



## From the Committee Chair

Maggie Carey, Chair, Consumer Committee

### Questions... Questions... Questions...

Welcome to 2013 everyone!! We are so pleased to be able to kick off the year with this information packed issue of *Common Concerns*. I have never met anyone with kidney disease who didn't have a list of questions a mile long.

Of course, your doctor, your dialysis unit or transplant center are the first places to look for answers. For those of us who like to gather more information on our own, we are providing you with all sorts of interesting links and contacts. As I have said before, knowledge is power and the more we know about the issues that we face, the

more power we have in making decisions regarding our care and way of life.

On a related note, there is a new buzzword going around in the Kidney Community—patient engagement. I think you will be seeing and hearing this phrase a lot in the future. Simply put, patient engagement means that your unit, your doctor, Network 11, and the Federal Government want YOU, the patient, to be involved in making decisions and setting policies.

New opportunities for your voice to be heard are going to open up. So, before you start changing the world, check out the information in this issue and be informed. Support your thoughts with knowledge and they will mean a lot more.

## Patient and Family Engagement

As Maggie Carey mentions in her article, there is a new phrase being heard in Medicare and Network circles this year. That phrase is patient engagement. One of the dictionary definitions of engage is "...induce to participate." That is exactly what patient engagement means, to encourage you, as a patient, to participate in your care and care systems.

During this year, Network 11 will be working with dialysis treatment centers to help them find ways to encourage more patient participation in their care as well as activities in the dialysis unit. But what does this mean for you? There are many ways that you and your family can become more involved in your care.

### Ask Questions about Your Care.

- Ask to see your laboratory results each month.
- If you have special tests, ask when the results will be available.
- If you don't understand something, ask for a more complete explanation.
- Learn as much as possible about your treatment.
- Attend your patient care conferences.
- Bring a list of questions. This is your opportunity to have a dedicated time with staff.
- Participate in the discussion and ask questions.
- Consider whether or not you might like to try a different modality (home dialysis or kidney transplant).

**DID YOU KNOW** there is an abundance of resources out there for kidney patients and their families but you need to contact them to get the full benefit of their information and services? We have listed several here for your information.

### **American Association of Kidney Patients (AAKP)**

The AAKP is a national non-profit organization founded by kidney patients for kidney patients. They provide education and seek to improve the health and well-being of chronic kidney disease patients.

Toll Free: (800) 749-2257

Website: [www.aakp.org](http://www.aakp.org)

### **American Kidney Fund (AKF)**

The AKF provides financial assistance to kidney patients. They have helpful information on their Website on many topics including finances, lifestyle ideas, and kidney disease.

Toll Free: (800) 638-8299

Website: [www.kidneyfund.org](http://www.kidneyfund.org)

### **American Diabetes Association (ADA)**

The ADA is a non-profit health organization providing diabetes research, information, and advocacy for patients with diabetes.

Toll Free: (800) 342-2383

Website: [www.diabetes.org](http://www.diabetes.org)

### **Americans with Disabilities Act**

This organization provides general information about the Americans with Disabilities Act as well as information on regulations about filing a complaint under Title III of the ADA, which prohibits discrimination based on disability by businesses and non-profit organizations.

Toll Free: (800) 514-0301 (voice)

(800) 514-0383 (TTY)

Website: [www.ada.gov](http://www.ada.gov)

### **Centers for Medicare and Medicaid Services (CMS)**

CMS offers information about Medicare and Medicaid services.

Toll Free: (800) 633-4227

Website: [www.cms.gov](http://www.cms.gov)

For questions regarding coordination of benefits

Toll Free: (800) 999-1118

### **Dialysis Facility Compare**

This Website provides tools to search for and compare dialysis facilities.

Website: [www.medicare.gov/dialysisfacilitycompare/](http://www.medicare.gov/dialysisfacilitycompare/)

### **Equal Employment Opportunity Commission (EEOC)**

The EEOC enforces and provides oversight and coordination of federal equal employment opportunity regulations.

Toll Free: (800) 669-4000 (voice)

(800) 669-6820 (TTY)

Website: [www.eeoc.gov](http://www.eeoc.gov)

### **Life Options**

The Life Options Website provides research-based materials and outreach to help people live long and well with kidney disease.

Toll Free: (800) 468-7777

Website: [www.lifeoptions.org](http://www.lifeoptions.org)

### **Medical Education Institute (MEI)**

MEI is a mission-driven, non-profit, private operating foundation dedicated to assisting people with chronic diseases learn to manage and improve their health.

Phone: (608) 833-8033

Website: [www.meiresearch.org](http://www.meiresearch.org)

### **National Kidney Foundation (NKF)**

The NKF provides education regarding prevention and treatment of chronic kidney disease.

Toll Free: (800) 622-9010

Website: [www.kidney.org](http://www.kidney.org)

MI: (800) 482-1455

MN: (800) 596-7943

ND, SD: (800) 596-7943

WI: (800) 543-6393

NKF also has a national telephone-based peer support program.

Phone: (855) 653-7337

### **National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)**

This organization offers educational materials regarding kidney and urologic diseases.

Toll Free: (800) 891-5390

Website: [www.kidney.niddk.nih.gov](http://www.kidney.niddk.nih.gov)

### **Office of Civil Rights (OCR)**

Civil Rights help to protect you from unfair treatment or discrimination because of your race, color, national origin, disability, age, sex (gender), or religion.

Toll Free: (800) 368-1019

Website: [www.hhs.gov/ocr](http://www.hhs.gov/ocr)

### **Rehabilitation Services**

These state agencies assist individuals with disabilities to achieve employment and independent living goals.

- Michigan Rehabilitation Services

Toll Free: (800) 605-6722

Website: [www.michigan.gov/mrs](http://www.michigan.gov/mrs)

- Minnesota Division of Rehabilitation Services

Phone: (651) 259-7366

Toll Free: (888) 438-5627

Website: [www.deed.state.mn.us/rehab/vr/main\\_vr.htm](http://www.deed.state.mn.us/rehab/vr/main_vr.htm)

- North Dakota Rehab

Toll Free: (800) 755-2745

Website: [www.nd.gov/dhs/dvr](http://www.nd.gov/dhs/dvr)

- **South Dakota Rehab**  
Toll Free: (800) 265-9684  
Website: [www.dhs.sd.gov/drs/](http://www.dhs.sd.gov/drs/)
- **Wisconsin Rehab**  
Toll free: (800) 442-3477 (voice)  
(888) 877-5939 (TTY)  
Website: [www.dwd.state.wi.us/dvr](http://www.dwd.state.wi.us/dvr)

### Renal Support Network (RSN)

The RSN is a patient-run non-profit organization. It offers non-medical services to those affected by kidney disease.

Toll Free: (866) 903-1728  
Website: [www.RSNhope.org](http://www.RSNhope.org)  
HOPEline: (800) 579-1970 Calling this toll-free number will connect you with someone who has lived successfully with kidney disease.

### Scientific Registry for Transplant Recipients (SRTR)

SRTR supports the ongoing evaluation of the status of organ transplantation in the United States. It is administered by the Chronic Disease Research Group of the Minneapolis Medical Research Foundation.

Phone: (877) 970-7787  
Website: [www.srtr.org](http://www.srtr.org)

### Social Security Administration

SSA's Website contains information about Social Security and the programs offered.

Toll Free: (800) 772-1213  
Website: [www.ssa.gov](http://www.ssa.gov)

### State Health Insurance Assistance Program (SHIP)

SHIP answers questions about Medigap policies, Medicare health plan choices, filing an appeal, and general health insurance questions.

Toll Free Numbers:  
MI: (800) 803-7174  
MN: (800) 333-2433  
ND: (888) 575-6611  
SD: (800) 536-8197  
WI: (800) 242-1060

### State Survey Agency (SSA)

The State Survey Agencies inspect dialysis and transplant facilities to assure compliance with Medicare requirements are met. The SSA also receives complaints regarding quality of care and access to care.

#### SSA Phone Numbers:

MI: (800) 882-6006  
MN: (800) 369-7994  
ND: (701) 328-2352  
SD: (605) 773-3356  
WI: (608) 266-0224

### United Network for Organ Sharing (UNOS)

This organization provides information about organ donation, transplantation and transplant survival data.

Toll Free: (888) 894-6361  
Website: [www.unos.org](http://www.unos.org)

### Veterans Resources

Provides information about VA benefits and services. Not all VA Medical Centers and Clinics offer dialysis and renal services. To obtain further information please contact your local VAMC or VA clinic.

Toll Free: (800) 827-1000  
Website: [www.va.gov](http://www.va.gov)

### Wisconsin Chronic Renal Disease (CRD) Program

The WI CRD pays Wisconsin health care providers for treatment of chronic renal disease for those eligible and certified CRD Program participants after all other sources of payment have been used.

Phone: (800) 362-3002  
Website: [www.forwardhealth.wi.gov/WIPortal/Tab/42/icscontent/provider/wcdp/index.htm.space](http://www.forwardhealth.wi.gov/WIPortal/Tab/42/icscontent/provider/wcdp/index.htm.space)



## Immunization Protects You and Those You Love

Immunization is one of the important ways that you can protect yourself from serious diseases such as influenza, pneumonia, and hepatitis B. The Centers for Disease Control recommends that all chronic dialysis patients get immunized for these diseases.

To support this national recommendation, Renal Network 11 plans to promote immunizations for both dialysis personnel and chronic dialysis patients. You can help. Please talk to your health care team about your immunization options.

# Renal Network 11 and You: Partnering to Improve Care

## Who is Renal Network 11?

The Renal Network of the Upper Midwest, also known as Renal Network 11, is a private, non-profit organization. We work with the Centers for Medicare & Medicaid Services (CMS), health care providers, and others to improve care for people with kidney disease in Michigan, Minnesota, North Dakota, South Dakota, and Wisconsin.

## What does Renal Network 11 do?

We work with dialysis facilities, kidney transplant centers, and others to improve quality of care. We respond to concerns that you or your family might have about:

- Quality of care related to dialysis or kidney transplantation,
- Access to dialysis and kidney transplant services,
- Vocational rehabilitation.

## How Do I Contact Renal Network 11?

Do you have a question, a concern, or a complaint? Do you need to file a grievance? Please contact us using any of the following ways.

Toll free: 1 (800) 973-3773  
Email: [info@nw11.esrd.net](mailto:info@nw11.esrd.net)  
Website: [www.esrdnet11.org](http://www.esrdnet11.org)  
Mail: Renal Network 11  
1360 Energy Park Drive, Suite 200  
St. Paul, MN 55108



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