

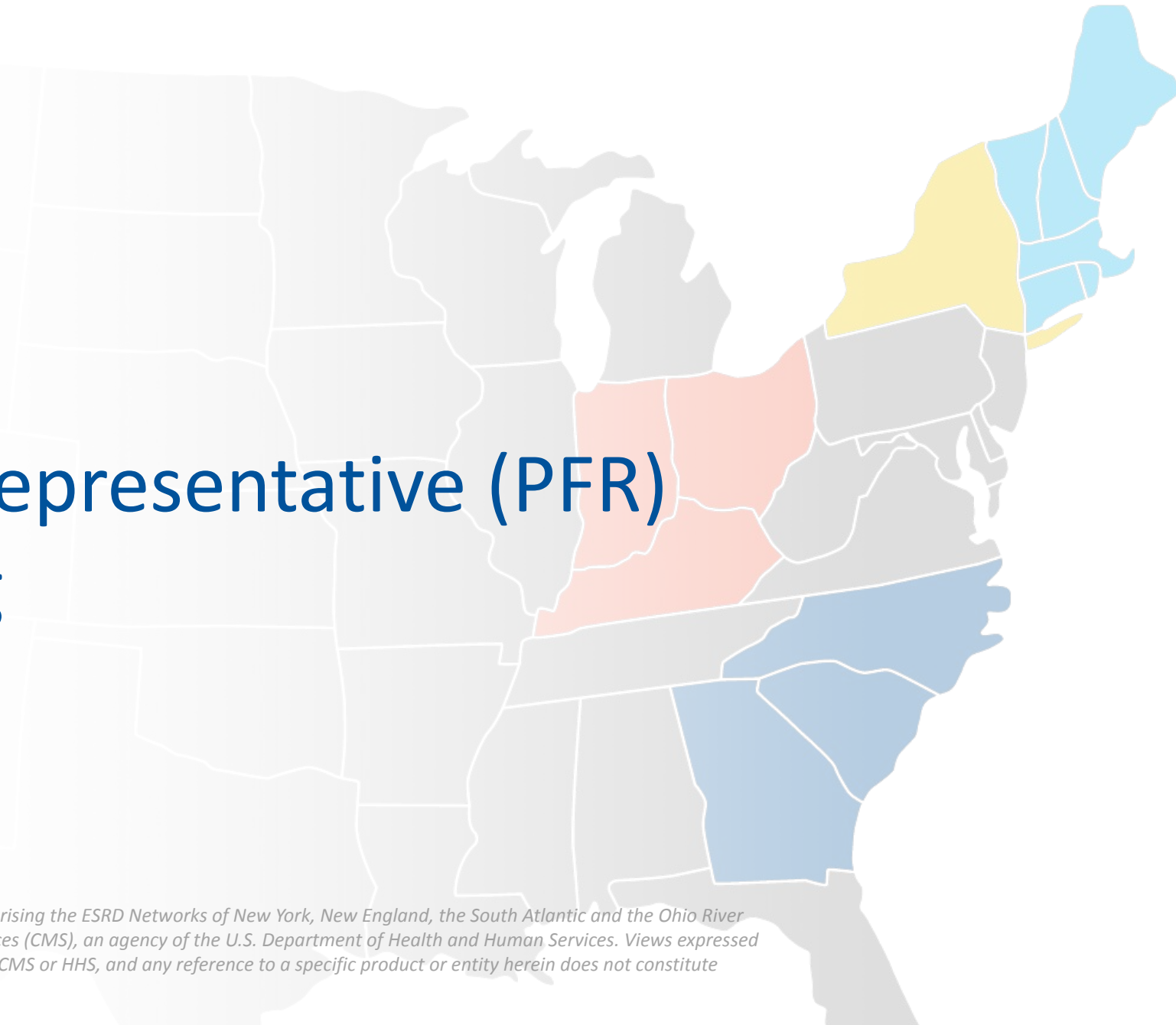


End-Stage Renal Disease  
Network Program

# Patient Facility Representative (PFR) Alliance Meeting

August 1st, 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 and Family Engagement**  
**Lead**

# Patient and Family Engagement Facilitators



**Shezeena Andiappen, MSW**  
**Patient Services Specialist**

# Today's Agenda

Topics for Review/Discussion



Meeting  
Reminders

Patient  
Services  
Topic

PFR Check-In

Closing  
Remarks

NKF Learning  
Hub



# Meeting Reminders



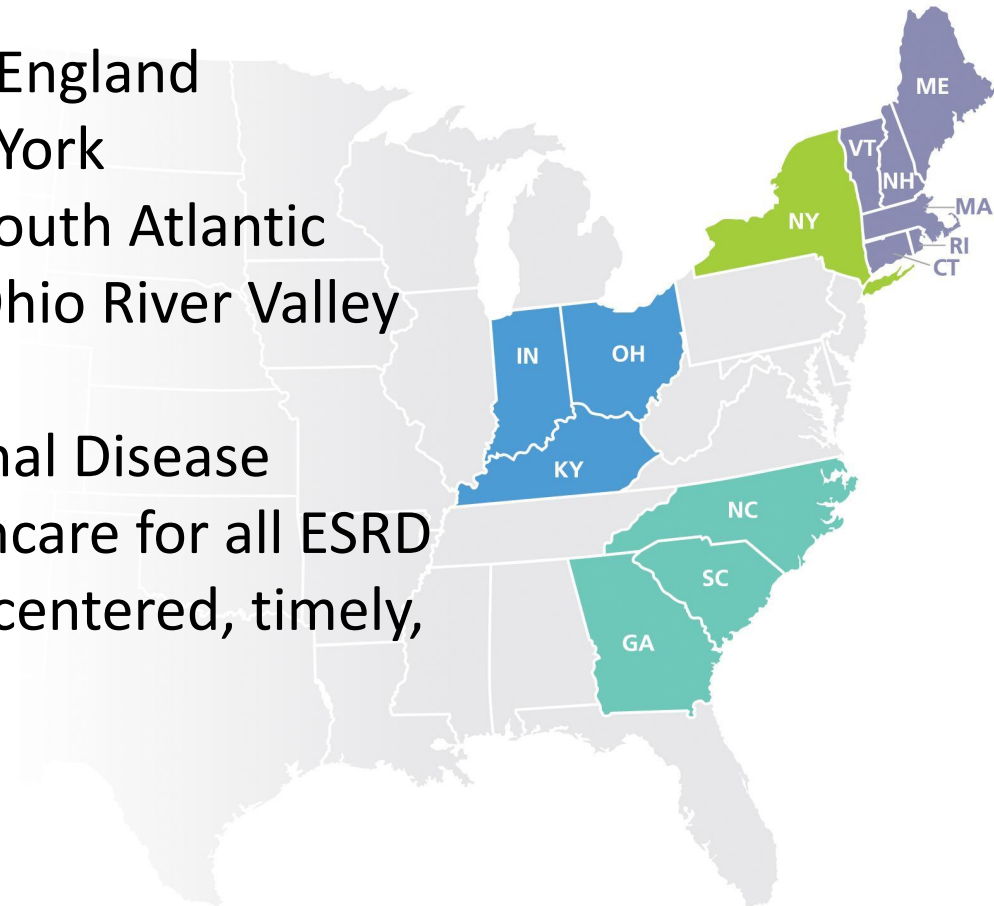
- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



# 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, patient-centered, timely, and equitable.



# 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)

Developed by the IPRO ESRD Network Program while under contract with the Centers for Medicare & Medicaid Services. Contract # F31CMC1100029 Publication # ES01PRD-GA-NW-2022013-138 v4 10/2022 IPRO, the End Stage Renal Disease Network Program, the Network of New England, Network of New York, Network of the South Atlantic, and Network of the Ohio River Valley, prepared the 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: F31CMC1100029. CMS Task Order Number: F31CMC1100029 (Network 1), F31CMC1100029 (Network 2), F31CMC1100029 (Network 3), F31CMC1100029 (Network 4), F31CMC1100029 (Network 5).



# Welcome Our New PFRs!



- German Vargas
- Steven Poe
- Chris Collier
- James Moore
- Pamela Greene
- Thomas Kowalski
- Valerie Abraham
- Zoilo Pacheco
- Debra Prater
- Brad Carroll
- Patrick Bell
- Arbrian Fant



# 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)



# Network Check-In

## Polling Question



**Are you familiar with the National Kidney Foundation Kidney Learning Center?**

- Yes
- No
- Unsure



# National Kidney Foundation

## Information about the Learning Center..



A screenshot of the National Kidney Foundation's Learning Center website. The interface has an orange header bar with two tabs: "Hub" and "About", with "About" currently selected. On the left side, there is a vertical navigation menu with icons and text for "Home", "Courses", "Curricula", "Events", "Forms", and "All Hubs". The main content area on the right contains a text box with the following text: "The NKF Kidney Learning Center is designed for patients to better understand and care for kidney disease. Here you will find educational activities on an array of carefully selected topics by well known health experts on the subject."

### Quick Links

[Kidney Learning Center:  
Instructions on how to register and  
complete a course](#)

This step by step guide will help you register and complete a course on the Kidney Learning Center.

[Transplantation & Living Donation  
Resources](#)

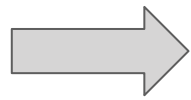
### [NKF Peers](#)

NKF PEERS is a peer mentoring program, where kidney patients are connected via phone with trained mentors who have been there themselves. Peer mentors can share their experiences with dialysis, transplant, or living kidney donation with you.

# National Kidney Foundation



First create an account and Login



Login Sign up

**National Kidney Foundation**

My Account

**CaseHippo**  
Create New Account

First Name:\*

Last Name:\*


Email:\*



Submit

Existing user? [Log in](#)  
Forgot password? [Reset](#)







# National Kidney Foundation





NATIONAL KIDNEY FOUNDATION.LoginSign up


National Kidney Foundation


HubAboutMy Account


-  Home
-  Courses
-  Curricula
-  Events
-  Forms
-  All Hubs

 Filter Newest

**Kidney Disease Education: Chronic Kidney Disease Basics**  
COURSE • ⌚ 0.3 hr  
In this activity, learners will hear about the basics of kidney disease, how it is measured, and what happens if you have kidney failure.  
Free

**Kidney Disease Education: Choosing a Treatment**  
COURSE • ⌚ 0.3 hr  
In this activity, learners will hear about choosing a treatment for kidney failure, including dialysis, kidney transplant, and no treatment, or medical management.  
Free


**After Transplant**  
What to expect after receiving a kidney transplant, including information about medications, rejection, mental health, and practical considerations for patients and care partners.  
Free

**Becoming a Living Donor**  
This course teaches everything you need to know about donating a kidney, including benefits and risks, how to start the evaluation process, the surgery, financial considerations, a... [more](#)  
Free

**Upcoming Events**

None

Generously Supported By



**Quick Links**

[Kidney Learning Center: Instructions on how to register and complete a course](#)  
This step by step guide will help you register and complete a course on the Kidney Learning Center.

[Transplantation & Living Donation Resources](#)

[NKF Peers](#)  
NKF PEERS is a peer mentoring



# Discussing the Grievance Process



Shezeena Andiappen, MSW

Patient Services Specialist

# Grievance Process

## What is a Grievance?



A grievance is any concern or issue you may have about the care you receive from your dialysis facility. A grievance can be submitted by patients, family members, dialysis staff members, or anyone who has a concern. A grievance can be in written or oral form. A grievance can be filed anonymously, confidentially or with full disclosure.



# Network Check-In

## Polling Question



**Do you know your facility internal grievance process?**

- Yes
- No
- Unsure



# Grievances & Concerns

## Filing a Grievance



Following federal regulations, all dialysis facilities are required to have a grievance process meant to address patient concerns.

As a dialysis patient, there are several options for filing a grievance.

- Option I: Filing at Your Dialysis Facility
- Option II: Filing with the ESRD Network
- Option III: Filing with Your State's Department of Health

# Network Check-In

## Polling Question



**Does your facility have the Grievance Speak Up Posters visible to all patients and family?**

- Yes
- No
- Unsure



# Grievances & Concerns

## Grievance Speak Up Posters



### ESRD Network of New England (Network 1)

Connecticut: [English](#) | [Spanish](#)

Maine: [English](#) | [Spanish](#)

Massachusetts: [English](#) | [Spanish](#)

New Hampshire: [English](#) | [Spanish](#)

Rhode Island: [English](#) | [Spanish](#)

Vermont: [English](#) | [Spanish](#)

### ESRD Network of New York (Network 2)

New York: [English](#) | [Spanish](#)

### ESRD Network of the South Atlantic (Network 6)

Georgia: [English](#) | [Spanish](#)

North Carolina: [English](#) | [Spanish](#)

South Carolina: [English](#) | [Spanish](#)

### ESRD Network of the Ohio River Valley (Network 9)

Indiana: [English](#) | [Spanish](#)

Kentucky: [English](#) | [Spanish](#)

Ohio: [English](#) | [Spanish](#)

The treatment you receive should meet your need for safety, your rights as a patient, clinical standards of care, and be provided by staff who treat you fairly and respectfully. If you feel your treatment does not meet these standards...

**DO YOU HAVE A GRIEVANCE?**  
**Speak Up.**  
Here's how...

**First:** Ask a staff member for a copy of your facility's grievance policy to find out how you can file a grievance.


**However...** If you are still unsatisfied or do not feel comfortable filing a grievance with your facility...

**Contact**

**IPRO End-Stage Renal Disease Network of New York**  
Corporate Address: 1979 Marcus Avenue, Lake Success, NY 11042-1072  
Toll-Free Patient Line: (800) 238-3773 (ESRD)  
Patient Services: (516) 231-9767 • Fax: (516) 403-5969  
E-mail: [esrdnetworkprogram@ipro.org](mailto:esrdnetworkprogram@ipro.org)

or

**New York State Department of Public Health**  
Centralized Hospital Intake Department  
Mail Stop: CA/DCS, Empire State Plaza, Albany, New York 12237  
Toll-Free: (800) 804-5447

 End-Stage Renal Disease Network of New York

This material was prepared by the IPRO ESRD Network of New York/New England/the Ohio River Valley/the South Atlantic, an End Stage Renal Disease Network Organization, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services (HHS). 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 # ESRD-IPRO-GA-NW2-20240405-309 v.1 4/12/2024 -v6

# Grievances & Concerns

## Tips on how to share your grievance effectively



- Write down your concerns
- Remain calm
- Be open to hearing other point of views and feedback.
- Suggest Solutions or be open to compromise

# Grievances & Concerns

## Professional Resources



### Professional Resources

- [Grievance Process Questions & Answers: A Guide for Dialysis Facilities](#)
- [Grievance Speak Up Posters](#)
- [Resolving Grievances Toolkit: The Role of the Network | IPRO Learn ESRD](#)
- [Dialysis Patient Grievance Toolkit](#)
- [Grievance Process Guide](#)
- [Decreasing Patient-Provider Conflict: A Pathway to Resolution](#)
- [ESRD NCC A Change Package to Improve Patient Experience of Care](#)
- [Effective Communication video](#)

# Grievances & Concerns

## Patients Resources



### Patients Resources

- [We Can Help You](#)
- Grievance Process Guide for Patients and Families Flyer
  - English: [Network 1](#) | [Network 2](#) | [Network 6](#) | [Network 9](#)
  - Spanish: [Network 1](#) | [Network 2](#) | [Network 6](#) | [Network 9](#)
- [Your Rights and Responsibilities as an ESRD Patient](#)
- [Dialysis Patients - Grievance Toolkit Summary](#)
- [Dialysis Patient Grievance Toolkit - English](#)
- [Dialysis Patient Grievance Toolkit - Spanish](#)
- [Thriving Without Fear](#)



# Next Steps



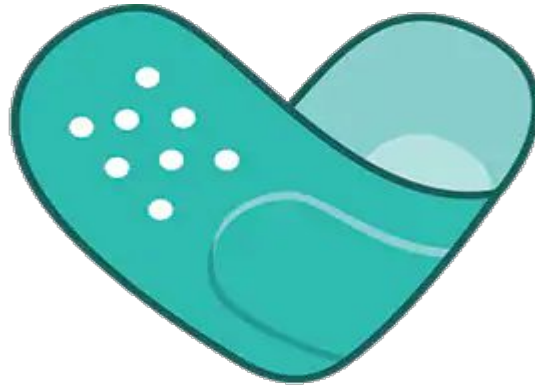
**Aisha Edmondson**  
Patient and Family Engagement Lead

# Community Awareness Campaigns

August is National Immunization Awareness Month!!



National Immunization Awareness Month (NIAM) is an annual observance held in August to highlight the importance of vaccination for people of all ages. Together, we can help raise awareness about the importance of vaccination and encourage people to talk to a healthcare provider they trust about staying up to date on their vaccinations.



## National Immunization Awareness Month

Use these NIAM graphics and share [vaccine resources](#) to help you promote routine vaccination on various social media platforms and websites.

# Next PRF Meeting - Mark Your Calendar!

Thursday, September 5th 2024 at 5:30pm ET



- Upcoming Topics: Emergency Preparedness
- Things to Think About: Are you involved in QAPI? Let's activate your voice!

[Guidelines for Patient Facility Representatives who attend QAPI](#)

The document is titled "Guidelines for Patient Representatives Who Attend QAPI Meetings" and is part of the IPRO End-Stage Renal Disease Network Program. It includes a list of nine guidelines for patient representatives attending QAPI meetings. The document also provides contact information for filing a grievance and lists the contract and publication numbers.

**End-Stage Renal Disease Network Program**

**Guidelines for Patient Representatives Who Attend QAPI Meetings**

1. No personal information about any patient will be discussed.
2. No identifying information that relates to or could connect to a particular patient or a staff member shall be discussed when a patient representative is present.
3. Input from patient representatives is given first priority in QAPI meetings. Patients need to share their positive and negative experiences during the preceding month.
4. To ensure the patient perspective is accurately represented, select patients from each shift to participate in the QAPI meeting. If this practice is not feasible, a facility may have one designated patient and continue to make efforts to recruit additional patients.
5. QAPI should serve as a platform to address center-wide issues and not individual or personal concerns. For individual and personal concerns, we have the grievance process. Patient representatives should help direct and guide the focus of the center's patient related QAPI goals.
6. The role of the patient representative is to voice any general comments, concerns "top of list" issues that matter most to patients on dialysis. This includes any suggestions for improvements that would result in making patients' visits to our facility more enjoyable, calm and comfortable as well as suggestions about needed patient education (e.g., insurance changes, Medicare or Medicaid rules, travel rules and requirements, etc.)
7. Patient representatives should be aware of the behaviors that could lead to an Involuntary Discharge, as well as the process, e.g., non-payment of co-payments or threats to other patients, staff members or any providers, etc.
8. Patients who act as a QAPI representative should be active members of the quality improvement team at the facility working with facility leadership on quality activities. They should also be active patient liaisons assisting new patients and existing patients to better understand and advocate for their care.
9. If patients are unable to attend the QAPI meeting they can also provide a written report or call into the meeting to provide their updates to encourage attendance.

**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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Contract # 75FCMC19D0029 Publication # ESRD-IPRO-G3-NW-20221003-137 v.2 12/12/2022

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# 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 and Family Engagement**  
**Tel: 216-755-3056 | E-mail: [aedmondson@ipro.org](mailto:aedmondson@ipro.org)**



**End-Stage Renal Disease  
Network Program**

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