



End-Stage Renal Disease  
Network Program

# Patient Facility Representative (PFR) Alliance Meeting

## January 6, 2022

# Patient and Family Engagement Program Team



Danielle Andrews,  
MPH, MSW, GCPH  
Health Equities Specialist



Deb DeWalt, MSN, RN  
Quality Improvement Director



Danielle Daley, MBA  
Executive Director

# TODAY'S AGENDA



**Meeting  
Reminders**



**PFR Check-In**



**QAPI**



**QIA Overview**



**Patient  
Experience of  
Care and IPRO  
Learn**



**Closing  
Remarks**

# Meeting Reminders

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



# Welcome to Our January Meeting!



Danielle Andrews, Health Equity Specialist

# Mission Statement



The IPRO End Stage Renal Disease Network Program includes four ESRD Networks:

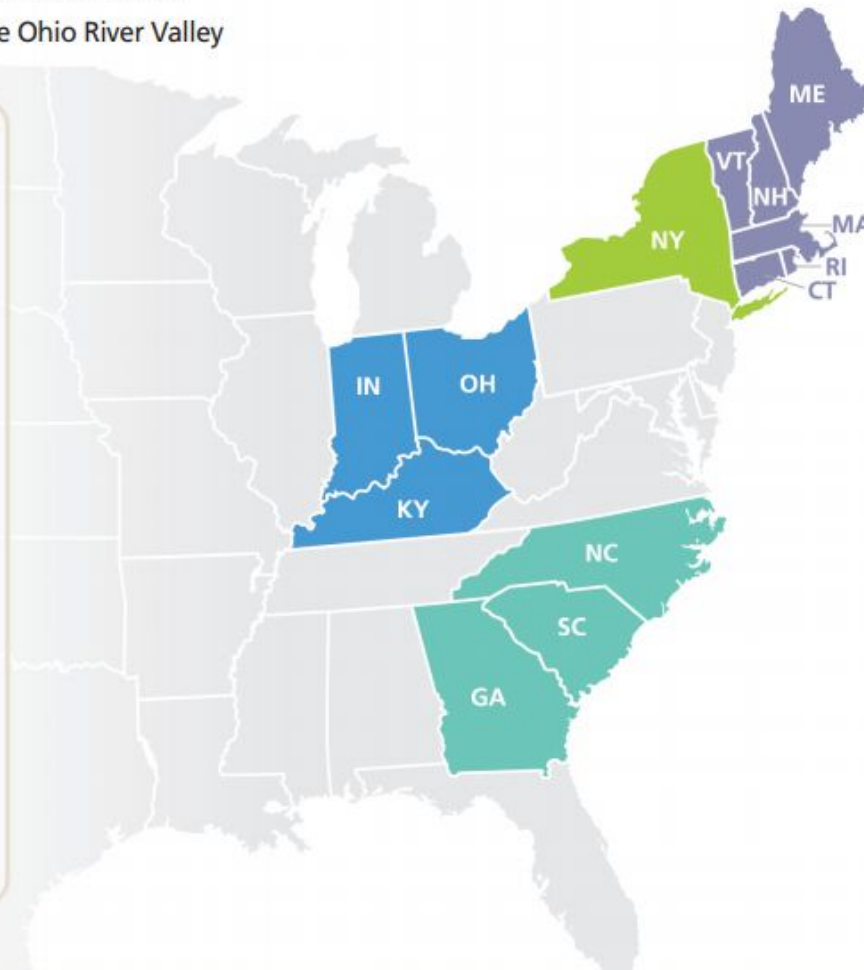
Network 1: ESRD Network of New England

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, effective, efficient, patient-centered, timely, and equitable.



# Network Check-in

## Which Network are you from?

- a) Network 1 (New England)
- b) Network 2 (New York)
- c) Network 6 (NC, SC, GA)
- d) Network 9 (IN, KY, OH)





# Network Check-in

**Has your facility held care planning meetings with you?**

- a) Yes
- b) No
- c) Unsure



# Network Check-in

**Have you engaged in life planning with your dialysis team?**

- a) Yes
- b) No
- c) Unsure

# Understanding Life Planning





# What is Life Planning?

**Life Planning is done with the goal of aligning a patient's** dialysis care with their needs and priorities. Life planning helps to create individualized care and places the patient at the core of the treatment planning process.

- To engage in live planning patients' should seek to be an active member of healthcare.
  - Through understanding your illness and patient and staff collaboration



# How Can PFRs be Heard?

## Tips for Talking with Your Care Team

- Understand your treatment plan
- Don't be afraid to ask question
- Know your treatment options
- Know yourself
- Notice Trends-Ask yourself
- Educate Yourself
- Speak Up (Be Your Own Advocate)
- Show-up Or Reschedule
- Connect with others
- Become involved



# Become an active member of your treatment team

- **Understand your treatment plan:** Your treatment plan should be a collaborative effort between you, your doctor and the dialysis staff. Your treatment plan is specific to you and contains your overall medical goals
- **Don't be afraid to ask questions:** As an active patient it's important to ask questions regarding your medication, dietary plans, fluid intake, and overall treatment.
  - Understand what your medication does and how dialysis works to replace the functioning of your kidneys.
  - Understand why certain foods don't work well with the renal diet, and which foods are healthier.



# Become an active member of your treatment team

- **Know your treatment options:** As an ESRD patient it's important to understand that your treatment options are not solely limited to in-center hemodialysis.
  - Home-Dialysis (Hemodialysis)
  - Peritoneal Dialysis
  - Transplantation
  - Nocturnal Dialysis (in-center)

# Become an active member of your treatment team



- **Know Yourself:** As a patient you are your best advocate. If a medication makes you feel unwell, discuss it with your medical team.
  - Tell your doctor and the staff exactly how you feel. Your feedback is needed to make sure you have the most effective plan of care.
- **Notice Trends (Ask yourself)**
  - Has your blood pressure been high lately?
  - Are you cramping more?
  - Are you having trouble sleeping at night?
  - **These symptoms could be an indication of possible treatment adjustment**

# Become an active member of your treatment team



- **Educate yourself:** Learn about your illness, and treatment options. Ask your care team to explain medical terms in words you can understand.
  - Use the Teach Back Method
- **SPEAK UP (Be Your Own Advocate):** Be heard! The more you take part in the meeting, the more you will benefit.
- **Show-Up or Reschedule:** Your care plan meeting is focused entirely on your health and how to improve it. Your medical team is there to help you, so if you are unable to keep your appointment, let them know in advance and reschedule as soon as possible.

# Become an active member of your treatment team



- **You Don't Have To Go Alone:** Peer and Familial Support is important. It's okay to bring a loved one, a family member, or a good friend to help you ask questions and understand the answers.
  - Under special circumstances, they could go in your place, but of course it's best for you to be there and actively participate.

[https://esrdncc.org/globalassets/patients/193-esrd\\_ncc\\_care\\_plan\\_tips\\_508.pdf](https://esrdncc.org/globalassets/patients/193-esrd_ncc_care_plan_tips_508.pdf)

# Get Involved with Your Peers



- **Connect with others:** Talk to other kidney or transplant patients. Share your experiences, identify your similarities and learn from your differences.
  - Find out if your facility has a peer mentoring program or Join a support group.
- **Become involved.** Attend QAPI meeting or work with your facility social worker to engage your ESRD peers.
  - Create an education station
  - Bulletin Board



# Network Check-in

**Are you willing to become more active in  
your Care-Plan meeting?**

- a) Yes
- b) No
- c) Unsure

# Questions or Comments?



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# Getting Involved in Quality Improvement



Deb DeWalt, MSN, RN, Quality Improvement Director

# Quality Improvement and PFR role

The Network conducts Quality Improvement Activities in the following quality measures:

- Depression Awareness
- Peer Mentorship Promotion
- Patient and Family Engagement
- Transplant Coordination
- Home Therapies Promotion
- Vaccination Promotion
- Hospitalization Reduction
- Care Transitions Coordination





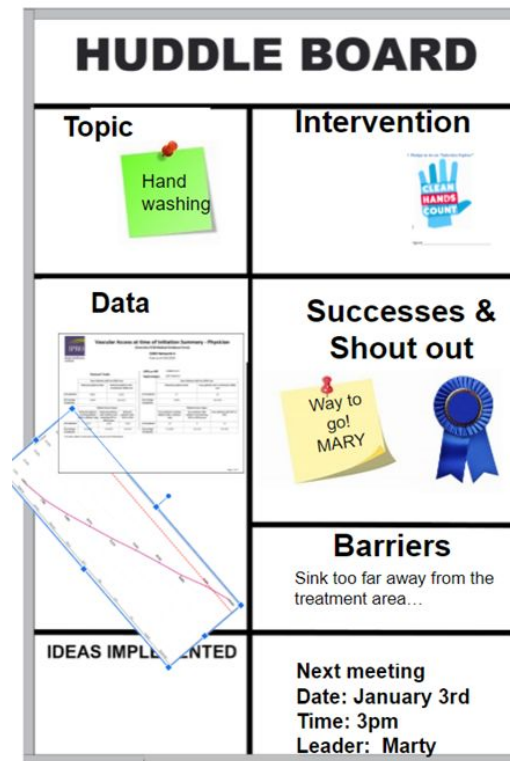
# How Can I help With the Work?

- Assist the Network in the development of resources
  - Review for content, ease of use and need
- Distribute materials to your peers
- Share your stories and experiences
  - virtual engagement – bulletin board
  - recorded messages
  - Peer support - telephonically
- Create and update a Huddle Board
- Make a Bulletin Board
  - Use Network and facility provided resources
  - Participate in virtual lobby days to assist Home leads in recruitment of home candidates





- Sharing of Data
  - Project Goals
  - Participation Reports
- Monthly Topic of Focus
- Intervention Release
- Celebrating successes
- Determining Barriers
- Schedule of next check in
  - Monthly meeting leader
  - QAPI representative



# Bulletin Board – PFR Led

Consult with Facility Lead to decide sharing information  
and resources- *let your creativity flow !*

- Network provided topics
- Network resources
- Facility materials



# What are we Working on?

## National Clinical Objectives and Key Results

### Goal: Decreasing Depression

- Helping patients to determine if they are depressed and offering treatment
- Helping patients to living their fullest life with kidney disease.
- Improving patient comfort in expressing concerns and need for support



# How Can I Help With Reducing Depression?

When you are ready to talk to a mental health professional Download this handout about talking to your doctor about mental health



**Zone Tool**  
Self-Management for Depression

**GREEN ZONE**

**GREEN ZONES: ALL CLEAR**  
Your Goals:

- Stable mood
- Sleeping well
- Healthy appetite
- Feeling hopeful
- Able to concentrate

**GREEN ZONE ACTION STEPS:**

- Having some fun
- Engage in activities you enjoy
- Your symptoms are under control
- ✓ Continue taking your medications as ordered
- ✓ Keep all physician appointments

**YELLOW ZONE**

**YELLOW ZONE: CAUTION means your symptoms are starting to change**  
The following symptoms may be early warning signs that your depression is worsening:

- Sad mood most of the time
- Not eating/eating too much
- Trouble concentrating
- Not sleeping well/sleeping too much
- Not finding pleasure in normal activities
- Increase in feelings of irritability/anger
- Loss of energy to do chores/activities
- Not taking medications as prescribed
- Missing physician appointments

**YELLOW ZONE ACTION STEPS:**

- Call your physician if you are going into the YELLOW zone

Your symptoms may indicate that you need an adjustment of your medications. Begin to use identified coping skills such as talking to a trusted friend or family member, gardening, needlework, watch a funny movie, etc...

Physician Name: \_\_\_\_\_  
Phone Number: \_\_\_\_\_

**RED ZONE**

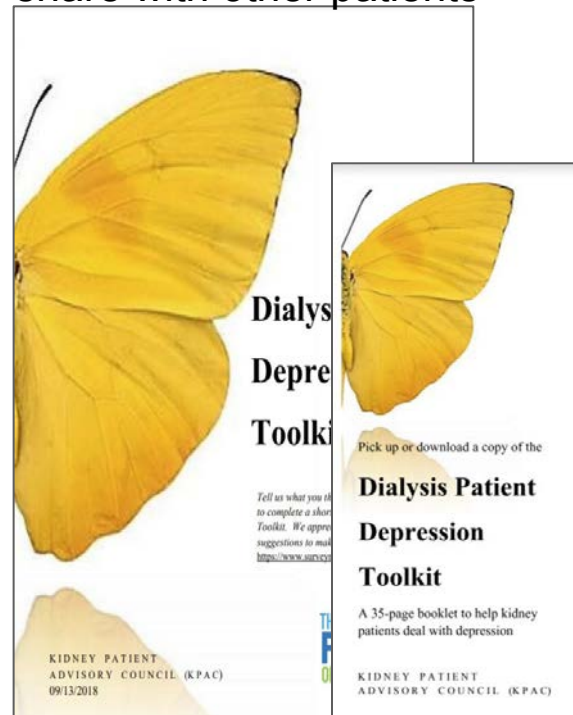
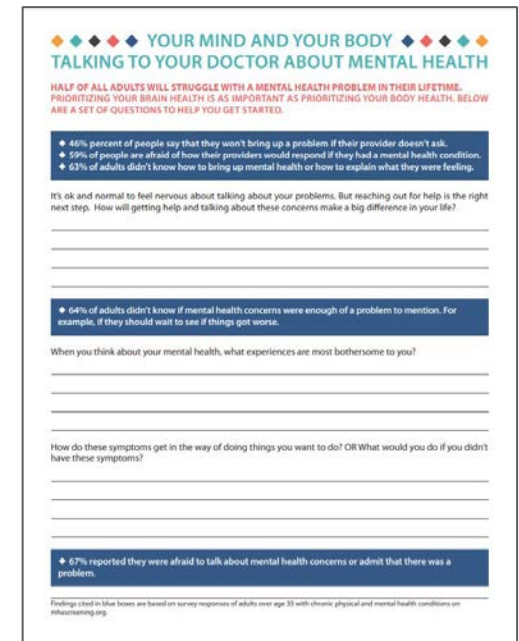
**RED ZONES: MEDICAL ALERT**

- Overwhelmed by feelings of sadness/despair
- Feeling hopeless and/or helpless
- Thoughts or feelings of killing or harming yourself
- Unable to leave the bed
- Not eating
- Not sleeping
- Stopped taking medications
- Missing physician appointment

**RED ZONE MEANS:**  
This indicates that you need to be evaluated by a physician right away.

**Get help immediately if you are in the RED ZONE. Call your physician, go to the nearest emergency room or call the National Suicide Prevention Lifeline at 1800-273-8255 (TALK)**

Want more information?  
Download the Depression Toolkit and brochure to share with other patients

**YOUR MIND AND YOUR BODY**  
TALKING TO YOUR DOCTOR ABOUT MENTAL HEALTH

HALF OF ALL ADULTS WILL STRUGGLE WITH A MENTAL HEALTH PROBLEM IN THEIR LIFETIME. PRIORITIZING YOUR BRAIN HEALTH IS AS IMPORTANT AS PRIORITIZING YOUR BODY HEALTH. BELOW ARE A SET OF QUESTIONS TO HELP YOU GET STARTED.

◆ 44% percent of people say that they won't bring up a problem if their provider doesn't ask.  
◆ 59% of people are afraid of how their providers would respond if they had a mental health condition.  
◆ 63% of adults didn't know how to bring up mental health or how to explain what they were feeling.

It's ok and normal to feel nervous about talking about your problems. But reaching out for help is the right next step. How will getting help and talking about these concerns make a big difference in your life?

◆ 64% of adults didn't know if mental health concerns were enough of a problem to mention. For example, if they should wait to see if things got worse.

When you think about your mental health, what experiences are most bothersome to you?

How do these symptoms get in the way of doing things you want to do? OR What would you do if you didn't have these symptoms?

◆ 67% reported they were afraid to talk about mental health concerns or admit that there was a problem.

Findings cited in blue boxes are based on survey responses of adults over age 35 with chronic physical and mental health conditions on mhcaretraining.org

Start here: Notice the symptoms, download the Zone Tool: Self-Management for Depression

# What are we Working on?

## National Clinical Objectives and Key Results



**Goal: Increase the number of patients receiving a home therapy and transplanted to improve patient outcomes**

- Work with patients to consider a dialysis therapy they can perform within their home.
  - Home treatments are more frequent and help patients feel better and live longer.
- Work with patients to consider a kidney transplant
  - A transplant works almost as well as your own kidney and offers the best quality of life and health for patients



# What are we Working on?

## National Clinical Objectives and Key Results



**Goal: Reducing the number of hospital admissions and emergency room visits to improve patient outcome**

- Increased hospitalizations and trips to the emergency room for care leads to more health complications for patients.
- Taking care of health issues before going to the hospital is much safer and better for everyone.



# What are We Working On?



## Goal: Increasing the Number of Patients Receiving Dialysis at Home

1. **Share resources provided by your project lead**
2. **Celebrate patients that move to home therapy**
3. **Share stories of patients who are successful at home**
  - a. We will be recording stories of transitions to home-including training, why you chose home, and why it is important to you. These recordings will be posted on the website.
4. **Work your project to increase the use of telehealth to improve access to home modalities**

Contact your project lead or the Network if you would like to volunteer to share your story



# How I Can Promote the Use of Telemedicine in Home Patients



## Kidney Patient Care: Your Guide to Using Telemedicine



### What is telemedicine?

Telemedicine simply means having a medical appointment in another way—not in person.

You can have a telemedicine visit with your healthcare team by phone or by using virtual technology. Technology connects you with your healthcare team by using a:



It makes it possible for your doctors or other healthcare professionals, to have a medical visit with you no matter where you are.

### Why are people talking about telemedicine now?

Because of Coronavirus 2019 (COVID-19), the Centers for Medicare & Medicaid Services (CMS) changed the rules on telemedicine. They made it easier for patients to get care in new way—from home. This means that everyone, especially people at higher risk, can see their doctors and stay healthy. It means less risk of getting, or spreading, the COVID-19 virus. Medicare, Medicaid, and private insurance will pay for many different types of telemedicine care. You can see doctors, nurses, practitioners, psychologists, and licensed clinical social workers with telemedicine.

Telemedicine may also be called telehealth. There are slight differences in these two words, but they mean similar thing. Telemedicine is when a healthcare worker gives medical care education from a remote location. The technology used to the medical service to patients is referred to as telehealth. guide, we will use the word telemedicine.

### What are the benefits of using telemedicine?

**It saves you time.**

- No travel or parking is needed.
- No waiting in lines or waiting rooms.
- Less disruption to work or family schedules.

**It helps keep you safe.**

- Avoid being exposed to germs and viruses.

**It helps you have easy access to routine preventive care.**

- This might be a follow-up with your diabetes or an appointment for medication management.
- Less worry about finding transportation.

### How might a kidney patient, like me, use telemedicine?

- Medication refills
- Dry weight checks
- Blood pressure follow-up
- Dialysis access check
- Nutrition and labs discussion
- Home dialysis monthly visit
- Kidney transplant follow-up
- Vision follow-up check
- And more

### What are some other issues I can address with telemedicine?

- Skin infection or
- Pain or soreness
- Cold or seasonal
- Mental health issues
- Stomach issues
- Sore throat
- Allergies
- And more.



### Remember:

Telemedicine is not for true medical emergencies. Call 911 for true medical emergencies.

### Preparing for Your Telemedicine Visit

Use this checklist to make sure you have everything you need to get ready for a telemedicine visit.

- ☐ **Choose a private location.**
  - Try not to take the call in your car or outside.
- ☐ **Check the lighting.**
  - You want to make sure your doctor can see you.
  - It is best to have light in front of you, not behind you.
- ☐ **What technology do you need to have a successful visit?**
  - A smartphone or tablet, or a computer and web camera
  - Reliable internet connection (WiFi or data plan)
  - If your doctor's office uses an app for telemedicine visits, download it in advance.
  - Pen and paper
- ☐ **Be prepared in case the call "drops," or it hangs up unexpectedly.**
  - Have the doctor's phone number available to call back.
- ☐ **If this is a new visit, be prepared to talk about your medical history.**
- ☐ **Have documents ready.**
  - List of prescriptions, over-the-counter medications, and supplements
  - Pharmacy phone number and address
  - Primary doctor's name and contact information
  - Insurance or credit card information
- ☐ **Write down questions to ask. Here are a few to start:**
  - What is the diagnosis?
  - Will I need any medical tests?
  - What can I do to get better?
  - Do I need a prescription?
  - What do I do if my symptoms continue?
  - How can I access the information/treatment plan from today's appointment?
  - Can I contact you if I have follow-up questions?
  - For additional questions, download [The Doctor Will See You Now: Telemedicine Makes it Easy](#) located on the ESRD National Coordinating Center (NCC) website.
- ☐ **Ask about follow-up care.**

# How Can I Help Promote Transplant?



Working with your Facility Lead you can pick the best approach and resources to use:

Starting at the basics?

Need a more complete review?


Focus on the Positive News!

Educate with an Activity!

Do you know all of your treatment options?


In-center Dialysis...  
Home Dialysis...  
Peritoneal Dialysis...

**Kidney Transplantation**



IPRO End-Stage Renal Disease Network Program  
Toll-free: 800-238-3773  
esrd.ipro.org

Is a kidney transplant right for me?  
*Your guide to the transplant process*



ESRD NCC  
NATIONAL COORDINATING CENTER

Newly Transplanted  
Let's Celebrate

Use this space to place a photo.

Write your personal message of congratulations.

Created by Patients for Patients

Start a spot to post and update each month!

End-Stage Renal Disease Network Program  
**Word Search Puzzle: Kidney Transplant**

Did you know that kidney transplantation is a treatment option for people with kidney failure? This option requires a surgical procedure to implant a healthy kidney from a donor. A donor can be a living family member, friend or stranger; it can also be someone who has passed away, but had decided they wanted to be a donor while they were still alive. A kidney transplant is not for everyone, but if you are considering a transplant, it is important for you to be evaluated by staff at a transplant center to see if you qualify. Take this word search puzzle challenge and learn more about transplant as a treatment option.

**Word Bank:**

KIDNEY TRANSPLANT	WAITLIST	RECIPIENT
IMMUNOSUPPRESSANTS	MULTI-LISTED	KIDNEY SCORE
KIDNEY SWAP	BLOOD TYPE	REFERRAL GUIDE
TRANSPLANT CENTER	DONOR SERVICE AREA	KIDNEY ALLOCATION SYSTEM
LIVING DONOR	NON-LIVING DONOR	UNOS
REFERRAL	TISSUE TYPE	FREEDOM
APPOINTMENTS	ELIGIBILITY	HEPATITIS C

**Glossary of Definitions:**

**KIDNEY:** Most people have two kidneys, each the size of a clenched fist. They are located on either side of the mid-upper part of the back. The kidneys are our organs responsible for cleaning the blood of waste.

**TRANSPLANT:** This is a surgical procedure in which a surgeon places a functioning kidney in a person whose kidneys are not working well enough to support their health. This is an optional treatment for kidney.

**IMMUNOSUPPRESSANTS:** After a kidney transplant, the recipient's immune (or fighter) cells will recognize the transplanted kidney as foreign and will try to eliminate it. This is called over-rejection. Transplant

# How Can I Help Reduce Hospital Admissions and Emergency Room Visits?



## Don't Miss A Minute Reducing Hospitalizations

**The Facts:** On average, a dialysis patient dialyzes three times a week for 4 hours each treatment. This treatment replaces the work that your kidneys perform 24 hours per day, seven days per week. Missing minutes of dialysis decreases the improved health benefits (outcomes) seen with dialysis and increases the likelihood of complications and hospitalizations.

### FREQUENTLY ASKED QUESTIONS

**Dialysis is so hard. Why is it important that I stay for my full treatment?** The dialysis treatment you are receiving replaces only a small amount of the work your kidneys do to remove fluid and waste products. If you don't get enough dialysis, your blood will accumulate those waste products and excess fluid.

**What will happen to my body if I miss dialysis?**

- Feeling weak, tired, and getting short of breath when moving around.
- Losing your appetite and feeling nauseated
- Swelling of your ankles, stomach or other areas
- Taste of ammonia in your mouth
- Prolonged bleeding times after dialysis

**Additionally, patients who shorten or miss three more treatments in a month have:**

- Higher risk of hospitalization
- May develop serious life threatening complications
- Could be delayed from getting wait-listed or removed from the transplant wait list
- A greater chance of infection
- Fluid may accumulate around the heart, causing the heart to swell and ultimately

**I feel fine and do not have any problems when I miss or cut my treatments, so why do I need to come or stay the whole time for my treatment?** The effects on your health from less dialysis may not show up overnight. You may not feel ill until there are lasting health effects on your body. For example, you may not notice the extra fluid building up in your body but it will make your heart pump harder which can cause it to swell and wear out your heart.

**I only miss or shorten a few treatments now and then, how can it hurt?**

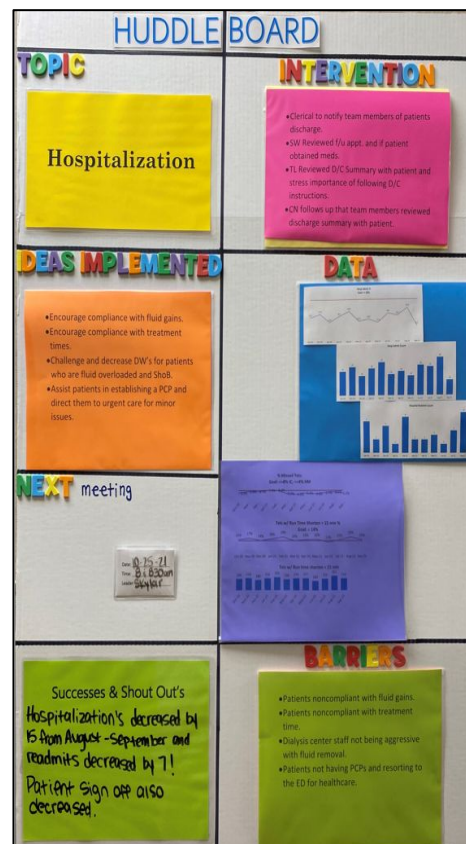
Missing 1 treatment per month = 12 treatments per year = missing an entire month of treatment per year. Shortening each treatment 1 hour = 144 hours of dialysis a year = 36 missed treatments per year.

**How can I make dialysis more enjoyable and complete all my required dialysis time?** Other patients who are successful coming and staying on treatment suggest that you make a plan to fill your time during dialysis. Suggested activities include:

- Cards or hand held games
- Hobbies (i.e., sketching, crochet, word puzzles, or reading)
- Be a patient facility representative! Join your facility team to improve the health and quality of life of your fellow patients

**What if I have an emergency or prior commitment on dialysis days?** Talk to reschedule your treatment so you don't miss a minute of your valuable dialysis.

Distribute the resource “Don’t Miss A Minute” to encourage patients to reschedule missed treatments in the facility rather than go to the Emergency Room



Work with your project lead for Hospitalizations to create a Huddle Board or bulletin board to show the number of missed treatments and hospitalizations and ED visits every month

### IPRO End-Stage Renal Disease Network Program Suggestions on How to Help Avoid Hospitalization

- Complete all treatments
- Reschedule missed treatments at your facility
- Follow your diet
- Keep hands and access clean
- Keep all doctor's appointments
- Take all medications as ordered
- Get your vaccinations



Coming Soon! Help complete and distribute Wallet Cards to patients to provide dialysis facility information to hospitals



To file a grievance, please contact us:  
IPRO End-Stage Renal Disease Network Program  
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042  
Patient Services: (516) 231-9767 • Patient Toll-Free: (800) 238-1100  
Email: esrdnetworkprogram@ipro.us • Website: esrd.ipro.org

# Questions or Comments?



# IPRO Learn



**Danielle Daley, Executive Director**


# What is IPRO Learn?

- Virtual learning platform that provides facilities, patients, and caregivers a centralized place for all ESRD Network-related project information, education, and best practice strategies
- Online platform created to help empower patients to work with their facilities to improve quality of care and overall quality of life



# How Do I Create a IPRO Learn Account?

- As a Patient Facility Representative (PFR), Patient Subject Matter Expert (PSME), or Peer Mentor you will have to create your own unique account that is associated with your Dialysis Facility
- IPRO staff will be reaching out to PFRs directly (email, text, and/or phone) to assist you with this process



Username / email

Password

☐ Remember username

Log in

Forgotten your username or password?

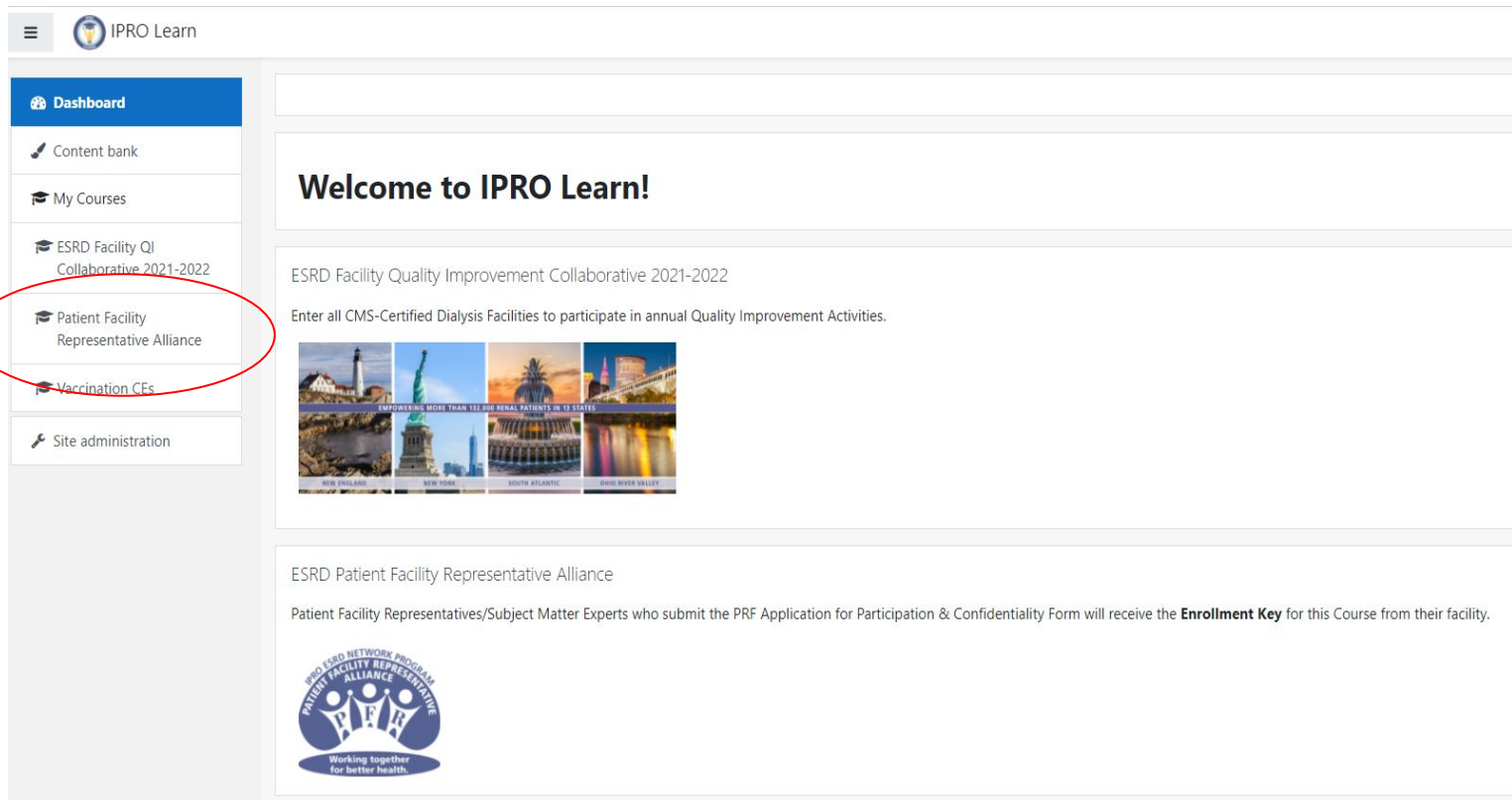
Cookies must be enabled in your browser ?

Is this your first time here?

Create new account


# IPRO Learn Dashboard


- Once your account has been created, and you are logged in, you will be directed to the IPRO Learn Dashboard
- Click the section on the left labeled, Patient Facility Representative Alliance



The screenshot shows the IPRO Learn dashboard interface. On the left is a navigation menu with the following items: Dashboard, Content bank, My Courses, ESRD Facility QI Collaborative 2021-2022, Patient Facility Representative Alliance (highlighted with a red circle), Vaccination CEs, and Site administration. The main content area has a header 'Welcome to IPRO Learn!' followed by a section for 'ESRD Facility Quality Improvement Collaborative 2021-2022' with the text 'Enter all CMS-Certified Dialysis Facilities to participate in annual Quality Improvement Activities.' Below this is a grid of four images representing different regions: New England, New York, South Atlantic, and Ohio River Valley. At the bottom of the main content area is a section for 'ESRD Patient Facility Representative Alliance' with the text 'Patient Facility Representatives/Subject Matter Experts who submit the PRF Application for Participation & Confidentiality Form will receive the Enrollment Key for this Course from their facility.' and a logo for the 'IPRO ESRD NETWORK PROGRAM PATIENT FACILITY REPRESENTATIVE ALLIANCE' with the tagline 'Working together for better health.'

# IPRO Learn PFRs Section Offerings

 IPRO Learn

 Patient Facility Representative Alliance


Grades

Dashboard

Content bank

My Courses

ESRD Facility QI Collaborative 2021-2022

 Patient Facility Representative Alliance

Vaccination CEs

Site administration

## ESRD Patient Facility Representative Alliance


Dashboard / My Courses / Patient Facility Representative Alliance

### What's New / Recent Announcements


Welcome to the **IPRO ESRD Patient Facility Representative (PFR) Alliance!**

**Click Here** to access resources that provided foundational information on the PFR Alliance, the different tiers, and the associated responsibilities.


We are thrilled to collaborate with you!


 11/11/2021 Webinar: ESRD Quality Improvement Best Practices November 11th (Thurs), 16th (Tues) & 18th (Thurs) 1:00PM-2:00PM EST

### PFR Training

 PFR Alliance Orientation

### To Do / PFR Activities

 Patient Experience of Care (PEOC): Improve PEOC by Resolving Grievances



## PFR Discussion Forum

Click on logo to join!



## PFR Alliance Newsletter:

Patient Voice-Expert Thoughts



- September 2021
- October 2021
- November 2021
- December 2021

## Need Some Help?

Email [ESRDNetworkProgram@ipro.us](mailto:ESRDNetworkProgram@ipro.us) and put "PFR IPRO Learn Question" in the Subject line.



# IPRO Learn PFR Access Pilot Testing

**Are you interested in joining our IPRO  
Learn focus group?**

**If so, please put your name in chat and a  
staff member will reach out to you after  
the meeting.**

# Questions or Comments?



.1

# Patients' Experience of Care (PEOC)



**Agata Roszkowski, Patient Services Director**


# Improving PEOC by Resolving Grievances and Access to Care Issues

- Issues may arise at dialysis facilities that cannot be resolved without mediation
- The Network has the responsibility to assist patients and dialysis facilities to resolve concerns in a manner that is satisfactory to all parties, as possible
- A grievance is defined as a formal or informal written or verbal complaint that is made to any member of the dialysis or transplant center staff, by a patient, or the patient's representative, regarding the patient's care or treatment
- If the grievant does not feel comfortable filing a grievance with the facility, a grievance may be filed directly to the Network

# Grievances Resources

**IPRO End-Stage Renal Disease Network Program**

## Your Rights and Responsibilities as an ESRD Patient



**End-Stage Renal Disease Network Program**

<http://esrd.ipro.org>

**End-Stage Renal Disease Network Program**

## 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 help 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.)

**NO**

I do not feel comfortable talking to someone at my facility.

**OR**

I spoke to someone and I don't feel like my grievance will be handled.

**YES**

I spoke to someone and feel my grievance will be handled.

**SUCCESS**

**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.)

**NO**

I do not feel comfortable talking to someone at the Network.

**OR**

I am not sure the Network can address my grievance.

**YES**

After speaking with the Network I feel my grievance will be handled.

**SUCCESS**

**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: [complaints@esrdnet.org](mailto:complaints@esrdnet.org) • Web: [esrdnet.org](http://esrdnet.org)

Developed by the IPRO ESRD Network Program with under contract with the Centers for Medicare & Medicaid Services. Contact: 757-621-1000/2019  
Published by: IPRO ESRD Network Program, 2019-2024

## Grievance Process Questions & Answers

### A Guide for Dialysis Facilities

**All patients, family members, and care partners have the right to file a grievance, internally or externally, without fear of retaliation.**

**What is a grievance?**  
According to the Centers for Medicare & Medicaid Services, a grievance is defined as follows:  
"A written or oral communication from an ESRD patient, and/or an individual representing an ESRD patient, and/or another party, alleging that an ESRD service received from a Medicare-certified provider did not meet the patient's expectations with respect to safety, quality, patient rights, and/or clinical standards of care."

**Who should be responsible for receiving and documenting a grievance?**  
Everyone. Any staff person who receives a grievance is responsible for documenting the grievance in the grievance log and reporting the concern to the facility Administrator/Clinic Manager for follow-up. Patients, family members and care partners should be able to report any problems and/or concerns to anyone at the site without complication. As care providers, it is our obligation to create an environment that fosters open communication and patient engagement with a willingness to take every opportunity available to improve care.

**Who is responsible for carrying out an investigation of a grievance?**  
The facility Administrator/Clinic Manager should take the lead in investigating and resolving all grievances. If the grievance involves the facility Administrator/Clinic Manager, the grievance should be investigated by that individual's direct supervisor. This helps to create a process that is easy for the grievant to understand and eliminates questions about with whom they should follow up if questions arise.

**What if the grievant wants to file a grievance anonymously?**  
The Network encourages facilities to develop an internal process for anonymous grievances to include the date of the incident, staff involved, description of incident and any witnesses, ensuring that the grievant can be identified to maintain anonymity. Grievances can also be reported to the Network anonymously if desired.

**What fosters an environment that encourages patients, family members and care partners to voice their concerns?**

- Ensure that all patients, family members and care partners are aware of the option to file a grievance internally at your site, with the Network, and with the department of health in your state.
- Display the Network provided grievance poster in an area that is visible to all patients and visitors.
- Place the Network provided grievance brochures in an area that is accessible to all patients and visitors.
- Consider making your own grievance materials that provide patients and family members with information about your internal grievance process. This may encourage a grievant to work with you prior to taking the concern to outside agency like the Network or the department of health in your state.

**End-Stage Renal Disease Network Program**

<http://esrd.ipro.org>

## The IPRO ESRD Network of New England 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.

The Network collaborates with the Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island and Vermont State Department of Health to advocate for individuals and help resolve concerns about care received at dialysis facilities.

For more information, visit the IPRO ESRD Network of New England website: <http://esrdnetnewengland.ipro.org>

To file a grievance, please contact:  
**IPRO End-Stage Renal Disease Network of New England**  
1952 Whitney Avenue, 2nd Floor, Hamden, CT 06517  
Patient Toll-Free: (866) 286-3773 • Main: (203) 387-9332  
Fax: (203) 389-9902 • E-mail: [esrdnetnewengland@ipro.org](mailto:esrdnetnewengland@ipro.org) • Web: [network1.esrd.ipro.org](http://network1.esrd.ipro.org)  
Contract: 54788-000-00000000 of New England under contract with Centers for Medicare & Medicaid Services, 2019-2024

**IPRO End-Stage Renal Disease Network Program**

## Kidney Chronicles

IPRO END-STAGE RENAL DISEASE NETWORK PROGRAM

**What is a Grievance?**

A grievance is any concern or issue you may have about the care you receive from your dialysis facility. Patients, family members, loved ones, dialysis staff members, or anyone else who has concerns about a facility may submit a grievance.

**YOU have Options!**

As a dialysis patient, if you are not satisfied with the care you receive there are several ways that you can share your concerns:

1. Attend a patient care plan meeting
2. Speak to members of your care team
3. File a complaint with your facility
4. Contact the State Department of Health
5. Contact your IPRO ESRD Network (see page 2 for info)

**Helpful Tips to Empower ESRD Patients as Consumers**

- Advocates for you
- Assesses your questions about treatment, medical choices or other issues
- Develops and provides educational materials for you and your family
- Works with real professionals to improve the care given to you
- Helps keep you informed and updated to support your involvement in your care and treatment options; and
- Facilitates and resolves grievances.

**Tips for sharing your concerns**

- Write down your concerns (this will help you to organize your thoughts).
- Remain calm (avoid using foul language).

**How the Network Serves You**

In an emergency, if you can't reach your facility, contact us.

**continued on page 2**

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...

## 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 Program**  
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072 Patient Services: (516) 231-9767 • Toll-Free Patient Line: (800) 238-3773  
E-mail: [esrdnetworkprogram@ipro.org](mailto:esrdnetworkprogram@ipro.org)

or

**Division of Long Term Care, Indiana State Dept. of Health**  
2 North Meridian Street, 4th, Indianapolis, IN 46204  
Toll-Free: (800) 246-8909 • Local: (317) 233-1325 (Main Switchboard)  
Local: (317) 233-7442 (Long Term Care) • Fax: (317) 233-7494  
E-mail: [complaints@isdh.in.gov](mailto:complaints@isdh.in.gov) • Website: [www.in.gov/isdh/23260.htm](http://www.in.gov/isdh/23260.htm)

**End-Stage Renal Disease Network Program**

<http://esrd.ipro.org>

**End-Stage Renal Disease Network of the South Atlantic**

## GRIEVANCE PROCESS GUIDE: A GUIDE FOR PATIENTS AND FAMILIES

**Filing a Grievance with your ESRD Network**

Your Network can work with you and your facility to help resolve your concerns. Before filing a grievance with us we encourage you to discuss your concern directly with a staff member at your facility. Ask to speak with someone with whom you feel comfortable sharing your concerns. If you do not wish to identify yourself, ask about how an anonymous grievance can be filed.

If you do not feel comfortable filing a grievance with your facility or you feel dissatisfied with the response of facility staff to your concerns, you have the right to file a grievance with your Network and with your state agency. Your state agency's contact information should be posted in the lobby of your facility. It is also provided on the back of this brochure.

**How can I file a grievance?**  
You can file a grievance in one of three ways. You can:

1. Call the Network using the toll-free line.
2. Mail us a letter or
3. Fax us the information.

The Network's contact information for all three options is available on the cover of this brochure.

To best help you, the Network may request information from you, such as your name, phone number, address and your date of birth. We will also ask for details (name and address) about the facility you have concerns about. If you do not feel comfortable giving us these details or sharing them with the facility you have the right to file a grievance confidentially or anonymously.

If you file a confidential grievance, the Network will collect these details; however, we will NOT share them with the facility. If you file an anonymous grievance, we will not collect these details at all during your case. If you decide to file a case anonymously and your concern relates directly to your personal care, the Network may be limited in the actions we can take during your investigation. We will respect your choice and protect your anonymity to the best of our ability.

**What should I expect during the grievance process?**

A member of the Network's Patient Services Department will listen to your concerns and help you to best organize your thoughts; they will also provide feedback to you and maybe offer another point of view.

The Network will collaborate with you and the facility staff to reach a resolution by advocating on your behalf based on your rights as a patient.

We may request to review documentation from your facility. This documentation may include treatment logs, social worker notes and policies and procedures of your facility.

We can provide recommendations to staff and patients/family members to build a more positive patient-provider relationship and encourage patients and staff to participate in care conferences to address issues at the facility level.

We can provide you educational materials on kidney disease or contact information for other kidney-related organizations.

When necessary, the Network may work with your state agency for further investigation or refer your case to other governing boards or government agencies for assistance.

The Network will work to resolve your case as quickly as possible. While some cases can be resolved within 7 business days other may remain open up to 60 days.

The Network will keep in contact with you throughout the process via phone and in writing.

# Access to Care Resources

## Dialysis Facility Involuntary Discharge Guidelines



**Note:** Discharging a patient for "non-compliance" is not an acceptable reason for discharge per the Centers for Medicare & Medicaid Services (CMS) Conditions for Coverage (CFC).

## IVD Guidelines

<b>Notify the Network of any</b>	Immediately notifying the Network provides an opportunity for the Network to review the issues and interventions with facility staff and see if there are other options that could be explored.
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Have a policy and procedure in place for IVDs

It is the medical director's responsibility to ensure "that no patient is discharged or transferred from the facility unless:

- The patient or payer no longer reimburses the facility for the ordered services
- The facility ceases to operate

- The transfer is necessary for the patient's welfare because the facility can no longer meet the patient's documented medical needs
- The facility has reassessed the patient and determined the patient's behavior is disruptive and abusive to the extent in which the delivery of care to the patient, or the ability of the facility to operate effectively is seriously impaired...

<b>Train facility staff</b>	<p>All staff should receive training in conflict management techniques.</p> <ul style="list-style-type: none"> <li>• Training must be documented</li> </ul>
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The Facility should establish IVD and transfer policies and procedures as outlined in 494.190 Condition Governance (Page 20484). A link to the full document is located on the ESRD website along with additional resources to assist you facility:  
<https://network1.esrd.pro/home/patient-and-family-resources/access-to-care/>

**Document everything** It is essential that staff document and address any and all problematic behaviors, no matter how insignificant they may seem. Include documentation of all:

- Related assessments/plans of care, meetings, and interventions
- Behavioral agreements that the staff and patients work on together (*all behavioral agreements should be mutual between the patient and facility and should be reassessed at specified time intervals*)

IVD should be the option of last resort

An involuntary discharge can begin only if:

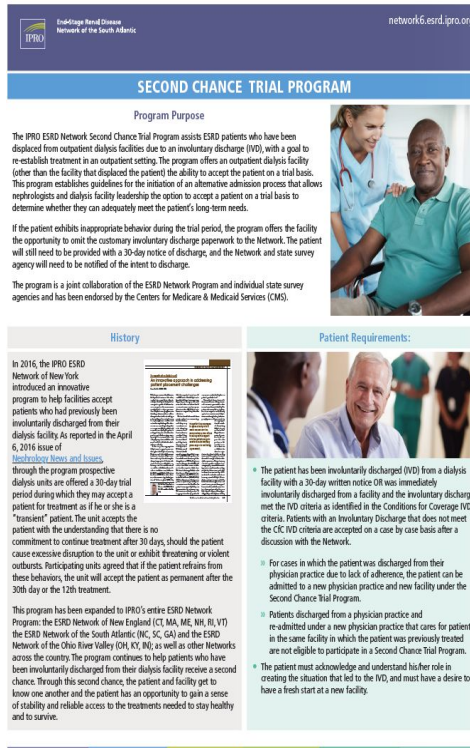
1. All efforts to resolve the problem have failed.
2. The issues and interventions to address them have been properly documented.

- The facility should assist the patient with establishing with a new physician and/or transferring to another facility if the IVD cannot be averted.
- When attempting to assist the patient in transferring to another facility, be sure to only send the medical information requested by the other facility.

**DO NOT** include additional documentation indicating that the patient is being involuntarily discharged or the circumstances surrounding the discharge unless it is specifically requested for transfer consideration. This is considered blacklisting and will be reported to the State Survey Agency.

**Immediate IVD** In cases of immediate severe threat to the health and safety of others, the facility may use an abbreviated IVD procedure. Per the CIC Interpretive Guidance, "An immediate severe threat" is considered to be a threat of physical harm. For example, if a patient has a gun or a knife or is making credible threat of physical harm, this would be considered an "immediate severe threat." An angry verbal outburst or verbal abuse is not considered to be an immediate severe threat."

Verbal abuse is not considered to be an immediate severe threat.	
<b>Notifying the State Survey Agency</b>	Facilities must notify the State Survey Agency of all IVDs and transfers. If the discharge or transfer is the result of immediate, severe threats, the State Survey Agency must be notified immediately.



**Before you discharge your patient from CROWNWeb:**




1. Have you made efforts to locate the patient?  
Efforts might include:
    - Mobile Crisis referral
    - Wellness checks
    - Phone calls to the patient and their caregivers
    - Coordination with patient's outpatient services (i.e. case management – housing/ mental health/house home)
    - Registered letters to patient
  2. After all efforts are made to locate the patient, it is determined that the patient is lost?
    - No contact with the patient
    - No reports of the patient at home
    - No reports of the patient at a hospital
    - No contact with patient's family
  3. If the location of the patient is known and they are not coming to treatment, you cannot discharge. Discharge for noncompliance is a violation of the Conditions for Coverage § 716 or § 719. <https://www.medicare.gov/medicare-conditions-for-coverage-and-certification-survey/certification/conditions-for-coverage/99-01.pdf>
    - Discuss with the patient what their barriers are returning to treatment at the facility
    - If the patient is utilizing a particular hospital's emergency department for care instead of returning to your facility, ask the patient their reason. Collaborating with the hospital's case management department may be helpful in assisting with mitigating barriers.
    - Utilize resources to assist: Mobile Crisis, Wellness checks, Adult Protective Services.
  4. If a patient is out of the unit for 30 days' time you cannot discharge out of CROWNwNet. (If the patient's whereabouts are known)
    - If the patient is hospitalized, coordinate a discharge plan for the patient with the case manager / social worker.
    - Discharge the patient from CROWNwNet once the patient has begun treatment at another facility.
    - If you discharge after thirty days it is considered an involuntary discharge. This must be reported to the IPRO ESRD Network of New England and New England State Department of Health.  
(The facility must do their due diligence to find the patient and can not discharge if the patient's location is known)
  5. If the patient is no longer medically suitable for outpatient dialysis at your dialysis facility, has a transfer to another specialized facility been pursued?  
Is the patient no longer medically suitable for outpatient dialysis?  
Has this decision been discussed with the patient and their family/caregiver?  
Have all options been discussed?
    - home modality
    - nursing home placement
    - hospice
    - Discontinuation of dialysis
- Contact the IPRO ESRD Network of New England's Patient Services Department at 204-258-1213 if you have specific questions related to your patient.




IPRO End-Stage Renal Disease Network of New England  
1952 Whitney Avenue, 2nd Floor Hamden, CT 06517  
Patient Toll-Free: 866-286-3773 • Main: 203-387-9332 • Fax: 203-389-9902  
E-mail: [esrdnetwork1@ipro.us](mailto:esrdnetwork1@ipro.us) • Web: [network1.esrd.ipro.org](http://network1.esrd.ipro.org)

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# IPRO Learn PEOC Activity

 IPRO Learn

 Patient Facility Representative Alliance


Grades

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ESRD Facility QI Collaborative 2021-2022

 Patient Facility Representative Alliance

Vaccination CEs

Site administration

## ESRD Patient Facility Representative Alliance


Dashboard / My Courses / Patient Facility Representative Alliance

### What's New / Recent Announcements


Welcome to the **IPRO ESRD Patient Facility Representative (PFR) Alliance!**

**Click Here** to access resources that provided foundational information on the PFR Alliance, the different tiers, and the associated responsibilities.


We are thrilled to collaborate with you!


 11/11/2021 Webinar: ESRD Quality Improvement Best Practices November 11th (Thurs), 16th (Tues) & 18th (Thurs) 1:00PM–2:00PM EST

### PFR Training

 PFR Alliance Orientation

### To Do / PFR Activities

 Patient Experience of Care (PEOC): Improve PEOC by Resolving Grievances



## PFR Discussion Forum

Click on logo to join!



## PFR Alliance Newsletter:

Patient Voice-Expert Thoughts



- September 2021
- October 2021
- November 2021
- December 2021

## Need Some Help?

Email [ESRDNetworkProgram@ipro.us](mailto:ESRDNetworkProgram@ipro.us)  
and put "PFR IPRO Learn Question" in the Subject line.



# IPRO Learn PEOC Activity



Better healthcare,  
realized.



IPRO Learn



Danielle Daley

Patient Facility  
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ESRD Facility QI  
Collaborative 2021-2022

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Representative Alliance

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Site administration

## ESRD Patient Facility Representative Alliance

Dashboard / My Courses / Patient Facility Representative Alliance / To Do / PFR Activities / Patient Experience of Care (PEOC): Improve PEOC by Resolving Grievances

### Patient Experience of Care (PEOC): Improve PEOC by Resolving Grievances



**Did You Know your IPRO ESRD Network can help you resolve Grievances? Let's learn how to improve the patient's experience of care!**

ESRD Networks are tasked by CMS to help patients clear up grievances related to treatment received by a Medicaid Certified provider that does not meet the needs of a patient, provides a safe environment, understands and respects patient rights, and performs safe and effective clinical services. The Network's goal is to create a strong relationship with both patients and medical providers to boost open communication. Therefore, patients should be aware of the Network's role in resolving patient issues and grievances and educational information available.

Use the following educational tools to learn where grievances can be filed, how to file one anonymously, as well as what resources are available to help improve your health care experiences:

- Visit the Network's website to understand the grievance process for your state: **IPRO ESRD Network Program: Grievances and Concerns**
- Check your facility's lobby area to ensure they are displaying the Network-provided **Grievance Posters** in an area that is visible to all patients and visitors.
- Ask facility staff for a copy of the **Grievance Process Guide Flyer** and *Grievance Process Guide for Patients and Families Brochure*, **then share and discuss with your ESRD peers:**
  - **Network 1** Grievance Process Guide for Patients and Families
  - **Network 2** Grievance Process Guide for Patients and Families
  - **Network 6** Grievance Process Guide for Patients and Families
  - **Network 9** Grievance Process Guide for Patients and Families

Was this Grievance Process easy to understand? Please let us know by answering a few questions below!

Answer the questions...

# Questions or Comments?



# Next Steps



**Danielle Andrews, Health Equity Specialist**

# Patient Virtual Support Group

**Join the Network in our virtual monthly patient support group!**

- We want to understand your thoughts and experiences as an ESRD patient or Caregiver
- Let us know what could have been done better, and what is working for you

**Every 4th Thursday of the month at 5:00pm ET**

- Meeting Link:  
<https://ipro.webex.com/ipro/j.php?MTID=m6de0a2dc11398746344a8dc525b9e7eb>
  - Call-In: 1-855-797-9485
  - Access Code: 616 535 334

# Mark Calendar: Next PFR Meeting

**Thursday, February 3, 2022**  
**at 5:30pm ET**


## Upcoming Topics:

- Home Dialysis
- Transplant

## Things to Think About:

- Are you interested in becoming a peer mentor?
- Have you spoken with your social worker about becoming a peer mentor?
- Have you visited the [NCC Kidney Hub-Peer Mentoring Page](#)

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–7 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.

Topics include

- Social Determinants of Health
- Peer Mentoring
- Behavioral Health
- Transplant Coordination
- Home Therapies
- Hospitalizations
- Vaccinations
- Care Transitions

**Webinar Access:** <https://ipro.webex.com/meet/IPROESRD>


**Meeting ID:** 178 506 9205

**Toll-Free Dial-in number:** 1-855-797-9485

**Access Code:** 178 506 9205

For more information, please contact the Network at (516) 231-9767

To file a grievance, please contact:  
**IPRO End-Stage Renal Disease Network Program (Network 1, 2, 6, & 9)**  
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072  
Patient Services: (516) 231-9767 • Patient Toll-Free: (800) 238-3773  
Email: [esrdnetworkprogram@ipro.us](mailto:esrdnetworkprogram@ipro.us) • Website: [www.esrd.ipro.org](http://www.esrd.ipro.org)



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

# Community Awareness Campaigns



## January

- National Thyroid Awareness Month
- National Glaucoma Awareness Month



**IPRO ESRD Network Patient  
Facility Representative (PFR)  
Alliance**

## Next Steps

- Follow us on social media
- Join the PFR Alliance Facebook Group  
<https://www.facebook.com/groups/IPROESRDPAC>
- Create your IPRO Learn Account <https://learn.ipro.org/>
- **Save the Date of our Next Meeting**
  - **February 3, 2022 at 5:30PM**
- If you're interested in being a peer mentor reach out to the Network for an [application referral](https://www.kidneylearninghub.com/)  
<https://www.kidneylearninghub.com/>

*Happy New Year!*

*May the New Year bring you happiness,  
peace, and prosperity. Wishing you a joyous 2022!*

*Sincerely,  
The IPRO ESRD Network Program*



## Follow Us on Social Media



- [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](#)

# Thank You!



**Danielle Andrews, MPH, MSW, GCPH**

*Health Equity Specialist*

End Stage Renal Disease Network Program

Tel: (516) 209-5549 | E-mail: [danielle.andrews@ipro.us](mailto:danielle.andrews@ipro.us)



**Agata Roszkowski, LMSW**

*Patient Services Director*

End Stage Renal Disease Network Program

Tel (203) 285-1213 | E-mail: [agata.roszkowski@ipro.us](mailto:agata.roszkowski@ipro.us)



**Danielle Daley, MBA**

*Executive Director*

End Stage Renal Disease Network Program

E-mail: [danielle.daley@ipro.us](mailto:danielle.daley@ipro.us)



Better healthcare,  
realized.

Corporate Headquarters

1979 Marcus Avenue

Lake Success, NY 11042-1072

<http://ipro.org>