



RENAL OUTREACH

ESRD Network 9/10

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Program Provides Transplant Patients with Lodging

The National Foundation for Transplants (NFT) and the pharmaceutical company Roche have partnered to offer the ***Home Away from Home*** program to transplant patients in need of short-term lodging. Since 2004, this program has been helping transplant patients and their families obtain free hotel lodging near transplant centers.

When Roche holds meetings at participating hotel chains, frequent meeting points are donated to the *Home Away from Home* program. The ability to help patients is based on the number of frequent meeting points currently in the system, as well as the availability of nights at participating hotels. Since the inception of the program, 256 patients and their families have received 500 nights of free lodging.

“Transplant patients and their families are already burdened with high medical costs,” said Jackie Hancock, Jr., president of NFT. “By providing free short-term hotel lodging, the *Home Away from Home* program ensures that expensive hotel stays don’t add to the burden.”

To qualify for the program, transplant patients must be recommended by their social worker or financial coordinator and prove financial need.

The *Home Away from Home* program is designed to help with one, two or three-night stays needed for pre-transplant evaluations or post-transplant check-ups. It does not provide lodging for longer stays, as those would quickly deplete all the available frequent meeting points.

To apply for the program, transplant patients should have a social worker or a financial coordinator from their transplant center call and request a *Home Away from Home* application. NFT should receive the completed application at least two weeks prior to the date lodging is needed. While NFT hopes to assist every family in need, room availability is not guaranteed.

National Foundation for Transplants also offers a fundraising assistance program to help with long-term needs, such as medications, insurance premiums, doctor and hospital bills, longer term temporary housing near the transplant center, travel and other expenses related to the transplant. For more information on the *Home Away from Home* program or the National Foundation for Transplants, please call 1-800-489-3863 or visit www.transplants.org.

April is National Donate Life Month

Every day in April, people will celebrate the wonderful group of people who have so generously helped to save lives by becoming organ, tissue, marrow and blood donors. More information about becoming an organ donor can be found at www.organdonor.gov.

Being Prepared for Spring Emergencies

In the Midwest, every season seems to have its own weather-related emergency situations. Below are some terms that you may need to understand to help you make good choices in a potential emergency situation:

Flood Watch and Flash Flood Watch:

There is a high flow or overflow of water from a river or lake, or heavy rain runoff into a low-lying area expected within six hours. This means you should continue to listen to weather and news reports, especially if you live close to a body of water. Stay prepared in case the situation worsens.

Flood Warning or Flash Flood Warning:

Flooding conditions are happening right now. Listen to news reports and evacuate if told to do so. Remember to take supplies, your medicines and your pets. Do not walk through moving water. Six inches of moving water can make you fall. Do not drive into flooded areas. If floodwaters rise around your car, abandon the car and move to higher ground if you can do so safely. You and the vehicle can be quickly swept away.

Tornado Watch:

Weather conditions are favorable for tornadoes. They may strike quickly, with little or no warning. You should continue to listen to the weather radio if you live in the tornado watch area.

Tornado Warning:

A tornado has actually been sighted and is occurring in the warning area. If you see approaching storms or any of the danger signs, be prepared to take shelter immediately. Go to a pre-designated shelter area such as a safe room. Go to the center of an interior room on the lowest level (closet, interior hallway) away from corners, windows,

doors and outside walls. Put as many walls as possible between you and the outside. Get under a sturdy table and use your arms to protect your head and neck. Do not open windows.

Make sure you know your dialysis unit emergency plan and what back-up facility will offer emergency medical treatment, if your unit is unable to provide services. Your unit can give you a Vital Patient Information Card to keep all of your medical information, just make sure you keep it updated. Give your unit updated information when your phone number or address changes as well as updated emergency contact information so they will be able to contact you if needed. Your unit also will teach you how to be prepared if you are dialyzing when an emergency situation occurs.

You can download a copy of *Preparing for Emergencies: A Guide for People on Dialysis* at www.therenalnetwork.org/home/disasterplan.php or ask your social worker for a copy of the booklet. You also can find important information to help you before and during emergencies at www.kidney.org/help.

Upcoming Patient Conference Call

The upcoming *AAKP HealthLine* conference call is titled **Meal Planning 101**. This call will take place April 17, from 1:30 p.m. - 2:30 p.m. ET.

Meal Planning 101 features detailed information on the importance of understanding food portion sizes, how to measure portion sizes and how to read and understand a food nutrition label.

To register for this *HealthLine* call, visit the AAKP Web site, www.aakp.org, or call toll-free (800) 749-AAKP.

Dialysis Facility Compare

Did you know that there is a Web site that will give you information about Medicare-certified dialysis facilities? Did you know that you could use this information to assist you in choosing a dialysis facility? The Web site is called Dialysis Facility Compare and is located at www.medicare.gov/dialysis. The site is hosted by the Centers for Medicare & Medicaid Services (CMS).

Dialysis Facility Compare provides characteristics, as well as quality measures, for each facility. The characteristics are updated monthly and include the following:

- Address and phone number
- Date of initial Medicare certification
- Whether or not there are shifts starting after 5:00 p.m.
- Number of treatment stations
- Types of dialysis offered (hemodialysis, PD, home hemodialysis)
- Type of facility ownership (profit or non-profit; corporate or independent)

The quality measures obtained from the Medicare billing database are updated and include:

- Percentage of patients with a URR > 65%
- Percentage of patients treated with Epogen with a hematocrit > 33%
- Patient survival information (better than expected, as expected, or worse than expected)

We encourage you to utilize this informative Web site. It can also be very useful when you are planning transient treatments or permanently moving. CHECK IT OUT!



In Memory of Kris Robinson

Kris Robinson (pictured left), a true champion and

advocate of patient quality care, died November 17, 2008 at age 44 after a losing battle with cancer. Ms. Robinson was the Association of Kidney Patients (AAKP) Executive Director and CEO for 18 years.

During her time at AAKP, Ms. Robinson was influential in many of its achievements. She represented AAKP before organizations around the world, including appointment to the Health and Human Services Advisory Board on the Demonstration of a Bundled Case-Mix Adjusted Payment System for ESRD Services, Health and Human Services (HHS) Advisory Committee on Organ Transplantation, and various committees of the Center for Medicare and Medicaid Services (CMS).

Ms. Robinson also testified before Congress on healthcare issues and wrote and spoke frequently on kidney care issues, patient partnership in their healthcare and rehabilitation, legislative issues and managed care.

Kris Robinson provided energetic leadership and a strong patient voice. However, many would say that her greatest accomplishment was helping other patients learn about themselves and how to live well with chronic kidney disease.

If You Really Want To Feel Better!

If you're looking for that overall, feel good article that solves your problems and cures your ills, including kidney disease, please keep moving.

This is probably not the article for you.

However, if a little work, a little pain, and the feeling of being on top of the world, in charge of yourself and what is going on with you, is of some interest, stay here. This might be interesting!

Have you ever had one of those days where you just feel like you've been in a gang fight and the gang won? You know, your body aches all over and you're just worn out from everything you've done that day. That's how I feel right now, only I know exactly why my body is hurting this way.

My legs are tired, my arms are weak, my chest aches and my back is pounding as though I've been digging ditches all day. I've just come home from the gym and I ache all over. I feel fantastic! You may be wondering if I'm crazy or at least a little wacky. Possibly both but more importantly, I'm like this every day because I do this to myself. I love to exercise!

Kidney disease, and its countless complications, is a daunting illness to deal with. When I was diagnosed in 1998, I was a pretty active man for my age. At 52, I loved to play racquet ball, golf, run, and take long walks and anything else that made me feel alive. My dog and I would walk for miles and then come home to a 30-minute game of catch. I was never a great athlete but I loved to play the game. Just the thrill of participating was all I really needed. It was always exhilarating and I seemed to respond to physical activity. I have found that this feeling I get from exercise or activity of any kind, would serve me well over the years.

When kidney disease was first thrust upon me it was like a kick in the face. I was completely caught off guard by this new challenge. I had no symptoms, wasn't overweight, had never been diagnosed with diabetes and my blood pressure had never been a major problem. I was pretty active and I had actually never heard the term nephrology. Oh how things can change.

As a new patient, I traveled through all of the emotional and physical stages that any kidney patient experiences - denial, anger, shock and so on. In the first two years following my diagnosis, I went through at least six surgeries, gained and lost a minimum 150 pounds of fluid, was informed I had contracted liver disease on top of my kidney problems, had my abdominal cavity drained at least 30 times, lost my ability to walk and, for a three-month period of time, it would take me almost 30 minutes each night to get to my bed on the second floor of my house.

When I was diagnosed in 1998, I was a pretty active man for my age. ...I had actually never heard the term nephrology. Oh, how things can change.

Throughout all of this, I reminded myself of everything I'd learned about sports. It really is how you play the game, not if you always win.

My first hurdle was to understand my problem and how it was affecting my body and could continue to affect me. I delved into kidney disease research, learning where it came from and how to get rid of it.

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That last problem became a big one as I learned you just don't get rid of it. As my understanding increased and my health decreased, I looked back at what had worked for me in the past.

What gave me peace? What helped me relax and cope with life's issues? What kept my belief system in order and how did things turn out when I accomplished various milestones? The answer was always "Exercise."

Early in my illness, my muscle mass was severely impacted by both the disease and the drugs I was taking to control it. I had regularly exercised and could, just prior to my illness, lift weights for an hour and a half and then enjoy a good thirty minute work out on a treadmill.

Within seven months of my early treatment regimen, I was lucky to curl soup cans as weights as this was all my arms could handle. I eventually gave up on the lifting completely since I could no longer walk. My muscles atrophied a great deal, and if I got on the floor to play with my dog, it would take me 15 to 20 minutes to get back up and I usually had to hold on to something to do so. I had to try and I had to believe and so, I did. Soup cans grew to be bean cans that turned into half gallons of water. My stairs became my built-in home gym. My wife began to help me learn to walk again, five to 10 feet at a time. It took three months for me to reach a point where I could walk a block



Jim Dineen working out at the gym.

from my house and get home again, but it took an hour.

I ultimately ended up on dialysis and returned to my gym, three years after my journey started. I had gone to the same gym for over six years and knew everyone there. Nobody recognized me for weeks. I had changed in so many ways.

Many fellow patients ask me why I so strongly believe in exercise as part of my regimen and I simply tell them where I was and where I am today. I just celebrated my five-year anniversary with my transplant and I go to the gym a minimum of four days a week. I walk at least a mile every day and although I'll never lift the kind of weight I did before, I can do pretty well for my "condition." Someone said age may have some bearing on this but I try not to factor that into the equation. I might start believing it!

I love sports but I'm not a good spectator. Now, what I mean is I can watch a good football game for only so long or get excited about golf for just short periods and then I must do something. There's nothing wrong with my attention span. I just like to participate in life, not just watch it. It's pretty much the attitude I've followed throughout my challenge with kidney disease. I remember thinking when I was diagnosed that if this disease was going to take anything from me, it wasn't going to be my ability to try or my capacity to believe I could win. I was going to stay in control.

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You don't have to be a professional athlete to live and love the benefits of exercise.

Perhaps your only exercise is walking or running or simply climbing the steps regularly instead of taking an elevator. Swimming is a wonderful exercise if you're fortunate enough to have access to a pool. I strongly encourage you to exercise to the very best of your ability. Talk with your doctor and, if necessary, hire a trainer. Look on the Internet or go to the library to find out what will work for you and, whatever it is you choose to do, you will feel better.

Do a little soul searching. Examine your own situation and ask a few questions:

- Would I like to feel better?
- Would I like to look better?
- How would it feel to have less stress in my life, especially related to my illness?
- What physical and mental goals would I like to achieve in the short and long term?
- Do I know my lab numbers and am I willing to track them if I start exercising? Make a log of your weight, blood pressure, cholesterol readings, blood counts, etc. It can be exciting to watch those numbers steadily improve.
- Write down your exercise program and keep track of your progress. Your soup cans can turn into 10 pound or 20 pound weights in no time at all. It's not the weight that matters but the progress.
- Ask yourself every day - Am I trying and do I believe exercise is helping me?

When I was a young man, actually just a boy, my parents taught me two important lessons:

- 1) I can do anything I'm willing to work for and,
- 2) I must believe with all my heart I can do it.

When I think about exercise, I remember mom and dad's advice. Until I try something and believe it will work for me, I'll never know the results. This thinking has taken me a long way in my battle with kidney disease. And sometimes a little pain makes life a whole lot more enjoyable.

Most importantly, look in the mirror each morning and ask yourself, "Am I willing to TRY and do I BELIEVE I can do it?" If the answer isn't yes, go find a soup can!

How do you know if you haven't tried?

By Jim Dineen, Member of the Patient Leadership Committee and Member of the Board of Trustees

Too Much Potassium and Phosphorus

Too much potassium can cause such problems as weakness, muscle cramps, irregular heartbeat and can increase the risk of heart attacks. Too much phosphorus can cause complications such as itching.

High levels of phosphorus also cause body changes that take calcium from your bones leaving them weak and brittle. Taking phosphate binder with meals and snacks helps to reduce the amount of phosphorus absorbed by your body from the foods you eat. To learn more visit, www.kidneypatientnews.org.

Do you have a complaint or grievance about your treatment or quality of care?

- Talk to your staff to resolve the issue.
- File a grievance with your facility, if it has not been resolved.
- File a complaint or grievance with The Renal Network at any time if it still is not resolved or if you prefer to go through the Network.

The Network Can

- Help you solve your complaint
- Contact the facility with your permission
- Provide a Network Grievance Packet
- Investigate the Grievance or Complaint

For more information or resources for complaints and grievances:

- Contact the Patient Services Department using the patient line at 800-456-6919
- Go to the Network's patient Web site: www.kidneypatientnews.org

Network Trends

In 2008, the Network received 114 complaints and two grievances from patients, family members, or other concerned individuals. The highest numbers of complaints were about the quality of treatment or about interactions with the staff.

The Role of THE RENAL NETWORK

The core purpose of The Renal Network (TRN) is to facilitate the achievement of optimal wellness for renal disease patients.

The Network takes on a number of different roles to accomplish its purpose. It has three major functions: quality improvement, data collection and patient education/complaint resolution. For more information, visit www.therenalnetwork.org.

Stay Informed

The *Renal Outreach* is one way patients can stay up-to-date on Network activities and projects. You can subscribe to this newsletter by completing and returning the form on the back cover or you can sign-up online for e-mail subscription at www.kidneypatientnews.org/resources/newsletter.php. Current or past issues are available for download.

Let Us Hear From You

The Renal Network wants to help patients and family members get the information and support needed to live well with kidney disease.

Please let us know what topics you would like to hear more about: vascular access care and management; transplantation, vocational rehabilitation and employment; diet and nutrition.

Send an email to kstark@nw10.esrd.net (label subject: Educational Needs) or write a post-card or letter letting us know what your needs are or what interests you most.

Subscription Form for the *Renal Outreach*

Dialysis patients are eligible to receive free home delivery of the *Renal Outreach*. To receive the *Renal Outreach* patient newsletter at home, just complete and return the form below to our Patient Services Department. If you already have a subscription, feel free to give the form to a fellow patient or copy this page and distribute to patients on your shift.

SUBSCRIPTION FORM FOR RENALOUTREACH

NAME: _____

FACILITY: _____

ADDRESS: _____

CITY: _____ **STATE:** _____ **ZIP:** _____

EMAIL: _____

Please send by mail email

Mail to: **Renal Outreach**
 The Renal Network, Inc.
 911 E. 86th Street, Suite 202
 Indianapolis, IN 46240

FAX to: **317-257-8291**

RENAL OUTREACH

Address Service Requested

The Renal Network, Inc
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