

Common concerns

News and information *for kidney patients and their families*

From the Consumer Committee Chair

In the last issue of Common Concerns, the Network 11 Consumer Committee announced the kick-off of its new initiative on Vocational Rehabilitation and Quality of Life. As we plan ahead to achieve the goals of the Vocational Rehabilitation project, we have realized that we have a significant source of information that we have not yet tapped -YOU, the consumers of Network 11.

We are asking all of you who have successfully continued to work while dealing with ESRD, who have found ways to return to work with ESRD, who have successfully gone back to or continued school with ESRD, to please share your stories with us. We want to know how you overcame the obstacles to these endeavors.

If you have a short story or tip to share about how you overcame barriers and/or worked with your employer or educational institution, please send them to us. We would like to collect as much practical and pertinent information as possible to use in upcoming issues of Common Concerns and on our Web page. As we all know, the best motivation comes from those who have successfully gone before us. Please send your story or tip to the attention of:

Mark Meier
Renal Network of the Upper Midwest
1360 Energy Park Drive, Suite 200
St. Paul, MN 55108

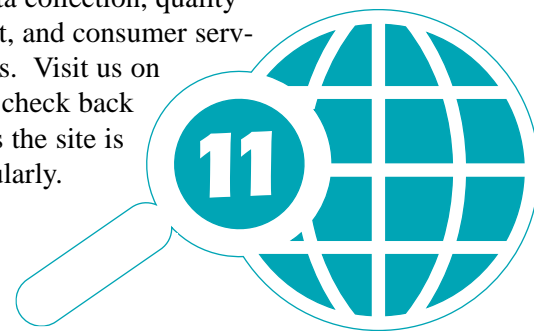
Or e-mail it to mmeier@nw11.esrd.net.

I am really excited about this and look forward to learning about all of the creative ways you have handled these issues.

Maggie Carey

DID YOU KNOW...

Renal Network 11 has a Web site (<http://www.esrdnet11.org>) with information that is pertinent to you as a consumer. The Network 11 Web site contains patient resources, as well as detailed information about the data collection, quality improvement, and consumer services activities. Visit us on the web and check back frequently as the site is updated regularly.



NETWORK 11'S NEW LOGO



CAN IT BE DONE?

Living and Working with Chronic Kidney Disease (CKD)

The barriers to employment for you, a patient living with Chronic Kidney Disease (CKD) may at times feel insurmountable. You have questions about your health and ability to attend work regularly; you might worry about your finances, disability payments, and health insurance. You might encounter negative attitudes from your employer, co-workers, or even your own family when trying to work. These and other barriers not listed here are all real concerns, which deserve some consideration. Sometimes returning to work, whether part-time or full-time, is not an option for CKD patients. But, if you are able, research shows that returning to work can have a positive impact on your quality of life.

The following interview might give you some insight into how barriers were faced and overcome by an individual living with CKD, Mitzi Reilly. Mitzi is a vibrant, engaging, 40-year old woman who lives in Michigan, works full time, and supports a 20 year-old daughter in college. Mitzi recently joined the Network 11 Consumer Committee and is fully committed to help improve the quality of life for the Network 11 consumers.

Here's a little more information about Mitzi.

Q: Tell us a little about your disease history.

A: I was diagnosed with lupus when I was 27 years old. It took the doctors a while to figure out what was wrong with me and I dealt with a great deal of pain from joint stiffness, swelling in my hands and ankles. My lupus progressed until the point that I had to initiate dialysis when I was 32. I started on peritoneal dialysis and was on that for about a year and a half, then I went to in-center hemodialysis for about 3 years, until I received a kidney transplant back in

December of 1999.

Q: Tell us about your education and work history.

A: I graduated from high school, attended about one and a half years of college, and I have worked full time ever since.

Q: So, you were working when you were diagnosed with lupus? Tell us about that.

A: It was hard. I was working for a company that made car parts and I was doing assembly work. I was in a lot of pain and some days I was almost crawling into work, but I had to keep working because I had a daughter and a home to support. After I was diagnosed with lupus and my pain was under control, working became routine again.

Q: What was it like when you were working and first started on peritoneal dialysis?

A: At first I was nervous and scared. I was concerned about infection and doing my exchanges. Once I talked with my employer, though, I felt much better. They provided me with a clean room to do my exchanges, and it quickly became part of my day.

Q: How about working and being on hemodialysis?

A: That did affect me more than being on peritoneal dialysis. When I went on hemodialysis I had to change my work schedule to the night shift. So, I would go into work from 11 p.m. until 7 a.m. and then go to get my dialysis. But, I did get used to it and I was able to continue working 40 hours a week. Also, I found work to be a good social outlet and a way to get my mind off of going to dialysis 3 days a week.

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Q: And what about now that you have a transplant?

A: Well, now it all seems much easier. I wish I could get back to the

dayshift, but that will just take some time.

Q: What type of support did you receive from friends and family?

A: Well, some of my family thought I was crazy for trying to work when they thought I should go on disability. I think, though, that I used that attitude as a way to stay motivated to keep working. I wanted to show them that I could still work even though I was on dialysis. Also, I had to be a role model for my daughter and show her the importance of maintaining as much of my regular life as I could.

Q: Besides a paycheck and other benefits, what have you gained personally from working?

A: I think that I have really learned that if I put my mind to something, I can see it through. Also, I have been able to help other people. When my co-workers began to understand my disease and that I was on dialysis, they began to come ask me questions. I was able to give them information about kidney disease and help them with any fears they had for themselves or others who were facing ESRD.

Q: What would you like the consumers in Network 11 who are considering returning to work to learn from you?

A: First, keep going no matter what. Whether you are going back to work or resuming other activities you used to enjoy, don't give up. I know that by working and making more money than disability would pay, I have been able to do more for my daughter and myself. I know that my mood and attitude toward this disease have been better because of working and staying active. Don't let this illness beat you, beat this illness!

ESRD SELF-SUFFICIENCY

Ticket To Work Program

Josephine Mahi

“Currently, there are approximately 9 million working-age adults who receive disability benefits, many of whom could take jobs if they could keep their government-financed health benefits.” - *Senator Edward Kennedy.*

What is This Program?

The Ticket To Work Program (TTWP) is an innovative centerpiece of the Social Security program for people who receive Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits. The Ticket To Work Program makes it possible for beneficiaries with disabilities to obtain employment, vocational rehabilitation (VR), or other support services from public and private providers. The goal is to help you earn enough money to become independent of Social Security cash benefits. Participation in the TTWP is voluntary and you do not have to participate in order to continue receiving your social security benefits. However, the benefits of returning to work, school, or other supportive services might improve your quality of life as an individual living with ESRD.

Am I Eligible?

There are three primary eligibility requirements for the TTWP:

- You are between 18-64 years old
- You are currently receiving a cash payment from social security
- Your medical condition is not expected to improve before your first medical Continuing Disability Review (CDR).

If you meet these criteria, it is likely that you have already received a packet from the Social Security

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Administration (SSA) containing your “Ticket” (which is a red, white, and blue certificate) along with an explanation of the TTWP. If you have not received a ticket and think you might be eligible, or if you have misplaced your ticket, you have two options. First, you can contact your local social security office and request a new ticket or you can call MAXIMUS, the agency contracted by the SSA to administer the TTWP at 1-866-968-7842 (Toll Free) for more information.

What Happens if I Choose to Participate?

If you have received your Ticket to Work and are eager to get started, call MAXIMUS at 1-866-968-7842 (Toll Free). MAXIMUS is available to provide many vital services.

Among its many duties, MAXIMUS is responsible for maintaining a current list of the Employment Networks (EN) available to you. These Employment Networks include public and private providers who have agreed to participate in the TTWP by providing employment, education, or other services such as job coaching, resume writing assistance, and employment searches. When you have picked an EN to work with (you do have the option of contacting more than one EN), you will be asked to visit the EN in person or to speak to a representative over the telephone. The EN will work with you to design an Individual Work Plan (IWP), which is the blueprint for your participation in the TTWP. This IWP is designed to outline the services that will make it possible to reach your employment or rehabilitation goal.

Does This Program Work?

Yes! The program is working and growing. The TTWP recognizes the challenges that individuals with disabilities face in seeking employment, improving their job skills, or improving their education, while maintaining the cash and health insurance benefits (Medicare and Medicaid) that are so important in their daily lives. You can read about specific success stories by visiting the MAXIMUS Website: www.yourtickettowork.com. In fact, there is a story about an individual who was on hemodialysis for

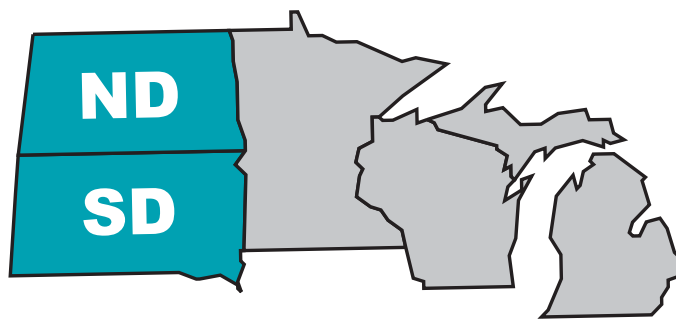
seven years and subsequently received a kidney transplant. The young man suffered complications following his transplant, and the maintenance of his social security benefits was vital. Once stabilized, he used his TTWP benefits to improve his employability, maintain his social security benefits, and secure a full time job as a buyer with a manufacturing company.

Conclusion

Although not all ESRD patients are eligible or capable of participating in the TTWP, there might be benefits and services to improve your quality of life. So, take a chance and call to see if you are eligible and learn how the TTWP might benefit you! Again, for more information on this program contact MAXIMUS at 1-866-968-7842 (Toll free), or visit the Website: www.yourtickettowork.com.

ANNOUNCEMENT

The National Kidney Foundation of South Dakota now includes the state of North Dakota. The new name of the affiliate is the NKF of the Dakotas. All requests for information and donations should be addressed to: NKF of the Dakotas, 1000 East 21st Street, Suite 2200, Sioux Falls, S.D. 57105; (605) 322-7025, Fax: (605)322-7029 or e-mail: info@nkfdakotas.org.



What is happening in Network 11?

THE FISTULA FIRST PROJECT

Important Announcement

The Centers for Medicare and Medicaid Services (CMS) is pleased to announce an important new initiative called “Fistula First,” aimed at significantly increasing the use of AV fistulas (AVF) for hemodialysis access. The initiative will engage nephrologists, vascular surgeons, dialysis facilities, primary care physicians, and PATIENTS in changing practices to assure that AVF’s are the first choice for every eligible patient.

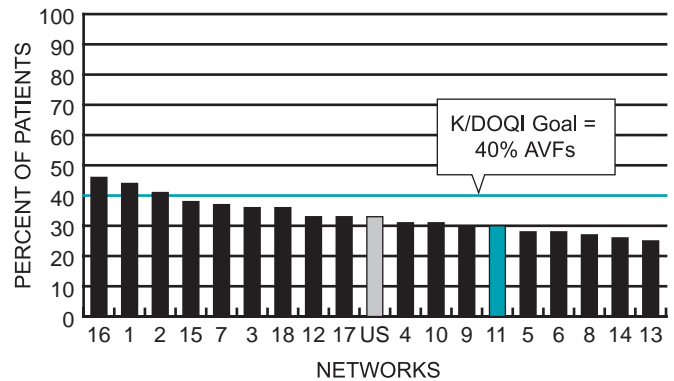
Goals

The Fistula First project aims to fulfill the goals recommended by the National Kidney Foundation’s Dialysis Outcomes Quality Initiative: AVF rates of 50% (or greater) of all patients who start dialysis, and at least 40% of patients who are currently on dialysis. This constitutes a significant increase over current national averages, which are 29% for new dialysis patients and 31% of all patients currently on dialysis. These goals are achievable. All across the United States, there are examples of providers who have harnessed the knowledge of the many disciplines whose care influences vascular choices for patients to meet or exceed the goals of this initiative.

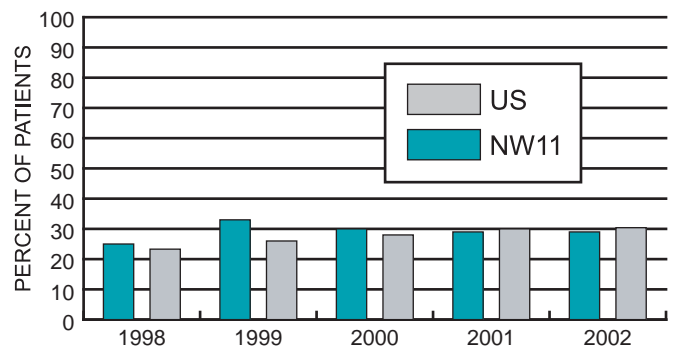
What Does This Mean To You?

Renal Network 11 is actively partnering with the physicians, surgeons, nurses, and consumers of our Network to meet this challenge. This initiative highlights the importance of all eligible patients receiving an AVF so they have the best access possible to improve their well-being. For more information about an AVF, please ask your health care team.

Percent of Patients Dialyzing with AV Fistula
Last Dialysis of 2002
CDC Survey



Percent of Patients Dialyzing with AV Fistula
Network 11 vs. US
CDC Survey



NKF EVENT DATES

NKF of The Dakotas - Call (605) 322-7025 for further information

April 26: KEEP in Huron, South Dakota
June 14: Cadillac Invitational Golf Tournament, Sioux Falls
July 10: Gift of Life Bike Ride
August 7: tentative: Kidney Walk
September 4: Gift of Life Poker Run

NKF of Michigan-Call (800) 482-1455 for further information

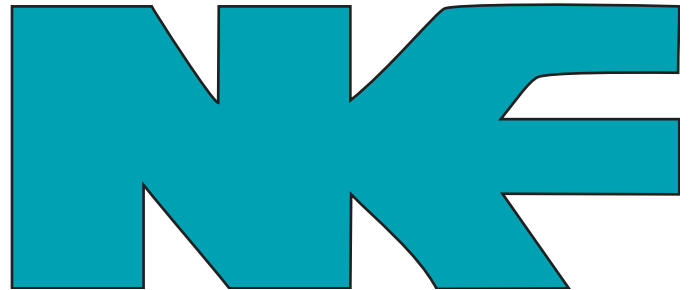
RISE – May 5, 7, 12, 14: Atheneum Hotel; Detroit, MI
Upper Peninsula Symposium – April 6, 2004; Marquette, MI
Spring Symposium – June 4, 2004; Romulus, MI
West MI Symposium September 14, 2004 Grand Rapids, MI

NKF of Minnesota – Call (612) 337-7300 for further information

NKF of Wisconsin - Call (262) 821-0705 for further information

People Like Us Live

Milwaukee, WI
Saturday, September 25, 2004
Thursday, September 30, 2004
Locations and Times TBD



Renal Network 11
1360 Energy Park Dr., Suite 200
St. Paul, MN 55108
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