

Patient Activities and Network 8, Inc.

YOUR ROLE AS A PATIENT REPRESENTATIVE



Thank you for your interest in serving as a Patient Representative for your dialysis facility. **The most important person on the health care team is YOU, the patient.**

The role of Patient Representative is valuable, and will not take a lot of time. The duties will vary from facility to facility, and may include providing to Network 8 information about the educational needs of patients at your dialysis facility, encouraging fellow patients to become involved in their healthcare, and serving as a resource to patients.

This booklet is intended to:

- Provide information about the federal End Stage Renal Disease Program (ESRD) and the Networks;
- Describe how Network 8 involves patients in Network activities; and
- Give some guidelines for your role as a Patient Representative.

Network 8's mission is to be an effective resource and advocate for all kidney patients, their families and providers through collaboration with others to promote quality outcomes and appropriate modes of therapy throughout their lives until the end of life.

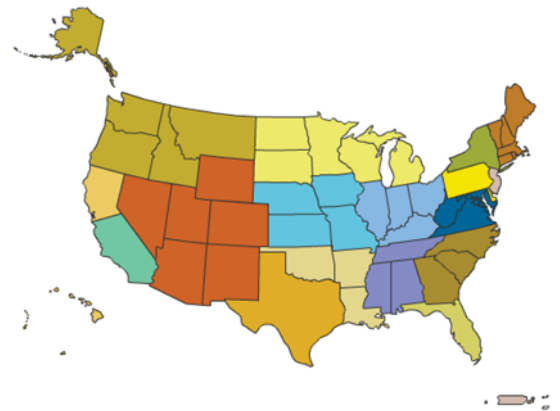
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ESRD Networks

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 promote the quality of care for dialysis facilities across the United States. Network 8, Inc. is the non-profit organization serving Alabama, Mississippi, and Tennessee. Network 8 is an affiliate of Alliant Health Solutions, a diversified southeastern health quality management company headquartered in Atlanta.

Network 8 works with dialysis facilities to improve quality of care and to improve communication between facility staff and patients. Network 8 also helps CMS maintain accurate data on the 24,000 dialysis patients in the Network 8 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

Network 8 maintains a Patient Advisory Committee (PAC) and a Patient Learning and Action Network (LAN) and encourages facilities to have at least one Patient Representative at their center. There are also patient members who serve on the Network’s Board of Directors and Medical Review Board.

PATIENT REPRESENTATIVES

Each facility is asked to name one patient to serve as a Patient Representative.

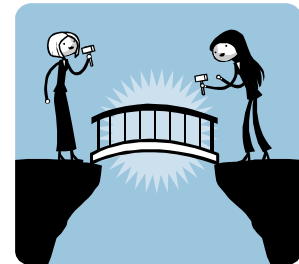
Patient Representatives may be asked to:

- Participate in patient focus groups for Network 8
- Act as a mentor to other patients
- Introduce patients to Network activities and publications
- Help patients understand their rights and responsibilities
- Help distribute the patient newsletter
- Suggest topics for patient meetings

The Network provides Patient Representatives with material from the Patient Advisory Committee, as well as other educational materials. Patient Representatives may be asked to distribute that information to the other patients in the facility.

PATIENT ADVISORY COMMITTEE

The Patient Advisory Committee (PAC) has 10 patient members who either receive dialysis or have a functioning kidney transplant. The role of the PAC is to help the Network identify common patient concerns and educational needs that are related to the mission and philosophy of Network 8. Some of the committee activities may include:



- Learning about CMS goals for the ESRD program
- Developing educational materials
- Assisting with writing the *Kidney Patient Update* newsletter
- Providing patient input into Network 8 policies

The PAC will meet face to face as necessary and correspond occasionally by email and conference calls. The committee includes persons from all treatment modalities and geographically represents the Network. PAC members serve 3-year terms. As a Patient Representative, you will be notified when a PAC position becomes available.



PATIENT LEARNING AND ACTION NETWORK

In January, 2013, CMS called on each ESRD Network to create a special patient committee called a Learning and Action Network (LAN) to promote greater patient involvement in their own health care. This committee of patients and other renal stakeholders has been asked by CMS to:

- Identify a Quality Improvement Activity (QIA) each calendar year that promotes patient-centered care and protects the interest of the patients.
- Develop two campaigns each calendar year that include the development of educational materials for patients focused on patient-centered goals.
- Make a measurable improvement in the QIA and campaigns chosen each year.
- Three members of the LAN will be asked to serve on a national LAN committee.

The patient's role on the LAN will be that of "subject matter experts" (SMEs) in recognition of the fact that patients live the experience of ESRD each and every day. The patient SMEs for the LAN were nominated by facilities in all three states in the Network 8 region.

Guidelines for the Patient Representative

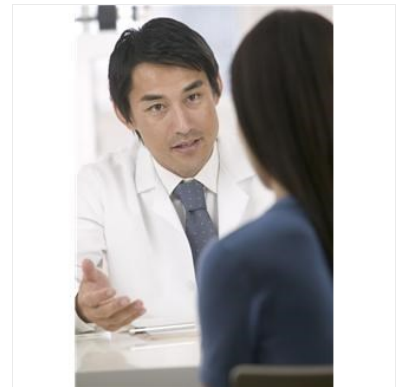
MEDICAL INFORMATION

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 if the problem cannot be resolved in an informal way.



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

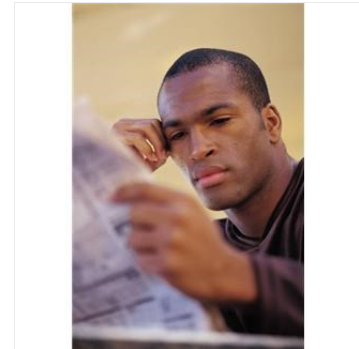
All health care personnel are required to observe confidentiality of patient records and personal information, and Patient Representatives are expected to follow the same standards of confidentiality:

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 Representative.

Other Rewarding Activities

Patient Representatives have creatively performed other activities in their facilities with the approval of facility management. These activities are not required of a Patient Representative. 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 newsletter, *Kidney Patient Update*
- 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

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 **877-936-9260**. The Network liaisons to Patient Representatives and the Patient Advisory Committee is Brenda Dyson, Community Engagement Coordinator and NaTasha Avery, Patient Services Director.

We are available to provide:

- Information about dialysis treatment options
- Vascular access options
- Complaints and grievances
- How to be involved in your care planning
- Other resources and information you may find helpful in the Patient Representative role



Network 8, Inc.

Network 8 Office Hours:

Monday through Friday

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

Phone: 601-936-9260

Patient Toll-Free: 1-877-936-9260

Fax: 601-932-4446

Website: www.esrdnetwork8.org

ADDITIONAL RESOURCES

Network-Related Organizations

Network 8, Inc.

601-936-9260

Patient Toll-Free: 877-936-9260

www.esrdnetwork8.org

Centers for Medicare & Medicaid Services (CMS)

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

www.medicare.gov

Dialysis Facility Compare:

www.medicare.gov/dialysis

Kidney End of Life Coalition

www.kidneyeol.org

Email: kidneyeol@nw5.esrd.net

Fistula First

www.fistulafirst.org

Email: fistulafirst@nw5.esrd.net

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>

Alabama: www.rehab.state.al.us

Mississippi: www.mdrs.state.ms.us

Tennessee: www.tennessee.gov/humanserv/rehab/vrs.html

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

Local Kidney Organizations

Alabama Kidney Foundation

205-934-2111

Toll-Free: 800-750-3331

www.alkidney.org

Mississippi Kidney Foundation

601-981-3611

Toll-Free: 800-232-1592

www.kidneymms.org

Tennessee Kidney Foundation

615-383-3887

Toll-Free: 800-380-3887

www.tennesseekidneyfoundation.org

Kidney Foundation of Greater Chattanooga

423-265-4397

www.kidneyfoundation.com

National Kidney Foundation of West Tennessee

901-683-6185

Toll-Free: 800-273-3869

www.kidney.org

March 2013