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End-Stage Renal Disease Network of New York
1979 Marcus Avenue
Lake Success, NY 11042-1002
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IPRO ESRD Network of New York

Patient Advisory Committee Manual

Susan Caponi
Executive Director

02/08/12
Date

REVISION HISTORY		
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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 this position 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 Patient Representative, you'll be receive mailings on various issues from us, so please keep us 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 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: *PAC Notes* in the Spring/Summer & Fall/Winter (in English and Spanish); and *PAC Chairs Speak* which is a two page, more frequent newsletter written by our PAC Chairs. Hopefully you are familiar with these publications, and please feel free to suggest future subjects that you would like covered.

Please feel free to contact the PAC Coordinator at the Network with any questions, concerns 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)
<http://www.ipro.org/index/pac>

Thank you again for volunteering your time and energy to help provides 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.

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 26,932 patients who are receiving treatment for ESRD during 2010.

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 1 of 18 ESRD Network Organizations under contract to 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 the patients and providers within the Network 2 area.

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.

The IPRO ESRD NETWORK of New York Patient Advisory Committee:

The Patient Advisory Committee, through its representatives in dialysis and transplant units, provides a link between patients and unit staff and opens opportunities for statewide communication for those in the renal community.

The Patient Advisory Committee (PAC) of the End Stage Renal Disease Network of New York is a statewide organization of patients or family members who volunteer their time to represent the Network to their unit and 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 in a team effort to address concerns and improve quality of care.
- 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.
- PAC reps at some units get involved in developing social activities to promote a sense of community in the unit. Examples would be organizing a bus trip to a picnic or other recreational area, or, having a group of patients volunteer to visit hospitalized patients, or, having an annual

vote among the patients for best staff person of the year, then arranging a ceremony to acknowledge the winner.

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SECTION 1: MEMBERSHIP REQUIREMENTS

PAC REPRESENTATIVE MEMBERSHIP

PAC Representatives are ESRD 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 life satisfaction 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 reps may be on hemodialysis, PD or have had a transplant; however, they must spend regular time at the unit. Many PD or transplant reps continue contact by working with the facility's support groups and others simply make it a point to continue visiting.

In certain cases, spouses of renal patients may serve as reps 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 rep since PAC activities take place within the framework of mutual understanding and cooperation between the staff and the representative.

Currently, more and more units are designating reps for each shift. 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 rep on every shift is the ultimate goal of the Patient Advisory Committee 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. Once facility staff designates a PAC representative, the "Patient Advisory Committee Representative Update Form" must be faxed to the Network office. The form is available for download at <http://www.ipro.org/index/pac>.

Orientation of new PAC Representatives

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

TERMS OF OFFICE

Designation as a PAC rep is automatically renewed every two years by mutual agreement between patient and facility staff. Resignation by a representative requires immediate notification to the Network by unit 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 facility staff and the Network.

MEETING ATTENDANCE

There will be at least one meeting per year conducted by the Network and Regional Chairperson in your local area. **Responses to these meeting notices are mandatory, whether you are attending or not.** Reps are strongly encouraged to attend the meeting as it is part of the role of a PAC Rep.

ACTIVITY REPORTS

PAC Representatives can utilize the *PAC Representative Activity Summary* form in section 3 of this manual. The completed reports can be kept in the manual with copies sent to the Network. In addition, these activity reports can be discussed at the regional PAC chairperson meetings. 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.

SECTION 2: PAC REPRESENTATIVE ROLES AND RESPONSIBILITIES

This section contains guides to help you in your work and educational material relevant to PAC activities. Included are the requirements for Patient Advisory Committee Representatives and Regional Chairpersons.

PAC REPRESENTATIVE MEMBERSHIP

ROLES

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

RESPONSIBILITIES

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

These are the basic roles and responsibilities of the Network's Patient Advisory Committee Representatives. However, individual differences in personality, approaches and preferences allow representatives to fulfill these responsibilities differently. Always remember that your primary role is to represent the patients in your facility to the Network and unit staff members.

IMPLEMENTATION OF ROLES AND RESPONSIBILITIES

Promote 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 PAC Notes to patients
- Regularly scheduled meetings with unit administrative staff with minutes on file
- Bulletin board space for Network announcements and PAC notices

Include yourself in this responsibility. Remember that your contact in the unit is usually the social worker and he or she has many duties in addition to the PAC.

Share your understanding of this fact with other patients and encourage an atmosphere of mutual respect and understanding between them and all facility staff members.

Inform patients about ESRD Network.

In order to do this, you must get to know the patients and establish good communication within a comfortable relationship.

Fundamental rules of a successful dialogue include:

- Approach patients as a peer to encourage open, frank 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 resource lists, staff professionals, or the Network.
- Refrain at all times from giving 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.
- If the case is medical or facility related, encourage patient to speak with their doctor or nurse manager.
- If the complaint is non-medical, direct the patient to the appropriate staff member.

Serve as a link between patients and the ESRD Network.

- Introduce yourself as a PAC representative to patients and make it clear that you are available to listen to any problems they may have or simply to spend time talking. Your ID badge will assure that you are known to both patients and staff members.
- 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 unit staff members of these expressed concerns and suggestions when appropriate.
- If there are any suggestions for the Network, you may use the form entitled, “Suggestions for the Network” in Section Three.
- If you have suggestions of your own, discuss them with patients, note comments and ideas (no matter how impractical they seem at the time).
- Be on the lookout for ways to add humor and lightness to dialysis days, and then, and most important, write these down on the PAC REP CONTACT form provided in the Manual and forward them to the Network.

Attend PAC meetings.

There are two opportunities to attend PAC meetings:

- Ask your facility team about having scheduled meetings with unit administrative staff to improve communications between patients and staff.
 - Second, there will be at least one Annual Regional Patient Meeting in your area. Network staff will attend these regional meetings. Representatives are strongly urged to attend the regional meeting, and to publicize these meetings with patients and staff at their dialysis facility.
- **Help patients understand information provided by the Network.**

The unit social worker will receive copies of *PAC NOTES*, the ESRD Network’s patient newsletter, twice a year.

- Assist in distributing them to patients. These 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 material supplied by the Network such as forms, brochures, questionnaires or similar publications.

Professionalism with unit staff and peers

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 – 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 facility staff have many tasks in addition to assisting PAC reps.

Also, have respect for, and be sensitive to, your fellow patients’:

- Cultural differences
- Individual feelings
- Personal attitudes
- General preferences

And, most important, respect yourself. Maintain a calm, dignified, non-confrontational manner that will invite mutual respect between you, patients and staff.

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 unit staff members.

Hopefully, you will also provide comfort and support by listening and sharing personal experiences in an honest but positive manner.

However, you must refrain from giving medical advice of any kind or commenting on specific orders of medical professionals

- Encourage patients to have a positive, confident relationship with their physician that includes an ongoing dialogue regarding treatment decisions and questions.
- Do not discuss or compare your own treatment and its results.
- Do not criticize a patient’s physician in any way.
- Do not imply doubt or negativity concerning details of a patient’s treatment plan. If they have concerns about their treatment plan refer them to the physician or staff nurse.

SECTION 3: PAC CHAIR ROLES AND RESPONSIBILITIES

PAC chairs, in each of the eleven regions, are responsible for overseeing activities of PAC representatives serving in local dialysis facilities 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 a regional support group

For assistance in any of these projects, as in all PAC related activities, the Network is always available.

MEETINGS

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

TERMS OF OFFICE

Chairpersons are elected for two-year terms, which are renewable, by mutual agreement.

COMMUNICATION WITH PAC REPS

PAC chairpersons are supplied with listings of each PAC representative.

The list includes:

Names

Facility

PAC rep telephone number

PAC rep e-mail address

If there is a reason for chairpersons to reach other reps, it should be done by use of the home phone number or e-mail address. **Do not call** the facility to speak to a representative. It is not encouraged that such calls be made to the unit with the expectation that social workers or staff members should deliver messages. If there is a need to contact all reps in your local area, the Network will be glad to do so by mail.

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 reps 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 reps in your area. Be sure to include the RSVP date and your phone number. The Network will cover the cost of light refreshments.
- Plan and write out important topics of discussion (if any) to be covered at the meeting. Send this with your invitation for printing by the Network.
- If you find it difficult to conduct the meeting and record minutes, ask someone in advance to act as secretary.
- Have each person fill out the “sign in” sheet. Send a copy of the minutes, and sign in sheet to the Network. This will be typed and mailed to all reps in the region.
- When you address patients in a meeting setting, many will have comments and questions, try to stick to the topics on the agenda, allowing the last hour for open discussion.
- Maintain control of the meeting and guide it within its time constraints. Politely quiet any member who is disruptive or infringing on the time of others, asking that they wait until the discussion hour. Allow everyone sufficient time to voice opinions and concerns and encourage those attending to be respectful of the opinions of others. Patients with complaints and grievances should be instructed to call the Network Office.

VISITING FACILITIES

One of the goals of the Patient Advisory Committee is to visit facilities without patient representation to recruit new PAC reps. These visits should be arranged through the Network. The Network will contact the facility to let them know that a Chairperson is interested in visiting. A date and time will be negotiated and the Chair will be informed of the arrangements.

- Call to confirm the appointment after receiving notification from the Network.
- On the first few visits, a Senior Chairperson or Community Outreach Coordinator will attend for support.
- Call the facility the day before for a final confirmation.
- Dress professionally and arrive early.
- Take a look at the patient waiting area, check for:
 - Network contact information
 - Grievance Policy with Department of Health contact information
 - Patient's Bill of Rights
 - PAC Notes
 - Dialysis Facility Performance Score Card
- Make friendly contact with everyone, especially patients in the waiting area, introduce yourself and tell them where you are from.
- If you are a guest speaker at a patient meeting, prepare index cards with information to discuss.
- 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 volunteer your contact information for future reference.
- Document each visit and report out to the Community Outreach Coordinator, keep a copy to include in your report for the Annual Meeting.

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.

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 Rep 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.
3. **PAC Representatives Activity Summary (Quarterly Report)** – These quarterly reports are very helpful in keeping your activities organized. Send them in to the Network every four months to keep the Network informed of your activities.
4. **PAC Rep Update Form** – Use this form for any address changes and/or give to your social worker to add or remove patient representatives from the Network database. Copies should be made for future reference.
5. **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.
6. **Emergency Take-Off Procedure** – All capable patients should be trained in this procedure at least once annually.



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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 ___

PERSONAL PROFILE

PAC REPRESENTATIVE OF ESRD NETWORK OF NEW YORK

NAME: _____ DATE _____

UNIT: _____

BRIEF PERSONAL BACKGROUND

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

VOLUNTEER AND 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?



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PAC REP CONTACT FORM

(for your use only- Do not give to facilities)

Received from: _____ **Submitted by**_____

- Patient**
- Staff Member** **Unit**_____

Nature of contact: _____ **Date**_____

- Inquiry**
- Suggestion**
- Complaint**

Summary of patient/staff comments:

Resolution:



**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 *PAC NOTES* 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 *PAC NOTES* that might involve patients, staff or activities in your unit?

Comments: _____

NAME _____ DATE ___/___/___

UNIT _____



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HOW TO GET OFF OF A DIALYSIS MACHINE IN AN EMERGENCY EVACUATION

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

- 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.



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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
- ❖ If it is not a personal issue, notify your PAC Representative
- ❖ Always try to resolve the issue at your facility first
- ❖ Write a letter to your Grievance Committee
- ❖ Request a meeting with the 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 at free number, 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.
- 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.

Source: <http://www.medicare.gov/Dialysis/Static/PatientRights.asp?dest=NAV|Home|Resources|PatientRights#TabTop>

New York State Patient Rights

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.

Source: NY State Dept of Health



End-Stage Renal Disease Network of New York
1979 Marcus Avenue
Lake Success, NY 11042-1002
(516) 209-5578
www.esrd.ipro.org

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Do You Have Questions About:

- Benefits
- Job Training
- Discrimination on the Job
- PAC Issues
- Filing a Grievance (Complaints)

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)

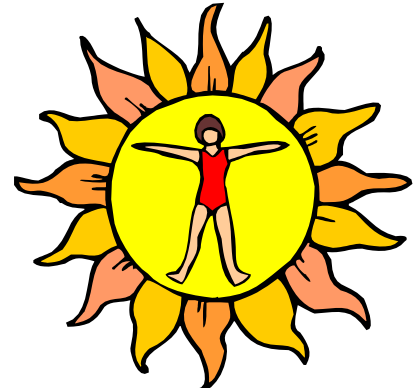
Main Phone: (516) 209-5578

Fax: (516) 326-8929

E-mail: info@nw2.esrd.net

Web site: esrd.ipro.org

Be Aware! Be Healthy!



Ask Questions

Watch Your Treatments

Alert Staff to Problems

React Quickly and Calmly

Educate Yourself

*Ways you can be **AWARE!***

- 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.

Presented by ESRD Network of New York and its Patient Advisory Committee (PAC),
whose representatives work to improve quality of life for kidney patients.

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