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Meet the Patient Advisory Committee (PAC) of Heartland Kidney Network

The Patient Advisory Committee (PAC) was established in 2007 with a representation of patients’ members from Iowa, Kansas, Missouri and Nebraska. They provide insight to the Network on patient-related issues and concern that involve improving patient centered care and quality driven outcomes.

The purpose of the Patient Advisory Committee is to help the Network respond to patient needs and seek ways to improve patient/staff relationships. The PAC membership is comprised of an equitable representation from across the Network. This 12 member committee provides insight to patient-related issues and concerns that involve improving patient-centered care and quality driven outcomes. Through the efforts of the PAC, patients are empowered with information, leading to informed patients and better treatment results.

The PAC is overseen by the Patient Services Coordinator and led by the Chairperson (Ardy) with positions including the Vice-Chair (Jenna) and the Secretary (Norma).

GOALS:

• Identify and present the needs and concerns of renal patients.
• Act as a liaison between the renal population and the Network.
• Promote patient empowerment and involvement in their healthcare issues.
• Develop and provide patient education to be used in the community at large.

Join AAKP at its 37th Annual Convention

September 2 - 4, 2010 in beautiful Tampa, FL

AAKP created its Annual Convention to provide kidney disease patients, as well as their friends and family members with the opportunity to discuss their concerns and share their experiences while learning about important issues affecting their health care. During this three-day event, attendees participate in educational topics for those with chronic kidney disease (CKD) to long-term dialysis and transplant recipients.
Heartland Kidney Network’s Patient Advisory Committee (PAC) developed the NPR program in October, 2009. Dynamic patients make up the NPR program, and they volunteer in their facilities to work with staff toward fostering a positive environment in their facility. An NPR is a patient in the facility who actively promotes patient education and well-being by maintaining a patient bulletin board that promotes patient and staff educational materials and activities. Working closely with facility staff, the NPRs may also coordinate other patient and staff activities in their facility.

The Network’s Patient Advisory Committee (PAC) developed the NPR responsibilities listed below. These responsibilities are only minimal guidelines. Each facility is free to expand this list as they wish by adding other duties to improve communication between patients and staff and to expand facility’s patient and staff education opportunities.

**Suggested Standard Responsibilities Include:**

1. Be a role model to other patients by learning information about treatments for kidney disease and following his/her own treatment plan.
2. Receive and distribute ESRD Network patient mail-outs.
3. At the facility’s request, communicate clinic updates or concerns to fellow patients.
4. Be available to assist the unit Social Worker with patient support groups.

**Suggested Optional Responsibilities Include:**

1. Read and answer patients’ questions about information from their facility and the Network.
2. Be available to:
   - Help with communications between patients and facility staff when needed or requested.
   - Assist with the orientation and support of new patients.
   - Assist with patient activities such as educational meetings and social events.
   - Help organize phone calls or visits (where appropriate) to other patients.
   - Write and distribute a patient newsletter for his/her own clinic with the aid of clinic staff.

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**SAVE THE DATES:**

- **Missouri Kidney Program - Patient Education Program. 2010 Kidney Disease Class Schedule**
  - **Saint Louis Area:** Call (314) 821-3434
    - March 13-14; May 1-2; July 17-18; September 11-12; November 6-7
  - **Branson Area:** Call (417) 461-1228
    - August 14-15
  - **Joplin Area:** Call (417) 461-1228
    - April 24-25; October 23-24
  - **Kansas City Area:** Call (913) 642-0269
    - March 13-14; May 15-16; July 10-11; September 11-12; November 13-14
  - **Springfield Area:** Call (417) 461-1228
    - June 12-13; December 11-12
  - **West Plains Area:** Call (417) 461-1228
    - March 20-21
  - **Cape Girardeau Area:** Call (913) 481-7672

- **American Association of Kidney Patients’ (AAKP) 37th Annual Convention**
  September 2-4, 2010
  Tampa, Florida
  For more information call (800) 749-AAKP or email info@aakp.com.

- **American Kidney Fund Podcasts**
  View the Website monthly to listen live or download previous podcasts about issues relevant to the kidney community.
  www.kidneyfund.org/kidney-health/podcasts

- **Renal Support Network (RSN)**
  Patient Lifestyle Meetings
  July 11, 2010
  Davenport, Iowa
  For more information call (866) 903-1728 or visit online at www.rsnhope.org

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**What is a Network Patient Representative (NPR)?**

- **If you are a patient interested in becoming an NPR, talk to your facility staff about contacting the Network.**
- **If you are a facility staff member who would like to recommend an NPR for the program, contact the Patient Services Coordinator to set up an orientation call.**

Anne Karanja, Patient Services Coordinator
816-880-1709 Patient Toll Free: 1-800-444-9965
Using Facility Resources to Resolve Patient Concerns

You might have spoken to Anne Karanja, Patient Services Coordinator at the Network. Anne is available to help you resolve issues that cannot be handled at your facility level. However, we do recommend that you start with your facility Social Worker when trying to work through any concerns that you have.

Sooner or later almost every patient will encounter a frustrating situation and will wonder where to turn. Fortunately, every dialysis facility in the United States has a process for dealing with these situations.

Heartland Kidney Network supports the use of the local facility grievance process because facility staff who are closest to the problem are usually in the best position to offer a solution. In most cases if the problem cannot be resolved at the facility, the local grievance process allows a patient to move up the line to a corporate administrator who can be called on to act as an arbitrator.

Many of your concerns may be resolved by talking to a key person at your facility. If the problem is more serious and requires a more formal approach, ask for and follow your facility’s written grievance procedure.

When approaching your nurse, social worker, or physician about a particular concern, do your best to discuss the issue in a calm manner. Your purpose is to open lines of communication with those who have the authority to respond to your concerns. It is very important during this first step that you present your concerns in the way that you would expect to be approached if someone objected to something you said or did. If this point is ignored, it is very likely that the important relationship between you and the staff may be damaged, and this may block efforts to turn attention back to your concern.

You have the right to express your concerns without interference and without discrimination or reprisal. You should expect to have your concerns responded to within a reasonable time frame. These rights go hand in hand with your responsibility to be accurate in your statements and reasonable in your expectations for the outcome of your concern. Some things simply may not be open to change, and what you are asking for may or may not be possible. Also, some changes that the facility may be willing to make to accommodate your concern may take some time to implement.

Patients do have a choice about where to report their grievances: they can work within their facility process (the recommended choice) or they can contact the Network office or state survey agency. Problems referred to the Network will be looked at to see if they relate to a facility policy. Any concerns related to facility policies will be referred back to the facility because the facility has control over these issues.

At the Network level, complaints not readily resolved are reviewed by a committee of the Medical Review Board. Network staff assists the committee by gathering information from the patient and facility personnel. The committee generally limits its activity to quality of care concerns or problems that involve access to care. If the matter does not fall into one of these categories, the Network will make every effort to help patients and facility staff work together toward resolution of the problem which should be everyone’s goal.

Culpepper Exum Scholarship for People with Kidney Disease

Beth Witten, nephrology social worker, established the Culpepper Exum Scholarship for People with Kidney Disease as a memorial to her brother who had diabetes and was on dialysis prior to his death from heart disease in 2002. This scholarship is intended to help two deserving dialysis or transplant patients attend any accredited educational program. The award is for $1,000 per scholarship for one school year paid directly to the institution. Two scholarships will be awarded in 2010—one to a Kansas resident and one to a Missouri resident.

Applications are due to the National Kidney Foundation Serving Kansas & Western Missouri no later than May 14, 2010 and will be considered by a committee appointed by the National Kidney Foundation Serving Kansas & Western Missouri. Scholarship recipients will be selected after the committee reviews each completed application and conducts personal interviews with the finalists. Applications are due by May 14, 2010. Please contact NKF or view their website for an application form http://www.kidney.org/site/news

For more information call (913) 262-1551 or (800) 444-8113
Scholarship recipients will be notified by June 11, 2010

National Kidney Foundation Serving Kansas & Western Missouri
ATTN: Scholarship Program
6405 Metcalf Avenue, Suite 204
Overland Park, KS 66202
FAX: (913) 722-4841
Why Should I Work?

Many dialysis patients continue to work, volunteer, or go to school. Although sometimes patients have to change their schedules for work, patients say it is worth rearranging their schedule. It is helpful to have other socialization other than going to dialysis. You might be asking yourself, “What are my benefits of working?”

- Often people who work can get a supplemental insurance policy that will assist paying medical bills
- Employers cannot legally discriminate against persons with kidney failure
- Working and exercising makes you feel better about yourself
- You will not lose your Medicare benefit based on End-Stage Renal Disease if you work

Vocational Rehabilitation Services are available to assist patients with identifying interest and skills for employment. You can meet with a counselor to assist with developing skills for employment, updating or creating a resume’ and assistance finding and keeping a job. If you are interested in getting back into the workforce, talk with your social worker at your dialysis unit or contact your area Vocational Rehabilitation to arrange an appointment.

Need to Work but have a Vision Problem?

Chances are someone you know and love has a vision problem and needs support. Alphapointe is a comprehensive rehabilitation and education center for the blind and visually impaired in the state of Missouri and it’s the largest single employer of blind and visually impaired individuals as well. Alphapointe’s Vision Rehabilitation services are designed to meet the needs of youth, adults, and seniors with all types of vision loss. Their programs are individualized and designed to give you the skills you need for living and working with vision loss.

Their vocational services include job search assistance, resume and cover letter writing, job interviewing skills, teamwork skills development, workplace protocol and direct job placement. Career counseling is available to evaluate options and determine realistic vocational goals. An individualized plan is developed that includes a specific job goal and the skills required to obtain and maintain that employment.

For more information, please call 816-421-5848 or visit their website at www.alphapointe.org

Every Right has an Equal Responsibility

As the Heartland Kidney Network Patient Advisory Committee (PAC) continues to work to empower patients to become involved in their healthcare, it is important for patients to be aware of their rights and more importantly their responsibilities as dialysis patients. Patients should voice their concerns and feelings; however, do so in an appropriate manner. Just as staff should not offend patients we must understand the staff members have feelings and should not be offended by the patients. Here are a few of the patient’s rights and responsibilities.

- **Right**: I have the right to put myself first sometimes.
- **Responsibility**: I have the responsibility to determine whether this action will cause harm to another and to decide if it is still appropriate to put myself first.
- **Right**: I have the right to ask for clarification.
- **Responsibility**: I have the responsibility to be attentive and to listen to information which is provided to me.
- **Right**: I have the right to be diplomatic to achieve change.
- **Responsibility**: I have the responsibility to understand that my diplomatic approach may not always be met with a diplomatic response, but to continue to use this approach anyway.
Emergency Preparedness: Practical Suggestions for Dialysis Patients

Preparation

1. Get your free copy of “Preparing for Emergencies: A Guide for People on Dialysis.” (available at www.heartlandkindey.org) You will cope a lot better if you have a plan and know what to do.

2. Federal regulations require every dialysis clinic to have an emergency plan and that staff and patients are informed about the plan. They are also required to have periodic drills. If you are NOT familiar with your clinic’s emergency plans, ask your clinic manager.

3. “Cut and Clamp” - Know how to get off the dialysis machine in an emergency evacuation. Insist that the facility staff teach you how to do this. Practice frequently.

4. Become familiar with the 3-Day Emergency Diet for dialysis patients.

5. Keep records of your medical history. Make a quick overview of the following:
   - cause of your renal failure
   - other medical conditions
   - allergies
   - name of your regular dialysis clinic
   - type of dialysis that you receive
   - your physicians name(s)
   - medications you take
   - past treatments and operations
   - copy of your insurance card

6. Keep a list of emergency telephone numbers.

7. Wear a medical ID bracelet identifying you as a dialysis patient.

8. Keep medicine, food and supplies on hand.

9. Stock up on non-perishable food and make sure it is kidney friendly.

10. Have an emergency box at home with everything you might need. Use the 72 hour, three day rule when you pack your box.

11. Know how to disinfect water at home. Keep distilled water at home for drinking.

12. Except for dialysis clinics located inside hospitals, there is at this time no federal requirement to have an emergency generator.

During an Emergency

1. If you cannot get to your dialysis clinic:
   - Contact your usual dialysis unit for information on where to go for your treatments.
   - Stay at home unless you are hurt. Wait for instructions about your dialysis clinic on television, radio, messenger or phone.
   - Begin the 3-Day Emergency Diet - 2 cups fluid per 24 hours, no fresh fruit or vegetables.
   - If you must go to a shelter, tell the person in charge about your special needs.

2. Hospitals and emergency rooms will be burdened with very serious cases (such as crush or burn victims) and will probably turn away anyone who does not need immediate attention. During an emergency dialysis patients should not expect to receive a chronic dialysis treatment at the hospital. Contact your dialysis center for information on where to go for your treatments.

Source: This tip sheet was adapted from the September 2002 issue of aakpRENA LIFE, Vol. 18, No. 2.
Dialysis saves your life, but it can also change it. Depending on which type you chose, dialysis may change what you can eat and drink, how many medications you need, and what you can do each day. If you work, dialysis can make you more or less able to keep your job. Health-related quality of life (HRQOL) is your rating of:

- Your own physical health
- Your own mental health
- How much of a burden kidney disease is

As it turns out, HRQOL is vital. Why? Because it predicts your risk of a hospital stay and a longer or shorter life. And there are steps you can take to improve your HRQOL and your chances of living long and well.

**Taking the KDQOL-36 Survey:**

Your social worker will measure HRQOL by asking you to take a survey called the KDQOL-36, which has 36 questions in 5 sections:

- Physical Health
- Mental Health
- Burden of kidney disease
- Symptoms and problems
- Effects of kidney disease on daily life

The questions ask things like, “During the past 4 weeks, how much were you bothered by itchy skin?” or, “Too much of my time is spent dealing with my kidney disease (True/False).”

There is no right or wrong answer. The point is just to find out how you feel about your own life in each of the five areas. The survey takes about 10-15 minutes to do. Not sure what to answer? Go with your first instinct. It’s best if you can complete the survey by yourself. The social worker may help you if you can’t—but answer honestly. The scores will not mean anything if you pretend to feel better than you really do.

You can choose not to take the KDQOL-36 or not to answer a question. Please answer the first 12 questions, though! Your clinic needs at least those 12 to look at your risk of poor outcomes and offer you help if you need it.

**Medicare Requires HRQOL Surveys:**

New Medicare rules as of October 14, 2008, require clinics to give all adults on dialysis the KDQOL-36 at least once a year. The results must be used to help make a Plan of Care for you, to help you feel your best. KDQOL-36 results are also a “benchmark” of good dialysis care across the U.S. So, like blood tests, results will be sent (as a group) to Medicare. They will help find out how people on dialysis in the U.S. feel physically and mentally and what helps them do better. Having Medicare require KDQOL-36 is a big deal! It marks the first time that clinics must ask you how you feel instead of just checking your blood tests.

*For more information on this topic or to read the entire article visit [www.homedialysis.org](http://www.homedialysis.org)*
Being Late for Dialysis

Being late for dialysis treatment causes a lot of things to be affected at the facility. To meet the needs of all patients, dialysis units have to keep to a very organized schedule.

• The dialysis center has the right to set the patient treatment schedule that allows it to function smoothly and to accommodate every patient while ensuring quality care is provided.
• It is every patient’s responsibility to be on time for treatments. If one must arrive late due to an emergency, please contact the dialysis center as soon as possible.
• A patient’s treatment time may have to be shortened or rescheduled.
• It is important to be considerate of others and arrive at the scheduled time.

**How are You and Others affected by late arrivals?**

**You:**
• Shortened dialysis may not be enough to get dialysis process complete
• Being late makes it difficult for the doctor to plan care correctly
• Staff time with you becomes limited. There may not be enough time to discuss your needs

**Other Patients:**
• Being late causes other patients to be delayed as well
• Other patients’ transportation plans may have to be altered
• Staff time with other patients is more limited
• Fellow patients may become frustrated
• Other patients may have to wait longer because the staff schedule is disrupted due to your lateness.

**Staff/Physician:**
• The physician may not visit with you when rounds are made to address specific questions/issues that you may have
• The staff members’ time with all of the patients is changed
• The care team can get frustrated when they don’t have time to care for you properly
• The staff may not be able to get the machines ready as expected

**Unit Management/Facility:**
• Overall patient satisfaction decreases
• More money is spent in supplies and staff overtime payments
• Clinical outcomes (patients meeting treatment goals) may not be as good

**Suggestions on how you can be on time**

1. Plan ahead: Pack items to take to dialysis the night before and put things in their special place
2. Transportation: Arrange transportation ahead of time with a reliable person and share how important it is to be on time for dialysis. If transportation is an issue, talk with the Social Worker about other options
3. Rest: Get enough rest to prepare help you prepare for the next day and set your clock ahead
Resources, Important Numbers and Websites

Kidney School
www.kidneyschool.com

One of the Best resources available for almost everything you need to know about kidney failure, dialysis and transplant. This site is organized into interactive, self-paced chapters.

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<tr>
<th>Medicare: Customer Service Line</th>
<th>United Network of Organ Sharing (UNOS)</th>
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<tr>
<td>1.800.813.8868</td>
<td>1.800.292.9547</td>
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<th>American Association of Kidney Patients (AAKP)</th>
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We welcome articles or information that will be helpful to the ESRD patient community. To submit article for consideration, call Anne Karanja, Patient Services Coordinator at 1.800.444.9965 or email akaranja@nw12.esrd.net.

Is There a Dialysis Unit Close To...?

Ask a staff member for a handout on how to use the Dialysis Facility Compare (DFC) website at www.medicare.gov/Dialysis/home.asp

DFC is a webpage on the Centers for Medicare and Medicaid Services (CMS) Web site. DFC allows you to search for dialysis facilities by state and provides information such as:

- Facility address and phone number
- Types of dialysis offered (in-center hemo or peritoneal dialysis)
- Facility ownership type (profit or nonprofit)
- Whether dialysis shifts are offered after 5 pm
- Number of treatment stations