



RENAL OUTREACH

ESRD Network 9/10

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The Robert Felter Memorial Award

The Robert Felter Memorial Award is presented to kidney patients who have actively worked on behalf of their fellow patients. This year we invited every patient in Network 9/10 to apply for the award. Twenty-seven patients applied. They shared how they have coped with the challenges of living with End-Stage Renal Disease, and what they have done to reach out to other patients. It was a hard decision to select the two winners, but Dadi Ding and James Dineen are the 2009 winners.

Dadi has been coping with renal failure since she was a very young child. At age 28, she made the decision to move to the United States as her home country did not have the capability to perform transplants or to offer dialysis treatments.

Dadi is currently working in a full-time position for the Loyola University Medical Center in the Chicago area. She has worked as a dialysis nurse,



James Dineen and Dadi Ding pictured at the Network Council award presentations.

patient educator for pre-ESRD patients, and a transplant coordinator.

Dadi's involvement as a volunteer for the kidney community includes working with The Renal Network Patient Leadership Committee, the National Kidney Foundation, the American Nephrology Nurse Association, and helping other kidney patients.

Dadi keeps herself physically and mentally healthy by adhering to the dialysis treatment plan, leading a productive life style, and staying

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positive. She will use the award toward educating and empowering patients and volunteering on kidney dialysis organization committees to share her knowledge and experience.

James Dineen is an inspiration to other kidney patients and individuals faced with hard times. He has the ability to reach out to others while at the same time cope with his own chronic kidney disease and other complex medical problems. He has creatively responded to the significant changes in his financial situation and is a real estate agent and a lector at his church. To keep fit, Jim lifts weights and walks 10 miles a week.

Jim, a first term member of the Patient Leadership Committee and Network Board of Trustees, enjoys learning, writing, and speaking on topics related to kidney disease.

He travels throughout the country as a motivational speaker focusing on coping and moving forward for Eagledreamer, a company he established in 1992.

His volunteer experience with the kidney community includes working with The Renal Network, the Renal Support Network, the Ohio Board of Nursing and working with transplant personnel to develop videos for patients.

In 2004 Jim and his wife Joyce were featured in *Reader's Digest*. They have also been interviewed for several local newspaper articles.

Jim plans to use The Robert Felter Award as a bridge to bring knowledge to the community on overcoming life's challenges. His philosophy is to "Pass It Forward." The more we help each other the better off we will be.

Resources for Visual Loss

There are many large print resources available for patients who have kidney disease and low vision. For example, the National Kidney Foundation (www.nkf.org) as well as Medline Plus (www.nlm.nih.gov/medlineplus/kidneyfailure.html) have resources that can be downloaded. Many of The Renal Network patient education resources can be copied for you in large print. Just contact the Network at 800-456-6919 to request specific resources. In addition, the American Foundation for the Blind (AFB) has resources to help people with vision loss stay independent. You can view its services at www.afb.org or contact the AFB at 1-404- 525-2303.

What to Expect After a Kidney Transplant

by Dadi Ding, RN, BSN, CNN

A kidney patient and nephrology nurse, currently working as a renal transplant coordinator.

Three treatment options are available for patients suffering from end-stage renal disease: hemodialysis (including in-center hemodialysis and home hemodialysis), peritoneal dialysis (usually done at home) and kidney transplantation. Kidney transplant is not a cure for your disease, but rather one of the treatment options. When a transplant is successful, it is the preferred treatment among all three. However, kidney transplant is not the best choice for all ESRD patients. When you are diagnosed with kidney failure, you need to choose the most appropriate treatment for your health and life style.

You need to learn as much as possible to help you make an informed decision. This article will provide you with some facts related to kidney transplantation and what to expect after a kidney transplant. You can compare them with facts about dialysis and decide which treatment would be the best for you.

A successful transplant will bring you near normal kidney function. The human kidney will clean your blood much more efficiently than an “artificial

kidney” or dialysis machine can. You will feel much better and have more energy. Your life expectancy is longer after a transplant compared with staying on dialysis. With a transplant, you will have fewer comorbidities from kidney failure, such as high blood pressure, heart disease, bone disease, neurological disorder, growth retardation for children, and infertility for women.

A successful transplant will bring more freedom to your life in comparison to dialysis. You do not have to be tied to a machine three to four hours, three times a week, as an in-center hemodialysis patient typically does. Home hemodialysis or peritoneal dialysis patients may have more freedom in scheduling the treatment time but they still have to commit three to eight hours a day to the therapy. All dialysis patients are restricted in traveling, while transplant patients can enjoy traveling without any limitations. There are very few dietary restrictions after transplant, and you are encouraged to drink a lot of fluid. The quality of life is definitely better with a successful transplant.

We have to keep in mind, however, that there are a few down sides of transplantation. Many of them are caused by the medications used to prevent rejection. There are multiple drugs a patient has to take for life after the transplant. These drugs all have

Home Hemodialysis – My Eighteen Years Experience

by Dadi Ding, a kidney patient and nephrology nurse, is a member of The Renal Network Patient Leadership Committee and works as a renal transplant coordinator.

I had kidney failure when I was 28. I soon had a transplant before starting dialysis. However, the transplanted kidney did not last very long. Within a week, it had to be removed due to acute rejection. I started peritoneal dialysis right after the transplant failed. I was on peritoneal dialysis for ten years and I did reasonably well on PD.

However, the peritoneal membrane started to fail after 10 years of use. The treatment could not deliver the clearance needed. I started to accumulate fluids and toxic material in the body. At that time, I received a second transplant which never worked and was removed after five months. My only option was to go on hemodialysis. I did in-center hemodialysis for about three months.

During that period of time it was very difficult to balance my job and the three-weekly treatments in the dialysis center. I was required to report to the center at 3:00 in the afternoon. I was a nurse clinician for a busy nephrology clinic at

the time. Leaving at 3:00 in the afternoon was almost impossible to do. I really did not want to give up my career as a nephrology nurse. My nephrologist, Dr. Susan Hou, told me that I could try to do hemodialysis at home in the evenings, and she tried finding a center to take me as a home patient. Luckily, Dr. Paul Balter accepted me to his home program. The nurses came to my home to teach me and my husband how to run the machine and complete the treatment.

Although it was not that easy at the beginning, especially performing self-cannulation with a new fistula which had not quite matured at the time, the flexibility of the time and being able to work were such big incentives for me that I was determined to overcome all the fears and difficulties to keep trying until I mastered the skills needed to dialyze at home.

My husband gave up better career opportunities in order to assist my treatment at home. I always dialyzed every other day without those two-days in between treatments as in-center patients normally do. I also stayed on the machine for four hours each treatment without ever shortening the time, in spite of my small body size.

The reward was significant, that I have been healthy enough to lead a normal life: I work full time as a nephrology nurse; I volunteer for many

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professional and patient organizations; my husband and I travel once or twice a year to many beautiful places in the U.S. and Canada; I have been enjoying cooking and baking at leisure. About six years ago, a new home hemodialysis machine became available, and I started short daily treatment. I dialyzed six times a week, two hours and forty five minutes each time.

I felt so much better on daily hemodialysis that sometimes I did not want to skip Saturdays since I did not feel well on Sundays. I had more energy, I was able to eat more fruits and vegetables which I love but was not able to eat when I was on every other day dialysis, I no longer suffered from the ups and downs as I often experienced on every other day dialysis, I was able to get off the machine and go to work immediately, I no longer felt the thirst and the urge to drink. I loved the short treatments because 2.75 hours on the machine seemed so short in comparison to four hours.

Four years ago, an even better home dialysis machine called NxStage

became available, which is much smaller in size and requires no special water supply treatment. I was so happy to move the machine to the bedside and dialyze during sleep. Dialysis treatment no longer takes

three to four hours away every day from my busy schedule. The machine is small enough that I took it on two vacations last year: in California and Texas.



Dadi Ding and her husband, Tien-yun Yang.

Dr. Orly Kohn, my nephrologist recommended that I dialyze overnight for six hours (called nocturnal

dialysis) three times a week and the other three days for three hours. Longer treatment allows better clearance of middle molecules which are toxic to the body and can cause amyloidosis, a very debilitating condition often seen in long term dialysis patients.

Since I started the nocturnal dialysis, my phosphorus has been lower, I require fewer binders, and I am able to enjoy dairy products. I no longer feel sick on Sundays regardless whether I dialyze on Saturdays.

Instead, I have begun to work out on Sundays in the gym.

As a transplant coordinator, I work eight to ten hours daily and often on-call at night. I am able to handle the long hours and the stress as a normal person would. My sick calls have been less than most of the staff in the office. I believe this is all because I do more dialysis.

I am not on the waiting list for another transplant, as I am not a good candidate for one. Two previous transplants resulting in high antibody levels and long-term dialysis have made me a poor candidate for a successful transplant. Clearly, transplantation is not the best treatment modality for everyone.

I will soon change to nocturnal dialysis six nights a week. I am also planning to bring my dialysis machine to Yellowstone National Park this summer. I hope by sharing my personal experience, more patients can learn about daily home hemodialysis, and will benefit from the best dialysis modality among all the ones available at present time.

For patients or family members who are interested in information on latest news and developments in home dialysis, and reviewing other patients' opinions/ experience, there is a Web site they can visit: www.homedialysiscentral.org.

some side effects. The major side effect is a weakened immune system, which lowers a person's ability to fight against infection and cancer.

As a consequence, transplant patients are at higher risk for all sorts of infection and cancer. Scientists are working to find better methods to control rejection without compromising the immune system. We closely monitor patients to prevent infection/cancer or detect them early so that treatment can be initiated quickly. Other side-effects include stomach discomfort, diarrhea, poor appetite, joint pain, tremor, and burning sensation of the feet. These symptoms usually subside after the body adjusts to the medication, or they can be treated with medication and dose adjustment. For patients on steroids as part of the anti-rejection regimen, drug-induced osteoporosis may develop over the years. It should be monitored and treated if indicated.

Post-transplant follow-up with the transplant center can be very time-consuming during the first year. It may interrupt your daily routine, especially if you are still working. During the first year after transplantation, the risk for rejection is much higher. You are required to have frequent lab tests, office visits, and radiological tests, sometimes as often as three times a week. You may need to be readmitted

to the hospital for observation, procedures, or operations if indicated. If your work needs a letter of documentation for absences from work, ask your doctor to write one for you.

Financial burden is another challenge transplant recipients have to face. Anti-rejection medications are very costly, ranging from \$2,000 to \$4,000 a month. Medicare covers 80% of the cost, and your secondary insurance may or may not cover the remaining 20%. Three years after the transplant, you will lose Medicare unless you are 65 years or older, or you have another disability. Some insurance plans cover the medication but require high co-pays from you. The best thing to do is to work with the social worker at the transplant center where you are listed to determine the exact amount you may need to pay out-of-pocket each month. There are many patient assistance programs which can help with the payment. Talk to the transplant social worker to see if you will qualify. Planning ahead can help you to avoid facing an unexpected large pharmacy bill immediately after the surgery.

In summary, kidney transplantation is not a cure for your disease. For some patients, it may be the best treatment option. In most cases, a patient's health, life expectancy and quality of life improve significantly after a

successful transplant. However, there are many facts that need to be taken into consideration when you are planning to pursue a transplant. Talk to your nephrologist, social worker at the unit and at the transplant center, and visit the Web sites listed in this brochure for additional information. A well-educated, informed patient is the key to a successful transplantation.

The Patient Leadership Committee (PLC)

The Renal Network has a Patient Leadership Committee (PLC) that acts as an advisory group to the Patient Services Department. This group gives input into patient publications, provides the patient perspective on current issues, and discusses issues such as adherence, complaints, and cultural diversity.

This group of volunteers represents patients in Indiana, Ohio, Kentucky, and Illinois. There are three meetings a year and conference calls as needed. If you are interested in learning more about becoming a member of this group, please visit the Network Web site at <http://www.therenalnetwork.org/about/patientlead.php> and you also can download the application. You also can ask your social worker for additional information and an application form.

Vocational Rehabilitation

One of the biggest losses a dialysis patient experiences when placed on dialysis is the temporary, and often permanent, loss of employment. While some patients are too ill to work even part-time, there are a number of people who, with the help of a vocational rehabilitation counselor, may be able to return work. This may mean learning a new trade or finding a different job setting, but even working part-time is an option for many people.

The Ticket to Work program is a national program that started in 1999 with the goal to increase opportunities and choices for Social Security disability beneficiaries to obtain employment, vocational rehabilitation and other support services from public and private providers, employers, and other organizations. The facility social worker can provide more information about this program. Visit The Renal Network patient Web site (http://www.kidneypatientnews.org/quality/voc_rehab.php) for more information about the Ticket to Work program as well as other rehabilitation resources.

Save the Dates!

Sunday, October 11th and Sunday, November 15th

The Renal Network and the Renal Support Network are planning two free patient conferences in the of Fall of 2009. The first one is in the Cincinnati area and the second one is in Indianapolis, Indiana . More information will be sent to units later in the summer; also check our patient site www.kidneypatientnews.org.

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