



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**



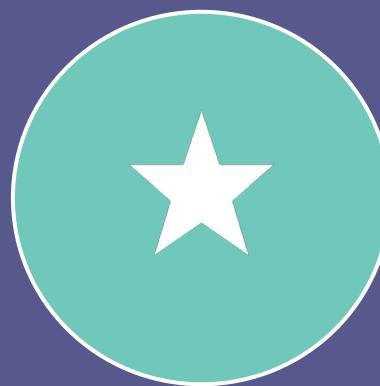
**PFR Check-In**



**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

# Welcome to Our January Meeting!



**Danielle Andrews, Health Equity Specialist**



# Mission Statement

The IPRO End Stage Renal Disease Network

Program includes four ESRD Networks:

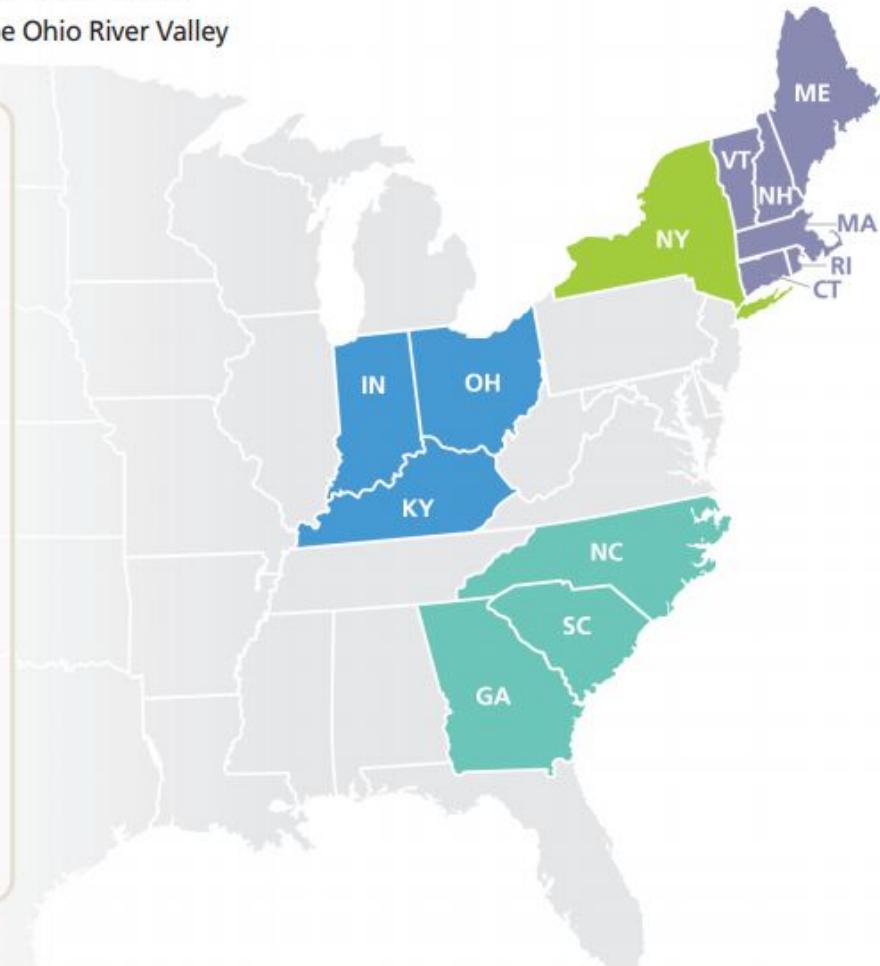
Network 1: ESRD Network of New England

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

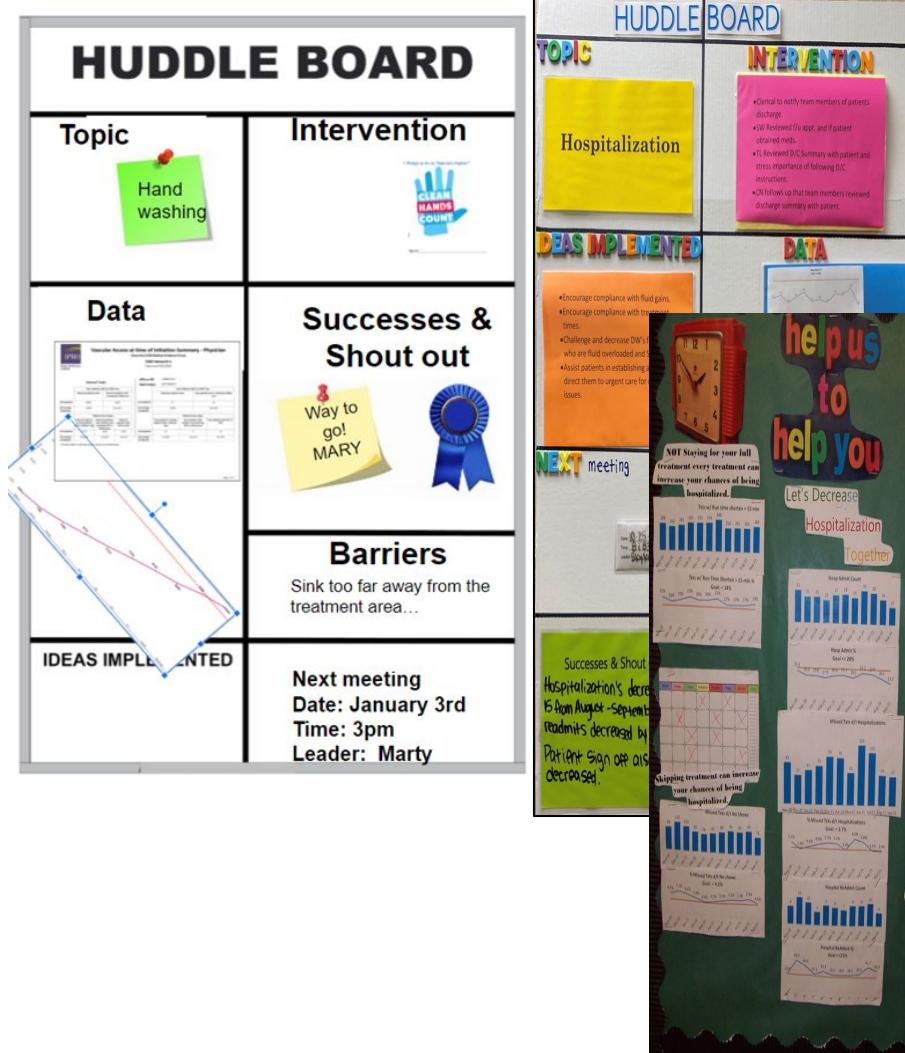


# Huddle Boards – PFR + QAPI Lead



*A visual way for the quality team to collaborate and assess all the tasks to accomplish a goal*

- 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

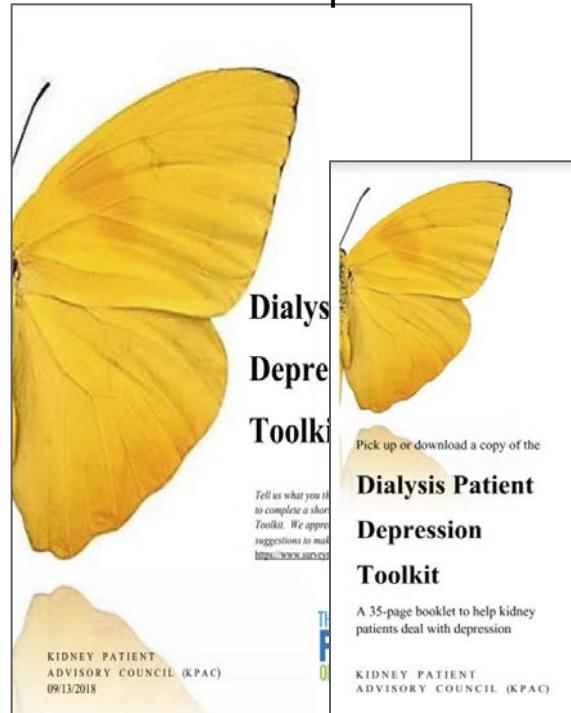
- Helping patients to determine if they are depressed and offering treatment
- Helping patients to living their fullest life with kidney disease.
- Improving patient comfort in expressing concerns and need for support



# How Can I Help With Reducing Depression?

 <p><b>GREEN ZONES: ALL CLEAR</b></p> <p>Your Goals:</p> <ul style="list-style-type: none"> <li>• Stable mood</li> <li>• Sleeping well</li> <li>• Healthy appetite</li> <li>• Feeling hopeful</li> <li>• Able to concentrate</li> </ul>	<h2>Zone Tool</h2> <h1>Self-Management for Depression</h1> <h3>GREEN ZONE</h3> <p><b>GREEN ZONE ACTION STEPS:</b></p> <ul style="list-style-type: none"> <li>• Having some fun</li> <li>• Engage in activities you enjoy</li> <li>• Your symptoms are under control             <ul style="list-style-type: none"> <li>✓ Continue taking your medications as ordered</li> <li>✓ Keep all physician appointments</li> </ul> </li> </ul>
<p><b>YELLOW ZONE: CAUTION means your symptoms are starting to Change</b></p> <p>The following symptoms may be early warning signs that your depression is worsening:</p> <ul style="list-style-type: none"> <li>• Sad mood most of the time</li> <li>• Not eating/eating too much</li> <li>• Trouble concentrating</li> <li>• Not sleeping well/sleeping too much</li> <li>• Not finding pleasure in normal activities</li> <li>• Increase in feelings of irritability/anger</li> <li>• Loss of energy to do chores/activities</li> <li>• Not taking medications as prescribed</li> <li>• Missing physician appointments</li> </ul>	<h3>YELLOW ZONE</h3> <p><b>YELLOW ZONE ACTION STEPS:</b></p> <ul style="list-style-type: none"> <li>• Call your physician if you are going into the <b>YELLOW ZONE</b>.</li> </ul> <p>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....</p>
<p><b>RED ZONE: MEDICAL ALERT</b></p> <ul style="list-style-type: none"> <li>• Overwhelmed by feelings of sadness/despair</li> <li>• Feeling hopeless and/or helpless</li> <li>• Thoughts or feelings of killing or harming yourself</li> <li>• Unable to leave the bed</li> <li>• Not eating</li> <li>• Not sleeping</li> <li>• Stopped taking medications</li> <li>• Missing physician appointment</li> </ul>	<h3>RED ZONE</h3> <p><b>RED ZONE MEANS:</b></p> <p>This indicates that you need to be evaluated by a physician right away.</p> <p><b>Get help immediately if you are in the RED ZONE.</b> Call your physician, go to the nearest emergency room or call the National Suicide Prevention Lifeline at <b>1800-273-8255 (TALK)</b></p>

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



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

# ◆◆◆◆◆ YOUR MIND AND YOUR BODY ◆◆◆◆◆

## TALKING TO YOUR DOCTOR ABOUT MENTAL HEALTH

# 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.



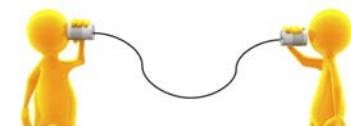


# What are We Working On?

## 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 a 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 things. Telemedicine is when a healthcare worker gives medical care education from a remote location. The technology used to provide the medical service to patients is referred to as telehealth. In this 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 easier access to routine preventive care.

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

### 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



**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 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 performs 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 your facility to reschedule your treatment so you don't miss a minute of your valuable dialysis.



To file a grievance, please contact us:

IPRO End-Stage Renal Disease Network Program  
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11040  
Patient Services: (516) 231-9767 • Patient Toll-Free: (800) 238-2343  
Email: esrdnetworkprogram@ipro.us • Website: esrd.ipro.org

## 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



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

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

# Questions or Comments?



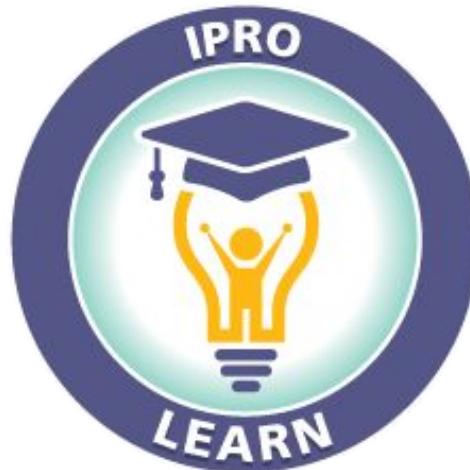
# IPRO Learn



**Danielle Daley, Executive Director**

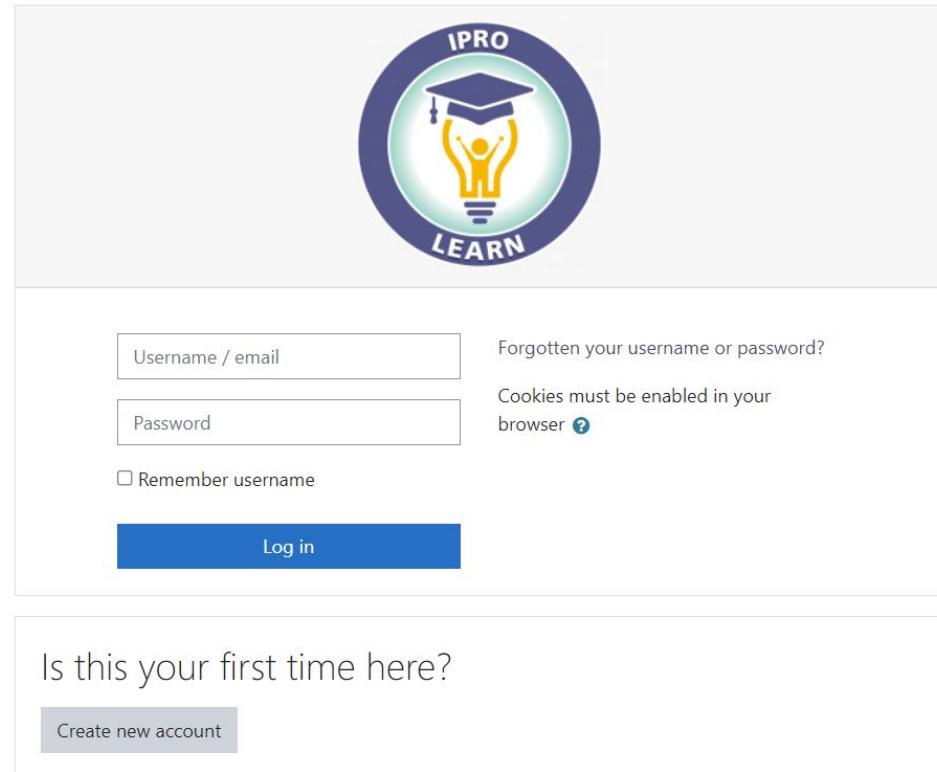
# What is IPRO Learn?

- 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?

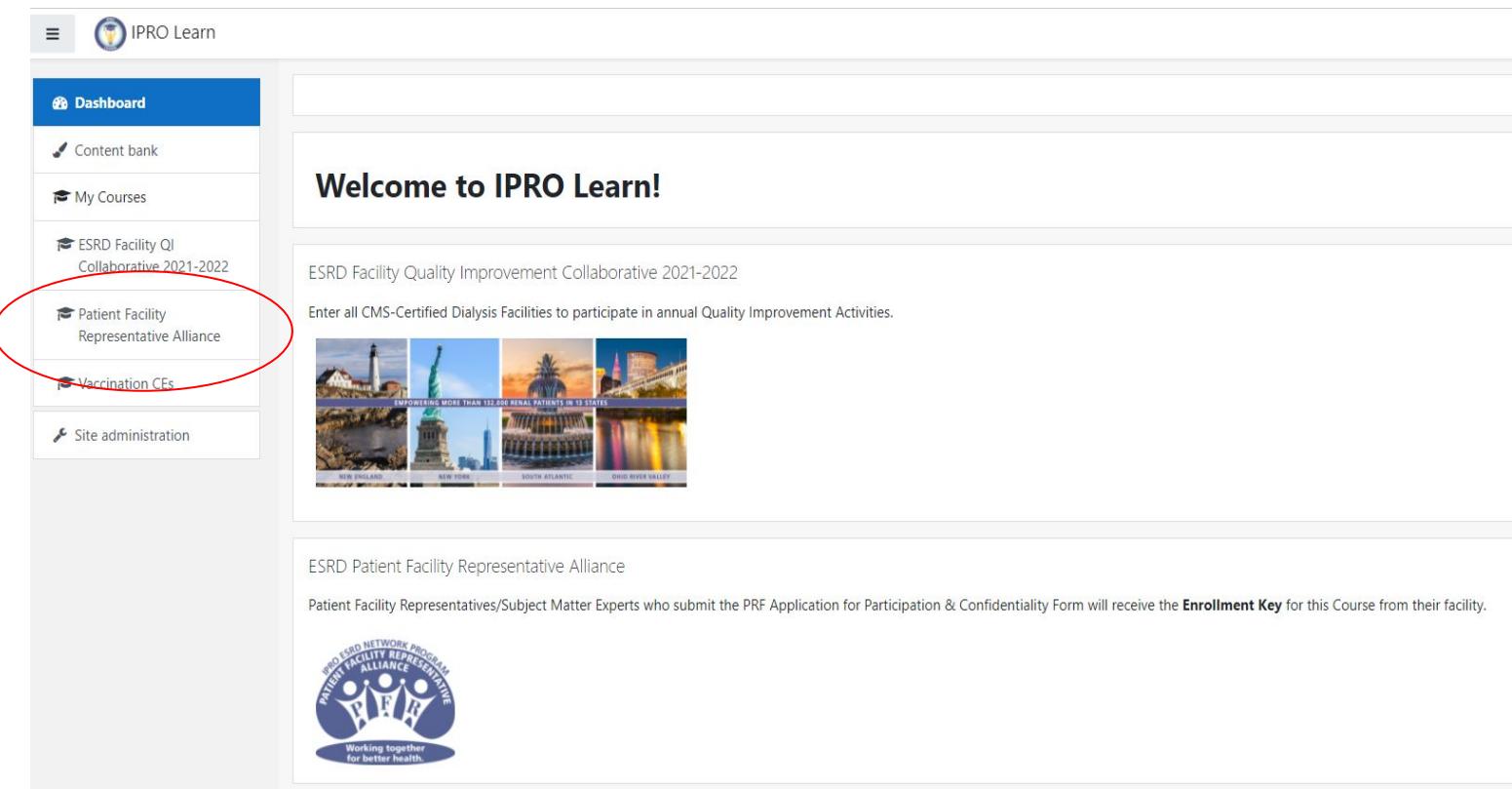
- As a Patient Facility Representative (PFR), Patient Subject Matter Expert (PSME), or Peer Mentor you will have to create your own unique account that is associated with your Dialysis Facility
- IPRO staff will be reaching out to PFRs directly (email, text, and/or phone) to assist you with this process



The image shows the IPRO Learn login page. At the top is a circular logo with "IPRO" at the top and "LEARN" at the bottom, and a graduation cap icon in the center. Below the logo are two input fields: "Username / email" and "Password". To the right of the "Username / email" field is a link "Forgotten your username or password?". Below the "Password" field is a link "Cookies must be enabled in your browser ?". There is also a checkbox "Remember username". A large blue "Log in" button is at the bottom. At the bottom of the page, a question "Is this your first time here?" is followed by a "Create new account" button.

# 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. On the left, a sidebar menu includes 'Dashboard', 'Content bank', 'My Courses', 'ESRD Facility QI Collaborative 2021-2022' (which is circled in red), 'Patient Facility Representative Alliance' (which is also circled in red), and 'Vaccination CEs'. Below these are 'Site administration' and a 'Logout' button. The main content area features a 'Welcome to IPRO Learn!' header, followed by a section for the 'ESRD Facility Quality Improvement Collaborative 2021-2022'. It encourages users to enter CMS-Certified Dialysis Facilities to participate in annual Quality Improvement Activities. Below this are four images representing different regions: 'NEW ENGLAND', 'NEW YORK', 'SOUTH ATLANTIC', and 'OHIO RIVER VALLEY'. At the bottom, there is information about the 'ESRD Patient Facility Representative Alliance' and a logo for the 'IPRO ESRD NETWORK PROGRAM ALLIANCE' featuring three stylized human figures and the text '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

NEWS

- 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>

**Kidney Chronicles**  
IPRO END-STAGE RENAL DISEASE NETWORK PROGRAM

esrd.ipro.org

HELPFUL TIPS TO EMPOWER ESRD PATIENTS AS CONSUMERS

**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)

**How the Network Serves You**

- Answers your questions about treatment, modality choices or other issues.
- Develops and provides educational materials for you and your family.
- Works with renal professionals to improve the care given to you.
- Helps keep you informed and updated on your involvement in your care and treatment options, and
- Evaluates and monitors grievances.

**Tips for sharing your concerns**

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

continued on page 2

**IPRO 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 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. (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.

**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.

**Step 3: Call Your State Agency**  
Your state agency or your facility 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 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.org](mailto:esrdnetworkprogram@ipro.org) • Web: <http://esrd.ipro.org>

Developed by the IPRO ESRD Network Program while under contract with the Centers for Medicare & Medicaid Services. Contract #P14MC100019  
Publication # ESRD IPRO GA-NW-1228-13  
12/29/2013

**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 a formal complaint:

- "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 health care provider or facility has violated the grievor'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. If the grievance is received by a Network staff member, the Network staff member should forward the grievance 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 unit without complication. As care partners, you should be encouraged to report any concerns 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 the grievance. If the grievance involves the Facility Administrator/Clinic Manager, the grievance should be investigated by that individual's direct supervisor. The Network staff member should be available to the grievant to understand and eliminate 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 grievance, the name of the grievor, and the name of the witness, ensuring that the grievance can be submitted 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 unit, with the Network, and with the department of health in your state.
- Make sure the Network-provided grievance poster is 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 running your own grievance materials that include a grievance form and instructions on how to file a grievance to work with you to take the concern to outside agency or the department of health in your state.

**Who to file a grievance, please contact us:**  
**IPRO End-Stage Renal Disease Network Program**  
1952 Whitley Avenue, 2nd Floor, Hamden, CT 06517  
Patient Toll-Free: (866) 286-3773 • Main: (203) 387-9332  
Fax: (203) 389-9902 • E-mail: [esrdnetwork@ipro.org](mailto:esrdnetwork@ipro.org) • Web: <http://network1.esrd.ipro.org>

Developed by IPRO ESRD Network of New England while under contract with Centers for Medicare & Medicaid Services. Contract Number 130-2013-00019C

**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 a formal complaint:

- "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 health care provider or facility has violated the grievor's expectations with respect to safety, quality, patient rights, and/or clinical standards of care."

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**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 resolution of your concern, 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 will collaborate with you and the facility staff to reach a resolution by advocating on your behalf based on your rights as a patient.

**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**

- 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.
- Example: "I need a fourth shift, and my facility does not offer it" The Network can provide you with a list of facilities in your area that offer a fourth shift (Dialysis Facility Compare tool available on [www.medicare.gov](http://www.medicare.gov))
- 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.
- 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 <https://network1.esrd.ipro.org>

**To file a grievance, please contact:**  
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Patient Toll-Free: (866) 286-3773 • Main: (203) 387-9332  
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We may request to review documentation from your facility. This documentation may include treatment logs, staff or nurse notes or 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

STOP

Before considering an involuntary discharge (IVD), a facility's interdisciplinary team (IDT) should:

1. Conduct a thorough assessment of the situation
2. Develop a plan to address any problems or barriers the patient may be experiencing

**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 (CFO).

**IVD Guidelines**

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.

**Notify the Network of any potential IVD**

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 patient has exhibited behavior that has 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.

**Train facility staff**

All staff should receive training in conflict management techniques.

- Training must be documented

The Facility should establish IVD and transfer policies and procedures as outlined in 494.190 Condition Governance (Page 2048A). A link to the full document is located on the ESRD website along with additional resources to assist you facility: <https://network1.esrd.ipro.us/home/patient-and-family-resources/access-to-care/>

**Document everything**

Document every patient interaction, including 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.

**Assist the patient with placement**

The facility should assist the patient with establishing with a new physician and/or transferring to another facility if the patient is available.

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 CFC Interpretive Guidance, "An immediate severe threat" is considered to be any form of physical abuse, including hitting, kicking, biting, pushing, pulling, using a gun or a knife or is making credible threats 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."

**Notifying the State Survey Agency**

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.



End-Stage Renal Disease Network of the South Atlantic

network6.esrd.ipro.org

**SECOND CHANCE TRIAL PROGRAM**

**Program Purpose**

The IPRO ESRD Network Second Chance Trial Program assists ESRD patients who have been discharged from outpatient dialysis facilities due to an involuntary discharge (IVD), with a goal to re-establish treatment in an outpatient setting. The program offers an outpatient dialysis facility (other than the facility that discharged the patient) the ability to accept the patient on a trial basis. This program is a collaborative effort between the IPRO ESRD Network and a dialysis facility that allows nephrologists and dialysis facility leadership the option to accept a patient on a trial basis to determine whether they can adequately meet the patient's long-term needs.

If the patient exhibits inappropriate behavior during the trial period, the program offers the facility the opportunity to emit the customary involuntary discharge paperwork to the Network. The patient will still need to be provided with a 30-day notice of discharge, and the Network and state survey agency will need to be notified of the intent to discharge.

The program is a joint collaboration of the ESRD Network Program and individual state survey agencies and has been endorsed by the Centers for Medicare & Medicaid Services (CMS).

**History**

In 2016, the IPRO ESRD Network of New York introduced an innovative program to help facilities accept patients who have previously been involuntarily discharged from their dialysis facility. As reported in the April 6, 2016 issue of *Healthcare News and Issues*, through the program patients can receive a 30-day trial period during which they may accept a patient for treatment as if he or she is a "transient" patient. The unit accepts the patient with the understanding that there is no commitment to continue treatment after 30 days, should the patient cause excessive disruption to the unit or exhibit threatening or violent outbursts. Patients who agreed that the patient refers to these behaviors, the unit will accept the patient as permanent after the 30th day of the 120 treatment.

This program has been expanded to IPRO's entire ESRD Network Program, the ESRD Network of New England (CT, MA, ME, NH, RI, VT) the ESRD Network of the South Atlantic (NC, SC, GA) and the ESRD Network of the Ohio River Valley (OH, KY, IN), as well as other Networks across the country. The program continues to help patients who have been involuntarily discharged from their dialysis facility receive a second chance. Through this second chance, the patient and facility get to know one another and the patient has an opportunity to gain a sense of stability and reliable access to the treatments needed to stay healthy and to survive.

**Patient Requirements:**

The patient has been involuntarily discharged (IVD) from a dialysis facility with a 30-day written notice of discharge.

The patient has been involuntarily discharged from a facility and the involuntary discharge met the IVD criteria as identified in the Conditions for Coverage (CFO) IVD criteria. Patients with an involuntary discharge that does not meet the CFO IVD criteria are accepted on a case by case basis after a discussion with the Network.

For cases in which the patient was discharged from their physician practice due to lack of adherence, the patient can be admitted to a new physician practice and new facility under the Second Chance Trial Program.

Patients discharged from a physician practice and re-admitted under a new physician practice that care for patients in the same facility in which the patient was previously treated are not eligible to participate in a Second Chance Trial Program.

The patient must acknowledge and understand his/her role in creating the situation that led to the IVD, and must have a desire to have a fresh start at a new facility.



IPRO  
Better healthcare, realized.

IPRO End-Stage Renal Disease Network of New England  
1952 Whitney Avenue, 2nd Floor Hamden, CT 06517  
Patient Toll-Free: 866-286-3773 • Main: 203-387-9324 • Fax: 203-389-9902  
E-mail: [cardnetwork1@ipro.us](mailto:cardnetwork1@ipro.us) • Web: [network1.esrd.ipro.org](http://network1.esrd.ipro.org)

This material was developed by IPRO and the ESRD Network of New York, the ESRD Network of New England, and the ESRD Network of the South Atlantic under CMS policy. CMS cannot be held liable for the use of this material.

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

**STOP**

1. Have you made efforts to locate the patient?

Efforts might include:

- Mobile Crisis referral
- Homeless shelter
- Phone calls to the patient and their caregivers
- Coordination with the patient's outpatient services (ex: case management - housing/mental health/home)
- Registered letters to patient

2. After all efforts are made to locate the patient, is it 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 should consider a trial period. Trial treatment is a violation of the Conditions for Coverage V.766 or V.767 (<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/Certification/GenIn-factDownloads2/SCLetter09-01.pdf>)

- Discuss with the patient what their barriers are to returning to treatment at the facility
- If the patient is utilizing a particular hospital emergency department for care instead of returning to your facility, ask the patient their reason. Collaborating with the hospital 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 CROWNWeb. (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 CROWNWeb 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 discharge if the patient's location is known)

5. If the patient is longer medically suitable for outpatient dialysis at your dialysis facility, consider a transfer to another facility or a different program:

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 modify
- nursing home placement
- hospice
- Discontinuation of dialysis

Contact the IPRO ESRD Network of New England's Patient Services department at 203-258-1213 if you have specific questions related to your patient.

**STOP**

# IPRO Learn PEOC Activity

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 PEOC Activity



12 Danielle Daley

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 / 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:	<a href="https://ipro.webex.com/meet/IPROESRD">https://ipro.webex.com/meet/IPROESRD</a>
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/>

# *Happy New Year!*

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

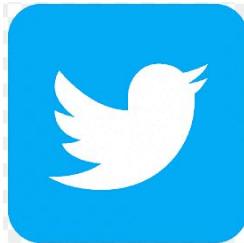
*Sincerely,  
The IPRO ESRD Network Program*



# 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!



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<http://ipro.org>