



End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

November 7th, 2024

This material was prepared by the IPRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic and the Ohio River Valley, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication #



Patient and Family Engagement Facilitators



Aisha Edmondson
Patient and Family
Engagement Lead

Patient and Family Engagement Facilitators



Caroline Sanner, MSN, RN-BC, CPHQ
Quality Improvement Speaker



Shezeena Andiappen, MSW
Patient Services Speaker

Today's Agenda

Topics for Review/Discussion



Meeting
Reminders

Patient
Services
Topic

PFR Check-In

Closing
Remarks

Quality
Improvement
Topic



Meeting Reminders



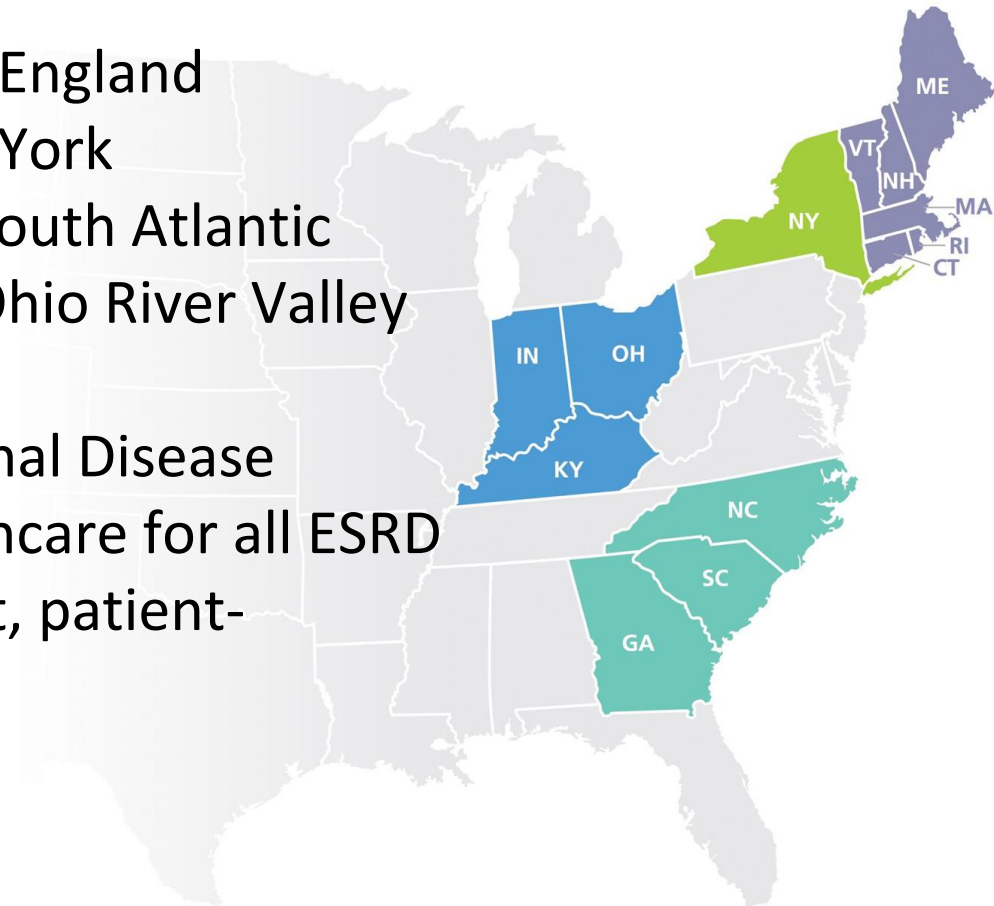
- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



IPRO ESRD Network Program



- The IPRO End-Stage Renal Disease Network Program includes four ESRD Networks:
 - Network 1: ESRD Network of New England
 - Network 2: ESRD Network of New York
 - Network 6: ESRD Network of the South Atlantic
 - Network 9: ESRD Network of the Ohio River Valley
- The mission of the IPRO End-Stage Renal Disease Network Program is to promote healthcare for all ESRD patients that is safe, efficient, efficient, patient-centered, timely, and equitable.



The Network's Role

What the Network's staff CAN and CANNOT do



Network staff CAN...

- Advocate for patients' rights, depending on the situation.
- Provide information and educational resources.
- Investigate concerns about issues related to quality of care.
- Help patients understand their rights and help them navigate the ESRD care delivery system.

Network staff CANNOT...

- Force a facility to accept a patient.
- Close a dialysis facility.
- Go onsite to investigate a facility's clinical procedures, witness interactions between staff and patients, or view a videotape of incidents (HIPAA violation).
- Add a patient to the transplant list.
- Recommend a lawyer and assist with a lawsuit.
- Get staff members fired or arrange for staff to have their pay docked.
- Force a facility to change its admissions policy regarding catheters.
- Verify Medicare coverage or give out Medicare cards.
- Interfere with facility surveys.
- Hide a patient's involuntary discharge (IVD) history.

[We Can Help](#)

The IPRO ESRD Network Program We Can Help



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 www.medicare.gov) |
| Investigate concerns about issues related to quality of care. | ~ Example: "I am upset about the care I am receiving at my facility" The Network can conduct a review of your medical record to evaluate the quality of care you are receiving. |
| Help patients understand their rights and help them navigate the ESRD care delivery system. | ~ Example: "I don't agree with a policy at my facility" The Network can advocate on your behalf and could help you work with facility staff to find a compromise that would work for you and the facility. |

| However, some concerns may be beyond the Network's scope. Network staff CANNOT.. | |
|---|--|
| ✘ Force a facility to accept a patient. | ✘ Get staff members fired or arrange for staff to have their pay docked. |
| ✘ Close a dialysis facility. | ✘ Force a facility to change its admissions policy regarding catheters. |
| ✘ Go onsite to investigate a facility's clinical procedures, witness interactions between staff and patients, or view a videotape of incidents (HIPAA violation). | ✘ Verify Medicare coverage or give out Medicare cards. |
| ✘ Add a patient to the transplant list. | ✘ Interfere with facility surveys. |
| ✘ Recommend a lawyer and assist with a lawsuit. | ✘ Hide a patient's involuntary discharge (IVD) history. |

The Network collaborates with the State Department of Health to advocate for individuals and help resolve concerns about care received at dialysis facilities.



For more information or to file a grievance, please contact us:
IPRO End-Stage Renal Disease Network Program Corporate Office:
1979 Marcus Avenue, Lake Success, NY 11042-1072
Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
E-mail: esrdnetworkprogram@ipro.org • Web: esrd.ipro.org

This material was prepared by the IPRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic, and the Midwest. Views expressed in this material do not necessarily reflect the official views or policy of CMS or IPRO, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or IPRO. Publication #1300-IPRO-001-000-000002-101 | 11/13/2015

Network Check-In

Polling Question



Which Network are you from?

- Network 1 (Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont)
- Network 2 (New York)
- Network 6 (North Carolina, South Carolina, Georgia)
- Network 9 (Indiana, Kentucky, Ohio)



Network Check-In

Polling Question



How is patient education done within your facility?

- A. Chairside
- B. Monthly Meetings
- C. Huddle Boards
- D. PFR/Peer Mentors
- E. Not at all



Transplantation



Caroline Sanner, MSN, RN-BC, CPHQ
Assistant Director, Transplant Lead

Overview



- Patient application developed in 2023
- Educational tool for patient seeking transplant
 - Allows you to search, save, and compare transplant center
- Shows transplant centers across 13 states on the east coast and 5 states in the Pacific Northwest
- hundreds of dialysis provider and patient testimony on usefulness
- Won the 2024 AAKP Dominick Gentile Award in September!

Introducing... Kidney Transplant Compare
transplantcompare.org

Putting patients and family members in the driver's seat of their transplant journey

DOWNLOAD FOR IPHONE DOWNLOAD FOR ANDROID USE YOUR WEB BROWSER

Welcome to IPRO's Kidney Transplant Compare!

Navigate through the sections below to learn about kidney transplant, search and save transplant centers, and compare those transplant centers to find the best one for you!

- Learn About Kidney Transplant >
- Search and Save Transplant Facilities >
- Compare Saved Transplant Facilities >
- Facility Directory >
- Contact IPRO >

Choose the Best Transplant Center For YOU.

1. Learn the basics of kidney transplant and find FREE patient resources. Consider your life plan and decide if kidney transplant is the best treatment option for you.
2. Search, filter, and save transplant centers that you are interested in based on their location, patient selection criteria, support services, and results.
3. Compare the transplant centers you are interested in to choose the best option for you!

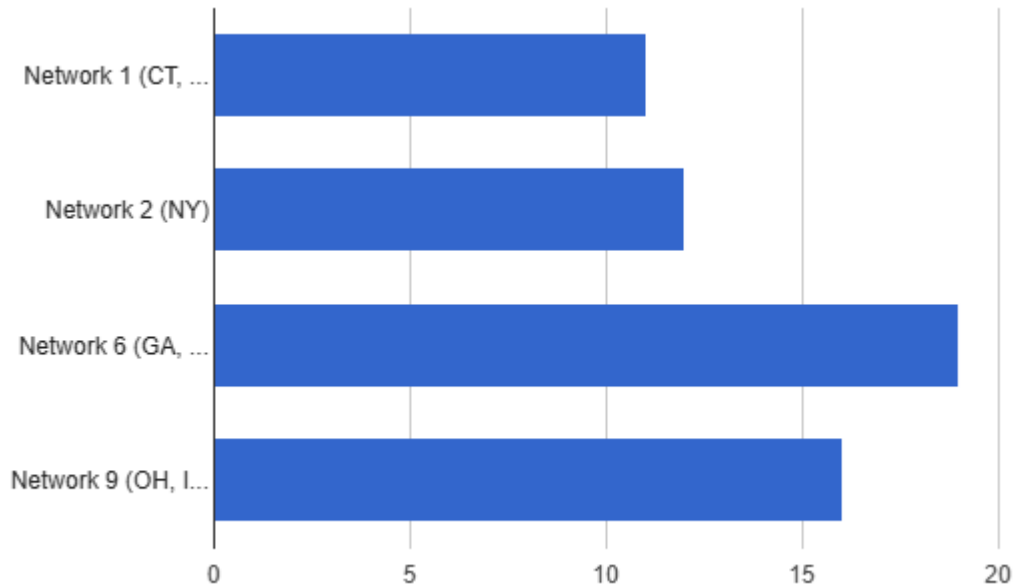
Use the camera on your mobile phone or tablet to scan this image code to learn more about Kidney Transplant Compare or visit esrd.ipro.org



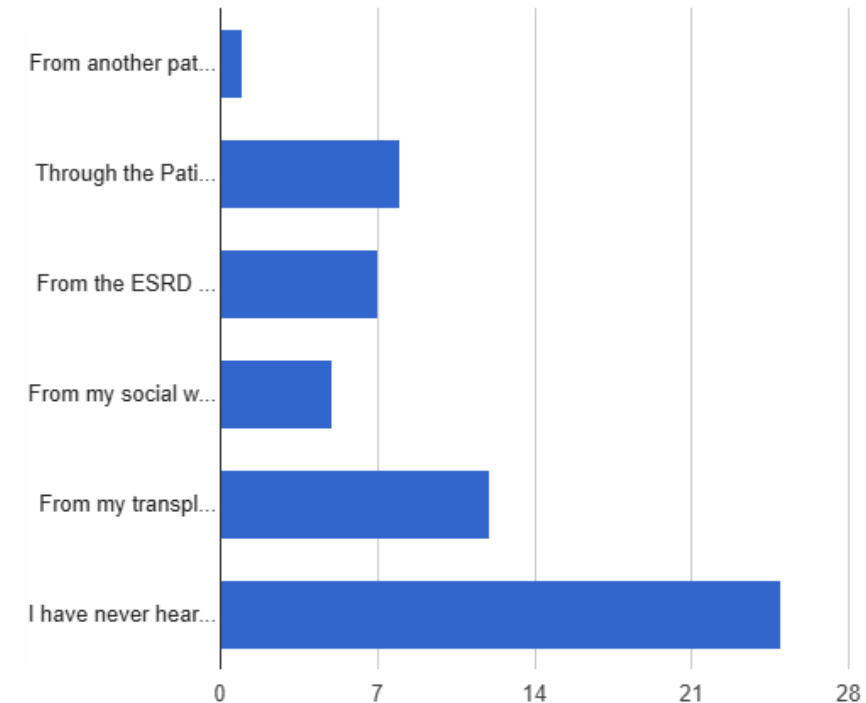
1 Year Anniversary Survey

- Survey sent out to dialysis providers, transplant centers, and the PFR Alliance

Respondents are from which Network:



Where did you hear about Kidney Transplant Compare?





Kidney Transplant Compare Demo



Kidney Transplant Compare

Important Links

- Patient Flyer: https://esrd.ipro.org/wp-content/uploads/2023/06/TranspCompare-Flyer-Patients_v5-508c-3.pdf
- Kidney Transplant Compare Desktop Application: <https://transplantcompare.org/home>
- Commercial Video: https://youtu.be/VpPyKJ_26o0?si=MP8cyyA2dngovAR-
- IPRO ESRD Website for Kidney Transplant Compare: <https://esrd.ipro.org/kidney-transplant-compare/>



Ohio River Valley Transplant Coalition

Looking for Patient Advocates!

To join:

- Email Csanner@ipro.org
- scan the QR code
- or go to <https://redcap.ipro.org/surveys/?s=ET8YAN9KXWHNNMPN>

Calling all dialysis staff, patients and kidney transplant professionals:

JOIN US!

- *Kidney Transplant*
- *Reducing Disparities*
- *Living Donation and more*



The graphic is a horizontal banner with a blue background and a yellow, teal, and orange striped border at the top and bottom. It contains text, a QR code, and a logo. The logo is a circular emblem with a blue border, containing a yellow map of the Ohio River Valley region with a stylized figure holding a kidney in the center. The text 'OHIO RIVER VALLEY' is at the top and 'TRANSPLANT COALITION' is at the bottom of the emblem.

Access to Care



Shezeena Andiappen, MSW
Patient Services Specialist

Network Check-In

Polling Question



Do you know what Access to Care means?

- Yes
- No
- Unsure



Access to Care

What does Access to Care means?



It refers to:

- Dialysis patients having permanent and stable access to their dialysis treatments with continuity of care from an interdisciplinary healthcare team.

Why is it important to preserve it?

- Dialysis is life-saving treatment for the ESRD community.
- Without an outpatient facility, patients are forced to dialyze emergently at the hospital removing regular continuity of care.
- Mortality rates are increased for patients without access to regular dialysis.
- Patients go to the hospital expecting immediate treatment or better care without knowing they will not receive dialysis unless their labs show elevated lab values.

Network Check-In

Polling Question



Do you think a facility can discharge a patient from their facility?

- Yes
- No
- Unsure



Can You Ever Be Discharged from Your Dialysis Clinic?

Reasons for discharge under Conditions for Coverage



End-Stage Renal Disease Network Program

Can You Ever Be Discharged from Your Dialysis Clinic?

Every person with End-Stage Renal disease (ESRD) has a right to life-sustaining dialysis treatments. However, Medicare outlines four situations that can cause a clinic to discharge someone.

Please be aware that if you are involuntarily discharged from a dialysis clinic, it can be very difficult for your current facility to find you placement elsewhere.

Other facilities have the right to review medical records and decide if they will accept or deny admission into their clinic.

1. Not paying for treatment when coverage is available
This is when someone qualifies for insurance, like Medicare or Medicaid, but chooses not to make the appropriate arrangements.

2. A medical need that the clinic cannot manage
On rare occasions, a patient's medical needs may be beyond the capabilities of the clinic—for example, a patient who needs a tracheostomy tube or a ventilator. If the dialysis clinic cannot meet a patient's medical needs, a member of the care team will contact the patient to discuss the issue and help find the right care setting.

3. Ongoing disruptive and abusive behavior in the clinic

- This is ongoing behavior that interferes with the clinic's ability to care for patients, despite repeat interventions and support from the clinical team.
- If a patient displays ongoing disruptive behavior, the clinic is required to notify the patient of the risk for discharge and will work with the patient to resolve the issue.
- If discharge is the only option, the clinic must contact the Network and give the patient a written and verbal notice 30 days prior to their last treatment. The clinic is responsible for helping the patient find another outpatient clinic.

continued on next page

Can You Ever Be Discharged from Your Dialysis Clinic?

continued

4. Immediate severe threat

If a patient makes a severe threat and/or acts on that threat by hurting anyone, the patient will be assessed, the police may be contacted, and the Network will be notified so an action plan can be created.

It's important you know your rights and your responsibilities as a patient. If you have any questions or concerns about your care, please reach out to the Network at **800-238-3773**. We're here to help!

For more information or to file a grievance, please contact us:
I PRO End-Stage Renal Disease Network Program
Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072
Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773
Email: esrdnetworkprogram@ipro.org • Web: esrd.ipro.org

This material was Developed by the I PRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic and the Ohio River Valley, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS.
Publication # ESRD.IPRO-G3-NW-20240308-280 4/12/2024 v:10 vb

[Can You Ever Be Discharged from Your Dialysis Clinic?](#)

Preventing Discharges

Effective Communication with Your Healthcare Team



- Be honest and transparent
- Express concerns calmly
- Be respectful
- Do not make any threats
- Take all measures to ensure your insurance coverage is active
- Seek community supportive services

Tools & Resources

Patients



- Patients Rights and Responsibilities: [Patient Guide](#)
- How IPRO Can Help: [English Spanish](#)
- Can You Ever be Discharged From a Facility? [Patient Handout](#)
- Emergency Medicaid Guide for Vulnerable Patients with ESRD: [Handout](#)
- Emergency Medicaid and Access to Care Flyer: [Network 1 | Network 2 | Network 6 | Network 9](#)

Tools & Resources

Providers



- Understanding Barriers to Dialysis Adherence: [Infographic](#)
- Before you Discharge Your Patient from EQRS: [Network Program](#)
- Patient Safety and Risk Solutions: [Guideline](#)
- Second Chance Trial Program Brochure: [Network Program](#)
- Second Chance Flier: [Network Program](#)
- Access to Care Management: [A Guide for Dialysis Facilities](#)
- Dialysis Facility Involuntary Discharge: [Guidelines](#)
- Decreasing Dialysis Patient-Provider Conflict (DPC): [Provider Manual](#) and [Addendum](#)
- Challenging Dialysis Placement: [A Comprehensive Guide](#)
- Emergency Medicaid Guide for Vulnerable Patients with ESRD: [Providers](#)
- Supporting Underserved and Undocumented Patients: [Providers](#)
- V-Tags and Patient Involuntary Discharge: [Federal Regulations](#)
- CMS Conditions for Coverage for ESRD Facilities: [Interpretive Guidance](#)

Access to Care: Traveling on Dialysis

What do you need to know



- Review and learn more about your facility travel policy. Do you need medical clearance for travel? How much notice does the facility require to make travel plans?
- Advance notice is necessary for proper planning and coordination especially during the holidays. Referrals may need to be made to multiple clinics.
- To begin planning for your trip, speak with your facility Social Worker. Some clinics has a specific Patient Travel Services team to assist with transient dialysis arrangements.
- Staff/patients can utilize [Find Healthcare Providers: Compare Care Near You | Medicare](#) to help locate a center near your destination.

Preparing for Travel

How to prepare for your trip once approved



Once you have the approval to travel from your care team, here are ways to prepare for your trip:

Medications: Make sure you have enough medicine for the entire trip. Keep them in your carry-on, as luggage may get lost, and bring a copy of the prescription with you, just in case.

Insurance: Check with your health insurance company to see if they cover the cost of dialysis while traveling.

Activities: Plan activities according to your abilities and allow for time to rest and recharge.

Fluid and diet restrictions: Pack or plan to buy healthy and nutritious meals, snacks, and drinks that follow all dietary recommendations from your doctor or kidney nutritionist.

Emergencies: Your personal doctor and the doctor at the local dialysis center should/will create a plan should you need to be admitted to a hospital while you are away from home.

Access to Care

Action Plan:



- Choose a resource that was shared in this presentation and share it with either patients or the facility team.

Next Steps



Aisha Edmondson
Patient and Family Engagement

Community Awareness Campaigns

November 12th is World Pneumonia Day!!!

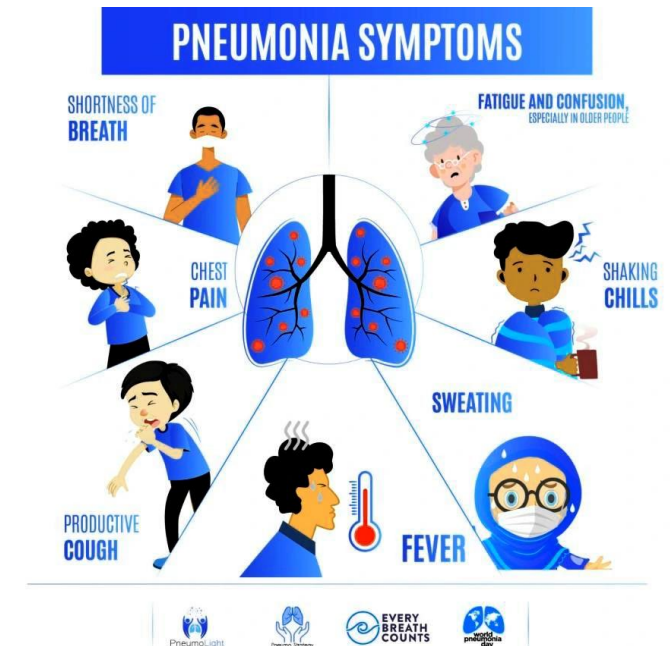


World Pneumonia Day is annually held on November 12 to raise awareness of pneumonia, promote prevention and treatment, and provide an annual forum for the world in the fight against pneumonia. The Theme of World Pneumonia Day 2024. Championing the fight to stop pneumonia will be the subject of World Pneumonia Day 2024.



Every breath counts.
Stop pneumonia now.
November 12th.

<http://www.worldpneumoniaday.org>





Next PRF Meeting - Mark Your Calendar!

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

- Upcoming Topics: Healthy Living- Nutritional ideas for Holiday Eating and Patient Services

- Things to Think About:

[AAKP Support Groups](#)



Social Media

Follow Us!



- [IPRO ESRD Network Program's Facebook Page](#)
- [IPRO ESRD Patient Facility Representative \(PFR\) Alliance Group](#)



- [IPRO ESRD Network Program's Twitter Page](#)



- [IPRO ESRD Network Program's LinkedIn Page](#)



- [IPRO ESRD Network Program's Instagram](#)

Questions? Comments?



Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

Aisha Edmondson
Project Manager: Patient and Family Engagement
Tel: 216-755-3056 | E-mail: aedmondson@ipro.org



**End-Stage Renal Disease
Network Program**

**IPRO End-Stage Renal Disease
Network Program Corporate Office:**
1979 Marcus Avenue, Lake Success, NY 11042-1072
Patient Toll-Free: (800) 238-3773 • **Main:** (516) 231-9767
E-mail: esrdnetworkprogram@ipro.org • **Web:** esrd.ipro.org

This material was prepared by the IPRO ESRD Network Program, comprising the ESRD Networks of New York, New England, the South Atlantic and the Ohio River Valley, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. Views expressed in this material do not necessarily reflect the official views or policy of CMS or HHS, and any reference to a specific product or entity herein does not constitute endorsement of that product or entity by CMS or HHS. Publication #