

Patient Services and Quality Insights Renal Network 5

YOUR ROLE AS A PATIENT LIAISON



Quality
Insights

Renal Network 5

Thank you for your interest in serving as a Patient Liaison for your dialysis facility. **The most important person on the health care team is YOU, the patient.** The role of Patient Liaison is valuable, and will not take a lot of time. The duties may vary from facility to facility, but the main responsibility of this role is to be a link between patients in your facility and Quality Insights Renal Network 5.

This booklet is intended to:

- Provide information about the federal End Stage Renal Disease Program (ESRD) and the Networks;
- Describe how the Network involves patients in Network activities; and
- Give some guidelines for your role as a Patient Liaison.



Quality
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Renal Network 5

Mission: Bringing people and information together to improve health.

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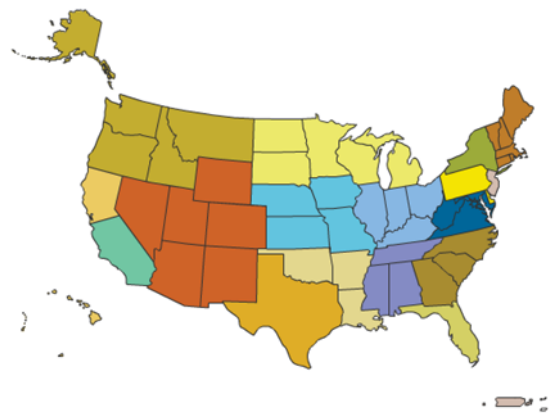
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ESRD Networks

In 1972, Congress established the End-Stage Renal Disease (ESRD) Program to provide payment for dialysis and transplant services through Medicare. The program is run by the Centers for Medicare and Medicaid Services (CMS). Under CMS, there are 18 organizations called “Networks” that oversee the quality of care for dialysis facilities across the United States. Quality Insights Renal Network 5 is a non-profit organization serving:

- Virginia
- West Virginia
- Maryland
- District of Columbia

Network 5 works with dialysis facilities to improve quality of care and provide educational material. Network 5 also maintains data on the 26,000+ dialysis and transplant patients in the Network 5 area. Patients can contact the Network if they have questions or concerns about the quality of care they receive at their dialysis facility.



Patient Involvement

Quality Insights Renal Network 5 maintains a Patient Advisory Committee (PAC) and encourages facilities to have at least one Patient Liaison at their center. There are also patients on the Network’s Board of Directors and Medical Review Board.

PATIENT ADVISORY COMMITTEE

The Patient Advisory Committee (PAC) is currently open to membership of any patients interested who either receive dialysis or have a functioning kidney transplant. Family members are also welcome! The role of the PAC is to help the Network identify common patient concerns, problems, and educational needs that are related to the mission and philosophy of the Network. Some of the committee activities include:

- Reviewing patient grievance data
- Participating as patient subject matter experts in quality improvement projects
- Assisting with writing the *Patient Insights* newsletter

The PAC meets in person once (1 time) a year and corresponds frequently by email and quarterly conference calls. The committee includes persons from all treatment modalities and geographically represents the Network.

PATIENT LIAISONS

To provide additional patient input, each facility is asked to name at least one (1) patient to serve as a Patient Liaison. The role of the Patient Liaison is to serve as a bridge between the patients in your facility and the Network. Patient Liaisons are selected for their outstanding involvement in their own care and willingness to help others improve their quality of life. Patient Liaisons are good role models.

Patient Liaisons may be asked to:

- Participate in patient focus groups for the Network
- Act as a mentor to other patients
- Introduce patients to Network activities and publications
- Help patients understand their rights and responsibilities
- Post notices of Network meetings
- Help distribute the *Patient Insights* newsletter
- Suggest topics for patient meetings
- Participate on Network workgroups

The Network provides Patient Liaisons with material from the Patient Advisory Committee, as well as other educational materials. Patient Liaisons are asked to distribute that information to the other patients in the facility. As a Patient Liaison, you will be notified about projects that need patient input and involvement.

Quality Insights Renal Network 5 has an educational Council meeting every year. The PAC helps plan this. Patients and families are encouraged to attend, and registration is free. We hope you will encourage others to attend also.



Guidelines for the Patient Liaison

MEDICAL INFORMATION

As a dialysis patient you have a lot to share with other patients about renal disease. Share your personal experiences cheerfully, but **you should not attempt to provide technical medical information.** Medical treatments or a diet that works for you as a patient may be dangerous or even fatal to another patient with a different combination of medical conditions.

- For medical questions, refer to the doctor
- For questions about diet, refer to the dietitian
- For questions about coping, refer to the social worker.

PATIENT CONCERNS

New patients can benefit from knowing that there is someone who understands what it means to be on dialysis, and they might want to approach you with their questions or concerns. If a patient comes to you with a complaint, you should encourage them to utilize the facility's grievance procedure. The Network is also available to help resolve grievances.



WHEN A PATIENT HAS A GRIEVANCE BE SURE THAT YOU:

- Know the grievance policies and procedures in your facility and encourage the patient to first try to resolve the complaint at the facility level.
- Become familiar with Network grievance procedures for concerns that cannot be resolved at the facility level.
- Take a positive approach to facility problems; be cheerful and approach staff at the right time. Avoid using a confrontational tone or accusatory words.
- Reassure patients that they have the right to file a grievance and cannot be retaliated against for filing a grievance with the facility or the Network. Federal regulations covering dialysis facilities make this clear.



CONFIDENTIALITY

All health care personnel are required to observe confidentiality of patient records and personal information. Patient Liaisons are expected to follow the same standards of confidentiality:

- **ALWAYS** get the patient's permission before approaching a staff member with a patient concern.
- Never repeat personal information you may learn in your role as a Patient Liaison.

Other Rewarding Activities

Patient Liaisons have creatively performed other activities in their facilities with the approval of facility management. These activities are not required of a Patient Liaison. However, you may find these activities enjoyable and helpful to others:

- Working with staff to start a patient support group
- Serving as a peer counselor to new patients
- Starting a facility newsletter
- Contributing articles or other items to the Network's *Patient Insights* newsletter
- Planning patient and staff events such as picnics and holiday parties
- Participating in community health fairs
- Working to promote organ donation
- Facilitating meetings between patients and staff
- Maintaining a bulletin board to post information for other patients to view



Contacting the Network

If you have questions or would like to discuss any concerns or recommendations from your facility, please feel free to call the Network's patient toll-free number **866.651.6272**. The Network staff person for Patient Liaisons and the Patient Advisory Committee is Amber Paulus, PhD, RN, CPHQ, Patient Services Coordinator.

The Network is available to provide:

- Information about dialysis treatment options
- Vascular access options
- Grievances
- How to be involved in your care planning
- Other resources and information you may find helpful in your role as Patient Liaison



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Renal Network 5

Office Hours:

Monday through Friday

8:00 am to 5:00 pm (ET)

Phone: 804-320-0004

Patient Toll-Free: 1-866-651-6272

Fax: 804-320-5918

E-mail: girn5@nw5.esrd.net

Website: www.girn5.org

ADDITIONAL RESOURCES

Network-Related Organizations

Quality Insights Renal Network 5

804-320-0004

Patient Toll-Free: 866-651-6272

www.qirn5.org

Email: qirn5@nw5.esrd.net

Centers for Medicare & Medicaid Services (CMS)

1-800-MEDICARE (1-800-633-4227)

www.medicare.gov

Dialysis Facility Compare:

www.medicare.gov/dialysis

Coalition for the Supportive Care of Kidney Patients

www.kidneysupportivecare.org

Email: csckp@nw5.esrd.net

Fistula First Catheter Last Workgroup Coalition

www.fistulafirst.org

Email: NCCinfo@hsag.com

Support Groups

AAKP Listing for Local Groups

www.aakp.org/outreach/List

Renal Support Network

HOPEline: 1-800-579-1970

www.kidneyspace.com

Kidney Patient Organizations

American Association of Kidney Patients (AAKP)

1-800-749-2257

www.aakp.org

Renal Support Network (RSN)

1-866-903-1728

www.rsnhope.org

Rehabilitation

Life Options

www.LifeOptions.org

Social Security

1-800-772-1213

www.ssa.gov

Ticket to Work: www.ssa.gov/work

Department of Rehabilitation Services (DRS)

www.DisabilityInfo.gov

Washington, DC:

<http://dds.dc.gov/dds/site/default.asp>

Maryland: www.dors.state.md.us

Virginia: www.vadrs.org

West Virginia: www.wvdrs.org

Disability Resources

www.disabilityresources.org

Kidney Education Resources

National Kidney Foundation (NKF)

1-800-622-9010

www.kidney.org

American Kidney Fund (AKF)

1-800-638-8299

www.kidneyfund.org

Kidney and Urology Foundation of America

1-800-633-6628

www.kidneyurology.org

Home Dialysis Central

www.homedialysis.org

Kidney School

www.KidneySchool.org

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