

IPRO End-Stage Renal Disease Network Program

Patient Advisory Committee



End-Stage Renal Disease
Network Program

esrd.ipro.org

March 2019

About IPRO

IPRO is a non-profit organization that works with government agencies, providers and patients to implement innovative programs that bring policy ideas to life. For over 30 years we've made creative use of clinical expertise, emerging technology and data solutions to make the healthcare system work better.

About the 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

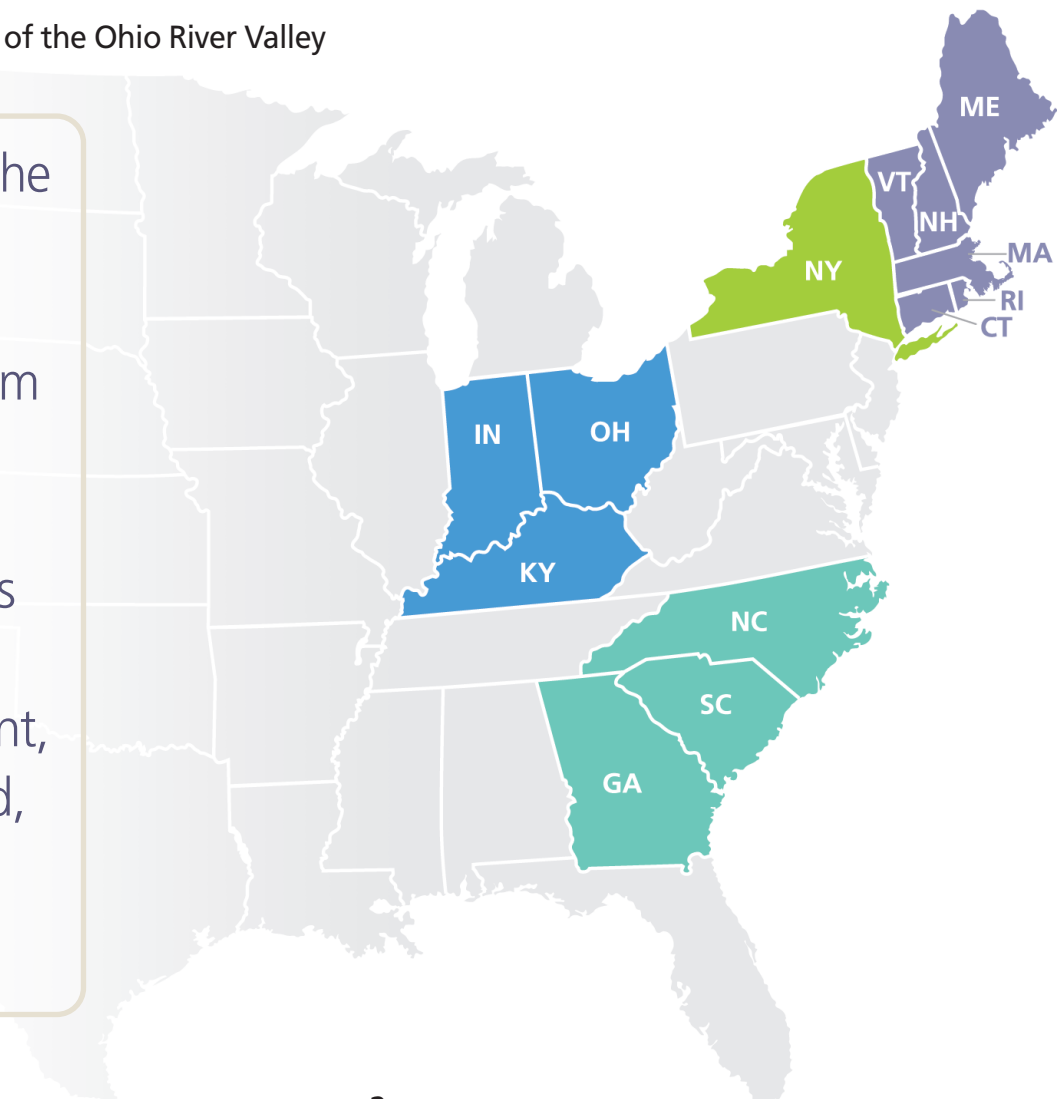
Network 6: ESRD Network of the South Atlantic

Network 9: ESRD Network of the Ohio River Valley

These four Networks, managed by IPRO, are part of the 18 ESRD Network organizations under contract with the Centers for Medicare & Medicaid Services (CMS). The IPRO ESRD Network Program is dedicated to assisting dialysis and renal transplantation centers in establishing and maintaining high standards of care for ESRD patients.

The IPRO ESRD Network Program is fully committed to promoting and achieving the goals and vision of the ESRD Network Program, as well as providing support to patients and providers throughout the 13 states served by the IPRO ESRD Network Program.

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.



About the Patient Advisory Committee

The Patient Advisory Committee (PAC) is an organized group of patients and/or family members who volunteer their time to represent the Network in their dialysis or transplant facility, and also represent their facility to the Network. Each of the four IPRO ESRD Networks has a dedicated PAC that works to support the unique needs of the Network's service area.

Patient Advisory Committee Structure

PAC participants can be involved in activities as much or as little as they like, based on their abilities and lifestyle. The Network has three levels of involvement created to best fit the diverse needs of the renal community.

The three tiers of PAC membership offer opportunities for patients/family members/care partners to participate at a level at which they feel most comfortable.

- **Tier 1: PAC Members** include those individuals who are interested in learning about becoming better advocates for their care. This level of involvement is ideal for those who are interested in learning more about ESRD and in receiving updates from the Network about educational seminars.
- **Tier 2: PAC Representatives** provide a link between patients and facility staff, and promote positive communication among patients, staff, and the Network in an effort to encourage other patients to take an active role in their healthcare. They work with the Network staff and their facility staff members to focus on key areas that are important to improve the health and safety of kidney patients at their facility.
- **Tier 3: PAC Advisors** support PAC Facility Representatives in their region and are available to answer questions and give advice as needed. They may also function as Network board representatives and members of national patient groups or expert panels.





Roles and Responsibilities

Individuals who participate in the PAC are ESRD patients or family members/care partners of patients who are treated at, or consider themselves associated with, a specific dialysis or transplant facility. They must have an interest in improving the quality of life of renal patients and be willing to exchange information and ideas with other patients and staff members.

At any time, PAC Members may consider increasing their engagement level.

Opportunities may include becoming a PAC Facility Representative, taking training to become a Peer Mentor or engaging in quality improvement interventions at their facility.

PAC participants are encouraged to attend facility and regional meetings and/or participate on conference calls as often as possible.

Participants may increase or decrease their level of involvement at any time during their membership. We understand that people's situations change and individuals may have to switch between the different roles due to health or family circumstances. Having tiered levels of involvement allows patients and families to participate at a level that best suits their needs. We welcome and encourage patients/family members/care partners to explore all levels of involvement in the PAC.

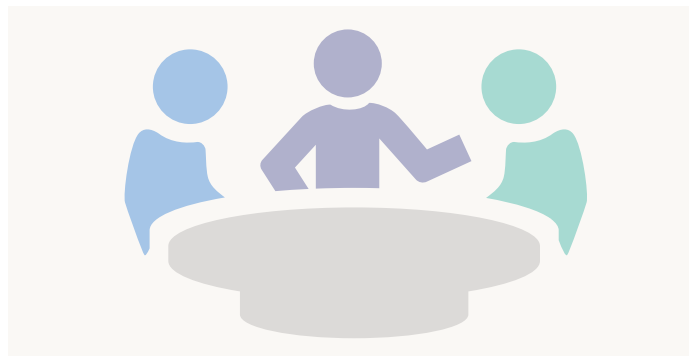
Tier 1: PAC Members Roles and Responsibilities

- ✓ Take an active role as a member of their healthcare team
- ✓ Educate themselves about renal disease and their treatment options
- ✓ Become familiar with the role of the ESRD Network
- ✓ Share this new information with family and friends
- ✓ Attend webinars and educational sessions held by the Network and our partner agencies
- ✓ Take advantage of additional training to increase level of involvement with the Network



Tier 2: PAC Facility Representatives Roles and Responsibilities

- ✓ Encourage fellow patients to be involved in their healthcare
- ✓ Share information provided by the ESRD Network and the facility with fellow patients
- ✓ Participate in the facility's quality improvement initiatives and provide information to the quality team on work with other patients
- ✓ Attend quality meetings and provide the patient perspective on quality issues to facility leadership
- ✓ Collect ideas and suggestions from other patients on the best ways to educate and support patients and provide this information to facility staff members and the Network.
- ✓ Assist the facility staff in developing support groups to educate patients about kidney disease and to help them adjust to dialysis
- ✓ Attend PAC meetings and conference calls when available
- ✓ Using Network surveying tools, provide feedback to the Network on their work
- ✓ Participate in local or national committees focused on quality improvement activities



Tier 3: PAC Advisors Roles and Responsibilities

- ✓ Participate and provide the patient perspective in local and national quality improvement projects
- ✓ Coordinate social or educational functions aimed at increasing awareness of ESRD
- ✓ Act as a subject matter expert working on national quality improvement projects identified by CMS
- ✓ Coordinate conference calls to assist other PAC Facility Representatives
- ✓ Participate in and provide the patient perspective in the Network board meetings and other Network supported meetings.



Welcome!



Staying in Touch with the Network

We want to be sure that we are communicating with you in a way that is most convenient for you. We have created a few communications options that allow us to notify you about upcoming events and you to provide your feedback. Below are examples of communications you will receive based on the preferred method of contact you provided (home phone, mobile phone, or email).

We hope you will find these communications are a good way to stay connected. If you have any concerns or would like to change your preferred method of contact, please call the ESRD Network.

If you agreed that the ESRD Network could contact you by phone, text, or email, please expect to receive communications from the phone numbers and/or emails shown below, which vary, depending on the state in which you live.

NETWORK	STATE(S)	PHONE NUMBER	EMAIL
1	CT, MA, ME, NH, RI, VT	866-286-3773	Info@nw1.esrd.net
2	NY	800-238-3773	Info@nw2.esrd.net
6	NC, SC, GA	800-524-7139	Info@nw6.esrd.net
9	IN, KY, OH	844-819-3010	Info@nw9.esrd.net

Text Message

If you provided your cell number we will reach you by text message. You can expect to see text messages from the Network like the one below:

*Hello Patient Facility Representative!
The Network is holding a poster contest to promote home dialysis. We would love your help! Text (1) if you plan to contact your facility lead to help with the contest. Text (2) if you cannot help.*

Home Phone

If you have provided a home phone number, you will receive automated calls. Calls will include survey options as well. Voice call surveys can be answered by pressing star (*) + (number choice) during the call.

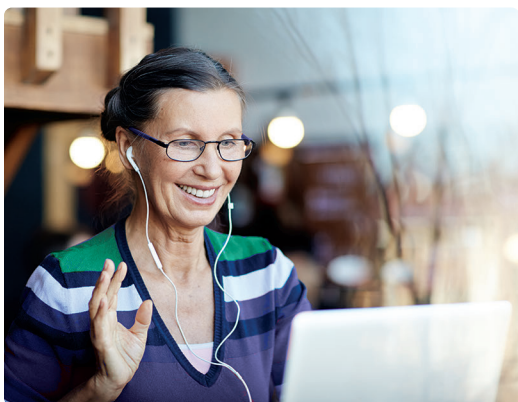
Cell Phone

If you add your Network phone number to your phone contact list as the ESRD Network you will recognize the number when we contact you.

Email

If you have provided us with your email address, you will receive email communication and surveys from the Network’s email address.

Click on the survey link and answer the questions to respond.



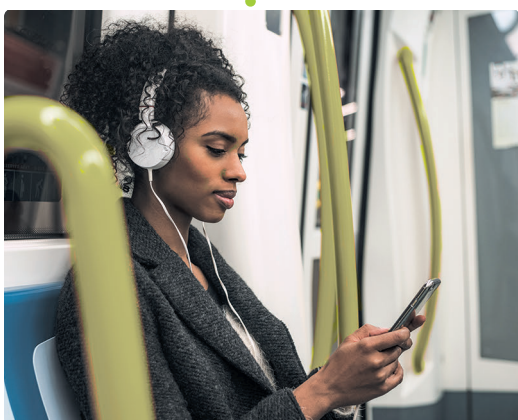
Joining Network or National Events

As a participant in the Network PAC, you will receive invitations to educational presentations throughout the year. These presentations are shown via a variety of online services which allow multiple people to call in and listen to a presentation or meeting. If you are at a computer you can also log in to see the materials that are being shared.

Call-in instructions are provided with each invitation. They usually require three steps. Here is a quick guide on how to participate in these calls by telephone:

1. Dial the number
2. Enter the Access Code
3. Enter the # sign

For computer access instructions, please contact your Network's Patient Toll-Free line on the back cover of this booklet.



Tips for Success



Practice Professionalism with Facility Staff and Peers

As a PAC Member or Representative, your activities are limited to PAC-related matters, which should be approached in a thoughtful, responsible manner, always with the cooperation and knowledge of the social worker or other involved staff at your facility.

If you would like to meet with a staff member at your facility and do not have a regularly scheduled meeting time, please request an appointment. It is important that you respect the work schedules of your social worker and facility staff. Keep in mind that staff members have many tasks in addition to assisting PAC Members and Representatives.

In addition, please remember it is important to show respect for, and be sensitive to, your fellow patients'

- ✓ Cultural differences,
- ✓ Spiritual or religious beliefs,
- ✓ Individual feelings, and
- ✓ Personal views.

Know Your Limitations and Boundaries

As discussed in the Roles and Responsibilities section (page 4) of this manual, one of your obligations is to represent the perspective of patients in your facility to the Network and facility staff members.

You can provide comfort and support simply by listening in a non-judgmental way and by sharing personal experiences in an honest and positive manner. However, you must refrain from giving medical advice of any kind or commenting on specific orders of medical professionals. Instead, encourage patients to talk with their healthcare team and to have a positive, confident relationship with their physicians and other care providers.

PAC “Don’ts”



- ✗ Do not compare your own treatment and its results with the experiences of other patients.
- ✗ Do not make demands; instead turn them into requests, suggestions, or questions.
- ✗ Do not criticize a patient’s physician or healthcare team in any way.
- ✗ Do not imply doubt or negativity concerning details of a patient’s treatment plan. If a patient has concerns about their treatment plan, refer him or her to his or her physician, nurse, or social worker.

Additional Information

PAC Tier 2: Patient Facility Representatives (PFR)

Getting started as a PFR

The first step is to review the information you have received from the Network to share with your fellow patients. Next, plan a time to talk with your facility contacts to determine what would be the best approach to support patients and the facility in quality improvement areas. Start with something small like distributing educational resources to patients in your facility or by completing a checklist your facility contact may provide.

Once you have become more comfortable with the quality improvement focus area you are working with, consider getting involved in other ways that might reach more of your peers. Here are some ideas on ways you can get more involved:

Schedule a Lobby Day

- Pick the day(s) and times you would like to host a lobby day. Work with your facility contact person so they are also available.
- Distribute announcement flyers, hang posters, and talk with patients/staff about the event beforehand.
- Invite patients and family; be sure to invite staff members to answer patients' questions.
- Make sure all materials are relevant and written to meet the needs of your audience
- Connect with interested and engaged patients and gather feedback on the topic being discussed.

Host an Education Station

- Work with your facility contact to select a public area that has the space to hold and display education materials
- Select materials for the station; these may be facility materials, Network materials, or materials from an ESRD group like National Kidney Foundation or American Association Kidney Patients.
- Hang signs that announce the topic area being featured at the station and the date materials will be available.
- Set up the education station and notify patients and staff it is available
- Gather feedback on the helpfulness of the materials as patients participate



Example of an Education Station

Become a Patient Peer Mentor

A peer mentor is a patient who agrees to help to empower other patients to make informed decisions and cope with their lives after being diagnosed with ESRD. Peer mentorship roles include

- Improving communication among patients, care advocates, providers and ESRD Network communities;
- Supporting patients learning from one another; seeking, sharing and spreading information and knowledge;
- Developing opportunities for patients to connect with other patients who have had similar experiences;
- Helping other patients become engaged, educated and empowered;
- Serving as a role model for other patients;
- Giving patients a comfortable place to ask questions without fear of judgement.

To become a Peer Mentor you will need to view some online presentations that will prepare you to effectively talk with other patients, share information, and support their personal choices and preferences. Your goal is to help other patients gather all the information they need to discuss their options with their care team and make an informed decision that is right for them.

If you are interested in becoming a Patient Peer Mentor, talk with your facility social worker or contact your ESRD Network.

Attend your Facility's Quality Meetings

- Talk to your facility contact about opportunities to join the facility quality meeting. At these meetings you'll offer suggestions or generate ideas on ways to engage patients in working together to meet the facility quality improvement goals.
- Provide an update or report on how the work you are doing impacts the facility's improvement efforts.

Start a Support Group

- Talk to your dialysis social worker about starting a support group. Support groups could be in person, in-center, online or via the phone.
- Identify the needs of patients at your facility.
- Recruit individuals interested in helping you form or be a part of the group.
- Create a goal or mission for your group based on what you have learned from your community.
- Find a location and time that works best for everyone to meet

Once the details are finalized, begin publicizing your support group and inviting patients or caregivers who may be interested.



Contact your Network's PAC Coordinator for more information.



NETWORK 1

Community Outreach Coordinator

1 (866) 286-ESRD (3773)

IPRO ESRD Network of New England

1952 Whitney Avenue, 2nd Floor

Hamden, CT 06517

<http://network1.esrd.ipro.org>

NETWORK 6

Community Outreach Coordinator

1 (800) 524-7139

IPRO ESRD Network of the South Atlantic

909 Aviation Parkway, Suite 300

Morrisville, NC 27560

<http://network6.esrd.ipro.org>

NETWORK 2

Community Outreach Coordinator

1 (800) 238-ESRD (3773)

IPRO ESRD Network of New York

1979 Marcus Avenue

Lake Success, NY 11042

<http://network2.esrd.ipro.org>

NETWORK 9

Community Outreach Coordinator

1 (844) 819-3010

IPRO ESRD Network of the Ohio River Valley

3201 Enterprise Parkways, Suite 210

Beachwood, OH 44122

<http://network9.esrd.ipro.org>

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