Patient Subject Matter Experts (PSMEs)
Semi-Annual Refresher Meeting

September 30, 2020
Patient and Family Engagement Program Team

Laura Rodriguez-Carbone, MPA, MPP
Community Outreach Coordinator

Danielle Andrews, MPH, GCPH
Community Outreach Coordinator

Jeanine Pilgrim, MPH, CHES, CPXP, CPHQ
Program Director
ROLL CALL

• Lines will be unmuted, one by one, as we call out your phone number.

• When you hear your phone number, please tell us your name and what state you live in.
Welcome/Introductions
Laura Rodriguez-Carbone
AGENDA

- Roll Call/Attendance
- Refresher on Roles and Responsibilities of PSMEs in Patient Community and Network Quality Activities
- Open Collaboration on Patient Educational Resources (see drafts in the packet)
  - Nutrition Tips for Avoiding Fluid Retention During COVID-19
  - Adjusting to Facility Changes During COVID-19
- Open Discussion: Patient Engagement in Facilities during COVID-19
- Brainstorm Ideas about tips on how to educate and support others during COVID-19 social distancing.
  - Ideas on a new virtual Jeopardy game for ESRD patients
  - Sharing of Helpful Resources to Pass Along to Patients
- Overview of To-Do list for next PSME Meeting: November 18, 2020
  - Patient Resource Poster
Meeting Reminders

- All phone lines are muted upon entry to eliminate background noise/distractions
- If you get disconnected, please don’t place the call on hold, instead disconnect your line and rejoin the call when able
- Be present and engaged in our topic presentations
- 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
What is the Network?

ESRD Network
Program Overview
Laura Rodriguez-Carbone
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.
ESRD Network Role/Responsibilities

- Contracted with Centers for Medicare & Medicaid Services (CMS)
- Liaison with Department of Health (DoH) and State Survey Agencies
- Lead Statewide Quality Improvement Activities (QIAs) to improve quality of care for ESRD patients (*Transplant Coordination, Home Therapies, Vocational Rehabilitation, Peer Mentoring, Infection Prevention, Vascular Access Planning*)
- Promote patient engagement, education, and patient experience of care
- Provide technical assistance, quality of care concerns, and grievance management for ESRD patients and providers
- Support emergency preparedness and disaster response
- Collaborate with Dialysis Facilities and Transplant Centers
- Support ESRD data systems and data collection, analysis and monitoring for improvement
What is the Patient Advisory Committee (PAC)?

PAC Overview
Danielle Andrews
Patient Advisory Committee (PAC)

The Patient Advisory Committee (PAC) provides an opportunity to patients, transplant recipients, and care partners for the purposes of lending perspective and assisting in the promotion of patient, family, and care partner engagement in ESRD care, as well as promoting positive relationships between patients, provider staff, ESRD stakeholders, and the Network.
Patient Advisory Committee (PAC) Structure

- **PAC Advisors**
  - Participates in local and national quality improvement projects
  - Serve as PSMEs
  - Coordinate social and educational functions to promote ESRD awareness
  - Provide insights on resources creation and development

- **PAC Representatives**
  - Participates in local and national quality improvement projects
  - Serve as PSMEs
  - Coordinate social and educational functions to promote ESRD awareness

- **PAC Members**
  - Active Health Care Team Member
  - Continuously learning about renal disease
  - Attends Network Hosted webinars and educational sessions
Role of a PSME

- Provide input into the development of informational or education materials for patients and families and caregivers
- Participate in the Network’s quality improvement projects
- Participate in national quality improvement projects
  - PFE LAN Calls
  - NCC Affinity Groups
- Participate in monthly phone calls with the Network to provide feedback on patient’s needs
- Peer Mentoring
- Coordinate social and educational events to increase awareness of ESRD
  - Lobby Days
  - Annual ESRD Luncheon
  - CKD Champions Thrive Event
Network engages in Quality Improvement Activities:

• To ensure the highest level of care
• Ensures that your dialysis facility is meeting all state and federal regulations.
• Conducts Quality Improvement Activities in the following quality measures:
  • Infection Prevention
  • Vascular Access Planning
  • Transplant Coordination
  • Promotion of Home Therapy
  • Vocational Rehabilitation/Peer Mentoring
PSMEs’ Role in QIA Projects

- Offers a patient perspective during Network QIAs presentations and huddles
- Offers a patient perspective to the Network during the development of interventions and resources
- Provides patient education and work with their facilities in the QAPI meetings to promote best practice strategies
- Assists in Network educational resource creation
- Becomes an ambassador for your QIA project
  - Actively engage with your ESRD peers and promote and dispense your QIA project materials and resources
  - Ex: Infection Prevention: Access Ambassadors; their roles are to provide education to patients on the disadvantages and advantages on catheters in comparison to fistulas.
Each year, the NPFE-LAN holds four separate groups, called Affinity Groups, focused on specific areas of dialysis and transplant care. The groups meet monthly by webinar (phone and/or computer) to share experiences and discuss ways to improve the quality of care for kidney patients and meet the Centers for Medicare & Medicaid Services (CMS) quality improvement goals.

- Five PSMEs from each Network are nominated to work collaboratively with the NCC
- Attendance is mandatory with the exception of illness and home life stressors
Each month, the each Network meets with our CMS COR to provide updates on the Network’s collaborative efforts with the PSMEs and the PAC.

- If asked each PSME will provide:
  - Feedback on issues that are prominent within their Dialysis facility and the ESRD Community
  - Discuss the work that the PSMEs are working on outside of the Network
  - Discuss the collaborative work being conducted with the PSMEs and The Network, as well as ongoing PAC Activities
The Affinity Groups meets monthly to discuss:
- Patient’s perspectives on the national issues pertaining to dialysis
- Patient’s feedback on ESRD NCC Resources and videos
- National discussions on the following topics:
  - Bloodstream Infections (BSI)
  - Home Therapy
  - Transplant
  - Patient Selected Topic
Questions or Comments?
Virtual Patient/Family Engagement During COVID-19 Pandemic

Laura Rodriguez-Carbone
Patient to Patient Engagement Reminders

- We are encouraging patients to limit the use of person-to-person engagement in favor of virtual, or passive, engagement to keep them safe.
- We are encouraging patients to consider Home Dialysis Modalities (Healthy at Home)
- We are encouraging patients to interact with each other virtually through the telephone, at a safe social distance while wearing a mask, and/or on social media.
Peer Mentoring

Within the first 6 months, PAC Representatives must complete the Peer Mentoring online course.

https://esrdlms.ipro.org
Mentoring to Support Choices

Module 1: Approximate Duration: 41 minutes

Mentoring to Support Choices

When your kidneys stop working there are many choices to make. As a patient, being involved in making those choices is the number one way that you can live a better life. Your role as a peer mentor is to inform patients and help them better understand some of the important choices they will have to make.

To download or print any resources covered in the training modules, please visit your Network's website for additional information.

Network 2 (New York)
Network 6 (North Carolina, South Carolina, Georgia)

*This module is required.*
Resources to Share With Other Patients

Know Your Network

- Helps Patients Learn more about the IPRO End Stage Renal Disease Network Program and its services.
- Contains contact info for each Network Program and information on the PAC, technical assistance and grievances.
Resources to Share With Other Patients

Patient Advisory Committee Manual

- Encourages Patients to learn more about the IPRO Patient Advisory Committee
- Informs patients about volunteer opportunities, roles and responsibilities
- Encourages patients to get involved!
Peer Mentor User Guide - E-University and Alternative Approaches Tips

- Have YOU signed up to be a Peer Mentor?
- IPRO End Stage Renal Disease Network Program E-University is an online learning system that provides ESRD training for patients and professionals that align with the ESRD Network and CMS quality improvement goals. Once you have created a user account, go to https://esrdlms.ipro.org to take training courses, download supporting materials, and obtain a certificate of completion. Visit the website at https://esrdlms.ipro.org to get started.
- Once you have created a user account, go to https://esrdlms.ipro.org to take training courses, download supporting materials, and obtain a certificate of completion. Visit the website at https://esrdlms.ipro.org to get started.
- Course Topics Include: Mentoring to Support Choices, Talking Effectively With Other Patients, Discussing Home Dialysis as an Option, etc.
- Tips for alternative methods to in person mentoring (online and telephone options)

Alternative Approaches to Peer Mentoring

Virtual Options During COVID-19 Pandemic

As the COVID-19 pandemic continues, direct face-to-face peer mentoring has become more challenging due to state regulations and the need for social distancing.

The good news is that there are other ways to stay connected with your peers.

Consider using some of these alternative methods:

- Direct phone calls
- Secure conference calls
- Social media
  - (e.g., Facebook, Twitter, Instagram, LinkedIn)
- Private online discussion boards
- Video calls and messaging
- Emailing
- Web conferencing

To help you make these connections, these are some examples of online (virtual meeting) tools to consider:

- Zoom: https://zoom.us
- Google Hangouts: https://hangouts.google.com
- Skype: https://www.skype.com
- WhatsApp: https://www.whatsapp.com
- Facebook Groups: https://www.facebook.com

IMPORTANT: Although the above tools are free, some will require you to create an account and download an app. Always read the User Agreement Policy carefully for any chosen tool.

To use these online platforms, here are some equipment and resources you might need:

- Internet service (at home and/or through your phone service provider)
- Mobile phone, tablet, and/or computer
- Built-in camera (included with most smartphones and some computers)
- Headset/microphone
- An active account on the platform of choice
- A downloaded program or app for the platform of choice

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# Resources to Share With Other Patients

## Your Roadmap to SMART Goals

- Great first resource to share with Mentees (or any patient)!
- Encourages patients to take charge of their life on dialysis and help them map out their path to success.
Resources to Share With Other Patients

Patient Rights and Responsibilities

- Overview of Rights and Responsibilities as an ESRD Patients (7 page booklet).
- Right to Information and Quality Care, Individual Treatment, Services Without Discrimination, Emergency Care and Dietary Counseling, Filling a Grievance, etc.
Questions or Comments?
Resource Development

Danielle Andrews
Resources

- Adjusting to Changes in Dialysis Facilities Due to COVID-19 Pandemic
- Nutrition Tips for Avoiding Fluid Retention During COVID-19 Pandemic

Upcoming Resources for November Meeting
- Virtual Jeopardy Educational Game
- Door/Window Poster - Kidney Disease Patient Lives Here - COVID Precautions/Reminders
Questions or Comments?
Closing Remarks/Next Steps

Danielle Andrews
Next Steps

● Complete Post-Event Evaluation – we value your feedback!
● Look out for NEW PSME Newsletter: Patient Voice-Expert Thoughts
● Follow Us on Social Media:
  ○ https://www.facebook.com/groups/1PROESRDPAC
  ○ https://www.facebook.com/ESRDNetwork1
  ○ https://www.facebook.com/ESRDNetwork2
  ○ https://www.facebook.com/NW6ESRD
  ○ https://www.facebook.com/ESRDNetwork9
  ○ https://twitter.com/IPROESRDNnetwork
● Visit the Network Peer Mentoring Training https://esrdlms.ipro.org
● Check out Network Program Website https://esrd.ipro.org/
● Review Network Educational Resource Library – think of ways to share and spread in your community, we need your help!
● Save-the-Date! Next Meeting: November 18, 2020
Upcoming Meetings

- **ESRD NCC: Receiving a Kidney Transplant During COVID-19**
  - Tuesday, October 6, 2020 at 4:00 PM to 5:00 PM ET
  - The presenters will:
    - Share a patient's perspective for receiving a kidney transplant during the COVID-19 pandemic
    - Discuss a transplant center's procedures during COVID-19
    - Help patients understand how to prepare for a kidney transplant during COVID-19
  - Registration Link: https://hsagonline.webex.com/hsagonline/onstage/g.php?MTID=e0fe0e4127438a6244aa4f56a2f1f2888

- NPFE Affinity Groups
Next Steps: Follow Us On Facebook

Help Us Reach our Goal of 100 Patient Group Members!
Follow us on Facebook at: facebook.com/groups/IPROESRDPAC
➔ Get Up to the Minute Info on Meetings, Resources and Connect with Other Patients between Meetings!
COVID-19 PATIENT RESOURCES

The ESRD Network Program has many resources relevant to COVID-19 including information on telemedicine and telehealth, mental health, and general COVID-19 resources. We update these pages frequently to provide you with the most accurate and up-to-date information as possible.

PATIENT ADVISORY COMMITTEE (PAC)

The Patient Advisory Committee (PAC) provides an opportunity for patients, transplant recipients, and care partners to lend their perspective and assist us in the promotion of patient, family, and care partner engagement in ESRD care, as well as promoting positive relationships between patients, provider staff, ESRD stakeholders, and the Network.

Learn More About the PAC

The PAC consists of three separate levels of involvement:

- **Members**
- **Representatives**
- **Champions**

Once a patient becomes involved in the PAC, a patient may also be considered to serve as a Subject Matter Expert (SME). SMEs are individuals who are able to devote more time each month to be involved in planning quality improvement activities with the Network and other federal agencies participating in national conference calls.

MEMBER LEVEL

Members at this level:

- Educate themselves on kidney disease and ways to be a healthier patient living with ESRD
- Become more empowered by being an active participant with their personal care team
- Learn more about patient advocacy and the Network quality improvement activities

END-STATE RENAL DISEASE NETWORK PROGRAM

PATIENT SUBJECT MATTER EXPERTS (PSMEs)

The IPRO ESRD Network Program works with committed and informed patients who advise and assist in promoting quality of care for their fellow patients. These patients serve as Subject Matter Experts (SMEs) and assist the network in developing patient-oriented projects to enhance the development of our Network activities at the state and national level.

Roles of a Patient Subject Matter Expert (PSME)

PSMEs are individuals who are able to devote more of their time to the Network to be involved in the planning of quality improvement activities and other state and federal agencies.

The roles of a PSME include:

- Participating in conference calls
- Reviewing and developing educational materials
- Planning for educational events including webinars, meetings, and conference calls
- Evaluating project interventions
- Sharing ideas and concerns to enhance learning for all

Upcoming Meeting Information

**NEXT MEETING:**

September 30, 2020, at 5:00 - 6:30 pm ET

Please note, we are actively seeking all PSMEs interested in this event and join the meeting on a computer or by using their smartphone. This will have a live audience. We will also be asking details of patient educational outreach.
Thank You!

Laura Rodriguez-Carbone, MPA, MPP  
Community Outreach Coordinator  
ESRD Network Program (Networks 1 & 9)  
Tel: (216) 755-3056 | E-mail: Laura.Rodriguez-Carbone@ipro.us

Danielle Andrews, MPH, GCPH  
Community Outreach Coordinator  
ESRD Network Program (Networks 2 & 6)  
Tel: (516) 209-5549 | E-mail: Danielle.Andrews@ipro.us

Jeanine Pilgrim, MPH, CHES, CPXP, CPHQ  
Program Director  
ESRD Network Program (Entire Program/All Networks)  
Tel: (516) 209-5365 | E-mail: Jeanine.Pilgrim@ipro.us