

### End-Stage Renal Disease Network Program



# Patient Advisory Committee (PAC) Semi-Annual Refresher Meeting

August 26, 2020

# **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.



# Patient and Family Engagement Program Team







Laura Rodriguez-Carbone,
MPA, MPP
Community Outreach
Coordinator

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Program Director

# **TODAY'S AGENDA**













# 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
Danielle Andrews



### **Mission Statement**



The IPRO End Stage Renal Disease Network Program includes four ESRD Networks:

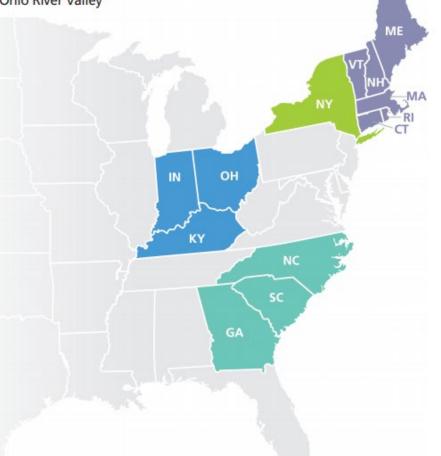
Network 1: ESRD Network of New England

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's New?

**New Program Approach** 

Laura Rodriguez-Carbone



### **COVID-19 BRINGS NEW OPPORTUNITIES** AND CHANGES TO PATIENT ENGAGEMENT

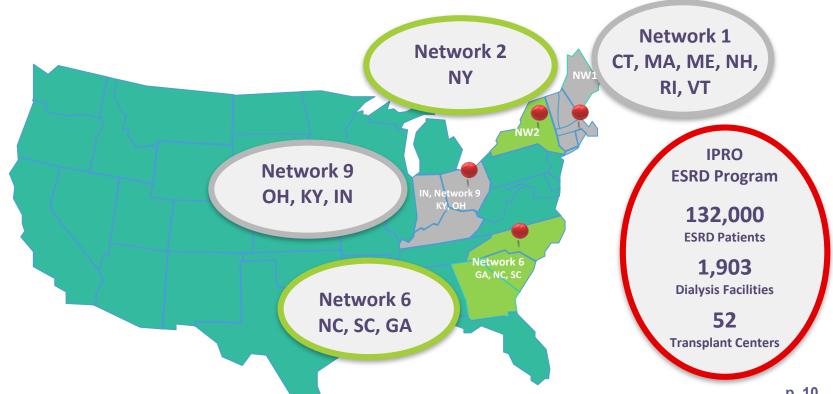


### **BEFORE**

The Network had four Patient Advisory Committees and four Patient Subject Matter Expert Groups - one for each Network.

### **NOW**

The Network has combined all patient groups for Network's 1 and 9 & Network's 2 and 6



# COVID-19 BRINGS NEW OPPORTUNITIES AND CHANGES TO PAC/PSME MEETINGS



### **BEFORE**

Patient Advisory Committee and PSME meeting times differed by Network – sometimes they happened quarterly, bi-monthly, or monthly.

### **NOW**

All PAC Meetings and PSME Meetings will be combined and occur bi-monthly (on opposite months)

### **BEFORE**

Patient Advisory Committee
Members and PSME's would
receive slides and resources either
before or after the meeting,
depending on which Network they
were in.

### <u>NOW</u>

PAC Members and PSME's will receive slides and resources prior to each meeting and be invited to provide feedback and recommendations on materials.

# **Levels of Involvement**

# PAC Refresher 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



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

# PAC Members Roles and Responsibilities



- PAC Members take on an active role as a member of their healthcare team by:
  - Working in collaboration with your medical team (nutritionist, nephrologist, social worker etc) to determine your plan of care
- PAC Members use their knowledge to educate their ESRD Peers by:
  - Reviewing and providing feedback on patient resources
  - Distributing resources to ESRD peers and Social Workers
- PAC Members attend Network-hosted webinars, meetings, lobby days and informational sessions



# PAC Representative Roles and Responsibilities (Patient Facility Representatives)

 Assist facilities in creating support groups that educate and help patients cope and adjust to changes made for dialysis treatment

### **Peer Mentoring**

- Gathering patient feedback on needed supports
- Patient Advocacy

# Participates in facility's QIA activities

- Serves as QIA Patient Facility Representative
- Participates in Education Stations

# PAC Advisor Roles and Responsibilities



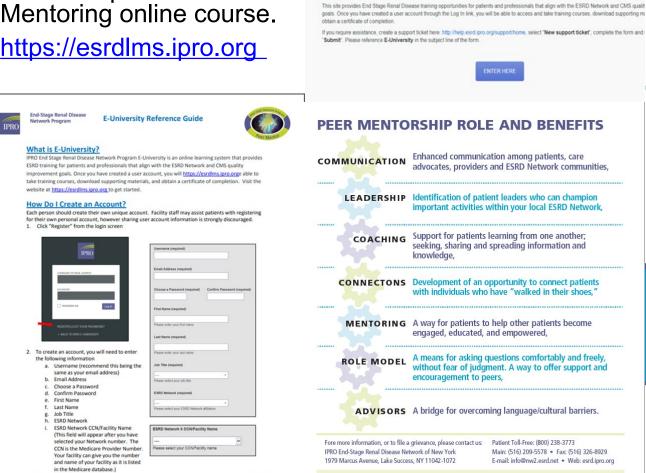
- Act as Patient Subject Matter Experts (PSMES)
- Provide input into the development of informational or education materials for patients, families and caregivers
- Participate in national quality improvement projects
- Engage in National PFE LAN
   Calls
- Participate in NCC Affinity
   Groups (if nominated)

- Participates in Network and facility QIA activities
  - Each PSME focuses on a specific QIA focus area
  - Serves as QIA Patient Facility Representative
  - Participates in Education Stations
  - Patient Champions
  - Peer Mentors

# **PAC** and Peer Mentoring

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

https://esrdlms.ipro.org



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COURSES SUPPORT LOGIN | REGISTER

**End-Stage Renal Disease Network of New York** 

Welcome to IPRO ESRD Network Program E-University

Resource content adapted from the National Patient and Family Engagement (N-PFE) Learning and Action Network (LAN), under the ESRD National Coordinating Center (ESRD NCC) peer membring toolkit. Developed by IPRO ESRD Network of New York while under contract

with Centers for Medicare & Medicaid Services. Contract HHSM-500-2016-00020C





Negative: I hate how ESRD makes me feel. I hate everything about it including the treatments Pointers: Engage with the patient to continue to get them to open up by acknowledging their statement in an empathetic way.

Example: understand living with ESRD can be so overwhelming and frightening at times. Is there
anything I can do to help you with these feelings? Would you like to speak with someone
about your feelings in private?

9. What is your understanding of your responsibilities relating to your dialysis care?

Positive: I feel like I'm adjusting well because I'm taking part in decisions about my treatment.

- . Pointers: Acknowledge the positive coping skills by providing positive feedback. Example: Great! I think it's very important for each patient to take part in decisions about their treatment. Your input is critical to a positive outcome for you.
- Negative: I feel like I have lost all control of my body and treatment decisions. . Pointers: Engage with the patient to continue to get them to open up by acknowledging their statement in an empathetic way.
- Example: understand learning that dialysis or a transplant will be needed can be overwhel
  at first. But, understanding your own needs and taking charge of your health rela
  responsibilities can help you to feel more in control of your file.

10. How are you feeling about beginning treatment?

- O Positive: I'm very scared, but I've been reading and working to understand what is going to happen
- . Pointers: Engage with the patient using understanding and compassion.
- Example: It is normal to have questions, fears and concerns relating to beginning treatment. But, you
  are correct; fear will dissipate with knowledge and understanding of what is happening to you and your body
- Negative: I don't want to talk about it! This is not my choice and I am very scared
- Pointers: Acknowledge patient's fears by showing empathy and compassion.
   Example: It is very roomal to have fears about the unknown. Sometimes it really helps to speak with your health care fears about your concerns and fears. Would you like to speak with someone in private to work on decreasing your fears and anxieties.





IPRO ESRD Network of New York 1979 Marcus Avenue Lake Success, NY 11042 Phone: (516) 209-5578 Fax: (516) 326-8929



Getting the Conversation Started

#### Congratulations on Completing Your Training and Becoming a Peer Mentor!

in the training modules will help you build a relationship with your mentee is that calling income was they possible and negative responses when talking to your mentees about how living with end-stage renal disease has affected their lives. Inside are some helpful scenarios to help keep the conversation going whether you receive a positive or negative response

care options.

# 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)

#### TAKE THIS COURSE

UNLIMITED ACCESS



COURSE CERTIFICATE



<sup>\*</sup>This module is required.

# **Virtual Patient Engagement**

New Program Approach

Laura Rodriguez-Carbone



# Patient to Patient Engagement Reminders

IPRO
Better healthcare,

- 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.



w.2 5/11/2020

Developed by IPRO ESRD Network of New York while under contract with Centers for Medicare & Medicaid Services

# Suggestions for Safe Patient to Patient Engagement at Facilities



Before engaging in any of the below activities, please talk to facility staff to ask for their assistance and to assess the individual social distancing situation at your facility.

- Ask Facility to make copies of, and pass out, resources to other patients;
- Ask Facility to help you set up a Virtual Lobby Day or Education Session (through Google Meet, Zoom, etc.,)
- Think about starting or joining a virtual support group (we have several patient SME's who have started support groups in their area and would be available to share their experiences).
  - Virtual Support Groups can take on many forms conference calls, Zoom calls, a mailing list).

<sup>\*</sup>Always wear your mask while in your dialysis facility and maintain a safe social distance of 6ft from other patients.

### We Want to Know What You Think!





- Your responses will remain anonymous
- Your feedback will help the Network develop resources to assist other kidney patients with accessing the care and support they need while keeping them safe.

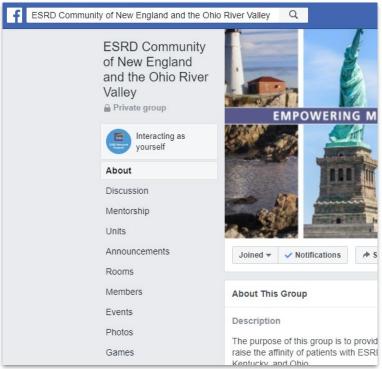
### **Questionnaire Link:**

https://forms.gle/HAyaYkm5tK6uW2vV9

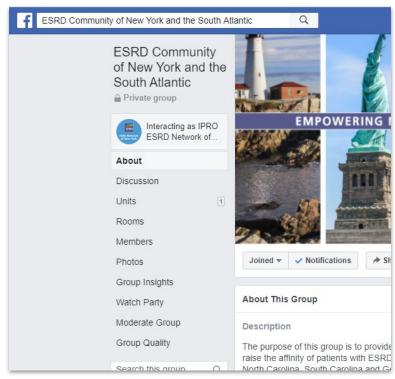
### **NEW Social Media - Join Our Facebook Patient Group!**



For Patients in Ohio, Indiana, Kentucky, Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont



https://www.facebook.com/groups/ ESRDNW19/ For Patients in New York, Georgia, North Carolina, and South Carolina



https://www.facebook.com/groups/ ESRDNW26/

# **Questions or Comments?**





## **Telehealth Toolkit**

Meet with Your Dialysis Team From the Comfort of Your Home

**Jeanine Pilgrim** 







# Telehealth: When Can I Use IT?

**Telehealth** refers to how healthcare providers can care for their patients remotely when they are not able to meet in person by communicating using video-conferencing tools such as cell phones, tablets or laptops. As a home dialysis patient, you may use Telehealth for your monthly clinic visit or to communicate issues with your Nurse.

# The Centers for Medicare and Medicare Services allow Telehealth when the following criteria are met:

- You must have dialyzed in your home for at least 3 months
- For 2 out of every 3 months you can meet with your dialysis team, including your Doctor, Nurse, Dietician and Social Worker via telehealth
- Home program must offer this service-request the service if not available



# Benefits of Using Telehealth



- Focused interaction with the team
- No travel concerns,
  - No worries about finding transportation
  - Decreased risk of car accident
  - No travel time
- No travel in inclement weather
  - Decreased risk of slips and falls walking on snow or ice
- Limited wait times, scheduled appointments
- Limited contact with others in waiting rooms
  - Less contact with germs and viruses
- Continued independence, make appointments to fit your work, leisure and family schedule

# **Technology: Getting Prepared**



What devise are you going to use? Computer, Tablet or Cell Phone?

Is your Device fully charged?



Does you Health System use an app for a Telehealth visit? Is so, Have you downloaded it?

Do You Have an Adequate Internet Connection

Address any concerns before your scheduled telehealth visit day

# Technology: Getting Ready on Appointment Day



- 1. Make sure you have a **comfortable place to sit for the visit** and that your **camera gives a clear view of you for the provider**,
- 2. You may **consider a trial run** to eliminate challenges prior to the telehealth appointment- **ask your clinic to assist you with this process**
- 3. On the day of the scheduled visit **log** in 10-15 minutes prior to the start time
- 4. Consider a "**technology buddy**" to help you overcome challenges in using this technology

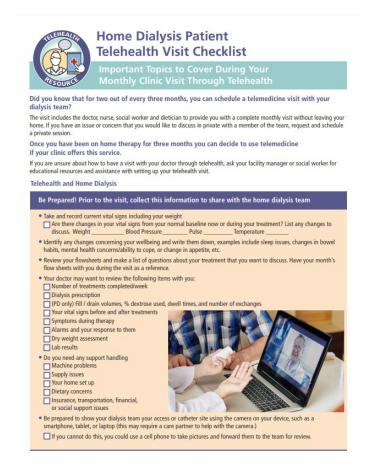
### Preview of Telehealth Patient Toolkit



### Scheduled release September 2020



#### 1. Fact Sheet





- 3. Resource Guide
- 4. Recorded Rollout Presentation



# Ideas To Help You – Be Prepared!



Taking the time to organize and prepare for your telehealth visit will maximize your time with you care team

### What information should I have?

- ✓ Write down your most recent sets of vital signs to share
- ✓ Have your medication list
- ✓ Do you have any concerns about your well being you wish to share?
- ✓ Be prepared to discuss your dialysis prescription.
- ✓ If on PD know your fill/drain volumes, dwell times and # of exchanges/day

### What is important to ask?

- ✓ Are there any symptoms you are experiencing during treatment that are new or a concern?
- ✓ Do you have any supply and or equipment issues you are experiencing?
- ✓ Do you have dietary concerns you may want to discuss?
- ✓ Are there any issues with Insurance, transportation or financial concerns?

# **Questions or Comments?**





# COVID-19 SUPPORT OPEN DISCUSSION FORUM





# **Closing Remarks**

**Next Steps** 

**Jeanine Pilgrim** 







# **Next Steps**

- Complete Post-Event Evaluation we value your feedback!
- Look out for NEW PAC Newsletter: *PAC Matters-Connecting the Community* and introductory announcement from new team members
- Complete the Virtual Patient Engagement Assessment <u>https://forms.gle/HAyaYkm5tK6uW2vV9</u>
- Follow Us on Social Media:
  - https://www.facebook.com/groups/ESRDNW19/
  - https://www.facebook.com/groups/ESRDNW26/
- Visit the Network Peer Mentoring Training <a href="https://esrdlms.ipro.org">https://esrdlms.ipro.org</a>
- Check out Network Program Website <a href="https://esrd.ipro.org/">https://esrd.ipro.org/</a>
- Review Network Educational Resource Library think of ways to share and spread in your community, we need your help!
- Save-the-Date! Next Meeting: October 28, 2020

# **Program Website**





### End-Stage Renal Disease Network Program

Search...

Home

About

Patients & Family

Providers a

**Emergency Management** 

Quality Improvement =

Events

ESRD Help Desk

### **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.

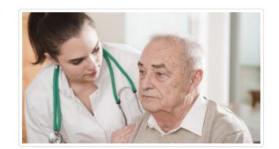
#### **General Information**



#### Telemedicine & Telehealth



#### **Mental Health**



## Thank You!

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**ESRD Network Program (Networks 1 & 9)** 

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