



End-Stage Renal Disease  
Network Program

# Patient Facility Representative (PFR) Alliance Meeting

December 7, 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



**Brooke Andrews, MSW**  
Patient Services Speaker



**Tiffany Reese-Arrington, CCHT**  
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





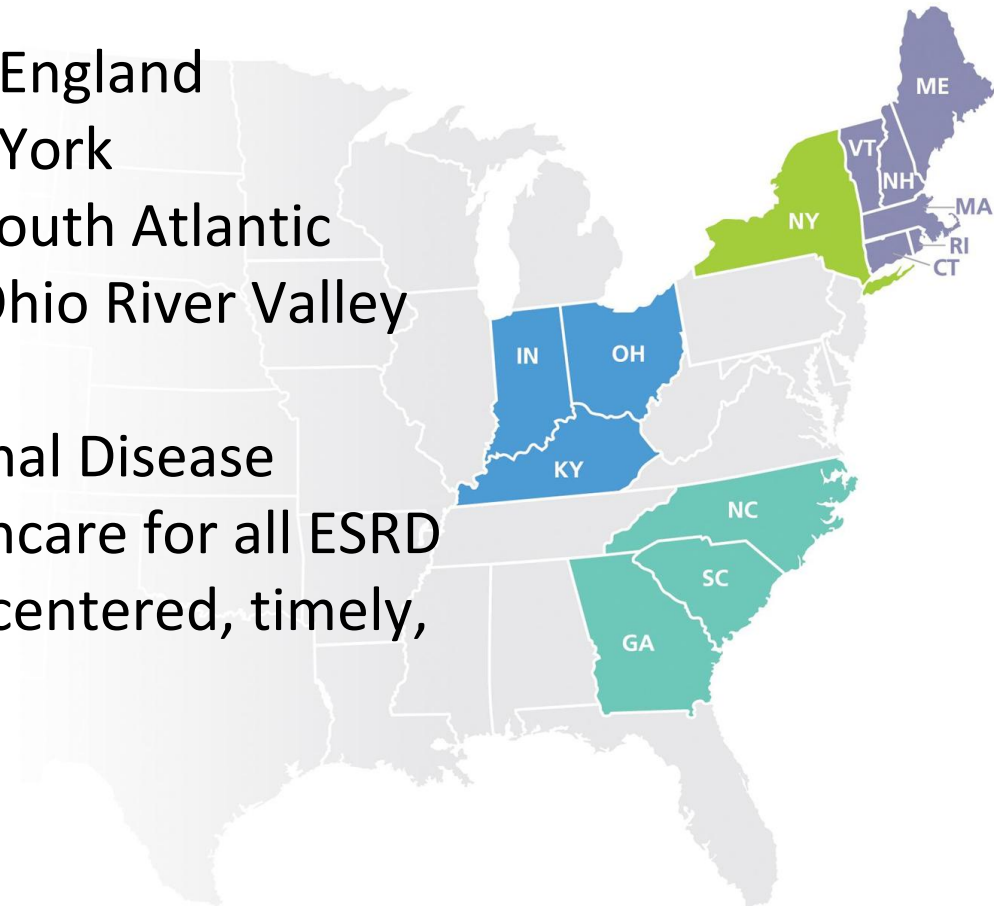
# Please Welcome Our New Members!

- Debra Wighaman
- Denise Truitt
- David Hawthorne
- Charmaine Blount
- Annette Gatewood
- Tina James
- Eric Hall
- Shirlee Wing
- Todd Rock
- Retha Powell
- Jamie Chapman
- Mary Didion
- Samantha Fordham
- Aunya Johnson
- Tomeka Jones
- Vera Guarino
- Pascual Meletiche
- Philip Corker
- Angela Davis
- Christopher Riddle
- Paula Esper
- Janet Costa
- Patricia Hawkins
- Paula Fortenberry
- Tasha Augustin
- Mark Hammond
- Christopher Wright
- Mary Martin
- Elizabeth Carter

# 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.



# 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...

Advocate for patients' rights, depending on the situation.	~ 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.
Provide information and educational resources.	~ 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 <a href="http://www.medicare.gov">www.medicare.gov</a> )
Investigate concerns about issues related to quality of care.	~ 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.
Help patients understand their rights and help them navigate the ESRD care delivery system.	~ 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.

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

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



Better healthcare, realized.

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](mailto:esrdnetworkprogram@ipro.us) • Web: [esrd.ipro.org](http://esrd.ipro.org)

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1/10/22 Version 4

# Effective Communication



**Brooke Andrews, MSW**  
Patient Services Specialist

# Network Check-In

## Polling Question



**Do you feel like your clinic communicates effectively with you?**

- Yes
- No
- Unsure



# Network Check-In

## Polling Question



### What are the most common ways to communicate?

- Spoken words
- Visual images
- Written words
- Body language
- All of the above
- Unsure



# Network Check-In

## Polling Question



**As a PFR how do you support other patients in the dialysis center?**

- Enter your answer into the chat box



# Communication Starts with You



- [Communication](#) is the process of transferring signals/messages between a sender and a receiver through various methods (written words, nonverbal cues, spoken words). It is also the mechanism we use to establish and modify relationships.
- Communicate at clinic level first
- Internal Grievance Process

# Ways We Communicate



- Engaging your audience
- Make eye contact
- Self Awareness of what message your body is conveying
- NOT clearly making judgments or assumptions
- Utilizing good listening skills and to show we care
- Speak clearly and slowly
- Requesting feedback to be sure what you have said is understood






# Network Resources

## Grievance Process Flyer




 End-Stage Renal Disease Network Program esrd.ipro.org

### Grievance Process Guide

Use this step-by-step guide to help you get your grievance handled in a direct and successful manner. After taking each suggested step, ask yourself whether or not the step helped. Then follow the arrows. Please note that it is not mandatory to follow the flow chart, patients may contact any of the three reporting agencies at any time.


**Step 1: Talk to Someone at Your Facility**

Ask to speak to someone at your facility with whom you feel comfortable sharing your concern.  
This might be your social worker, kidney doctor or the facility manager.  
(Talk to the staff about how a grievance can be filed anonymously at your facility.)

<b>NO</b> I do not feel comfortable talking to someone at my facility. <b>OR</b> I spoke to someone and I don't feel like my grievance will be handled.	<b>YES</b> I spoke to someone and feel my grievance will be handled. → 
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**Step 2: Call Your Network**

Your Network can work with you and your facility to help resolve your grievance.  
The Network can be reached via this toll free number: (800) 238-3773.  
(If you wish to remain anonymous, ask the Network how to file a grievance anonymously.)

<b>NO</b> I do not feel comfortable talking to someone at the Network. <b>OR</b> I am not sure the Network can address my grievance	<b>YES</b> After speaking with the Network I feel my grievance will be handled → 
--	--

**Step 3: Call Your State Agency**

Your state agency contact number should be posted in your dialysis facility lobby or you can ask the Network for the number to call.  
(The state can address your grievance anonymously. Please let them know if that is what you prefer.)

**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.us](mailto:esrdnetworkprogram@ipro.us) • Web: [esrd.ipro.org](http://esrd.ipro.org)

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12/29/2021



# Healthy Living BINGO!!!



Tiffany Reese-Arrington, CCHT  
Project Lead, Healthy Lifestyles

# Network Check-In

## Polling Question



**Does your facility incorporate fun activities?**

- Yes
- No
- Unsure



# Healthy Living Initiative

## Objective



Focusing on the optimal health of each patient while incorporating preventative measures to help patients manage their comorbid conditions better.

- Facilities to elect a Wellness Champion to foster culture change
- Working with clinical staff, dietitians, and social workers to promote health and wellness in their patient's everyday lives through
  1. Weight management
  2. Exercise
  3. Active engagement in their treatment plan
  4. Preventative care such as vaccinations and testing.

# Game Key Points!



## What

- Fun, interactive approach to bring awareness on ways to maintain a healthy lifestyle
- Engages and promotes health literacy
- Inclusive of all areas of health including access care, weight management, prevention measures, etc.
- Increase in clinic morale for ALL and help in other metrics

## How

- Can be played both virtually and live
- Bingo Cards, Key Sheet, and PowerPoint is provided
- Include the Healthy Living Champion and/or IDT to help facilitate
- Can be played in Home and ICHD

# Resource Highlights

## BINGO



<https://esrd.ipro.org/>

### 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 and involvement with their own care. The game provides patients with a unique opportunity to connect with each other, either in person or virtually, and to have fun while learning more about managing their care.

#### Prepare to Play:

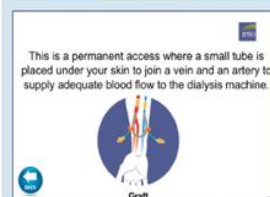
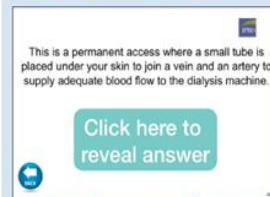
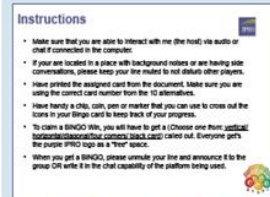
- Distribute the set of Bingo Cards and the Bingo Glossary Key to the game participants prior to the scheduled game. You could ask the facility's social worker to print copies for the participants, or you could send the documents electronically if you and the participants have exchanged email addresses.
- Make sure that each participant knows which card they will use to play. (Each of the 10 cards is identified by a number on the bottom of the card.) You will have up to 10 unique cards to play with; if you decide to play with more than 10 participants, please be aware that you may have more than one winner in one round.
- Advise the participants to have on hand bingo chips, coins, or a marker that they can use to mark icons on their card after definitions have been read.
- Schedule a virtual meeting on a platform that allows you to share your computer or laptop screen (e.g., Zoom, Google Hangout, WebEx, or Skype). Share the meeting information with your game participants via email or text. To further promote the game, you could also ask your facility to help you create and distribute a flyer!
- Before you host the meeting, be sure to review the PowerPoint presentation and test out its navigation. On the very last slide, you have the option to add your contact information: your name and phone number and/or email address.
- In the instruction slide (slide #2) you will be able to decide what type of bingo combinations you will accept. Options include vertical, horizontal, diagonal, or all-card marked icons.
- If you would like to select the numbers at random, you can use a copy of the Key Sheet. Cut each row into a strip that includes the Bingo number, ESRD term, definition, and image. You can fold each strip of paper and place it along with others in a bowl or hat. This will allow you to pick the number at random that will guide you to click on the bingo ball in the PowerPoint presentation.



Note: The purple IPRO logo in the center of the card serves as a "Free" space.

#### Instructions:

- When you host the virtual Bingo Game, make sure that you are sharing the PowerPoint document on your screen in "Full Screen" mode so that the buttons work.
- You may call the numbers 1 through 32 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.
- Each slide with a definition has a **Click here to reveal answer** 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 **Back** button.
- If players 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.
- Once a winner has been identified, click on the **BINGO!** button at the bottom right of the "Let's PLAY" slide. That will take you to a winner celebration slide. After you have celebrated the winner, you may click on the **Exit** button at the bottom right. This will direct you to a "Thank You" slide that provides a space for you to add your name and any contact information that you want to share with the game participants.
- Play as many rounds as you'd like. (You may want to suggest to participants that they should have more than one copy of the card[s] if you anticipate playing more than one round of Bingo).



Navigation Buttons		
Icon	Name	Action
	<b>Click here to reveal answer</b> Button	This button will allow you to reveal the image and key word after having read the definition.
	<b>Back</b> Button	After you have revealed the image and word related to the definition, use the <b>Back</b> button to return to the "Let's PLAY!" slide to call another number/ definition.
	<b>BINGO!</b> Button	When a participant has called a BINGO, find this button in the bottom right side of the "Let's PLAY!" slide. This will take you to the "Congratulations!" slide to celebrate the winner.
	<b>Exit</b> Button	After celebrating the winner, use the <b>Exit</b> button to end the game. This will take you to a "Thank You" slide, where your contact information will appear if you choose to share it with your game participant group.




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# Let's PLAY!



<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	<u>6</u>	<u>7</u>	<u>8</u>
<u>9</u>	<u>10</u>	<u>11</u>		<u>12</u>	<u>13</u>	<u>14</u>	
<u>15</u>	<u>16</u>	<u>17</u>		<u>18</u>	<u>19</u>	<u>20</u>	
<u>21</u>	<u>22</u>	<u>23</u>	<u>24</u>	<u>25</u>	<u>26</u>	<u>27</u>	<u>28</u>
		<u>29</u>	<u>30</u>	<u>31</u>	<u>32</u>		



Your choices about what to eat and drink while on dialysis can make a difference in how you feel and can make treatments work better.



Click here to  
reveal answer





# ESRD BINGO GAME

 Graft	 Home Dialysis	 Feel the thrill	 PFR	 Clamp & Disconnect
 Dialysate	 Social Worker	 Doctors / Specialist	 Fistula	 Heart Healthy
 Living Donor	 Anemia	 Better healthcare, realized.	 Care Team	 Medicare Part D
 Exercise	 Diet	 Infection Prevention Stop the Spread.	 Grievance	 The Patient
 Catheter	 High Blood Pressure	 ESRD Network	 Preventative Care	 Diabetes





Your choices about what to eat and drink while on dialysis can make a difference in how you feel and can make treatments work better.



# Possible Barriers

## Ways to Mitigate



- Time – downtime, advertise and schedule, play online
- Language – bilingual staff, Interpreter devices
- Engagement – Bragging Rights, Incentivize
- Staffing – utilize all (RN's, Techs, IDT, PFR)
- Clinic Floor/Set-up – Project using clinic resources (TV's, Intercoms, staff)

# Next Steps



**Aisha Edmondson**  
**Patient and 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, January 4th 2023 at 5:30pm ET

- Upcoming Topics: How Old is to Old for Home Dialysis?  
Emergency Preparedness
- Things to Think About: What information would you like to discuss and how can we make it fun and interactive!!

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:  
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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](http://help.esrd.ipro.org/support/home) • Website: [esrd.ipro.org/](http://esrd.ipro.org/)

Developed by the IPRO ESRD Network Program while under contract with Centers for Medicare & Medicaid Services. Contract # 75FCMC19D0029

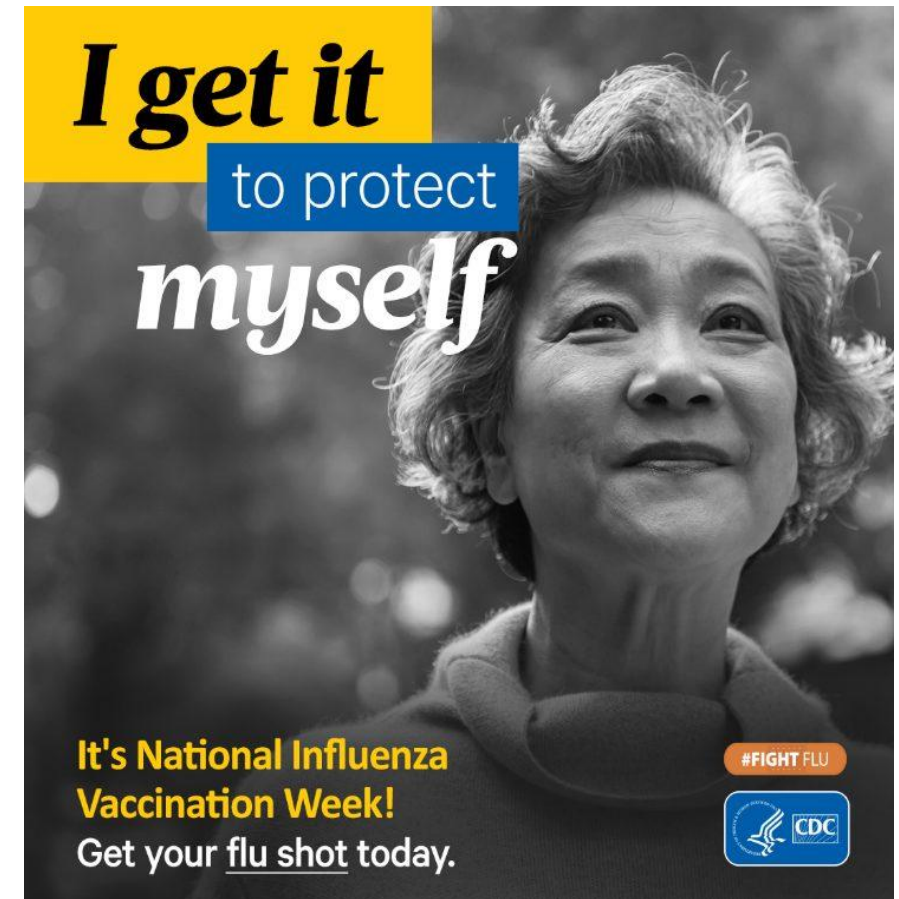
# Community Awareness Campaigns

December is National Handwashing Awareness Week (December 5-11) National Influenza Vaccination Week (December 4-8)



Together, we can take steps to improve health in communities nationwide!

1. Wash your hands when they are dirty and before eating.
2. DO NOT cough into your hands.
3. DO NOT sneeze into your hands.
4. DO NOT put your fingers into your eyes, nose or mouth.





<https://www.facebook.com/IPRO.ESRDNetworkPgm>

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*We're on the move...*

Follow us to our new Facebook page.  
<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](#)





**Questions?  
Comments?**



# Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

**Aisha Edmondson**  
**Project Manager: Patient Family Engagement**  
**Tel: 216-755-3066 | E-mail: [aedmondson@ipro.org](mailto:aedmondson@ipro.org)**

**Stephanie Cole, BA, PSM, QP**  
**Project Manager: Community Outreach Specialist**  
**Tel: (919) 928-6042 | E-mail: [scole@ipro.org](mailto:scole@ipro.org)**



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