



End-Stage Renal Disease  
Network Program

# Patient Facility Representative (PFR) Alliance Meeting

November 2nd, 2023

*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 Family Engagement**  
**Lead**

# Patient and Family Engagement Facilitators



**Stephanie Cole, BA, PSM, QP**  
**Community Outreach Specialist**



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



**Stephanie Roy, MPH**  
**Health Equity Specialist**

# 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



# New Members

## Welcome to the PFR!

- Nataki Batchelor
- Larry Miller
- Anne Waszmer
- Alfred Dawson
- Charles Baron
- Trina Venters
- Helton Briggs
- Jonna Corlett
- Douglas Lilly
- Kim Heiman
- Lisa Willard
- Melissa Watkins
- Renee Hightower
- Heather White
- Berta McCall
- Patrice Lagrande
- Angela Walker
- Karen Haynes
- Debra Tones
- Mary Martin
- William Cabiness
- Ildfonso Rodriguez
- Georgia Anderson



# A Special Thank You to Our NPFE-LAN Members!

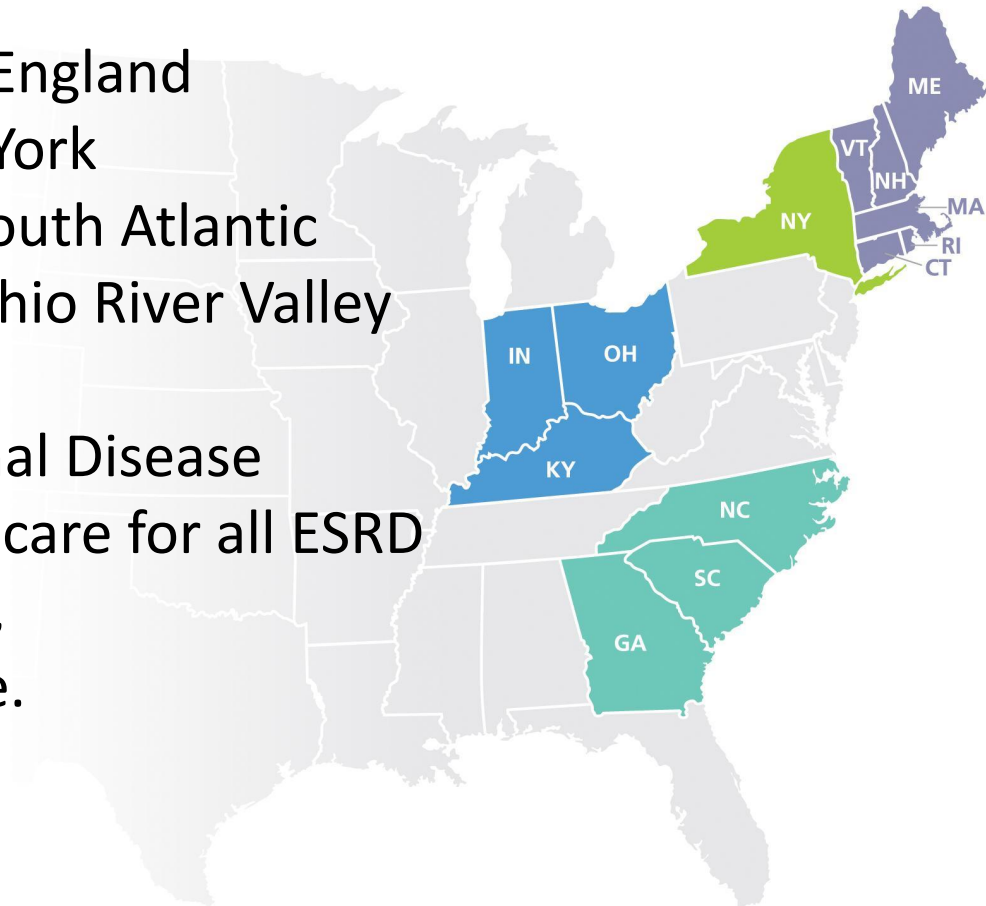
- Steven Cooper
- Niesha Neal
- Peggy Williams
- Philip Fisher
- Samantha Stark
- Angela Gray
- Jamie Smythe
- Ken Teasley
- Stephanie Dixon
- Gail Graham
- Michael Duckworth
- Kim Pratt
- Sherrie Shivley
- Laurie Pease
- Christine Richer
- Michael Zavarelli
- Stephen Radin
- Devon Jacobs
- Rhonda Dias
- Nealand Lewis
- Angel Brown
- Jamall Wimberly
- Nathan Hennigan

Thanks to all your hard work and cooperation, we accomplished 100% attendance rates for ALL FOUR Networks for the month of October!

# 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.





# 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)



# Patient Services Department Function

and

# Access to Care when Traveling during the Holidays



Shezeena Andiappen, MSW  
Patient Services Specialist

# Network Check-In

## Polling Question



**Do you understand the role of IPRO Patient Services Department?**

- Yes
- No
- Unsure



# National Initiatives

## Improve the Patient Experience of Care by Resolving Grievances and Access to Care Issues



- As required by the conditions for coverage, all patients must be educated on the grievance process and the various options when filing a grievance
- Clinics should display the Network "Speak Up!" poster in a common area that patients and visitors have access to (such as the unit lobby)

| ESRD Network of New England<br>(Network 1)   | ESRD Network of New York<br>(Network 2)   | ESRD Network of the South Atlantic<br>(Network 6)  | ESRD Network of the Ohio River Valley<br>(Network 9)   |
|--|---|--|--|
| <ul style="list-style-type: none"><li>• Connecticut: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• Maine: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• Massachusetts: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• New Hampshire: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• Rhode Island: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• Vermont: <a href="#">English</a>   <a href="#">Spanish</a></li></ul> | <ul style="list-style-type: none"><li>• New York: <a href="#">English</a>   <a href="#">Spanish</a></li></ul> | <ul style="list-style-type: none"><li>• Georgia: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• North Carolina: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• South Carolina: <a href="#">English</a>   <a href="#">Spanish</a></li></ul> | <ul style="list-style-type: none"><li>• Indiana: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• Kentucky: <a href="#">English</a>   <a href="#">Spanish</a></li><li>• Ohio: <a href="#">English</a>   <a href="#">Spanish</a></li></ul> |

# Grievance Process Guide

## How to file a Grievance



### **Step 1: Talk to Someone at Your Facility**

Ask to speak to someone at your facility with whom you feel comfortable sharing your concern. This might be your social worker, kidney doctor or the facility manager. (Talk to the staff about how a grievance can be filed anonymously at your facility.)

### **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.)

### **Step 3: Call Your State Agency**

Your state agency contact number should be posted in your dialysis facility lobby or you can ask the Network for the number to call. The state can address your grievance anonymously. Please let them know if that is what you prefer.

# 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"<br>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"<br>The Network can provide you with a list of facilities in your area that offer a fourth shift (Dialysis Facility Compare tool available on <a href="http://www.medicare.gov">www.medicare.gov</a> ) |
| Investigate concerns about issues related to quality of care.                               | ~ Example: "I am upset about the care I am receiving at my facility"<br>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"<br>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...

|  |  |
|--|--|
| <ul style="list-style-type: none"> <li>✘ Force a facility to accept a patient.</li> <li>✘ Close a dialysis facility.</li> <li>✘ Go onsite to investigate a facility's clinical procedures, witness interactions between staff and patients, or view a videotape of incidents (HIPAA violation).</li> <li>✘ Add a patient to the transplant list.</li> <li>✘ Recommend a lawyer and assist with a lawsuit.</li> </ul> | <ul style="list-style-type: none"> <li>✘ Get staff members fired or arrange for staff to have their pay docked.</li> <li>✘ Force a facility to change its admissions policy regarding catheters.</li> <li>✘ Verify Medicare coverage or give out Medicare cards.</li> <li>✘ Interfere with facility surveys.</li> <li>✘ Hide a patient's involuntary discharge (IVD) history.</li> </ul> |
|--|--|

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](mailto:esrdnetworkprogram@ipro.us) • **Web:** [esrd.ipro.org](http://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 # ES01IPRO-GA-MW-2022013-138 v4 10/2022 IPRO, the End Stage Renal Disease Network Program, the Network of New England, Network of New York, Network of the South Atlantic, and Network of the Ohio River Valley, prepared the material under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. CMS Contract Number: F31CMC1100029. CMS Task Order Number: F31CMC1100029 (Network 1), F31CMC1100029 (Network 2), F31CMC1100029 (Network 3), F31CMC1100029 (Network 4), F31CMC1100029 (Network 5)

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# Network Check-In

## Polling Question



**Are you planning on traveling for the holidays?**

- Yes
- No
- Unsure



# 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.



# Home Modality

## Home Hemodialysis (HHD) and Home Peritoneal Dialysis (PD)



- PD patients should consider shipping supplies ahead of time. HHD patients need to travel with their machines.
- If you travel by plane, ask the airline if you can bring your dialysis machines in your carry-on luggage.
- If you have a dialysis partner to help with your treatments, they will need to travel with you.
- If you stay at a hotel, call ahead to make sure it has the right kind of electrical outlet for your dialysis machine.
- Make a list of dialysis centers in the area in case you need help or lose any equipment during your trip.

# Clinical Documentation

## How would the new clinic know your information



Your travel-destination dialysis center needs to know as much about you as possible to appropriately care for you. Complete any paperwork that is required by the center. Keep a copy of your records with you at all times and have your home dialysis center also fax your records to the dialysis center you're visiting:

- The dates you need dialysis treatment
- Your name, address, etc.
- Medical history and recent physical exam reports
- Recent lab results
- Recent EKG
- Recent chest x-ray
- Your dialysis prescription and 3 to 5 recent treatment records
- Dialysis access type
- Special needs or dialysis requirements
- Information about your general health
- Insurance information
- Where you will be staying in the area
- A list of the medications you take during treatment and at home

# 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 medication for the entire trip. If flying, 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.

# Resources

## Traveling Tips, Education



- [Traveling while having kidney disease \(kidneyfund.org\)](https://www.kidneyfund.org)
- [Travel Tips: A Guide for Kidney Patients | National Kidney Foundation](#)
- [Travel while on dialysis? Absolutely—with preparation | American Kidney Fund](#)
- [Easy Ways to Eliminate the Stress of Traveling for Dialysis Patients – AAKP](#)

# What is Health Equity and How Can We Improve It?



**Stephanie Roy, MPH**  
Health Equity Specialist

# Network Check-In

## Polling Question



**Do you know the difference between health EQUALITY and health EQUITY?**

- Yes
- No
- Unsure



# What is Health Equity?

## Equality vs. Equity



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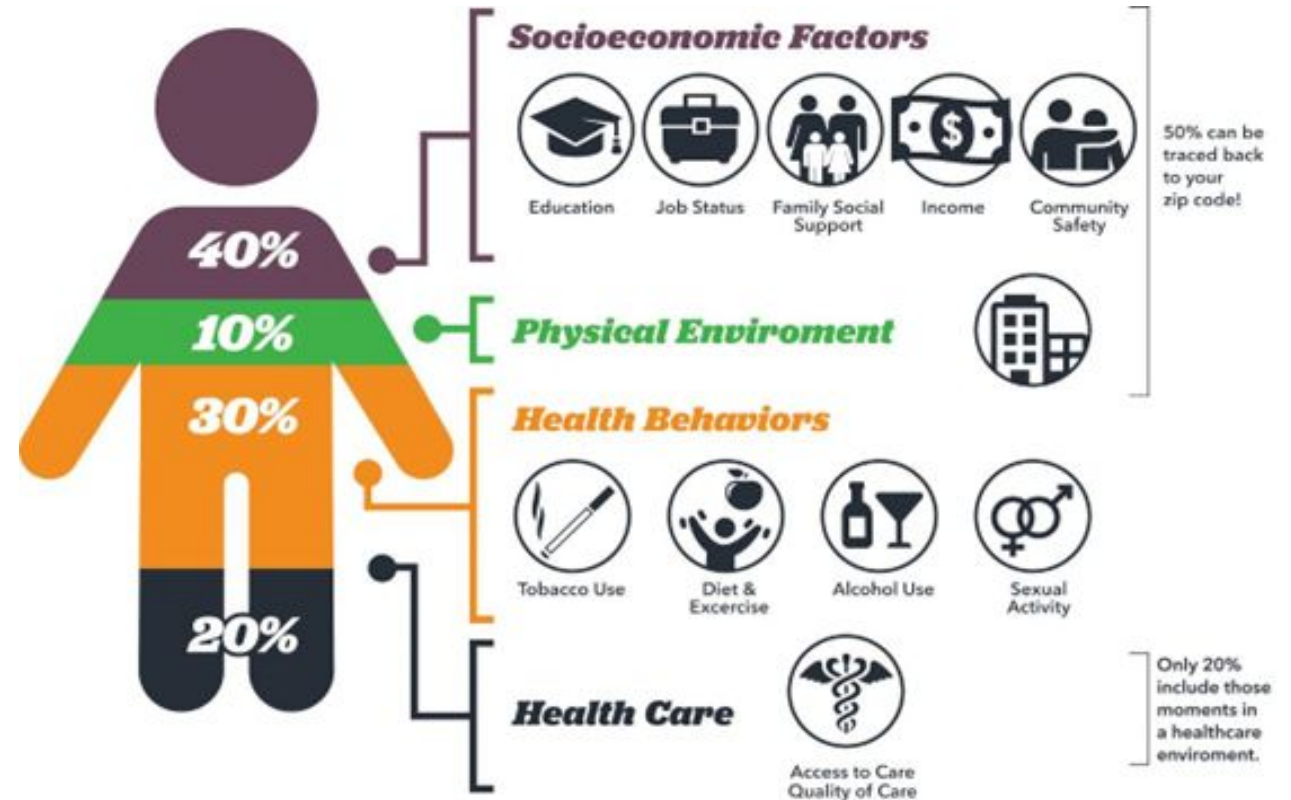
# What Influences Our Health?

## Social Determinants of Health



Aside from genetics, a person's health is influenced by:

- Socioeconomic factors
- Physical environment
- Health behaviors
- Health care



Source: Institute for Clinical Systems Improvement, Going Beyond Clinical Walls: Solving Complex Problems (October 2014)



# What is a Health Disparity?



A health disparity is a health difference that is closely linked to social, economic, or environmental disadvantage.

Health disparities include:

- Lack of access to care
- Uninsured/underinsured
- Language barriers
- Food insecurity
- Lack of peer support



# How can facilities address health disparities?



- Build awareness through education and training for facilities.
- Identify and understand the community and patient populations.
- Provide resources to reduce identified barriers.



# How can you help improve health equity?



- Complete demographic questionnaires at your doctor's appointments
- Inform your **doctor, nurse, or social worker** of your needs
  - Assistance with accessing food and understanding what foods are appropriate for your specific dietary needs
  - Necessary language services
  - Cultural and religious beliefs that may relate to medical decisions.
- Spread awareness about health disparities and equitable care



# Network Check-In

## Polling Question



### How has your facility addressed health disparities?

- Easy to understand health resources
- Language services
- My facility has not addressed identified health disparities
- Unsure



# Next Steps



**Aisha Edmondson**  
**Patient and Family Engagement**

# Next Steps



- **Follow** us on social media!
- **Join** the PFR Alliance Facebook Group <https://www.facebook.com/groups/ipropfralliance>
- **Create** your IPRO Learn Account <https://esrd.iprolearn.org/login/index.php/>
- **Participate** in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care - volunteers needed each month!
- **Become** a Peer Mentor:
  - Understand the steps <https://esrd.ipro.org/patients-family/pfe/peer-mentoring/>
  - Sign up to become a peer mentor!
  - Have questions?
- **Review** the Frequently Asked Questions resource <https://esrdncc.org/globalassets/peer-mentoring-operational-toolkit/14pmlmsfaq508.pdf>
- **Contact** Aisha Edmondson at (216)755-3056 or Stephanie Cole (919) 928-6042



# Next PRF Meeting - Mark Your Calendar!

Thursday, December 7th 2023 at 5:30pm ET

- Upcoming Topics: Communication & Healthy Living
- Things to Think About: Healthy Living and ESRD!

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:  
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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](http://help.esrd.ipro.org/support/home) • Website: [esrd.ipro.org/](http://esrd.ipro.org/)

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

# Community Awareness Campaigns

November is American Diabetes Month!!

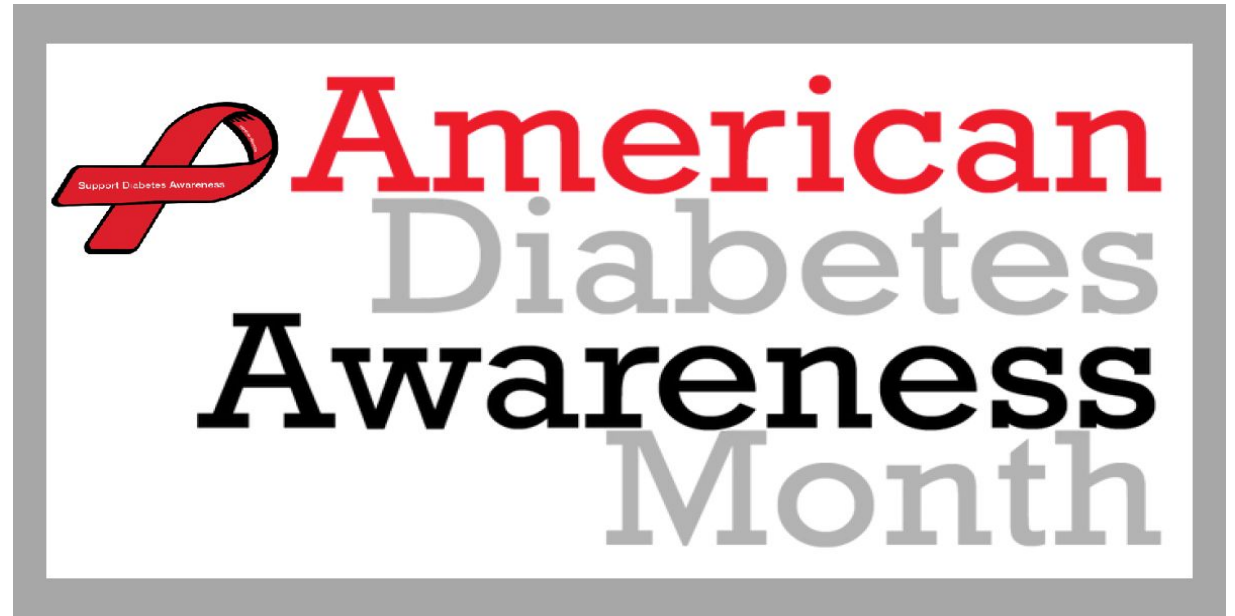


November is National Diabetes Month, a time when communities across the country seek to bring attention to diabetes. This year's focus is on taking action to prevent diabetes health problems.

Take Charge of Tomorrow: Preventing Diabetes Health Problems.

[Take Charge of Tomorrow](#) English

[Take Charge of Tomorrow](#) Spanish





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

**Stephanie Cole, BA, PSM, QP**  
Project Manager: Community Outreach Specialist  
Tel: (919) 928-6042 | E-mail: [scole@ipro.org](mailto:scole@ipro.org)



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