IPRO ESRD Network of New York

Patient Advisory Committee

Manual

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CEO, ESRD Program

6/01/2015
Date

REVISION HISTORY

<table>
<thead>
<tr>
<th>Revision #</th>
<th>Reason</th>
<th>Effective Date</th>
</tr>
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<tbody>
<tr>
<td>0</td>
<td>Initial Release</td>
<td>04/08/1999</td>
</tr>
<tr>
<td>1 - 4</td>
<td>Revisions: Updated responsibilities</td>
<td>01/13/2009; 04/21/2009; 09/30/2010; 11/02/2011</td>
</tr>
<tr>
<td>5</td>
<td>Revision: Updated Responsibilities and formatting change.</td>
<td>2/08/2012</td>
</tr>
<tr>
<td>6</td>
<td>Revision: Updated Responsibilities, and Involvement</td>
<td>6/01/2015</td>
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Mission Statements

The IPRO ESRD Network of New York:

The End-Stage Renal Disease (ESRD) Network of New York (Network 2) is operated by IPRO, an independent, not-for-profit corporation, and the Medicare Quality Improvement Organization (QIO) for New York State. Network 2 is the fifth largest Network in the ESRD Network Program, serving over 26,000 patients who are receiving treatment for ESRD during 2013.

Network 2 is dedicated to assisting dialysis and renal transplantation centers in establishing and maintaining high standards of care for ESRD patients. The organization is one of 18 ESRD Network Organizations under contract with the Centers for Medicare & Medicaid Services (CMS.) IPRO 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 in New York State.

The IPRO ESRD Network of New York Patient Advisory Committee:

The Patient Advisory Committee (PAC) of the End-Stage Renal Disease (ESRD) Network of New York is a statewide organization of patients and/or family members who volunteer their time to represent the Network to their dialysis or transplant unit, as well as representing their unit to the Network.

This is accomplished in several ways:

- Representatives informing patients of the Network and its function.
- Representatives communicating with patients in the unit to identify concerns, ideas for unit improvement, and potential problems with staff or other patients.
- Facility administrative staff is asked to meet regularly with their PAC representatives to communicate the needs of the unit and the needs of the patients to each other and to work as a team in an effort to address concerns and improve quality of care for ESRD patients.
- Representatives can assist in the orientation of patients new to the unit. Oftentimes, new patients are overwhelmed with information provided by professionals, yet will understand what is being said by another patient.
- Representatives may also get involved in developing social activities to promote a sense of community in the unit. Examples are: Organizing a bus trip for a picnic or other recreational activity, arranging visits to hospitalized patients, or having an annual vote among the patients for staff person of the year and arranging a ceremony to acknowledge the winner.

The Mission of the End Stage Renal Disease Network of New York is to promote health care for all ESRD patients that is safe, effective, efficient, patient-centered, timely and equitable.
Introduction

Welcome to the IPRO ESRD Network of New York’s Patient Advisory Committee. As a Patient Advisory Committee (PAC) Representative, you will be an invaluable link between patients, unit staff, and the Network. As you begin your work as a PAC Representative, you’ll have the opportunity to work with your peers, your facility staff, and us at the Network.

Please keep in touch with us and your area PAC Chair with any questions, comments, or concerns that you may have. Remember, you can tailor your role as a PAC Representative to your desired activity level. The most important part of your role as a PAC member is for you to know what resources are available to you, and for you to be able to share this with your peers. It is not a test, it is a beginning; a time for you to be empowered and at the same time empower others. Together, we can make a difference in the experience of living while on dialysis.

During your time as a PAC Member, you’ll receive mailings on various issues from the Network, so please keep your Network PAC Coordinator informed of any address or phone number changes, and if you use e-mail, please send us your e-mail address.

The Network is a resource for publications and educational materials. As a PAC Rep, we encourage you to familiarize yourself with the Network, our publications, our website (if you have access) and resources. Please share our publications with your peers at your facility. If you need additional copies of anything, please fax or e-mail us the Publications Order Form (you can fill out the form and ask your facility to fax it to the Network for you).

The Network produces two patient oriented publications: A monthly e-Newsletter, Kidney Chronicles (available in both English and Spanish); and The PAC Speaks which is a two page, newsletter written by PAC Members, which is distributed as content becomes available. Hopefully you are familiar with these publications; if not, please visit our web page www.esrdny.ipro.org or contact the Network. Please feel free to suggest future subjects that you would like covered in our publications. Please submit your thoughts and ideas to the network either by e-mail or by calling, or writing.

Please contact the PAC Coordinator at the Network with any questions or concerns you may have, or if you need guidance.

PAC Coordinator
IPRO ESRD Network of New York
1979 Marcus Avenue, Suite #105, Lake Success, NY 11042-1002
Tel: 800-238-ESRD (3773)
Email: info@nw2.esrd.net
http://esrdny.ipro.org/overview/

Thank you again for volunteering your time and energy to help provide a link between patients, unit staff, and the Network. This is an amazing opportunity to help everyone affected by ESRD and we are looking forward to working with you.
How the PAC is Organized

PAC Representatives are nominated by and work with their dialysis facility staff. They are also asked to coordinate with their regional PAC Chair if one is available. At ANY time, a PAC member may contact the Network directly.

[Diagram of the PAC organization structure]

PAC Regions by County

**Albany-Utica**
- Albany
- Clinton
- Essex
- Franklin
- Fulton*
- Hamilton*
- Herkimer
- Montgomery
- Otsego
- Rensselaer
- Saratoga
- Schenectady
- Schoharie*
- Warren
- Washington*

**Hudson Valley:**
- Columbia
- Delaware*
- Dutchess
- Greene
- Orange
- Putnam
- Rockland
- Sullivan
- Ulster
- Westchester

**Manhattan/Staten Island**
- New York
- Richmond

**Nassau County**

**Queens County**

**Rochester Region:**
- Allegany*
- Chemung
- Livingston
- Monroe
- Ontario

**Suffolk County**

**Brooklyn Region**

**Buffalo Region**
- Cattaraugus
- Chautauqua
- Erie
- Genesee
- Niagara

**Syracuse Region**
- Broome
- Cayuga
- Chenango*
- Cortland
- Jefferson
- Lewis*
- Madison
- Oneida
- Onondaga
- Oswego
- Saint Lawrence
- Tompkins
- Tioga*

* County has no dialysis facilities
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SECTION 1: PAC MEMBERSHIP REQUIREMENTS

PAC REPRESENTATIVE

PAC Representatives are ESRD patients or family members/care partners of patients who are treated at, or consider themselves associated with, a specific dialysis unit 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 patients and staff members. In order to do this, they must regularly interact with other patients.

- Active PAC Representatives may be on hemodialysis (In-Center, Nocturnal or Home), Peritoneal Dialysis (PD), or may have had a transplant; however, they must spend some time at their facility. Many home, PD, or transplant PAC Representatives keep in contact by working with the facility’s support groups or by simply making it a point to continue visiting their facility.

- In certain cases, family members or care partners of renal patients may serve as a PAC Representative throughout the patient’s treatment at a specific facility or transplant unit.

- Representatives most often volunteer in the unit in response to a request from the social worker or facility staff. Since the PAC has grown larger, patients frequently volunteer by phone, directly to the Network office. In this case, the unit Social Worker is notified before the volunteer is designated as a PAC Representative since PAC activities take place within the framework of mutual understanding and cooperation between the staff and the PAC Representative.

Several units have from ten to twelve representatives who see each other only at meetings held within the facility. Many of these groups have begun their own newsletters and have initiated other activities within the unit. A PAC Representative on every shift is the ultimate goal of the PAC and, hopefully, our present group will help identify, encourage and eventually recruit new members. If more than two patients are interested in representing patients on a shift, it is up to the Social Worker and facility staff to decide who will serve. The other(s) may serve on another shift, if possible, or be the backup when the active representatives cannot fulfill their duties.

ORIENTATION OF NEW PAC REPRESENTATIVES

Once a Representative is designated, he or she will receive a packet from the Network containing: a Network Identification Badge; PAC Confidentiality Agreement; PAC Representative Agreement and other materials that will help you perform your work as a PAC Representative.
**TERMS OF OFFICE**

Designation as a PAC Representative is renewable every two years by mutual agreement between patient and facility staff. Resignation by a representative requires immediate notification to the Network by facility staff. In the event a patient representative is not adhering to the role and responsibilities of the PAC, he or she may be dismissed after careful review by the Network.

**ACTIVITY REPORTS**

PAC Representatives may utilize the *PAC Representative Activity Summary* form in section 3 of this manual. 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 the 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.

**PAC AND NETWORK MEETINGS**

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

**PARTICIPATION WITH OTHER KIDNEY RELATED ORGANIZATIONS**

PAC Representatives are encouraged to be members of other Kidney Organizations/Web Based Discussion Groups* (Please see a list of groups on page 26)
SECTION 2: PAC REPRESENTATIVE ROLES AND RESPONSIBILITIES

This section contains guidelines and educational materials relevant to PAC activities. Also included are the requirements for PAC Representatives.

PAC REPRESENTATIVE

Role

- Promote communication between patients and staff
- Inform patients about the ESRD Network and its role
- Serve as a link between patients and the ESRD Network

Responsibilities

- Encourage patients to be involved in their healthcare
- Empower patients to seek counsel from their health care team
- Share information provided by the ESRD Network
- Help patients understand information provided by the ESRD Network
- Gather and note ideas and suggestions from other patients
- Attend PAC meetings and conference calls when available
- Inform appropriate unit staff members of patient concerns

These are the basic roles and responsibilities of PAC Representatives. However, individual differences in personality, approaches, and preferences allow representatives to fulfill these responsibilities differently. Always remember that your primary role is to provide a link between patients and unit staff, and to promote positive communication between patients, staff, and the Network.
WAYS TO BE A SUCCESSFUL PAC REPRESENTATIVE

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

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.

INFORM PATIENTS ABOUT 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.*
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. Speak with them. Your ID badge will assure that you are known to both patients and staff members as a facility PAC Representative.
- 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 IPRO at (800) 238-3773, or you can use the form, “PAC Rep Contact Form” in Section Three.
- 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 on the PAC REP CONTACT form provided in the Manual and then forward the form to the Network to be shared.

ATTEND PAC MEETINGS

Opportunities to attend PAC 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 PAC 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.
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. We are asking that the social worker print and distribute *Kidney Chronicles*. If your facility is NOT distributing *Kidney Chronicles*, please contact the Network so that we can find a way to get *Kidney Chronicles* to all patients monthly.

- 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.

PRACTICE PROFESSIONALISM WITH FACILITY STAFF AND PEERS

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.

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.

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.
KNOW YOUR LIMITATIONS AND BOUNDARIES

As we have mentioned previously in the Roles and Responsibilities portion of this manual, one of your obligations is 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, confident relationship with their physician and other care providers.

PAC DON’TS:

- Do not compare your own treatment and its results with other patients.
- Do not criticize a patient’s physician or health care team in any way.
- Do not imply 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.

NOTES:
SECTION 3: PAC CHAIR ROLES AND RESPONSIBILITIES

PAC Chairs, in each of the eleven regions, are responsible for overseeing activities of PAC Representatives in their region. and are to be available to answer questions and give advice when called upon to do so. For those who are able, and wish to pursue more extensive PAC involvement, possibilities may include:

- Local projects and social or educational functions
- Establishing a patient newsletter for the region
- Starting regional, or local support groups
- Establish regional conference calls

For assistance in any of these projects, the Network is always available and will provide resources when necessary.

TERMS OF OFFICE/ STATUS AND PARTICIPATION GUIDELINES

Chairpersons are elected for two-year terms, which are renewable, by mutual agreement. If in the course of a term, a Chair is unable to attend at least two quarterly conference calls per year, they may change their status from Active PAC Chair to Inactive PAC Chair. In this case they will be invited to all PAC events, but attendance will not be compulsory, nor will any absence be counted against them if they are on inactive status. If a Chairperson has served at least two full terms (four years) she or he may retire at any time with Emeritus Status. They will be listed on all PAC materials as PAC Chair Emeritus, and will be invited to participate in all PAC Events.

MEETINGS

All PAC Chairs are officers of the Patient Advisory Committee and as such, are required to attend the Network Annual or PAC Chair Face to Face Meeting. Attendance at these meetings will include paid expenses for round trip air/train fare or car mileage and transportation to and from the airport (where applicable). Lunch is included at any day long meeting.

COMMUNICATION WITH PAC REPRESENTATIVES

PAC Chairpersons are supplied with a list of PAC Representatives in their region.

The list includes: Dialysis Facility; PAC Representative names; PAC Representatives’ telephone numbers; and PAC Representatives’ e-mail addresses.

If there is a reason for chairpersons to contact PAC Representatives, it should be done by use of the home phone number or e-mail address. Do not call the facility to speak to a PAC Representative. If there is a need to contact all reps in your local area, the Network will be glad to do so by mail or by e-mail blast.
GUIDELINES FOR CONDUCTING PAC MEETINGS

Decide on a place, date and time, always keeping in mind the two dialysis schedules: Monday, Wednesday, Friday and Tuesday, Thursday, Saturday. If you have a large number of representatives in your area, you might want to do two meetings so everyone has an opportunity to attend.

- **Write out your invitation with all the necessary information** (include separate travel directions where needed) and send it to the Network. The Network will print the information and mail it to all representatives in your area. Be sure to include the RSVP date and your phone number.
  - **Plan an agenda:** List important topics of discussion to be covered at the meeting. Send this with your invitation for printing by the Network.
- **Record minutes:** If you find it difficult to conduct the meeting and record minutes, ask someone in advance to act as secretary.
- **Take attendance:** Have each person sign the Attendance Sheet¹.
- **Report to the Network:** Fax a copy of the minutes, and sign in sheet to the Network.
- **Keep track of time:** Remember, many participants may have comments and questions, so try to stick to the topics on the agenda, and allow time for open discussion. If you're running out of time, you can ask participants to write down their questions to be answered at a later date.
- **Maintain control of the meeting and guide it within its time constraints:** You should be able to politely quiet any member who is disruptive or infringing on the time of others, asking that they wait until the open discussion period. Allow everyone sufficient time to voice their opinions and concerns and encourage attendees to be respectful of the opinions of others.
- **Patients with grievances (complaints) should be instructed to call the Network.**

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¹ Attendance Sheets are available from the Network or can be downloaded from the Network website.
PAC CHAIRPERSON FACILITY VISITS

One of the goals of the Patient Advisory Committee is to visit facilities without patient representation to recruit new PAC Representatives. These visits should be arranged through the Network.

The Network will contact the facility to arrange a meeting with the PAC Chair. A date and time will be finalized and the Chair will be informed of the date and time of the meeting.

Steps for arranging a facility visit:

- Call to confirm the appointment and facility contact after receiving notification from the Network.
- On the first few visits, a Senior Chairperson or Network employee may attend for support.
- Call the facility contact the day before for a final confirmation.
- Dress professionally and arrive early.
- Don’t forget your PAC Chair Badge and Business Cards.
- Make sure that you have a copy of the Network’s Site Visit Checklist
- Take a look at the patient waiting area and check for:
  - Network contact information
  - Grievance Policy with Department of Health contact information
  - Patient’s Bill of Rights
  - Kidney Chronicles
  - Dialysis Facility Performance Score Card
- Make friendly contact with everyone, especially patients/family members/care partners that may be in the waiting area, introduce yourself and tell them who you are and where you are from.
- If you are a guest speaker at a patient meeting, prepare index cards with information to discuss, and ask the Network in advance for any handouts.
- Do your homework; make sure you know what you’re talking about. Get Network guidance to be sure. If there is a question you don’t know the answer to, tell them you’ll get back to them or have them call the Network.
- Remember, you may not be able to answer every question; your objective is to provide the patients with the resources they need to answer questions or resolve issues.
- At the end of the visit, thank the patients and staff for allowing you to visit and offer your contact information for future reference.
- Document each visit and report to the Network. Remember to keep a copy of your report and Site Visit Checklist.
Notes:
SECTION 4: PAC FORMS, RESOURCES AND HANDOUTS

The forms on the next pages are for use by chairpersons as well as facility representatives. Completed forms may be faxed or mailed to the Network. Additional copies of these forms are available from the Network or can be downloaded from the Network Website:

http://esrdny.ipro.org/overview/

1. Grievance Policy Verification Form – Use the provided form to verify the facility grievance form has all of the necessary elements and is visible to all patients.

2. PAC Representative Personal Profile – Use this form to update the Network with your profile.

3. PAC Representative Contact Form – Make copies of this form to use when discussing concerns, complaints or comments from patients or staff. Use a new form for each contact. Include as much detail as possible.

4. PAC Representatives Activity Summary – If you are very active in your unit, you can fax copies of your reports to the Network to keep the Network informed of your activities. These reports are very helpful in keeping your activities organized.

5. Emergency Training: How to disconnect from a dialysis machine – All capable patients should be trained in what to do if there is an emergency at their facility. This training MUST be done once a year.

6. Tips for Positive Communication – Communications guidelines

7. Problem Solving Tips

8. Patient Rights and Responsibilities – Refer to this often, reminding patients of them when the opportunity presents itself. This is an excellent tool to use when invited to speak at facility meetings.

9. Patient & Family Engagement Dialysis Facility Site Visit Checklist – To be used by PAC Chairs when making a facility visit

10. A Brief List of Kidney Patient Organizations – We encourage you to be a part of the kidney community in addition to being a PAC Member.
Grievance Policy Verification Form

Dialysis Unit Name_______________________________ Date_________________

PAC REP/Chair Name:________________________________________________

To help assure the availability and implementation of the Grievance Process in all facilities, a PAC representative will complete the checklist and return it to the Network.

1. Is the Grievance Policy posted where patients can see it?   YES ___ NO____

2. Does it list names of people on the Grievance Committee?  YES ___ NO____

3. Does it list the name of the physician?   YES ___ NO____

4. Does it list the name of the social worker?   YES ___ NO____

5. Does it list the name of the registered nurse?   YES ___ NO____

6. Does it list the name of the administrator?     YES ___ NO____

7. Does it list the name of a patient?   YES ___ NO____

8. Does it include the address of the ESRD Network?   YES___ NO____

9. Does it include the address of the NYS Department of Health? YES___ NO____
PAC Representative Personal Profile

Please fill out and ask your SOCIAL Worker to FAX to the NETWORK (516) 326-8929

NAME____________________________________________DATE__/__/____

UNIT _____________________________________________________________

BRIEF PERSONAL BACKGROUND:

HOW DO YOU HANDLE ACTIVITIES AS A PAC REP (YOUR OWN PERSONAL PHILOSOPHY)

VOLUNTEER/EMPLOYMENT HISTORY

WHAT DO YOU SEE AS BEING A REP’S MOST IMPORTANT FUNCTION?

WHAT WAS THE MOST REWARDING EXPERIENCE YOU HAVE HAD?

BRIEF PERSONAL COMMENTS, THOUGHTS, AND WISHES? (FEEL FREE TO CONTINUE ON SEPARATE PAGE)
PAC Rep Contact Form

(for your use only- do not give to facility staff)

Received from: Submitted by______________________________

☐ Patient
☐ Staff Member

Unit______________________________

Nature of contact: Date______________________________

☐ Inquiry
☐ Suggestion
☐ Complaint

Summary of patient/staff comments:

Expected Outcome:
PAC Representative Activity Summary

Quarterly Report

1) Communication with patients in my unit (*BRIEF COMMENTS*):

2) Communication with staff in my unit (*BRIEF COMMENTS*):

3) Unit PAC Meetings attended within the last 4 months:
   (Please list dates and places)

4) Have you been receiving *Kidney Chronicles* from the unit social worker and distributing copies to patients? Yes______  No______

5) Where do you usually talk to patients in your unit?

6) Is there an active support group in your unit? If so, briefly describe its purpose, frequency of meeting and who leads it.

7) What are the most important issues of concern in your unit?

8) Do you have any suggestions for stories in *Kidney Chronicles* or the *PAC Speaks* that might involve patients, staff or activities in your unit?

Comments:

NAME________________________________________DATE__/__/____

UNIT________________________________________
Tips for Positive Communication

1. **Stay Focused:** Sometimes it’s tempting to bring up past seemingly related conflicts when dealing with current ones. Unfortunately, this often clouds the issue and makes finding mutual understanding and a solution to the current issue less likely, and makes the whole discussion more taxing and even confusing. Try not to bring up past hurts or other topics. Stay focused on the present, your feelings, understanding one another and finding a solution.

2. **Listen Carefully:** People often think they’re listening, but are really thinking about what they’re going to say next when the other person stops talking. Truly effective communication goes both ways. Don’t interrupt. Don’t get defensive. Just listen and reflect back what they’re saying so they know you’ve heard. Then you’ll understand them better and they’ll be more willing to listen to you.

3. **Try To See Their Point of View:** Most of us primarily want to feel heard and understood. We talk a lot about our point of view to get the other person to see things our way. Ironically, if we all do this all the time, there’s little focus on the other person’s point of view, and nobody feels understood. Try to really see the other side, and then you can better explain yours. (If you don’t ‘get it’, ask more questions until you do.) Others will more likely be willing to listen if they feel heard.

4. **Use “I” Messages:** Rather than saying things like, “You really messed up here,” begin statements with “I”, and make them about yourself and your feelings, like, “I feel frustrated when this happens.” It’s less accusatory, sparks less defensiveness, and helps the other person understand your point of view rather than feeling attacked.

5. **Look for Compromise: Solutions That Meet Everybody’s Needs.** This focus is much more effective than one person getting what they want at the other’s expense. Healthy communication involves finding a resolution that both sides can be happy with.
Problem Solving Tips

- Be calm
- Make notes so that you will remember everything
- If it is a medical issue, speak to your nurse manager or doctor first
- If non-medical, speak to appropriate staff member
- Do not be confrontational
- Always try to resolve the issue at your facility first
- Write a letter to your facility Grievance Committee
- Request a meeting with the facility Grievance Committee
- Call the Network if you need any assistance along the way

If you aren't satisfied with the care you receive at your facility, we are available to answer any questions or concerns that you may have.

We will help you to resolve your issues or file a complaint or grievance.

ALL CALLS ARE CONFIDENTIAL

Call us Toll Free: 1-800-238 ESRD (3773)
Patients' Rights and Responsibilities

As a person with kidney failure, you have certain rights and responsibilities. When you go to a treatment center, ask for a copy of your rights and responsibilities. This will help you know what to expect from your health care team and what they can expect from you. Your center may have lists like the following:

Your Rights

- I have the right to be told about my rights and responsibilities.
- I have the right to be treated with respect.
- I have the right to privacy. My medical records can’t be shared with anyone, unless I say so.
- I have the right to meet with my whole health care team to plan my treatment.
- I have the right to see the dietitian for help with food planning and the social worker for counseling.
- I have the right to be told about my health in a way that I understand.
- I have the right to be told about and to choose my treatment options.
- I have the right to be told about any tests ordered for me and the test results.
- I have the right to be told about the services offered at the center.
- I have the right to be told about the process of dialysis and dialyzer re-use.
- I have the right to be told about any expenses that I have to pay for if they are not covered by insurance or Medicare.
- I have the right to be told about any financial help available to me.
- I have the right to accept or refuse any treatment or medicine my doctor orders for me.
- I have the right to be told about the rules at the treatment center (for example, rules for visitors, eating, personal conduct, etc.)
- I have the right to choose if I want to be part of any research studies.

Your Responsibilities

- I need to treat other patients and staff as I would like to be treated, with respect.
- I need to pay my bills on time. If this is hard for me, I can ask about a payment plan.
- I need to tell my health care team if I refuse any treatment or medicine that my doctor has ordered for me.
- I need to tell my health care team if I don’t understand my medical condition or treatment plan.
- I need to be on time for my treatments or when I see my doctor.
- I need to tell the staff at the center if I know that I'm going to be late or miss a treatment or visit with my doctor. [Remember: Missing Treatments will shorten your life. If you have to miss a treatment, notify your center and try to re-schedule as soon as possible]
- I need to tell my health care team if I have medical problems, am going to the dentist, am being treated by another doctor, or have recently been to the hospital.
- I need to follow the rules of the center.
- I need to get to and from the center for my treatments. I can talk with my social worker if I need help doing this. Medicare does not pay for transportation.

New York State Patient Rights

Source: NY State Dept of Health

751.9 Patients' rights. Policies and procedures shall be developed and implemented regarding the patients’ rights. The operator shall have in effect a written statement of patients’ rights which is prominently posted in patient care areas and a copy of which is given to the patient. Such statement shall include the patients' rights to:

(a) receive service(s) without regard to age, race, color, sexual orientation, religion, marital status, sex, national origin or sponsor;
(b) be treated with consideration, respect and dignity including privacy in treatment;
(c) be informed of the services available at the center;
(d) be informed of the provisions for off-hour emergency coverage;
(e) be informed of the charges for services, eligibility for third-party reimbursements and, when applicable, the availability of free or reduced cost care;
(f) receive an itemized copy of his/her account statement, upon request;
(g) obtain from his/her health care practitioner, or the health care practitioner’s delegate, complete and current information concerning his/her diagnosis, treatment and prognosis in terms the patient can be reasonably expected to understand;
(h) receive from his/her physician information necessary to give informed consent prior to the start of any nonemergency procedure or treatment or both. An informed consent shall include, as a minimum, the provision of information concerning the specific procedure or treatment or both, the reasonably foreseeable risks involved, and alternatives for care or treatment, if any, as a reasonable medical practitioner under similar circumstances would disclose in a manner permitting the patient to make a knowledgeable decision;
(i) refuse treatment to the extent permitted by law and to be fully informed of the medical consequences of his/her action;
(j) refuse to participate in experimental research;
(k) voice grievances and recommend changes in policies and services to the center's staff, the operator and the New York State Department of Health without fear of reprisal;
(l) express complaints about the care and services provided and to have the center investigate such complaints. The center is responsible for providing the patient or his/her designee with a written response within 30 days if requested by the patient indicating the findings of the investigation. The center is also responsible for notifying the patient or his/her designee that if the patient is not satisfied by the center response, the patient may complain to the New York State Department of Health's Office of Health Systems Management;
(m) privacy and confidentiality of all information and records pertaining to the patient's treatment;
(n) approve or refuse the release or disclosure of the contents of his/her medical record to any health-care practitioner and/or health-care facility except as required by law or third-party payment contract;
(o) access his/her medical record pursuant to the provisions of section 18 of the Public Health Law, and Subpart 50-3 of this Title;
(p) authorize those family members and other adults who will be given priority to visit consistent with your ability to receive visitors; and
(q) make known your wishes in regard to anatomical gifts. You may document your wishes in your health care proxy or on a donor card, available from the center.

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2 This is what should be posted for a free standing dialysis facility. If your facility is Hospital based, there will be a different set of rights.
Patient & Family Engagement Dialysis Facility Site Visit Checklist

Please Fax to the Network at: (516) 326-8929

Facility Name__________________________________________________ Facility CCN #__33-________

# of Staff_________ Date Visited__________ Is facility a 5 Diamond Facility? ________________

Network Staff/PAC Chair: __________________________ Title: ________________________________

Met with Staff/Titles:_______________________________________________________________

DIGNITY AND RESPECT

Staff listens to and honors patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into care planning and decision-making.

- Are Patient Rights and Responsibilities posted? __________
- Is the PSC Posted?_________________________________
- Do Patients/Staff have any questions RE: the QIP or PSC?_________________________________________

INFORMATION SHARING

Staff communicates and shares complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, accurate information in order to effectively participate in care and decision-making. Review for the presence of patient and family meetings (e.g., patient council, support groups, vocational rehabilitation groups, new patient adjustment groups)

- Does the facility convene or publicize Patient and Family Meetings? ________________________

PARTICIPATION

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose. Review and discuss policy and procedures related to family participation in the patient’s care such as involvement in the development of the individualized plan of care and cannulation

- Total Patient Census: _________
- How many patients and/or family members/care partners participate in plan of care meetings? ______ (Estimate)
- Do you review Policies and Procedures and Patient Rights and Responsibilities with patients and family members at annual care plan meeting? ______

COLLABORATION

Patients, families, and providers collaborate in policy and program development, implementation, and assessment; in health care facility design; and in professional education, as well as in the delivery of care. Review and discuss patient and family involvement in the governing body of the facility

- Do Patients/Family Members/Care Partners Participate in the Quality Assurance Performance Improvement Program? __________
- Is there a Patient/Family Member/Care Partner on the Governing Body of the Facility? __________
- Is there a Patient/Family Member/Care Partner on the Grievance Committee? __________________
A Brief List of Kidney Patient Organizations

**American Kidney Fund (AKF)  [www.akfinc.org]**
The AKF is a voluntary health organization providing direct financial assistance for the benefit of kidney patients. It has helpful information on financial assistance programs, lifestyle ideas, and kidney disease facts.
Phone:  (301) 881-3052  Toll-free HelpLine:  (800) 638-8299
E-mail:  helpline@akfinc.org

**American Association of Kidney Patients (AAKP)  [www.aakp.org]**
The focus of the AAKP is to provides renal-specific information on patient education, conventions, and newsletters that assists patients in becoming active participants in planning and managing their CKD.
Phone:  (813) 636-8100  Toll-free:  (800) 749-2257  E-mail:  info@aakp.org

**Dialysis Patient Citizens  [www.dialysispatients.org]**
DPC is a dialysis patient organization, dedicated to improving dialysis patients’ quality of life by developing awareness of dialysis-related issues, advocating for dialysis and pre-dialysis patients, improving the partnership between patients and caregivers, and promoting favorable public policy.
Phone (toll-free):  (866) 877-4242  E-mail: dpc@dialysispatients.org

**Home Dialysis Central**  Website:  [www.homedialysis.org]
Learn about all the options for home dialysis, including a listing of every center in the US offering this modality of treatment, equipment and new technology, patient profiles, Medicare reimbursement, discussion boards, and how pending laws may affect dialyzing at home.
Phone:  (608) 833-8033  E-mail: info@homedialysis.org

**I HateDialysis.com (IHD)**  Website:  [www.ihatedialysis.com/forum]
I HateDialysis is a website/forum for patients, by patients. We are not negative, we hate dialysis - but we love life. A supportive community that helps both new and veteran patients cope with the daily struggles of living with kidney disease.
E-mail:  admin@ihatedialysis.com

**National Kidney Foundation (NKF)** Website:  [www.kidney.org]
The National Kidney Foundation is dedicated to the awareness, prevention and treatment of kidney disease for healthcare professionals, patients and their families, and Americans at risk.
Phone:  (800) 622-9010  E-mail: info@kidney.org

**Northeast Kidney Foundation (NeK)**  Website:  [www.healthykidneys.org]
The Northeast Kidney Foundation is a voluntary health organization dedicated to preventing kidney disease and enhancing the lives of all those affected. NeK operates many Kidney Clubs throughout NY and New England.
Phone:  800-999-9697 Email:  info@healthykidneys.org

**Renal Support Network (RSN)**  Website:  [www.RSNhope.org]
Renal Support Network (RSN) values people with kidney disease and helps them become self-sufficient through education, advocacy and employment resources. RSN is a nonprofit, patient-focused, patient-run organization.
Phone:  (818) 543-0896  Email:  info@RSNhope.org
SECTION 5: EMERGENCY PREPAREDNESS

Emergencies caused by severe weather or disasters can happen with or without warning. If you need dialysis, having power and water, transportation, or supplies may be very important. Some emergency situations may make it impossible for you to get to your dialysis facility or give yourself dialysis. It is important to be prepared so you can feel better and stay healthier.

The Network works with Federal, State and local government agencies as needed to assist with patient safety and keep dialysis facilities up and running during and after any emergency situation.

As a PAC Member, you can be an important link for your fellow patients to be prepared for an Emergency. If you have provided an e-mail address to the Network, you will receive copies of all Emergency Notices sent during any wide scale emergency situations. The following “TIP Sheets” were developed to help you and your fellow patients during an emergency.

On the following pages:

- General Emergency: Tips for People on Dialysis
- Emergency Diet Guidelines (Available in English and En Español)
- How to get off a Dialysis Machine (Fistula or Graft)
- When to call 911 (Available in English and En Español)
- Extreme Summer Heat: Tips for People on Dialysis
- Snowstorm Health: Tips for People on Dialysis
General Emergency: Tips for people on dialysis
From the IPRO ESRD Network of New York ESRD Disaster Preparedness Coalition (EDPC)

1. Stay at home unless you are hurt, as long as it is safe to do so. Instructions for dialysis patients may be available on TV, radio, or by phone or messenger. Depending on the nature of the emergency, you might want to call your dialysis facility or doctor, because he or she might be able to help you manage this emergency.

2. Take a fanny pack or backpack stocked with emergency supplies, food, and medication with you if you will be away from home when severe weather or a natural disaster is predicted.

3. Make sure your dialysis facility knows where to find you.

4. Start your emergency diet as soon as an emergency situation is predicted or occurs, if it could delay your next regular dialysis treatment.

5. If you must go to a shelter, tell the person in charge about your special health needs.

6. If you need medical treatment, make sure your dialysis access is not used for anything other than your dialysis treatment. No one should use your access to give you fluid or medication.

Travel Tips

* Make arrangements for dialysis at your destination, or have necessary equipment or supplies delivered ahead of time.

* Carry an extra 2-3 day supply of all your medicines/supplies in your hand-carried luggage and keep it with you at all times. A fanny pack or backpack may be more convenient. If your luggage is lost or misplaced, you will still be able to take your medicine until it is found or you can get another supply

Most of this is what to do after the event, but number four (Start Your Emergency Diet) is key for the unique situation of a hurricane; Especially a hurricane hitting a part of the country that is vulnerable to widespread and prolonged power outages. You have the opportunity to act ahead of the event.

Remember: If you call 911 the ambulance ride will be ONE WAY, and will ONLY take you to the hospital. Hospitals may not do dialysis treatments unless you are in distress, or it is medically indicated that you need dialysis immediately.
Emergency Diet Guidelines: Tips for people on dialysis  
From the IPRO ESRD Network of New York ESRD Disaster Preparedness Coalition (EDPC)

Fluid

- Fluids need to be restricted further. A total of 2 cups a day for three days should prevent symptoms of shortness of breath and fluid buildup.
- Drink only 4oz of fluid with meals (total 1.5 cups fluid). This leaves ½ cup to take with medications.
- Incorporate phosphate binders into fluid allowance.
- Chew gum for thirst.
- Limit fresh fruit and vegetables. Keep a supply of canned fruit and vegetables on hand. Drain extra fluid from canned products. Always purchase "no salt added" canned vegetables, and if you have diabetes, purchase light or no-sugar added products.

Sodium

- Avoid table salt and salt substitutes.
- Flavor/Season foods with fresh or powdered onion, garlic, spices, herb blends, vinegar or lemon juice.

Remember: Many products marked “low sodium” can also be high potassium. When buying packaged food, use the Nutrition Facts label to check salt/sodium content. Use the % DV to look for foods that are low in sodium and low in potassium (potassium is not always listed on food labels). Avoid "low sodium" foods which list "potassium chloride" on the ingredients label.

Potassium

- Avoid fruits and vegetables high in potassium.
- Keep a list of high potassium foods on your refrigerator.
- Avoid high potassium fruits: e.g., apricots, bananas, dates, honeydew melon, kiwifruit, nectarine, oranges, orange juice, prune juice, prunes, and raisins.
- Avoid high potassium vegetables: e.g., artichokes, avocado, fresh beets, brussels sprouts, chard, “greens” (beet, collard and mustard), okra, parsnips, potatoes, pumpkin, rutabagas, spinach, sweet potatoes, tomatoes and tomato sauce, winter squash and yams.
- Other foods to avoid: bran, dried beans & peas, nuts, potato chips, salt substitute, soy or nut milk, yogurt.

Tip: Purchase light or no-sugar added fruit such as pineapple, pears, mixed fruit (drain extra fluid from can). Read the labels carefully (for low salt/sodium and low potassium) on any canned vegetables.

Good choices are: string beans, corn, carrots, peas, cauliflower or canned beets.

If you have electricity and internet access, the booklet: Guide for People on Dialysis: Preparing for Emergencies, is available on line. It provides a three-day emergency diet and other helpful information.

How to Get off a Dialysis Machine in an Emergency Evacuation
From the IPRO ESRD Network of New York ESRD Disaster Preparedness Coalition (EDPC)

Fistula or Graft

Your dialysis facility staff should show you what to do if you are on a dialysis machine in an emergency. The instructions should include where your emergency pack is kept and how to disconnect yourself from the dialysis machine. An emergency pack usually contains scissors, tape, clamps and other medical items and should be kept within your reach while you are on the dialysis machine.

If you are on a dialysis machine during an emergency, stay calm and wait for instructions from the facility staff. If no staff person is available to help you or give you directions, here is what to do. Remember, these directions are for emergency evacuation situations only. Your access needles should be left in place until you get to a safe place. NEVER cut your access needle lines.

How to Clamp and Disconnect (Review with your medical staff first!)

- Clamp both access needle lines.
- Clamp both of the thicker blood lines. If the lines have pinch clamps, pinch all four clamps closed. Cut or unscrew the lines between the closed clamps. If you must cut your lines, cut only the thicker blood lines.
- NEVER, NEVER cut your access needle lines. NEVER cut the line between the clamp and your access – you will bleed to death.
- If you have a CATHETER, your professional staff should assist you. Do not try to disconnect yourself.

After you have been disconnected from your dialysis machine, go to the designated safe area. Wait for directions from the person in charge. This person could be a dialysis facility staff member, or emergency personnel such as a paramedic, police officer, or firefighter. Do not remove your access needle until you have been checked by medical personnel, or until you are sure that you are in an area out of immediate danger.

Under no circumstances should any medical personnel unfamiliar with your dialysis status place or inject anything into your vascular access.
Emergency Guidelines:  
Signs & Symptoms of Distress and When to Call 911  
Tips for people on dialysis  
From the IPRO ESRD Network of New York ESRD Disaster Preparedness Coalition (EDPC)  

If you experience any of these symptoms, call 911

<table>
<thead>
<tr>
<th>Changes in breathing patterns:</th>
<th>Intense headache</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Unable to sleep at night due to difficulty breathing</td>
<td>- Sudden generalized weakness</td>
</tr>
<tr>
<td>- Heavy, labored breathing</td>
<td>- Chest pain</td>
</tr>
<tr>
<td>- Difficulty breathing</td>
<td>- Nausea, vomiting</td>
</tr>
<tr>
<td>Swelling throughout the body</td>
<td>- Bleeding i.e. blood in vomit, or black tarry stool; any excessive bleeding</td>
</tr>
<tr>
<td>Confusion</td>
<td>- Abdominal pain</td>
</tr>
<tr>
<td>Any sudden changes in access</td>
<td>- Fever</td>
</tr>
<tr>
<td>Unusually high blood pressure</td>
<td></td>
</tr>
</tbody>
</table>

Remember: If you call 911 the ambulance ride will be ONE WAY, and will ONLY take you to the hospital. Hospitals may not do dialysis treatments unless you are in distress, or it is medically indicated that you need dialysis immediately.
Extreme Summer Heat: Tips for Dialysis Patients*

From the IPRO ESRD Network of New York ESRD Disaster Preparedness Coalition (EDPC)

When it’s hot outside, it can be even hotter inside. Air conditioning can be a life saver. You can be safe, comfortable, and save money by setting your air conditioner to 78° or low cool.

- Use your air conditioner when you are at home. Fans alone will not keep you cool when it is really hot outside.
- If you do not have an air conditioner:
  - Go to a cool place like a library, a friend’s home with air conditioning, or a cooling center.
  - Call your county department of health and ask “Where is the cooling center nearest to me?”
- Try to stay in the shade. Exposure to the sun causes perspiration and the urge to drink.
- Avoid strenuous physical activity.
- Wear light, loose-fitting clothes.
- If you’re really thirsty try sucking on an ice cube, a piece of hard candy or a wedge of lemon or lime to help quench your thirst.
- Frozen grapes, pineapple chunks or frozen cubes of apple or cranberry juice are also refreshing.
- Brush your teeth often. It cleans your teeth, freshens your mouth and lessens the urge to drink.
- If you really have to drink, sip slowly rather than gulping the whole glass down.
- Avoid salty and spicy foods; they can make you thirsty.
- If you have diabetes, maintain good blood sugar control. High blood glucose can make you thirsty.

Recognize the symptoms of too much heat

Call 911 or go to the emergency room right away if you or someone you know has symptoms of heat illness, such as:

- Hot, dry skin OR cold, clammy skin
- Weakness
- Dizziness
- Nausea or vomiting
- Trouble breathing
- Confusion, hallucinations, disorientation

*Adapted from: NYC DOH, OEM and Dept for the Aging: Summer Heat It’s Enough to Make You Sick and http://dialysispostings.com/beat-the-heat/
Snowstorm Health: Tips for people on dialysis
From the IPRO ESRD Network of New York ESRD Disaster Preparedness Coalition (EDPC)

If you are on dialysis, it is important that you are prepared for any changes in your treatment schedule due to an emergency.

If it is possible, you should have an emergency stock of supplies, food and medicines.

If you are on Home Dialysis, it is important that you are prepared for the possibility of delivery delays and power outages. Watch the weather forecasts, if a snowstorm is coming, start your treatment earlier rather than later in case there are power interruptions.

Remember, if there is a storm and it affects electricity, having warm blankets, gloves and a hat on hand can help prevent hypothermia. Generally, if there's no electricity, there's no heat.

If a snowstorm makes it impossible for you to get to dialysis:

- Call your facility as soon as possible for guidance about what you should do.
- Be more careful than ever about following your dietary restrictions and limiting fluid intake.
- You need to start the Emergency Diet as soon as you know that you will be missing treatments.
- If you are running out of prescription medications and can’t leave your home, ask a friend, relative or neighbor for help.
- If you must go to a shelter, tell the person in charge about your medical needs (the type and frequency of your dialysis).
- If you have to leave home, make sure your dialysis facility knows where to find you.
SOCIAL MEDIA (FACEBOOK, TWITTER)

Facebook

The Network has a Facebook Page that shares information on living with ESRD in New York State. Please “Like” the page, and share the information with your friends and family.

Facebook: @ESRDNW2

Twitter

Please follow us on Twitter. The Network uses Twitter as an Emergency Messaging Channel #ESRDNetwork2

During an emergency event, the Network will update its Emergency Preparedness and Response webpage with facility closures, and other information as it becomes available. The Network also sends updates (weather/services/resources) frequently via e-mail.

The Network works with Federal, State and local government agencies as needed to assist with patient safety and keep dialysis facilities up and running during and after any emergency situation.
Do You Have Questions?

About:

- Health Insurance
- Job Training
- Discrimination on the Job
- Being a part of the PAC or Learning and Action Networks (LANs)
- Filing a Grievance (Complaint)

Contact us at the Network Office:

IPRO/ESRD Network of New York
1979 Marcus Ave.
Lake Success, NY 11042-1002

Toll Free Patient Telephone: (800) 238-ESRD (3773)
Main Phone: (516) 209-5578
Fax: (516) 326-8929 E-mail: info@nw2.esrd.net

Web site: esrd.ipro.org

For more information or to file a grievance, please contact:
ESRD Network of New York 1979 Marcus Avenue, Lake Success, NY 11042-1072
Patient Toll-Free: 800 238-3773 E-mail: info@nw2.esrd.net www.esrdny.ipro.org
THANK YOU!

Living with ESRD: You can do it, WE can help.

Living with kidney failure is not easy. It can be a daily struggle for patients, their family members, and care partners just to survive. By volunteering your time to work with your dialysis provider, other patients, and the Network, you are helping everyone to have a better life.

In 2009, the Network received a National Special Recognition for the work of the PAC from the Centers for Medicare & Medicaid Services.

The Award was earned because of the effort of all Patient Advisory Committee members, and it would not exist were it not for the dedication and work of patient volunteers just like YOU.

May 2014: A special THANK YOU to the PAC Members & Facility Staff who put so much effort into creating, editing, and reviewing this manual:

**Current & Former PAC Chairs**
*(In alphabetical order)*

Aaron Battle  
Barbara Breckenridge  
Brenda & Ron Maeder  
Dawn Edwards  
Elizabeth Credele  
Evelyn Davis  
Frank Ireland  
Gemma Baptiste  
Harold Jones  
Hazel Parker  
Kathe LeBeau  
Kim Healy  
Lachyel Vaughn  
Larry Wilson  
Laura Joseph  
Lorraine Langdon  
Margaret Vinson  
Monica Richter  
Nelson Nuñez  
Osmond Adams  
Peter Savage  
Richard Atkinson  
Richard Gallagher  
Shane Carmen Dietz  
Vickie Kiedel  
Vivian Davis  
Vivian King  
Warren Edmonds  
Wendy Rivers  
William Williams

**Facility Staff**

Sue Barra, RD  
Maureen Hutcheon, LMSW, MPA  
Victoria Malara, RN, BA  
Deborah Warden, LCSW
Ways you can be AWARE!

Ask Questions
Wash Your Hands
Alert Staff to Anything Abnormal
React Calmly, Professionally and Quickly
Educate Yourself

Be Aware! Be Healthy!

- **Medications** – Know what kinds of medicine you take and know about your dialysis prescription.
- **Access** – Protect your arm (or where your access is).
- **Diet** – Know what foods are good and safe for you to have. Know how much fluid is safe for you to have.
- **Advocacy** – Speak up for yourself! Or ask your social worker to help you.

Edited and reviewed by the ESRD Network of New York’s Patient Advisory Committee, whose representatives work to improve quality of life for kidney patients.

This material was prepared by IPRO End-Stage Renal Disease Network of New York, the ESRD Organization for New York State, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy.

CMS Contract Number: HHSM-500-2013-NW002C