

IPRO End-Stage Renal Disease Network of New England

Patient Advisory Committee (PAC) ORIENTATION MANUAL



End-Stage Renal Disease
Network of New England

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SECTION 1: WELCOME

1.1 Introduction:

Welcome to the IPRO ESRD Network of New England's Patient Advisory Committee (PAC)! As a member of the PAC, you will be an invaluable link between patients, unit staff and your local Network.

Your role as a member of the PAC can always be tailored to your desired activity level. The most important part of this position is providing you with the resources that you need in order to make a positive impact on the lives of those currently on dialysis; by spreading education, awareness and patient advocate empowerment with your peers.

During your time as a member of the PAC, you'll be receiving publications and mailings on various topics from us, so please keep us informed of any address or phone number changes. Additionally, if you use e-mail, please send us your e-mail address.

Please also feel free to contact the Patient Services Department at the Network with any questions, concerns or if you need guidance:

IPRO ESRD Network of New England
1952 Whitney Avenue, Hamden, CT 06517
Main: 203-387-9332
Toll Free: 866-286-ESRD (3773)
Email: info@nw1.esrd.net
<http://esrd.ipro.org>

We are truly looking forward to working with you and thank you again for volunteering your time and energy towards improving the lives of those affected by ESRD.

1.2 Mission Statement:

1.2a. IPRO ESRD Network of New England Mission Statement: Promoting healthcare for all ESRD patients that is safe, effective, efficient, patient-centered, timely and equitable.

1.2b. IPRO ESRD Network of New England PAC Mission Statement: Providing a link between patients, unit staff and their local network through the utilization of patient advocates that volunteer their efforts towards channeling communication and spreading awareness of resources available to the renal community.



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1.3 Leadership Terms:

1.3a. Preliminary Qualifications: PAC Members are ESRD patients who are treated at, or consider themselves associated with, a specific dialysis unit or transplant facility, and have an interest in improving the life satisfaction of renal patients. PAC Members must be willing to exchange information and ideas with patients and staff members through consistent interaction, followed by accurate representation of the patients in your facility to the Network and unit faculty.

1.3b. Length of Term: Designation as a PAC Member continues throughout a calendar year and is automatically renewed every year by mutual agreement between the patient and facility staff. Resignation by a PAC Member requires immediate notification to the Network by unit staff. In the event a PAC Member is not adhering to the roles and responsibilities of the PAC, he or she may be dismissed after careful review by the facility staff and the Network.

1.3c. Meeting Attendance: At a minimum, there will be at least one (1) face to face meeting and three (3) conference calls per year. Additional meetings may be scheduled – when necessary – in order to provide the Network staff and Medical Review Board with essential patient input regarding the concerns and needs of beneficiaries. Unless otherwise excused, attendance at PAC meetings (in-person or by telephone) is mandatory in order to retain membership in the PAC. Missing 3 consecutive scheduled meetings without an excused absence will result in dismissal from the PAC.

1.3d. Limits and Boundaries: The primary goal of PAC Members is to respond to patient questions and problems, by locating the needed information through the appropriate resources; staff professionals and/or the Network. As such, **PAC members must refrain from giving medical advice of any kind or commenting on specific orders of medical professionals.** We ask that you instead encourage patients to have a positive, confident relationship with their physician that includes an ongoing dialogue regarding treatment decisions and questions. Patient confidentiality must also be observed and respected at all times.

1.3e. Activity Reports: PAC Members may utilize the **PAC Representative Activity Summary** form provided in the **Resource Manual** that you will receive after your agreement forms have been submitted to the Network. The completed reports may be kept in the manual with copies sent to the Network. In addition, these activity reports can be discussed with your regional PAC Chairperson. Maintaining these reports will help you keep track of the work that you have done. You can use these reports when you meet with facility staff as well as at patient meetings. They will help you focus your comments and statements and bring clarity to your meetings. Their use is not currently required, but can be extremely helpful in keeping track of occurrences.

1.3f. Participation in Other Kidney Related Organizations: PAC Representatives are encouraged to be members of other Kidney Organizations/Web Based Discussion Groups. A summary of **Other**



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Kidney Organizations will be provided for you in the **Resource Manual** that you will receive after your agreement forms have been submitted to the Network.

SECTION 2: RESPONSIBILITIES OF PAC MEMBERS:

2.1 How PAC Representatives Make A Difference:

The following is only an outline regarding the roles and responsibilities of PAC Representatives and how you can make a difference in the renal community. Please note that individual differences in personality, approaches and preferences allow representatives to fulfill tasks differently. **Always remember that your primary role is to represent the patients in your facility to the Network and unit staff members.**

- ✓ Engage in patient peer-to-peer guidance
- ✓ Promote communication between patients and staff
- ✓ Inform patients about the ESRD Network and the resources available to them
- ✓ Serve as a link between patients and the ESRD Network

2.2 How PAC Chairs Make a Difference:

PAC Chairs are members of the PAC that have been actively involved for at least one term of two years. Similarly to PAC Representatives, PAC Chairs also engage in the following:

- ✓ Engage in patient peer-to-peer guidance
- ✓ Promote communication between patients and staff
- ✓ Inform patients about the ESRD Network and the resources available to them
- ✓ Serve as a link between patients and the ESRD Network
- ✓ Serve as peer-to-peer mentors for newly recruited Representatives

SECTION 3: WAYS TO BE A SUCCESSFUL PAC MEMBER:

3.1 Promote Positive Communication between Patients and Staff

- ✓ Request a regularly scheduled, brief meeting time with your social worker or head nurse to discuss PAC activities in your unit such as:
 - » Regular PAC/Patient meetings within the facility
 - » Welcoming new patients to the facility
 - » Handing *out Kidney Chronicles* to patients
 - » Regularly scheduled meetings with unit administrative staff with minutes on file
 - » Bulletin board space for Network announcements and PAC notices



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- ✓ Remember that as a PAC Representative, you are working with facility staff, usually the social worker, and he or she will have many duties in addition to the PAC. Please plan on scheduling your time with facility staff well in advance.
- ✓ Encourage an atmosphere of mutual respect and understanding between patients and all facility staff members.

3.2. Inform Patients about the ESRD Network

- ✓ Get to know your fellow patients, and establish positive and comfortable communication
- ✓ Fundamental rules of a successful dialogue include:
 - » Approach patients as a peer to encourage open, honest conversation
 - » Be non-confrontational with peers and staff
 - » Focus on the positive side of patient interaction and be aware that you are not a “complaint collector”
 - » Learn to listen and not interrupt
 - » Your primary goal in responding to patient questions and problems is to locate the needed information from appropriate sources
 - » Do not give medical advice, opinions, or your own interpretation of anything that concerns orders of medical professionals
 - » Observe strict confidentiality
 - » Do not gossip about personal issues told to you by patients
 - » Remember not to jump to conclusions before getting all the facts
 - » If there is a medical question or facility issue, encourage the patient to speak with their doctor or the facility nurse manager
 - » If a patient brings you a complaint, be sure to follow the proper procedures for complaints*

Your Dialysis Facility Should Have a Grievance (Complaint) Policy Posted

3.3 Serve as a Link between Patients and the ESRD Network

- ✓ Introduce yourself as a PAC Representative to your fellow patients and make it clear that you are available to discuss any questions or concerns that they may have
- ✓ Make it a point to seek out and welcome new patients, if permitted
- ✓ Use frequent contact to familiarize yourself with the needs, concerns, and suggestions of your fellow patients
- ✓ Inform facility staff members of any suggestions or concerns when appropriate
- ✓ If there are any suggestions for the Network, feel free to contact the Patient Services Department at (866) 286-ESRD (3773), or you can use the **Feedback Form** that will be included with your **Resource Manual**
- ✓ If you have suggestions of your own, discuss them with patients, and note their comments and ideas when you present your suggestions to facility or Network staff
- ✓ Be on the lookout for ways to add humor and lightness to dialysis days. You can highlight positive experiences and share them Network



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3.4 Facilitate Meetings

- ✓ Try to schedule time for you to meet with your Social Worker, Administrator or Nurse Manager to discuss ways to encourage communication between patients and facility staff
- ✓ Ask your facility healthcare team about having scheduled meetings including patients and staff to share information and to communicate ideas to build positive working relationships at your facility
- ✓ If there are Network meetings, calls, or webinars in your region, PAC Representatives should publicize these events with patients and staff at their dialysis facility
- ✓ If at all possible, PAC Representatives should attend Network events

3.5 Help Patients Understand Information Provided by the Network

- ✓ The facility social worker will receive *Kidney Chronicles*, the ESRD Network's patient newsletter via email each month. Please work with your facility social worker to print and distribute *Kidney Chronicles* to all patients
- ✓ Ask if you can assist with distributing *Kidney Chronicles* when your facility has printed them. Whenever possible, the Newsletter should be handed to each patient individually
- ✓ Try to make it a point, at some time, to help those who may have difficulty reading because of either physical difficulties or language barriers
- ✓ Be prepared to explain and answer questions about materials supplied by the Network such as forms, brochures, questionnaires or similar publications. If you are not sure how to explain or answer a question, please contact the Network to discuss

3.6 Practice Professionalism with Facility Staff and Peers

- ✓ Partnering with Staff:
 - » As a PAC Representative, your activities are limited to PAC related issues and they should be approached in a thoughtful, responsible manner, always with the cooperation and knowledge of the social worker or other involved facility staff
 - » We ask that you please do not make demands; instead turn them into requests, suggestions or questions
 - » If you do not have a regularly scheduled meeting time, request an appointment. Respect the work schedules of your social worker and facility staff. Keep in mind that staff have many tasks in addition to assisting PAC Representatives
- ✓ Partnering with Patients
 - » Please remember to have respect for, and be sensitive to, your fellow patients':
 - Cultural differences
 - Spiritual or religious beliefs
 - Individual feelings
 - Personal views
- ✓ Most importantly, respect yourself and others. Maintain a calm, dignified, non-confrontational manner that will invite mutual respect between you, patients, and staff



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3.7 Embracing Your Role

- ✓ We encourage you to represent the 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 sharing personal experiences in an honest and positive manner
- ✓ You must refrain from giving medical advice of any kind or commenting on specific orders of medical professionals
- ✓ **YOU CAN Do This By:**
 - Encouraging patients to talk with their Health Care Team and to have a positive and confident relationship with their physicians and other care providers
- ✓ **We ask you to please refrain from the following:**
 - » Comparing your own treatment and its results with other patients
 - » Criticizing a patient's physician or health care team in any way
 - » Implying doubt or negativity concerning details of a patient's treatment plan. If the patient has concerns about their treatment plan refer them to their physician, nurse, or social worker

SECTION 4: NEXT STEPS

4.1 Orientation of New PAC Members

Congratulations, you've already taken the first step by having a discussion with your facility staff and expressing your interest in serving on the PAC!

Here are the next steps for you to take:

- Review all of the information covered in this PAC Orientation Manual
- Review, complete and return the PAC Agreement Form (Section 4.2)
- Review, complete and return the PAC Confidentiality Agreement Form (Section 4.3)
- Complete the PAC Personal Profile Form (Section 4.4)
- The Network's receipt of these forms will finalize your designation as a PAC Member
- The Network will send you a packet containing useful materials that will guide you through the next steps of fulfilling your role as a PAC Member

If you have any questions or concerns regarding this process or anything contained in this PAC Orientation Manual, please don't hesitate to contact the Network directly.



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4.2 Patient Advisory Committee (PAC) Agreement Contract

The Centers for Medicare & Medicaid Services (CMS) has contracted with IPRO End Stage Renal Disease (ESRD) Network of New England to promote education and resources to ESRD patients and providers. In order to support this endeavor, the Network maintains a Patient Advisory Committee for the purpose of lending perspective and giving feedback to the Network on educational materials, programs and ESRD issues.

The committee will be reasonably represented by: peritoneal dialysis patients, hemodialysis patients, transplant recipients and family members that represent the entire area of the Network, which includes Maine, Vermont, Rhode Island, Connecticut, New Hampshire and Massachusetts. The Network's Patient Services Department will staff the committee, with approval by the Network Council.

The Patient Advisory Committee (PAC) will:

- Advise the Network Council on the concerns and needs of ESRD patients in New England.
- Review material developed by the Network to make sure it is "patient-centered" as requested.
- Help create educational materials for other patients, as requested.
- The Patient Advisory Committee is required to have one (1) face to face meeting and three (3) conference calls a year or as often as necessary to provide input to the Network staff and it's Board on the concerns and needs of patients. **"Attendance at PAC meetings (in-person or telephone) is mandatory to retain membership in the PAC, unless otherwise excused. Missing 3 consecutive scheduled meetings without an excused absence will result in dismissal from the PAC.**
- Assist in thinking of topics, and writing, for the Networks patient educational newsletter.
- Provide advice or patient perspectives to assist with conflict resolutions.

By signing below, I agree to actively participate in the charges of the PAC. I give permission to the IPRO ESRD Network of New England to publicize that I am a member of the PAC, by means of email, fax, and written document. I also agree to and authorize the IPRO ESRD Network of New England to use my name and picture on their website, <http://esrd.ipro.org>, or in any patient publication. I agree that the IPRO ESRD Network of New England can discuss my PAC status with my facility. I plan to share my patient experiences as a benefit to the ESRD community when there is a need, as requested by the Network.

Signature

Date

Print Name



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4.3 PAC Confidentiality Form:

The IPRO ESRD Network of New England (Network 1) acknowledges both a legal and ethical responsibility to protect the privacy of patients, providers, practitioners, reviewers, and employees. To meet this responsibility, Network 1 has adopted the following policies:

- Any unauthorized review, use, disclosure, or re-disclosure of confidential patient, provider, practitioner, and reviewer or employee information is expressly prohibited.
- Confidential information shall be stored in a secure place, and any documents containing patient or provider identifiers shall be shredded before disposal.
- All materials written for and used by the Network are exclusive property. No materials shall be copied for personal use or given to another individual outside the Network without prior written approval.
- No party shall represent Network 1 without prior authorization and any disclosure concerns regarding Network 1 shall be reported to Network 1's Patient Services Department.

Unauthorized release of confidential information may be subject to civil and criminal sanctions pursuant to the provisions of 42 CFR (Code of Federal Regulations) Part 480. Any violation may result in disciplinary action up to and including termination of service and referral to the appropriate government agency for investigation. Re-disclosure of confidential information is also prohibited except as permitted under 42 CFR 480.107, and penalties for re-disclosure are listed in 42 CFR 480.108.

I have read and understand this Confidentiality Statement. By signing below, I agree to comply with the requirements set forth by Network and CMS. I understand that a breach in confidentiality may result in immediate termination of my service with Network 1 and possible civil and criminal penalties.

Printed Name: _____

Signature: _____ Date: _____



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4.4 PAC Personal Profile Form: Please complete this form with your personal information. If you are a care giver, please provide both of your names and the treatment information of the person for which you care for.

Name: _____ **Date:** _____ / _____ / _____

Facility: _____ **Modality:** _____

Treatment Days: _____ **Treatment Times:** _____

Brief Personal Background:

What do you hope to gain/achieve from becoming a PAC Representative?:

As a dialysis patient, what is a barrier that you've successfully overcome?

If you could provide one tip to other dialysis patients, what would it be?

What's your favorite kidney-friendly snack during treatments?

Please share one fun-fact about yourself:



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SECTION 5: Network Service Contacts:

Please always feel free to contact the staff at the Network regarding any questions, comments or concerns that you may have. We are here to serve you and look forward to working with you. Thank you again for volunteering your time and energy towards improving the lives of all of those affected by ESRD.

5.1 General Contact Information

Local Phone: (203) 387-9332

Toll Free Patient Line: (866) 286-ESRD (3773)

Fax: (203) 389-9902

Email: info@nw1.esrd.net

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

Facebook: <http://www.facebook.com/IPROESRDProgram>

YouTube: <http://www.youtube.com/user/IPROESRDProgram>

5.2 Staff Listings by Department

Department	Title	Name	Phone	Email
Administration	Executive Director	Danielle Daley, MBA	(203) 285-1212	ddaley@nw1.esrd.net
Patient Services	Patient Services Director	Brittney Jackson, LMSW, MBA	(203) 285-1213	bjackson@nw1.esrd.net
	Community Outreach Coordinator	Merari Rosario, MHA	(203) 285-1223	mrosario@nw1.esrd.net
Quality Improvement	Quality Improvement Director	Sarah Keehner, RN, BSN, CNN	(203) 285-1214	skeehner@new.esrd.net
	Quality Improvement Coordinator	Heather Camilleri, CCHT	(203) 285-1224	hcamilleri@nw1.esrd.net
Program Support	Senior Program Support Coordinator	Cheryl Pettway	(203) 285-1222	cpettway@new.esrd.net
Information Systems	Operations Director	Jaya Bhargava, Ph.D., CPHQ	(203) 285-1215	jbhargava@nw1.esrd.net
	Senior Data Coordinator	Krystle Gonzalez	(203) 285-1225	kgonzalez@nw1.esrd.net