The Renal Network’s
Facility-Based Patient Representative Program

Patient Services Department
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Facility-Based Patient Representative Program

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Section 1: Introduction For Staff

Over the years the Network’s Patient Advisory Council Program has undergone a variety of transitions. Each change sought to make the program more responsive to patient needs for information and educational materials.

After a review and evaluation of the program’s operations, the Network’s Board of Trustees recommended that The Renal Network’s Patient Advisory Council Program (PAC) become a facility-based Patient Representative Program. The Network believes it is important to have identified patient volunteers involved in patient education and peer support activities. The Network also believes that each facility is in the best position to determine the ways to get patients involved in their facilities.

A transition to a completely facility-based program would make record keeping and follow-up simpler. No longer will staff be requested to send in the name of a PAC Representative and Alternate. Nor will staff be requested to submit an annual PAC Rep Activity Form. Thus, facilities can continue to run the program to fit their facility’s needs without the need to send information to the Network.

Advantages of Facility Based Patient Representative Program:

**Advantage of having a Patient Representative:**
- Patients adjust better to their chronic illness when they are knowledgeable of their disease and ways to cope with it.
- Patients also respond differently to patients sharing information than staff sharing it and patients often do better when they can relate to peers who also have the same illness.
- Patients can benefit from volunteer opportunities where they can “give back” to others and have valuable input to the facility staff.

**Advantages of having the program facility-based:**
- You no longer have to choose just one patient to represent your facility and its patient activities – you can start your own council made up of patients on all shifts
- Patients may be more inclined to be involved when they know they do not have to travel, will only report to the facility, and will determine all activities in conjunction with the staff
- You do not need to send in names for PAC Reps – you can keep it all at the facility level
- You will receive educational material periodically from the Network that you can share with your Patient Representative and determine how to best use it
- You will have more resources and likely more patient volunteers to help you implement programs
• You can continue to nominate exemplary patient volunteers for the Patient Leadership Committee – this committee has 3 year term of office and patients participate from all states and all modalities
• Facility Patient Reps can be liaisons between the staff and patients within the facility
• Patients often like to have peer support and your Patient Reps can provide it – we can provide you with the peer support training materials, The Patient-to-Patient Program, or we can conduct the one-day training program in your area.
• The Client Communication System (CCS) is facility-based and it is more consistent to have the whole program facility-based
• The Network can provide resources for health fairs, patient education days, etc.

Using this booklet:

The enclosed material is to be used as a guide to working with patients who want to volunteer or for working with current PAC Rep who will continue as your Facility-based Patient Representative.

It gives an overview of the Network and describes the levels of activity you might want to incorporate. It also describes the Client Communication System (CCS), which is one approach towards increasing communication between patients and staff.

You can find copies of many of the Network’s patient resources at the Network’s patient website, www.kidneypatientnews.org. Information about new patient resources will be sent to you as they become available.
Section 2: Overview of the Network

What are the end-stage renal disease networks?

In 1972, Medicare coverage was extended to individuals diagnosed with End-Stage Renal Disease (ESRD). A need to coordinate effective treatment was identified. So the Health Care Financing Administration (HCFA) established the End-Stage Renal Disease Networks for the purpose of monitoring the quality of care in dialysis facilities and transplant centers. The ESRD Networks were conceived to serve as both a monitoring organization and as a link between HCFA and the facilities and the patient population. In 1977, thirty-two such networks were set up to monitor delivery of care across the country. In 1986, the ESRD network system was reorganized into 18 regional offices.

In 1988, Tri-State Renal Network was awarded the contract for ESRD Network 9, which under the national reorganization plan of the network system encompassed the former networks 22 (northern Ohio), 16 (Indiana), and 17 (Kentucky and southern Ohio). On August 1, 1996, Tri-State was awarded the contract for Network 10 (Illinois). As a consequence, the organizational name was changed to The Renal Network, Inc.

Currently more than 450 dialysis programs are members of the Network, representing a patient population close to 35,000 hemodialysis and peritoneal dialysis patients. Additionally, the 25 transplant centers within Illinois, Indiana, Kentucky and Ohio are also members of The Renal Network.

What is The Renal Network’s core purpose?

The core purpose of The Renal Network is to facilitate the achievement of optimal wellness for renal patients. The Renal Network monitors and implements federal regulations and develops standards in collaboration with patients, health care professionals and others.
The Renal Network also works to assist renal health care organizations to meet or exceed existing standards through education and application of quality of life and quality of care model practices.

The Renal Network’s core values are:

- To act compassionately and responsibly
- To be unbiased
- To advocate for excellence
- To be productive and innovative

How is The Renal Network set up?

Following federal guidelines, The Renal Network is governed by a Network Coordinating Council, a Board of Trustees and a Medical Review Board. Additionally, The Renal Network has established two patient-focused committees, The Patient Leadership Committee and The Patient Advisory Council.

The Network Coordinating Council (NCC) is comprised of representatives from each of the facilities in the Network area. Facility representatives act as a liaison between the dialysis providers and the Network.

The Board of Trustees (BOT) implements policy and reviews and approves Network operations and distribution of resources, both financial and staff. Patients participate on this committee.

The Medical Review Board (MRB) follows the regulations issued by the Secretary of Health and Human Services, as well as other duties related to quality assurance, vocational rehabilitation, and patient concerns as requested by the Network Coordinating Council. The MRB is made up of physicians, nurses, patients, administrators, technicians, social workers and dietitians.

The Patient Leadership Committee's (PLC) purpose is to identify and address ESRD patient needs and concerns through the development of educational projects and activities. It focuses on the overall needs of renal patients in the Network. Its membership consists of patients, family members, and renal staff members from across the Network.
The Renal Network staff works to implement the goals and objectives as set out by its boards. The Renal Network is administered from its headquarters located in Indianapolis, IN.

What does The Renal Network do?

The Renal Network has three major functions: quality improvement, data collection and patient education.

- **Quality improvement** – The Network works in a variety of ways. It provides continuing education and timely patient outcomes feedback to help the dialysis health care team work with patients to achieve optimal wellness. The Medical Review Board (MRB) assesses the quality of patient care and the appropriateness of services delivered. MRB members are also responsible for evaluating patient grievances.

- **Data collection** – To further promote quality care, the Network continually gathers information from member facilities on patient care. This data is compiled statistically, analyzed and reported back to renal professionals to help them manage their end-stage renal disease programs. The Network also uses these data to identify universal areas for improvement and to educate facilities in general on how to improve patient outcomes.

- **Patient education** – To educate patients, their family members and friends, the Network works through its Patient Services Department to provide an array of services. These free services include educational materials and publications, workshops and a newsletter.

  The Patient Services Department also maintains two active patient committees, The Patient Advisory Council and The Patient Leadership Committee work to create and bring resources to other patients both network-wide and at the unit level.

How does The Renal Network serve the larger renal community?

The Renal Network is actively involved in pursuing scientific topics of interest through special study. These include:
• Catheter Reduction Quality Improvement Project
• Vascular Access Quality Improvement Project
• CPM National Data Project

Results have been made available to the provider community as the studies progressed and made available nationally through published papers and articles and through presentations at conferences and professional association meetings.

The Renal Network is an active member in The Forum of ESRD Networks and other national professional associations.

Furthermore, The Renal Network sponsors an annual Nephrology Conference, which attracts a multi-disciplined audience from across the region including members from the regional chapters of The Renal Physicians Association, American Nephrology Nurses Association, Ohio Renal Administrators, National Association of Nephrology Technicians, and local dietitian and social work groups. Renal patients can attend the conference at no cost, although they still need to register.
Section 3: Information For All Patients

It is federally mandated that all patients be informed of their rights and responsibilities and how to file a grievance.

The Network has a model patient’s rights and responsibilities statement. Facilities may choose to create their own statement of patient rights and responsibilities or they may use the one provided by the Network.

Social workers are encouraged to use the Network’s patient rights and responsibilities statement not only to educate patients but also to monitor their understanding of how they function on a day-to-day basis. The Network encourages social workers to review the statement with new patients and then to go over it with them again after three months and then once more six months later.

This allows the patient the time to experience dialysis and ask questions that may surface over a period of time. This process promotes a greater understanding of how things work and provides opportunities for patients to share their questions and concerns as they come up.

As stated previously, facilities are directed by federal guidelines to have a formal grievance process. Patients must be notified of their facility’s grievance process. Patients are encouraged to get a copy of their facility’s grievance process and to obtain a Network grievance statement as well.

The Network encourages patients to file grievances with their facility first and then follow-up with the Network if it’s not resolved satisfactorily, although the patient can file with the Network at any time.

As a Patient Representative, informing patients of these important issues may be one of your most important tasks. Work with your social worker to plan a way to highlight different rights and responsibilities and to increase patient awareness of them. For example, you can post one each week on a bulletin board. Or you can use a suggestion box as a way to identify issues and concerns and then work with your facility staff to address them. Be creative!
A goal of The Renal Network is to make sure that all ESRD patients in Illinois, Indiana, Kentucky, and Ohio are able to receive medical care and are treated with dignity and respect. The following Rights and Responsibilities have been revised by the Network’s Patient’s Leadership Committee and approved by the Board of Trustees.

Your Patient Rights are to:

1. Know your rights and responsibilities.

2. Know how to protect your rights and responsibilities.

3. Receive quality, competent care and be treated with respect and dignity no matter what your age, color, culture, race, religion, or how your medical expenses are being paid.

4. Be told about your kidney disease and other medical problems that may concern you.

5. Be told about all the types of treatment that could be used to do the work your kidneys did before they stopped working; and for you to help decide which treatment might be best for you.

6. Be given the help you need for any difficulty or problem that keeps you from fully understanding your medical care (be it physical like a hearing or vision loss, or social like speaking a language other than English), or not understanding technical or complicated terms.

7. Expect that all healthcare workers responsible for your care will talk to each other about important medical information they need to know about your care like your medications, treatments, allergies, etc.

8. Have your personal and medical records be open only those people who have to know about your care. You can decide who can see your
records outside of the unit where you are treated, except if you change to another unit. If you change to another unit, your records must be given to the new unit according to government regulations and the law.

9. Be told the reasons for all tests, and have test results explained to you when the results are known.

10. Make sure you are told how, and that you understand why, things are done to you.

11. Know your primary doctor.

12. Know that you can meet privately with your doctor on a regular basis.

13. Be able to get another doctor’s opinion about your healthcare and know how much it will cost you.

14. Be told about how much your care will cost, about ways to get help paying for these costs, and about how much should be paid by you and your family.

15. Be able to choose or change doctors, type of treatment, and/or the place where you dialyze. However, this does not mean that the staff has to change the type of treatment to match your choice.

16. Be able to see the social worker, dietician, rehabilitation caseworker, psychologist, or other healthcare worker in a timely manner as needed.

17. Write down a concern or grievance and give it to the person at your facility who takes care of grievances. You can also send your grievance to The Renal Network. Filing a complaint will not have an effect on your care.

18. Be told exactly what to do in case of emergency while you are being treated.

19. Be given help to find a place to dialyze when you are planning to travel.

20. Be told about new treatments that might help you, and be told the good points and bad points of those new treatments.
21. Decide if you want to be part of a research study.

22. (If you choose to be part of a research study), you must understand what the research study is about and the results of the study.

23. Refuse to have someone watch you if they are not part of the staff giving you care.

24. Refuse treatment (as allowed by law) and be told what will happen to your body if you do so.

Your Patient Responsibilities are to:

1. Learn as much as you can about your disease, treatments, medicines, possible problems that could happen, and your rights and responsibilities as a kidney patient.

2. Bring as much information as you can when you are giving your medical history to the healthcare workers caring for you.

3. Tell your doctor or healthcare workers if you do not understand something.

4. Follow the diet the doctor and dietician order for you.

5. Get and take the medications the doctor orders for you. Also, tell the doctor if the medications are not working or cause problems for you.

6. Make an appointment, as needed, to see your doctor at his/her office and not just at the unit.

7. Arrive on time for your treatments, appointments, and meetings. Stay the entire time for your treatment; don’t leave early. You need to call if you are going to be late or cannot make it in that day.

8. Think about the needs of other patients, just as you would like them to think about your needs.

9. Tell your healthcare workers if there are changes in how you feel.
10. Follow the rules of the unit where you receive your treatments.

11. Pay your bills when you get them, and provide the necessary papers to the facility to help them collect the money for the bills.
The Renal Network’s Grievance Process

Any patient receiving End-Stage Renal Disease (ESRD) care or services has a right to bring attention to a problem they see in a unit or facility. Any patient may file a grievance without fear of unfair treatment or penalty.

A grievance is a formal complaint about a situation, event, or condition involving a person receiving End-Stage Renal Disease (ESRD) care or services. Each facility is required to have an official procedure for resolving such complaints. If you have a problem concerning your care, it is recommended that you first try to resolve it informally with the facility staff or use the facility’s formal grievance policy.

If the grievance has not been adequately addressed at the facility level, a grievance may be filed with the Network. Also you may choose not to file a grievance with the facility and go directly to the Network. To file a formal grievance a signed written complaint outlining the problem must is the preferred method to start the Network’s grievance process.

The Network will keep all grievances, discussions and correspondence related to the grievance confidential, unless the grievant gives permission to share the information. As a result of a grievance being filed, the Network may choose to act as a facilitator or intermediary between the patient and facility or the Network may directly consider the grievance. The individual who filed the grievance will be notified in writing of the outcome.

A patient, a family member, someone representing the patient, or a staff member, can file a grievance. If you think you may have a grievance or want to have a confidential discussion about a situation, event or condition involving your ESRD care or services, you may call the Renal Network at 317-257-8265 or toll free at 1-800-456-6919.

Or you may visit our patient Web site, Kidney Patient News (www.kidnepatiennews.org) and download information on how to submit a grievance.
Section 4: A Facility-Based Patient Representative Program

Some Suggestions for Communication

To be successful the Patient Representative must be able to communicate effectively with staff and other patients:

1. Gaining Recognition as the Patient Representative:
   • If your facility already has a patient newsletter, write a column introducing the Patient Representative.
   • If your facility has patient support meetings, arrange for the Patient Representative to be a speaker at one of the meetings.
   • On an on-going basis, introduce the Patient Representative to new patients in your facility.

2. Establish a way for the Patient Representative to disseminate information:
   • Notices of up-coming meetings and workshops.
   • Descriptions of new books and pamphlets that are available from The Network, etc.
   • A copy of the latest Network’s Renal Outreach newsletter and information on how to order.
   • A copy of the latest facility newsletter.

3. Make it easy for others to reach the Patient Representative by having a mailbox at the facility for them - this could be as simple as a manila envelope kept at the nurse's station.
4. Make it easy for everyone to communicate their thoughts and ideas by having a suggestion box and encouraging people to use it - even if anonymously.

Patient Representative Program – A Multi-Volunteer Model

Keeping the lines of communication open and moving among a large number of patients spread over several shifts is not an easy task.

The Renal Network recognizes that good communication is at the center of the helping process, so it has taken the best local model of patients, facility staff and the Network working cooperatively and pulled it together into a written format and made it available to all.

The Client Communication System (CCS) is a process, a guide that helps organize the flow of communication among patients, the facility and the Network.

The Client Communication System is an outgrowth of the Kentucky PAC, the Network’s Patient Leadership Committee and the Network’s Patient Services Department.
Client Communication System

Program Overview

The Network recommends the adoption of the Client Communication System (CCS) as the means to establish and maintain the flow of communication.

Purpose:

The purpose of this program is to improve the sharing of information among facility administration, unit staff, and patients.

Structure:

To function effectively, the Client Communication System requires the cooperative efforts of the following:

A. A facility appointed Patient Representative
B. A Staff Coordinator;
C. Spokespersons (for each modality / hemodialysis shift the facility serves);

How it works:

• Generally, one or two people cannot effectively be available to every patient on every shift throughout the week. So the Client Communication System suggests that additional volunteers, or Spokespersons, be recruited for every shift to be available to all patients on that shift, as well as, a separate spokesperson for home dialysis, peritoneal dialysis and transplant persons.

These volunteers, or spokespersons, will stay in touch with patients directly and pass along information and news while gathering and relaying concerns and views on issues, needs and interests from patients on their shift to the patient representative.

• Ideally, the patient representative and staff coordinator will hold general meetings on a regular basis in the facility to familiarize the spokespersons and other interested persons with facility activities and
to gather and document the ideas, needs, concerns and comments of the facility patients and staff.

- Together, the patient representative and CCS Staff coordinator meet to discuss ways to address the ideas, needs, concerns and comments coming from the patients. Some they may be able to resolve themselves, others they may bring to another department and still other issues they may bring to administration or the Network for a response.

**How to Have a Successful Meeting**

To have a successful meeting, you must be organized and some preparation will be required. The following are some basics to help you prepare for a favorable and productive meeting.

A. Before the Meeting

1. Set up the time and place of the meeting.
2. Notify everyone who needs to be a part of the meeting of the date and time.
3. Develop an agenda. An agenda helps you keep on track and make sure that everything you need to cover is covered.
4. Make sure that you have gotten all of the relevant information regarding any agenda item.
5. Decide who will take minutes of the meeting. Minutes are a good way of keeping track of what was discussed and of any outcomes from the discussion. Also if you are planning an activity, minutes are a good way of keeping track of what needs to be done by whom and when.

During the Meeting

1. Be sure to stay on track.
2. Make sure you are heard; express your concerns and ask questions.
3. Make note of action items and make sure they are included in the minutes.

4. Be open to suggestions and comments.

5. If some items are not covered or cannot be resolved hold off on them for further discussion.

B. After the Meeting

1. Create a plan for each actionable item resulting from the meeting

2. Share a summary of the meeting with the patients

Examples of how the program works:

Just so you can get an idea of how this flow of communication could possibly work, this section presents two examples.

Example A: Information from the facility administration to the patient population may follow this route:

1. The facility administrator informs the staff coordinator and patient representative of a change in facility policy.

2. The staff coordinator and patient representative may meet to work out the strategies for distributing the policy and obtaining feedback. Copies of the policy and posters are created for distribution.

3. The patient representative and staff coordinator hold a meeting of spokespersons and other interested persons to present the policy change and provide materials to be distributed and posted.

4. The spokespersons distribute policy changes and suggest that questions or concerns be reported back to him/her or placed in the suggestion box.

5. At the next meeting spokespersons may report back to the staff coordinator and patient representative any comments or concerns
voiced to them or spokespersons may choose to report back individually.

Example B: Patient information to the facility may follow this route:

1. A patient talks to the shift spokesperson about a concern or need.

2. The spokesperson collects all concerns of all patients on that shift regarding the concern or need and informs the patient representative.

3. The patient representative and staff coordinator hold a meeting of all spokespersons, allowing them to share common concerns. (If a meeting is not possible, the patient representative may canvass the spokespersons and gather information in this way.)

4. The patient representative and staff coordinator meet with the administration to address the issues and take whatever action they need to solve patient concerns.

These are not the only routes that communication may follow. It’s up to everyone to be creative and open to making the system work.
In Conclusion…

We encourage you to appoint a patient to be part of your facility’s team. Facility Patient Representatives, as well as CCS Spokespersons, can be invaluable in sharing correct information to other patients and to halt the spread of gossip and misunderstood information. They can assist you in sharing educational materials with other patients and be a great asset when planning patient education programs.

If you are part of a larger corporation, you may want to have meetings for all of your patient representatives on a yearly or semi-annual basis. You may want to find unique ways to highlight their volunteer role. A show of appreciation for what they do is important and will help prevent their volunteer burnout.

As a last point, be creative and determine ways that this Facility-based Patient Representative Program can be beneficial to you and the facility. Although it takes some time to get a good program in place, the benefits derived from having better educated and informed patients, is worth the time invested.

The Renal Network’s Patient Services Staff is available to consult with you regarding your Facility-based Patient Representative Program at any time.