

End-Stage Renal Disease Network Program



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







Better healthcare, realized.

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?

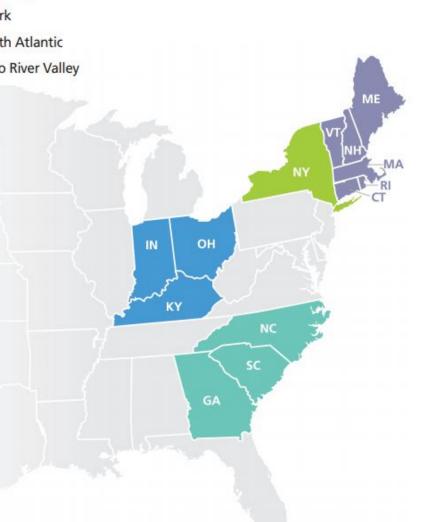
ESRD Network Program Overview Laura Rodriguez-Carbone



Mission Statement

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)

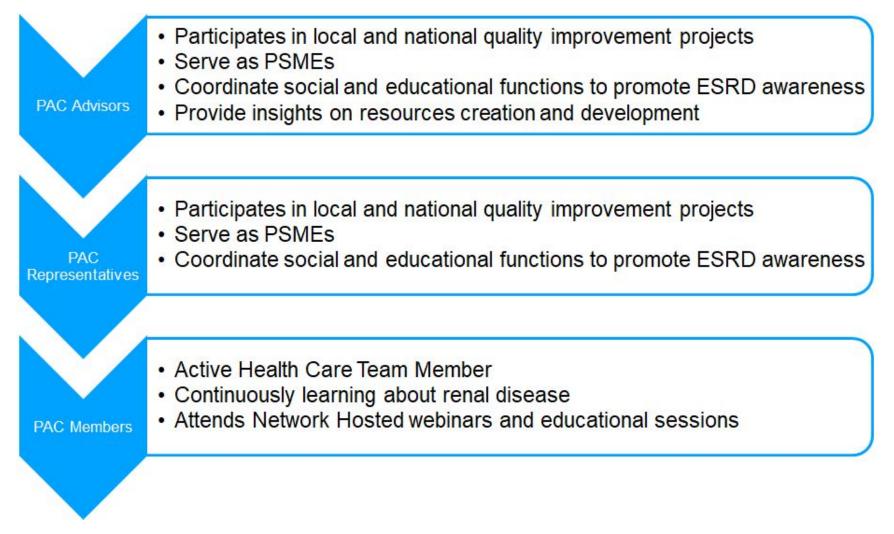


The Patient Advisory Committee (PAC) provides and opportunity to patients, transplant recipients and care partners for the purposes of lending perspective and assisting in the promotion of patient, family and care partner engagement in ESRD care, as well as promoting positive relationships between patients,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



Patient Advisory Committee (PAC) Structure





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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.

Role of a PSME and NCC NPFE LAN & Affinity Groups



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

Role of a PSME and the CMS COR Call



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

Role of a PSME and the NCC NPFE Affinity Groups



- 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?





NCC NPFE LAN AFFINITY GROUP REPORT-OUT





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.



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Peer Mentoring

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Within the first 6 months, PAC Representatives must complete the Peer Mentoring online course. <u>https://esrdlms.ipro.org</u>

Welcome to IPRO ESRD Network Program E-University

This site provides End Stage Renal Disease training opportunities for patients and professionals that align with the ESRD Network and CNIS-guality improvement goes. Once you have consider a user account through the Log Is link, you will be able to access and take training courses, di obtain a certificate of completion.

If you require assistance, create a support toket here. Mp Jhelp and gos org/support/home, select 'New support toket', or "Submit". Please reference 6-Delveraby in the subject line of the form.



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What is E-University?

End-Stage Renal Disease

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E-University Reference Guid

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Each person should create their own unique account. Facility staff may assist patients with registering for their own personal account, however sharing user account information is strongly discouraged. 1. Cick "Register" from the login screen.

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	in the Medicare database.)		

V.3. N/3J/30283 University Reference Guile Page

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)

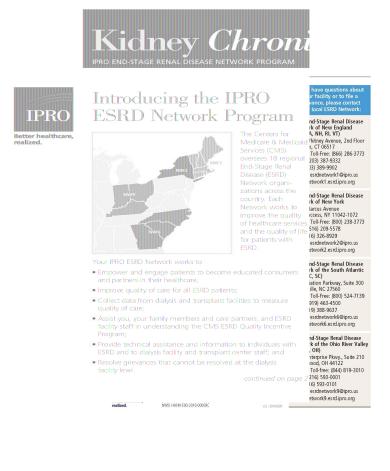
Network 6 (North Carolina, South Carolina, Georgia)

*This module is required.

TAKE THIS COURSE

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Ex





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.



IPRO End-Stage Renal Disease Network Program Patient Advisory Committee nee End-Stage Renal Disease esrd.ipro.org Network Program

IPRO

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!

continued on next page



End-Stage Renal Disease Network Program

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What is E-University?

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. One you have created a user account, you will <u>https://ecadims.ipro.org</u>e able to take training course, download supporting materials, and obtain a certificate of completion. Visit the website a <u>https://ecadims.ipro.org</u> patients.

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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 to become an official Peer Mentor.
- Once you have created a user account, go to <u>https://esrdlms.ipro.org</u> 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)





This material was prepared by the IPRO ESRD Network Program, under contrad with the Centers for Medicare & Medicard Services (CMS), an agency cittle U.S. Department of Health and Human Services. The contents presented do not necessary netect CMS policy. CMS Contract Numbers: HHSM-500-2016.00019C, HHSM-500-2016-00000C, HHSM-500-2016-00000C, 2016-00000C, 2016-0000C, 2016-000C, 20

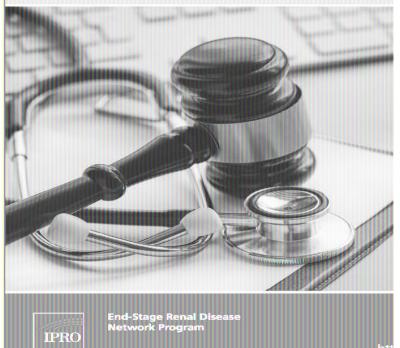
Your Roadmap to SMART Goals

- 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.



IPRO End-Stage Renal Disease Network

Your Rights and Responsibilitie as an ESRD Patient



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, Flling a Grievance, etc.

Questions or Comments?





Resource Development

Danielle Andrews







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

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:
 - o <u>https://www.facebook.com/groups/IPROESRDPAC</u>
 - o <u>https://www.facebook.com/ESRDNetwork1</u>
 - <u>https://www.facebook.com/ESRDNetwork2</u>
 - o <u>https://www.facebook.com/NW6ESRD</u>
 - o <u>https://www.facebook.com/ESRDNetwork9</u>
 - <u>https://twitter.com/IPROESRDNetwork</u>
 - Visit the Network Peer Mentoring Training https://esrdlms.ipro.org
- Check out Network Program Website <u>https://esrd.ipro.org/</u>
- 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

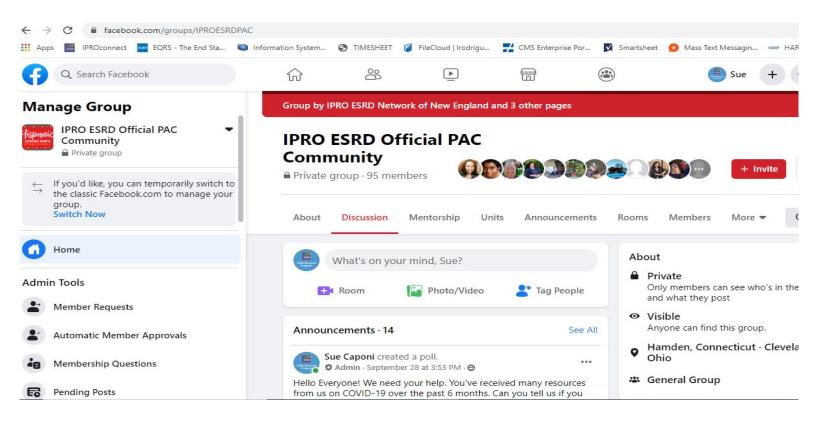
Upcoming Meetings



• ESRD NCC: Receiving a Kidney Transplant During COVID-19

- O 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: <u>facebook.com/groups/IPROESRDPAC</u>

→ Get Up to the Minute Info on Meetings, Resources and Connect with Other Patients between Meetings!

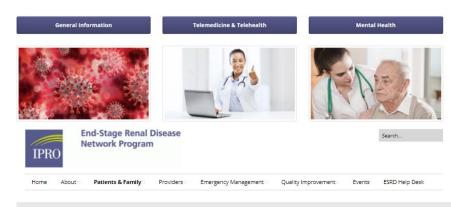
End-Stage Renal Disease	
Network Program	

Home About Patients & Family

Providers D Emergency Management D Quality Improvement D

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
- Chairpersons

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



Search.

ESRD Help Desk

Events

If you have questions or want to get involved, please contact the Patient Services Department for your Network:

Contact Us

PAST MEETINGS

August 2020: Presentation



End-Stage Renal Disease Network Program

Home About Patients & Family

Providers Emergency Management Events ESRD Help Desk

Quality Improvement

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-centered 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 asking that all PSMEs register for this event and/or join the meeting on a computer or by using their smartphone. This will assist us with taking attendance. We will also be editing drafts of patient educational



Network Program

PAC Matters CONNECTING THE COMMUNITY





End-Stage Renal Disease Network Program

esrd.ipro.org



Patient Voice: Expert Thoughts

INSIGHTS FROM PATIENT SUBJECT MATTER EXPERTS (PSMEs)



If you have questions or need assistance, please contact us:

Laura Rodriguez-Carbone, MPA Community Outreach Coordinator J Main Line: 216-755-3056 Iaura.rodriguez-carbone@ipro.us

Danielle Andrews, MPH, GCPH Community Outreach Coordinator J Main Line: 516-209-5549 danielle.andrews@ipro.us

esrd.ipro.org

Thank You!

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

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



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http://ipro.org