Patient Facility Representative (PFR) Alliance Meeting

April 4th 2024
Patient and Family Engagement Facilitators

Aisha Edmondson
Patient and Family Engagement Lead
Patient and Family Engagement Facilitators

Stephanie Cole, BA, PSM, QP
Community Outreach Specialist

Brooke Andrews, MSW
Patient Services Speaker

Caroline Sanner, MSN, RN-BC, CPHQ
Quality Improvement Speaker
Today’s Agenda
Topics for Review/Discussion

- Meeting Reminders
- PFR Check-In
- Quality Improvement Topic
- Patient Services Topic
- Closing Remarks
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
Welcome Our New PFRs!

- Tashawn Owens
- Michelle Morris
- JaKarta Bentley
- Lorita Washington
- Yolanda Arlee-Scott
- Keyon Bounds
- Brenda Paneto
- April Snell
- Karen Harvey
- Cinthia Velez
- Fitzroy Jackson
- Stephanie Taylor
- Lynnann Westhoff
- Portia Bibbs
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)
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.
Living Your Best Life on Dialysis!! Save the Date NW1

SAVE THE DATE
Living Your Best Life on Dialysis
You’re Invited to attend a FREE Kidney Patient Educational Event
Saturday, April 27, 2024 • 8:00 AM – 3:15 PM
La Quinta Inn Springfield 100 Congress Street, Springfield, MA 01104

The day will include:

- Patient presentations
- Expert Panels
- Modality educators whose goal is to support, educate, and help patients thrive—not just survive—with kidney disease
- We will address common misconceptions about dialysis treatment options, health equity, and patient concerns.
- Free food, fun, and giveaways for all registered guests.

All attendees and sponsors register here:
https://redcap.ipro.org/surveys/?s=LPPDHLY87M8YMX9

Presented by:

American Kidney Fund
Fighting on All Fronts

IPRO
End-Stage Renal Disease Network of New England

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Join us
Access to Care

Coping

Brooke Andrews, MSW
Patient Services Specialist
It’s Okay not to be Okay

The stages of grief

Denial  Anger  Bargaining  Depression  Acceptance

Reality
Network Check-In
Polling Question

Do you feel like you have healthy coping skills?

- Yes
- No
- Unsure
Open Discussion: How do you cope?
Coping Strategies

9 WAYS TO MANAGE STRESS

- Say Your Prayers
- Practice Yoga
- Spend Time in Nature
- Do Your Exercises
- Spend Time with Friends
- Manage Time
- Read Books
- Practice Art
- Think Positive
SELF-CARE VS. COPING SKILLS: HOW ARE THEY DIFFERENT?

**Self-Care**
- A preventative measure
- Acts attending to your emotional, mental, spiritual, & physical health
- Decrease extreme distress and burnout
- Can decrease the need for coping skills in the future

**Coping Skills**
- Used to get you through the tough times
- Activities or tactics you use when you’re in a stressful situation
- Strategies you can use when you need to buy a bit more energy or time, like hitting the “pause button” when stressed
Ask for support

• Clinic Social Worker or other staff members
• Clergy
• Friend
• Family
• Each other
Resources

- **American Association of Kidney Patients (AAKP) Community**: AAKP recognizes the value of local patient support groups. Through its website and various publications, the AAKP Community provides a centralized resource to locate ESRD support groups within patients’ communities.

- **Helparound Phone App**: Helparound assists chronic kidney disease patients and their support systems, overwhelmed by a life-changing condition, to simplify the day-to-day management of dialysis treatment. NxStage delivers information and support resources as needed, when needed, via smartphone.

- **Home Dialysis Central Forums**: Home Dialysis Central is an online discussion forum and a one-stop resource for patients and professionals who want to learn more about home dialysis options—what they are, where they can be found, and why someone might want to choose one over another. Patients, family members, and caregivers can get advice from experts or other members of the home dialysis community, or they can share their knowledge with others.

- **Nephkids Cyber-Support Group**: This resource is a cyber-support group for parents of children with CKD. It offers an interactive email group (listserve) for parents of children with many types of chronic kidney disease.

- **National Kidney Foundation (NKF) Peers Lending Support**: 1-855-653-7337 (1-855-NKF-PEER) This NKF website is specifically for new patients who need support and want to connect with peers who “have been there.”

- **Renal Support Network (RSN) HOPEline Peer Support**: 1.800.579.1970 The RSN website empowers people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future, and to make friends through informative, patient-directed programs.
Increasing Education and Access to Transplant

Caroline Sanner
Transplant Project Lead
What is my role?

I work to:

1. increase the number of patients who get added to the transplant waiting list
2. increase the number of patients who get a kidney transplant

How?

1. Work directly with transplant centers and dialysis facility staff to provide education, resources, and help to improve their approaches to waitlist/transplant
2. Work directly with patients (YOU!) to learn what challenges you face in getting waitlisted and transplanted
3. Take everything we learn and put forward actionable items to make an impact in the community
Network Check-In
Polling Question

Have you used Kidney Transplant Compare?
• Yes
• No
Network Check-In
Time to Unmute!

Please share your experience with Kidney Transplant Compare
Kidney Transplant Compare
Commercial

https://youtu.be/VpPyKJ_26o0?si=HRlDd_ta7oUyTaoX
Kidney Transplant Compare

41/48 Transplant Centers Represented (85%)

Patient and Provider Feedback

• Encourages multi listing
• Allowed patients to choose a center with a shorter wait time
• Reduces “trial and error” of finding a center that will accept patients of older age and higher body weight
Kidney Transplant Compare

Action Items

1. Talk about this tool with patients and providers at your facility

2. If your transplant center is not listed, connect with the Network to help advocate for that center to get involved!
Better Than Dialysis Kidneys
New Resource!

These kidneys may shorten your wait time!

a GREAT option for older patients!

EC/KDPI are fancy ways to explain the kidneys condition

Accepting any kidney is better than staying on dialysis!

https://files.constantcontact.com/3c70efff001/423e2d1f-f354-4d3c-ad8a-b888e10baba3.pdf
Network Check-In
Polling Question

Do you think education about Expanded Criteria (EC) or High Kidney Donor Profile Index (KDPI) Kidneys is too advanced for most patients at your facility?

- Yes
- No
- Unsure
Network Check-In
Time to Unmute!

Being knowledgeable about these kidneys and choosing to accept one of these kidneys is important for a patient's quality of life off of dialysis.

Share how you think we can work to inform more patients about Better Than Dialysis Kidneys?
How to Access Resources?

1. https://esrd.ipro.org/

Tools & Resources for Patients

A kidney transplant is a type of surgery where you (the recipient) gets a kidney that was donated by someone else. Transplantation can improve the quality of life and increased health compared to other treatment options. Below are tools and resources to help you access to kidney transplant. The resources are listed based on the Five Steps Towards Kidney Transplant.

FIVE STEPS TOWARDS TRANSPLANT

1. Interest in Transplantation
   - What is a Kidney Transplant: English | Spanish | Video
   - Get the Facts: Kidney Transplantation: English | Spanish
   - Do You Know Your Treatment Options Brochure: English | Spanish
   - How Much Does a Kidney Transplant Cost: English | Spanish
   - Planning for a Kidney Transplant: English | Spanish
   - Turning Negatives into Positives: Why transplant is a good idea for me! English | Spanish

   Patient Stories
   1. Your Life, Your Choice
   2. Motivational Patient Stories
   3. Is a Kidney Transplant Right for Me?

2. Referral to Transplant
   - How to Find a Transplant Center
   - Find a Transplant Center Today

Scroll Down
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](https://www.facebook.com/groups/ipropfralliance)
• **Create** your IPRO Learn Account [https://esrd.iprolearn.org/login/index.php/](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/](https://esrd.ipro.org/patients-family/pfe/peer-mentoring/)
  ○ Sign up to become a peer mentor!
  ○ Have questions?
• **Contact** Aisha Edmondson at (216)755-3056 or Stephanie Cole (919) 928-6042
https://www.facebook.com/IPRO.ESRDNetworkPgm
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
Next PRF Meeting - Mark Your Calendar!
Thursday, May 2nd 2024 at 5:30pm ET

• Upcoming Topics: Patient Spotlights!!!

• Things to Think About: How will you use the information shared on these calls?
Community Awareness Campaigns
National Donate Life Month!

April is National Donate Life Month!

April 6
Dress Up Your Pets

April 7
Make Blue & Green Treats

April 8
Thank Your Healthcare Heroes!

April 9
Write a Message of Hope

April 10
Donate Life Flag Raising Day

April 11
Create Donate Life Rocks

April 12
National Donate Life Blue & Green Day
Questions?
Comments?
Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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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 #