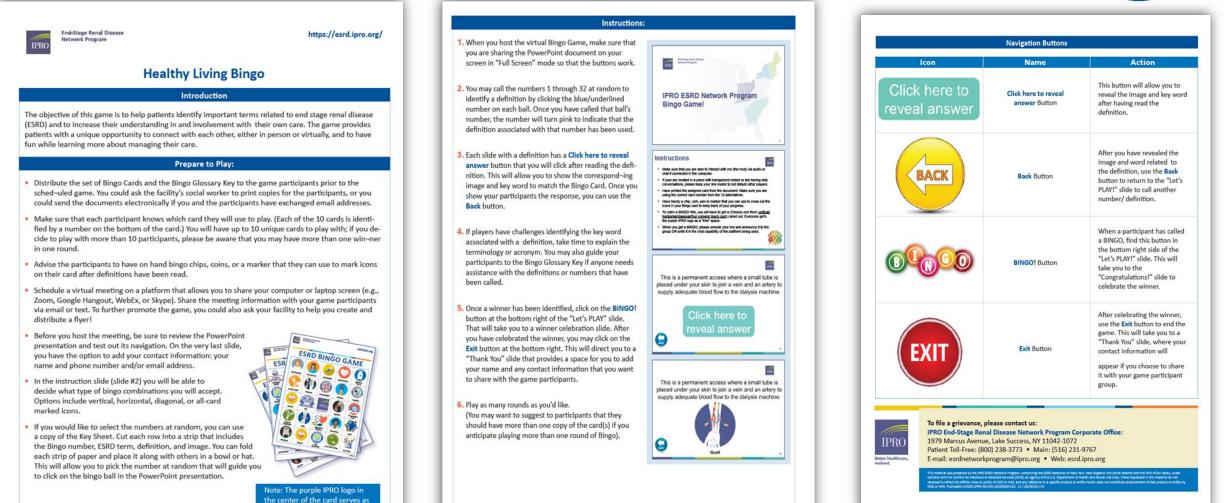
# Healthy Living BINGO Game!!



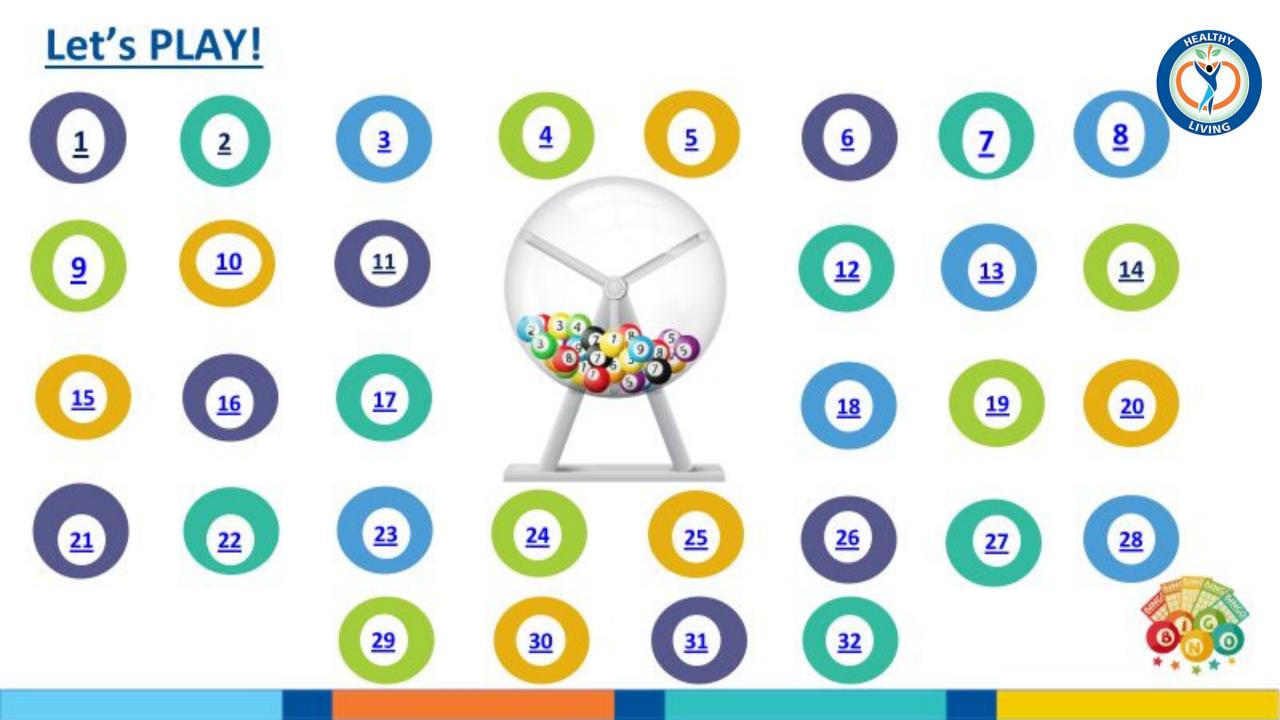
Tiffany Reese-Arrington, CCHT Healthy Lifestyles

## **Resource Highlights** BINGO

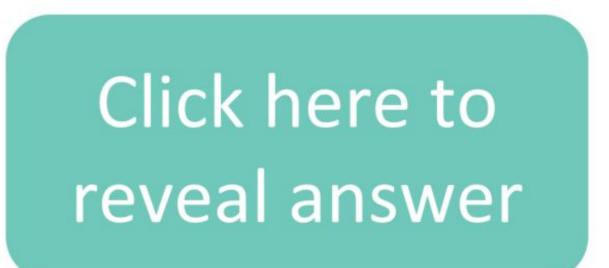
a "Free" space.



KEALTHP CONSCIENCE



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.





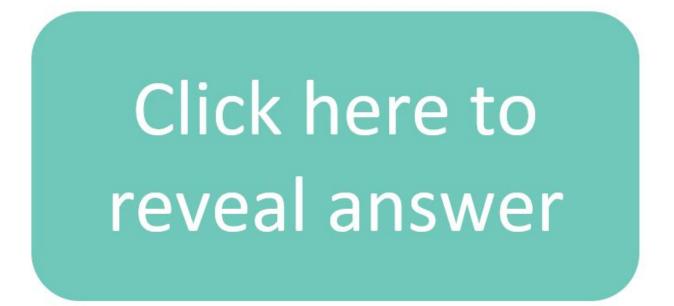
IPRO

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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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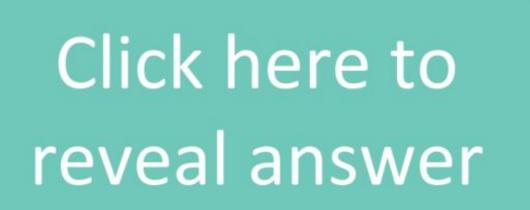








This provides a number of health benefits, both physical and emotional. Benefits include improved heart function, stronger bones and muscles, improvement in doing everyday activities and improvement in your emotional state.







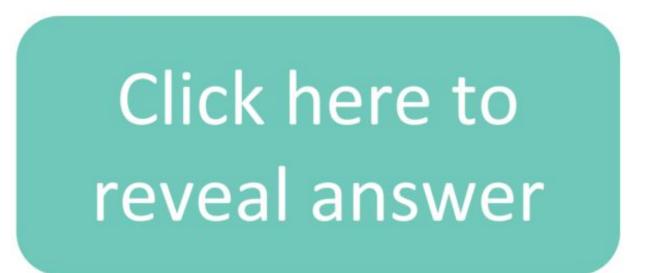
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If there is a life-threatening emergency while you are on the dialysis machine, you should learn this procedure to safely disconnect yourself from the machine. This procedure should be used only if you have a fistula. If you have a catheter wait for a member of the healthcare team to disconnect you from the machine.







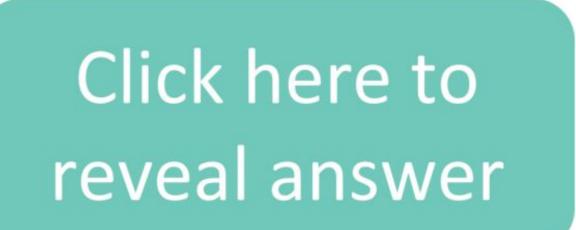
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A trained professional who provides support to patients and their families, discusses treatment goals and goals for life outside of dialysis. Talk to them if you are feeling depressed or having a hard time adjusting to life with dialysis.







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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.

> Click here to reveal answer





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A treatment option in which an organ is replaced with a healthy organ from a living or deceased donor.

> Click here to reveal answer





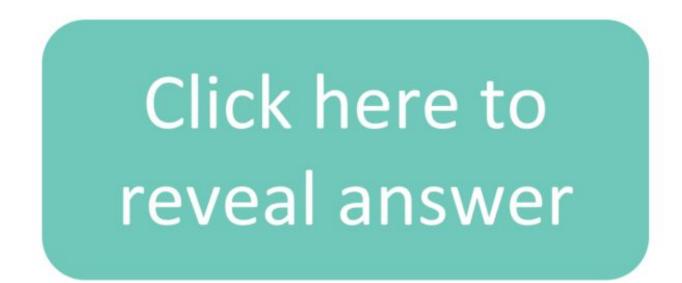
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A common and treatable condition in which your red blood cell levels are low. If you have this, your body does not get enough oxygen-rich blood, and you may feel tired, weak, and short of breath.







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# Next Steps



Aisha Edmondson Patient Family Engagement

## **Next Steps**



- Follow us on social media!
- Join the PFR Alliance Facebook Group <u>https://www.facebook.com/groups/ipropfralliance</u>
- **Create** your IPRO Learn Account <u>https://esrd.iprolearn.org/login/index.php/</u>
- **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 <u>https://esrd.ipro.org/patients-family/pfe/peer-mentoring/</u>
  - $\circ$  Sign up to become a peer mentor!
  - $\circ$  Have questions?
- Review the Frequently Asked Questions resource <u>https://esrdncc.org/globalassets/peer-mentoring-operational-toolkit/14pmlmsfaq508.pdf</u>
- **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:

Aisha Edmondson Project Lead: Patient and Family Engagement Tel: 216-755-3056| 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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