



End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

May 2nd, 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

Today's Agenda

Topics for Review/Discussion



Meeting Reminders

Awareness Campaign

PFR Check-In

Closing Remarks

Patient Spotlight



Meeting Reminders



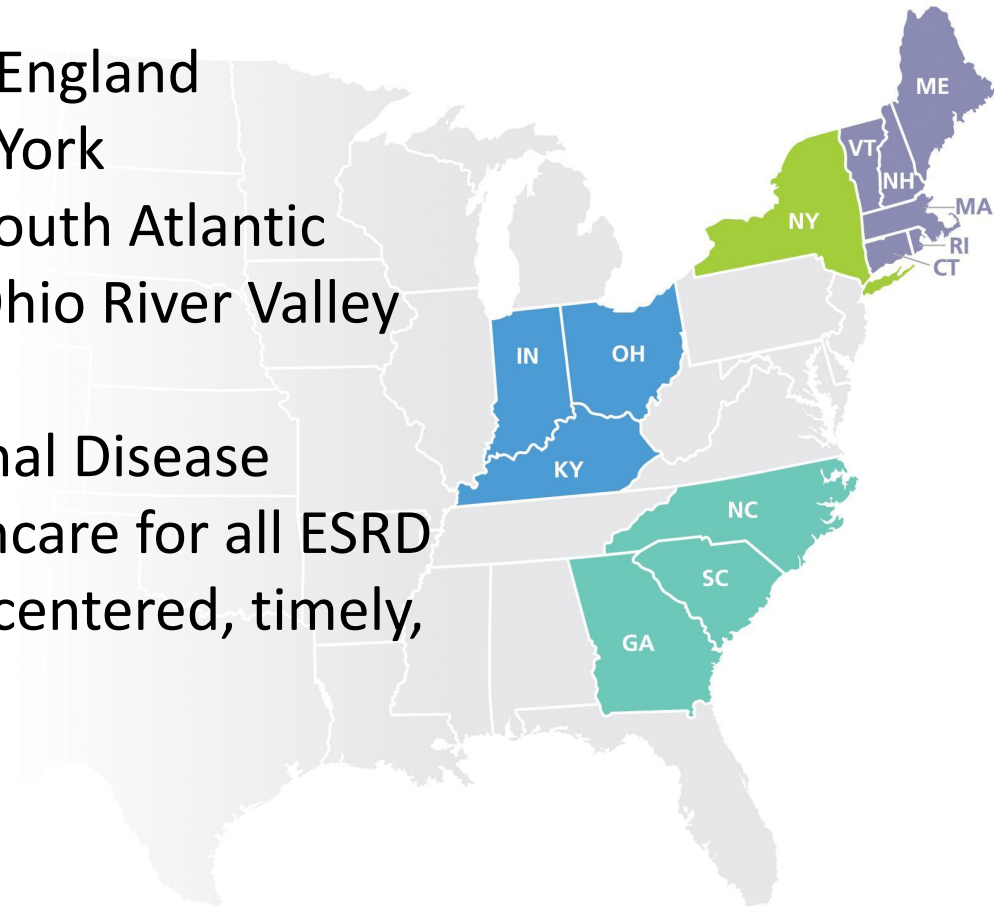
- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



IPRO ESRD Network Program



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



Welcome Our New PFRs!

- Erin Kinsella
- Hwatung Chiang
- Michelle Morris
- Michele Pecora
- Richard Gaines
- Leroy Reid





NPFE-LAN Members!

- Patient Safety Affinity Group
- Health Equity Committee
- Transplant AG Group
- Hospitalization Affinity Group
- Vaccinations AG Group

*Thank
you*

The Network's Role

What the Network's staff CAN and CANNOT do




Network staff CAN...

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

Network staff CANNOT...

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

The IPRO ESRD Network Program can help resolve many concerns you may have about the care you receive as a dialysis patient.



The mission of the IPRO End Stage Renal Disease (ESRD) Network Program is to promote health care for all ESRD patients that is safe, effective, efficient, patient-centered, timely, and equitable.

Network staff CAN...	
Advocate for patients' rights, depending on the situation.	~ Example: "My unit is too cold" With your permission, a Network staff member can contact your facility to find out if the temperature can be controlled.
Provide information and educational resources.	~ Example: "I need a fourth shift, and my facility does not offer one" The Network can provide you with a list of facilities in your area that offer a fourth shift (Dialysis Facility Compare tool available on 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.

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

Better healthcare, realized.

Developed by the IPRO ESRD Network Program while under contract with the Centers for Medicare & Medicaid Services. Contract # F31CMC1100029 Publication # ES01993.GA.MW.020209.3.014 v1.0/02/2022 IPRO, the End Stage Renal Disease Network Program, the Network of New England, Network of New York, Network of the South Atlantic, and Network of the Ohio River Valley, prepared the material under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. CMS Contract Number: F31CMC1100029. CMS Task Order Number: F31CMC1100029 (Network 1), F31CMC1100029 (Network 2), F31CMC1100029 (Network 3), F31CMC1100029 (Network 4), F31CMC1100029 (Network 5).

Network Check-In

Polling Question



Which Network are you from?

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



Network Check-In

Polling Question



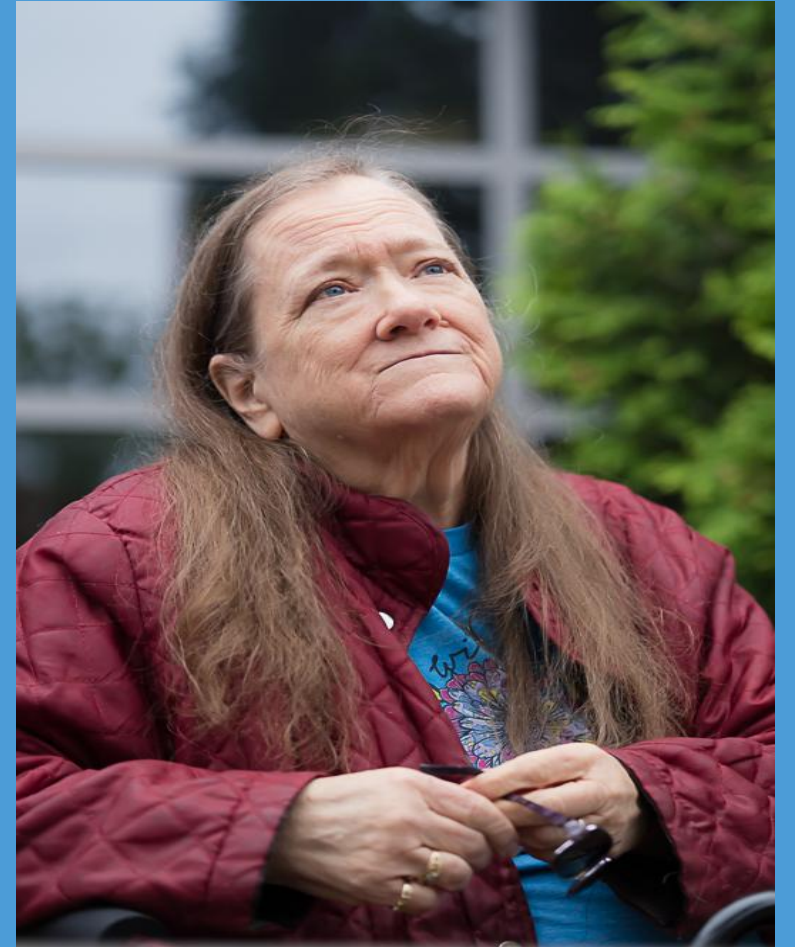
Are you interested in telling your story?

- Yes
- No
- Unsure



Patient Spotlight

My Story!



Sherrie Shivley
Patient Facility Rep NW1

The Beginning....



My story really starts back in 2011. I married a man who was blind, and on dialysis. Charlie had the same ailments that I had but they were much further progressed. He was on dialysis for 11 years and I went to treatments with him to help him with whatever was necessary. That was back when you could have someone sit with you in the center. We spent Tuesday, Thursday, and Saturday in the center for 4 hours. That was my indoctrination to dialysis and kidney disease. I was Charlie's caregiver. In 2015 Charlie got an infection in his foot that led to hyperbarics and lots of wound care (I did wound care for him at home and we went to a center every other day for hyperbarics and the doctor to look at the foot). We did all of this for almost a year but were not able to save it. In May of 2015, he had a below-the-knee amputation of his left foot. We dealt with recovery and rehabilitation and he did quite well. Then, in 2016 almost the identical situation with the right foot. We tried to save it with surgeries, and wound care, and nothing worked.

On March 17 he went into surgery for a second below-the-knee amputation. He wound up doing well during surgery but in recovery, he coded 3 times. They were able to bring him back but on the third time, he was in a coma. He did not wake from that and I had to disconnect him from life support. He stayed with us, in a coma for 12 days. On the 29th of March at noon we moved him to hospice. At 8:23 that night he passed.

My Life....



Charlie and I were very active as advocates for AKF and NKF. We also did tables at the local community college, and Charlie was also the PFR for his clinic. We had fun doing that together. We celebrated birthdays monthly, had cookouts at the clinic, and became family with all of the shifts at the clinic. We decorated the clinic for holidays and tried to keep people as happy as possible. Charlie and I also went to Washington with AKF to speak to senators and congresspeople.

A big part of me went with him. I knew that I had kidney disease and I knew that someday that could be me. I swore that night that no matter what I would NEVER do dialysis. I couldn't see having to be stuck on a machine 3 days a week. Not able to eat what I wanted, having to restrict my fluids, and not able to travel to see my grandchildren. There were just too many restrictions.

Fast forward to 2020. I moved from TX back to CT where my siblings are. I am a 63-year-old widow and a grandma of 15 amazing grandchildren. Only one of my grands lives in CT everyone else is in KS, TX, and SC. The one in CT lives with me. He is 3. The others range from 1 to 25 years of age.

My Life cont.....



In December of 2019, I started retaining fluid in my legs. The doctor put me on Lasix to try and get rid of it. It was not enough so he put me on an additional booster. I took it and at the beginning of January, I got sick. I thought I had the flu but it got so bad I was having trouble walking, my thought processes were cloudy and I was just wiped out. I finally had to call an ambulance. They came and I went to the ER. Turns out I had lost almost all of the potassium in my body. The doctor neglected to do bloodwork to monitor it. My kidneys failed. I spent 25 days in the hospital trying to remove fluid, that was predialysis. I finally got to the point where I knew we had to do something more. After many, many talks with the nephrology team, I finally agreed to do dialysis. surgery was done to create the fistula, a central line was put in and we started dialysis. I was not happy. I was blessed in that I did know a lot (almost too much). It was scary but I was okay. We did dialysis in the hospital for a week and then I went to a nursing home for rehab. My legs had lost their strength. It was hard but I was okay. I started dialysis at US Renal Care in North Haven, CT and have been there ever since.

My Work.....



I am the Patient Facility Rep there and as such I am trying to do things that will help the people in my clinic to be able to deal with dialysis and all of the "stuff" that comes with that. I am also trying to promote interaction between the different shifts and the different days. We are currently doing a monthly patient spotlight. I interview a different patient each month and write up an article about them and their story. We have a picture of them that accompanies the article and it is posted in the clinic.

The goal is to try and show that each of us has a story and hopefully, there will be something that will help inspire others to keep going. We all have a story and we are all stuck in the same boat. We need encouragement from people who understand where we are at.

We are also planning on spotlighting staff so that we all know who is who and perhaps see them more as regular people.

My Work cont.....



We participate every year in activities to celebrate Kidney Month in March. This year I had people from my clinic help me to do a Kidney Friendly Food Drive at a local grocery store on World Kidney Day. The Mayor of my city made a proclamation declaring March Kidney Month and also World Kidney Day, It was exciting.

We collected healthy food for a local food pantry, distributed information about kidney disease, and gave out ribbons. It was a great way to get others involved and educate the community. We have one woman who has become my ribbon maker. She lives in a residential living center and has people that she knows there helping her to make the ribbons so that we can use them for other functions. The food drive was successful and I have scheduled others. We gave out ribbons and a serving of jelly beans to everyone in our clinic. Last year we gave out jelly beans and inspirational bracelets. The year before someone hand-painted inspirational phrases on rocks and personalized each one with a patient's name on it.

My Work cont.....



In December each year, we have a small tabletop tree with small wooden ornaments placed on a table in the reception area. People can write the names of those who have passed during the year on ornaments and hang them on the tree. We usually do some kind of ornament each year for Christmas. It's always personalized with each patient's name and the year on it. This last year we put them all on the Christmas tree in the lobby and everyone could take it home. There were a lot of patients that chose to leave it on the tree.

Currently, I am working with the clinic to try and get US Renal Care to approve the form that allows us to be able to share information about what is going on with a patient. It's so hard when someone is missing and we all sit and wonder why. I usually start contacting hospitals and find them and get permission to share what's happening. In the interim, I now, as PFR, have a list of contact information so that I can call whoever is missing or a family member. We just want to be able to call or visit people who are in hospitals and let them know that we are all thinking of them.

My Work cont.....



I make sure to connect with every new patient that is at the clinic. I am a Monday, Wednesday, and Friday first-shift patient. I don't drive so I travel by way of the CT Paratransit system. I schedule my pick-up time so that I am available to see the second shift folks too. Each month I also choose a day or two and go in to visit with the Tuesday, Thursday, and Saturday folks so that they know who I am and that there is someone they can connect with who is in their corner.

In addition to being the PFR for my clinic, I am also on the KPAC, an advocate for AKF and NKF. I enjoy being able to educate the community and have a unique perspective because I have been the spouse/caregiver and know the frustrations of having that responsibility but now I am on the other side of that fence as a patient. I get it and I consider it a blessing to be able to use that to help other people who are dealing with kidney disease, dialysis, and all that goes along with it. I believe that God has given me all of this for a reason and feel obligated to share what I know with everyone that I can. I firmly believe that this is why I am here.

Network Check-In

Polling Question



Did you enjoy the patient spotlight?

- Yes
- No
- Unsure



Next Steps



Aisha Edmondson
Patient and Family Engagement

Community Awareness Campaigns

May is Mental Health Awareness Month!!



As Mental Health Awareness Month, May is a time to raise awareness of and reduce the stigma surrounding behavioral health issues, as well as highlighting the ways how mental illness can affect all of us – patients, providers, families, and our society at large.

Remind yourself that mental health can be as vital as physical health, and seeking help when needed is not a sign of weakness but a testament to strength



Community Awareness Campaigns

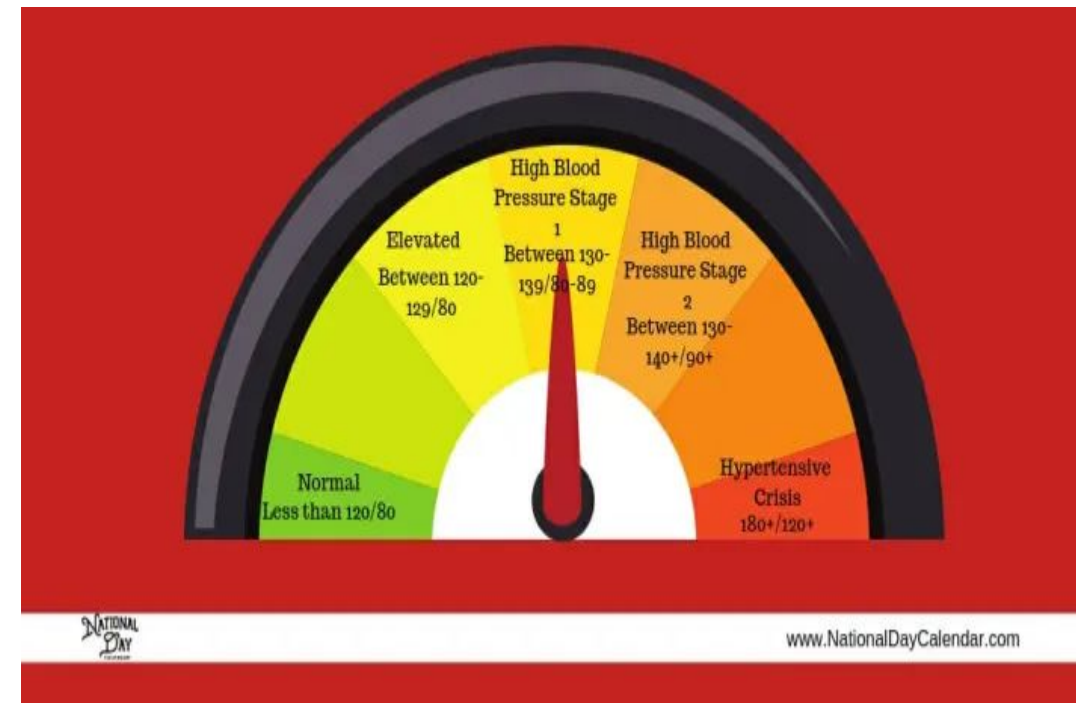
May is National High BP Education Month!!



National Blood Pressure Month in May provides awareness regarding hypertension. It's important to know your numbers and how to read them.

Centers for Disease Control and Prevention created National High Blood Pressure Education Month, and it is recognized by the National Heart, Lung and Blood Institute.

Use #BloodPressureEducationMonth to share on social media.





Next PRF Meeting - Mark Your Calendar!

Thursday, June 6th 2024 at 5:30pm ET

- Upcoming Topics: Patient Spotlights!

- Things to Think About: Social Media Content!

Please join us each month for an IPRO ESRD Network Program hosted **webinar for patients!**



Patient Facility Representative (PFR) Alliance Conference Call
First Thursday of Each Month • 5:30 PM–6:30 PM EST

Please join us in our informative monthly webinars hosted by the Network to help understand quality-of-care expectations for dialysis facilities.

Learn about new goals and priorities and how they will affect ESRD patient care.

Scan the QR Code to log onto the meeting!



Topics include:

- Patient and Family Engagement
- Emergency Preparedness
- Health Equity
- Behavioral Health
- Hospitalizations
- Healthy Lifestyles
- Transplant Coordination
- Home Therapies Utilization
- Peer Mentoring

Webinar Access: <https://tinyurl.com/PFRAllianceMeeting>

Meeting ID: 2426 823 7622

Toll-Free Dial-In: 1-855-797-9485

Password: IPROPFR

For more information, please contact the Network at 516-686-9790.

 To file a grievance, please contact us:
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
Data Management: (516) 268-6426 • Administration: (516) 686-9790
Support Portal: help.esrd.ipro.org/support/home • Website: esrd.ipro.org/

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



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

IPRO End-Stage Renal Disease Network Program

We're on the move...
Follow us to our new Facebook page.
<https://www.facebook.com/IPRO.ESRDNetworkPgm>

The graphic features a stylized truck with a blue cab and a white trailer. The trailer has a large white Facebook 'f' logo and a QR code. A cloud of smoke is coming out of the back of the truck, suggesting movement.

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:

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**End-Stage Renal Disease
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