

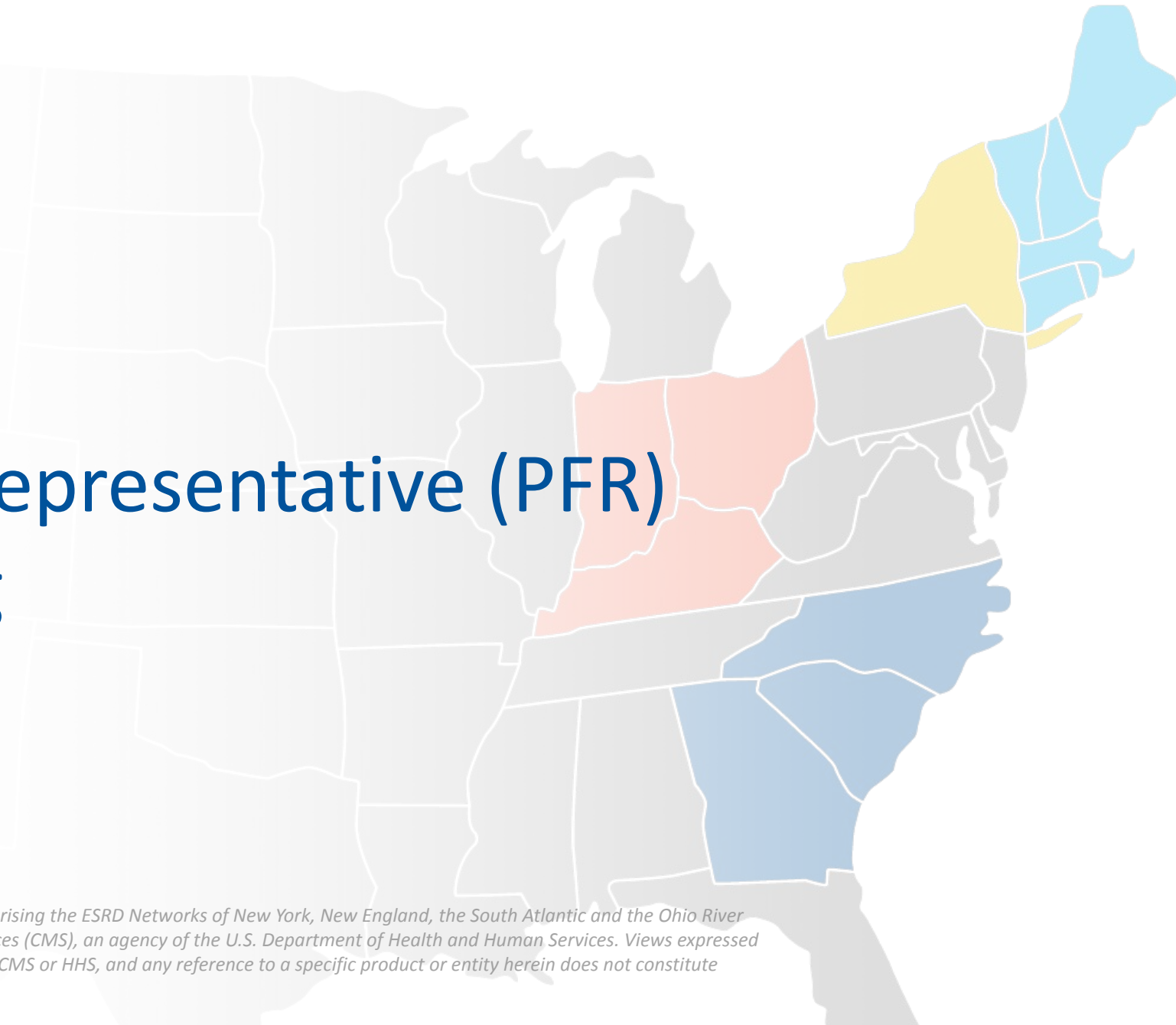


End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

10/05/2023

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



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

Patient
Services
Topic

PFR Check-In

Closing
Remarks

Quality
Improvement
Topic



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





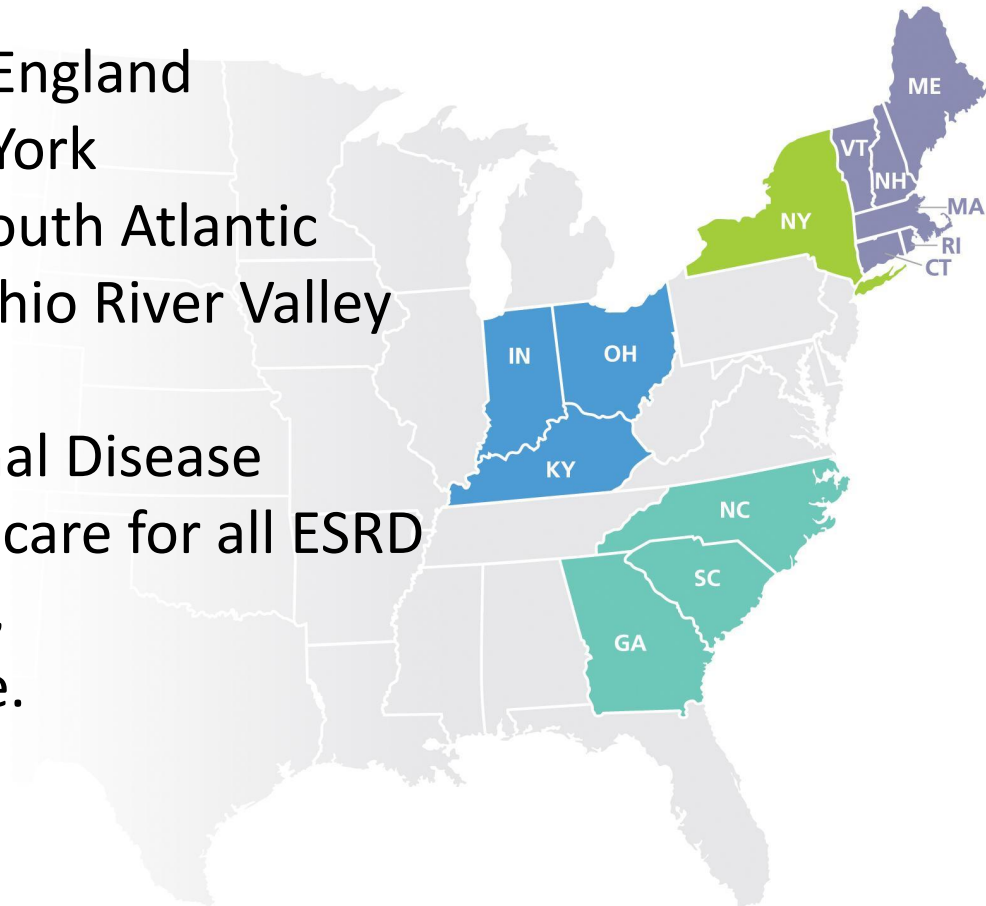
Please Welcome Our Newest Members!

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

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)



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](#)
- Using "Ask-Tell-Ask" in Person-Centered Case: Promoting Goals of Care Conversations with Dialysis Patients and Families During COVID-19: [Slides](#)
- 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.

Resource



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.



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

WHAT TYPE OF CARE DO I NEED? continued

Condition, Signs, Symptoms	Primary Care Doctor	Urgent Care Facility	Hospital Emergency Department
Fainting			❖
Fever	❖	❖	
Headache	❖	❖	
Head injury (without loss of consciousness [not blacking out])		❖	❖
Head Injury (blacking out)			❖
Insect bite	❖	❖	
Nausea/vomiting	❖	❖	
Pink eye	❖	❖	
Pneumonia (Persistent cough, shortness of breath, fever, weakness, and or/chest soreness)			❖
Poisoning			❖
Rash	❖	❖	
Seizure (convulsions and/or blacking out)			❖
Sepsis (confusion, shortness of breath, high heart rate, fever, pain, clammy and/or sweaty skin)			❖
Sore throat	❖	❖	
Muscle sprain/strain	❖	❖	
Severe stomach pain			❖
Swallowed object			❖
Urinary infection (pressure, pain, or blood and/or more frequent urination)	❖	❖	
Vomiting	❖	❖	
Change in mental state (confusion, disorientation, being unsure of who or where you are)			❖



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 11042-1072

Patient Services: (516) 231-9767 • 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, prepared this material 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: 75FCMC219D0029. CMS Task Order Numbers: 75FCMC21F0001 (Network 1), 75FCMC21F0002 (Network 2), 75FCMC21F0003 (Network 3), 75FCMC21F0004 (Network 4), 75FCMC21F0005 (Network 5), 75FCMC21F0006 (Network 6), 75FCMC21F0007 (Network 7), 75FCMC21F0008 (Network 8), 75FCMC21F0009 (Network 9). Publication # ESRD-IPRO-G2-NW-20230703-221 v.5 8/24/2023 vb

Signs and Symptoms Education & Teaching

Instructions for Facility Interactive Activity



- 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>
- **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/>
 - 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>
- **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)?

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-of-care 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

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:

Aisha Edmondson
Project Lead: Patient 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



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