

US NETWORKING FOR YOU...

...YOU NETWORKING FOR US



KIDNEY CONCERNS

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Vocational Rehabilitation Counselor has Ear of the Governor

Robert Washington is the Vocational Rehabilitation Director for the Iowa Tribe of Oklahoma. He was appointed to an advisory board to the Governor of Oklahoma on issues faced in vocational rehabilitation. Mr. Washington has been a dialysis patient since 1994, CAPD initially and hemodialysis since 1996. Robert is also a bi-lateral amputee. This does not slow him down. Robert states, "Dialysis patients can work, as we are only hooked up to our dialysis machine 9-12 hours a week; that gives us between 156-159 hours of time that belongs to us. My employer has made several 'reasonable accommodations' which allow me to work full-time."

Robert reports that his employer, the Iowa Tribe, "allows me to adjust my work schedule to fit my dialysis schedule. The tribe's headquarters is in Perkins, Oklahoma, fifty miles from my home and dialysis unit. My adjusted schedule allows me to work two afternoons at outreach sites that our grant has established at the Absentee Shawnee Tribe and the Citizen Potawatomi Nation, both in Shawnee. Technology plays an important part in allowing me to work full-time. The tribe has provided me with a fax, copier and scanner all-in-one for my home office and a cell phone. Even though I am a double amputee, I can drive due to hand controls and a driver's side third door pick-up that allows me to load my wheelchair myself. A reasonable accommodation does not always involve a lot of money, sometimes just a slightly adjusted work schedule is enough. The ADA does not fully outline what a 'reasonable accommodation' is, sometimes it is really simple. For example a handicapped water fountain is not always necessary, a paper cup dispenser can be used instead."

"The staff at Shawnee Dialysis Center also helps me a whole lot. They adjust my schedule if I have a meeting or a conference to attend, and arrange transient dialysis when needed. They have worked me in on some of their busiest days. They have allowed me to fax a client when I was on the machine."

"I think the primary barriers that a dialysis patient faces are lack of knowledge of renal disease by the general public, the time constraints because of treatments and the physical constraints of our disease. My experience with dialysis has not been all pleasant, but the good days outnumber the bad and it is surprising how after a few months, dialysis becomes 'normal'."

"American Indians with end stage renal disease who want to return to work may qualify for assistance from one of seven American Indian Rehabilitation Programs in Oklahoma. This program can help you with training from colleges, universities, or vocation-technology centers and other employment expenses such as work clothing. Some programs offer assistance with self-employment or small business start-up costs. The program's primary goal is to help disabled persons to become gainfully employed."

"If you are not an American Indian or if an Indian Vocational Rehabilitation program is not serving your area, I encourage you to call the state Vocational Rehabilitation Office in your area."

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"Glad You Asked That . . ."

QUESTION: *What is transient dialysis and what are some related issues?*

ANSWER:

One of the leading problems facing dialysis patients today is that of transient dialysis. It is getting harder and harder for patients to schedule transient dialysis. Those of us who travel are finding it more difficult to get dialysis scheduled in certain areas of the country also. This article is an effort to define transient dialysis and to try to give each of you as dialysis patients a handle on what is necessary to make this process go smoothly.

First let's try to define transient dialysis. Transient dialysis is the need for routine dialysis while a patient is away from his or her home dialysis unit on a trip for personal or business reasons. This would be necessary when going away from your home over an extended period of time. When traveling for more than 3 or 4 days, it will be necessary to schedule dialysis where you will be located.

When you are going on a trip there are a few things you need to remember. First, when you are traveling, it is important to notify your social worker at your unit first to plan your trip. Most times they are an important resource for locating a possible unit for your trip and "getting the ball rolling" in the exchange of information. Secondly, when your trip is planned, contact the unit you will be visiting. They may have different ways of doing things that may go opposite from your experience. They may also need specific information to be provided from your unit.

Finally, there is an important thing to remember. When you are traveling to another dialysis unit, you will be under the care of another physician. You need to make contact with this physician and remember that they will be your contact for any problems that arise during your vacation until you return to your home dialysis unit.

I hope that these points and opinions help the dialysis traveler with those little nagging questions and problems. I hope that everyone has great traveling experiences. by Carl Nettleton

If you have any questions for "Glad You Asked That," forward them to ESRD Network 13, 6600 N. Meridian, Suite 155, Oklahoma City, OK 73116-1411, or phone 1-800-472-8664. Selected questions will appear in future issues of *Kidney Concerns*.

Transplant News:

1. Good News!!! As of July 1, 1999, Medicare began coverage for pancreas transplants when performed in conjunction with or following a Medicare funded kidney transplant. This is great news for kidney patients who previously had to raise funds of 15 to 85 thousand dollars to cover the costs of the pancreas transplant.
2. Drug Assistance Programs for Immunosuppressants: Work with your Transplant Coordinator or Social Worker for these programs.

CellCept (Roche)	1-800-772-5790
Imuran; Azathioprine (Faro)	1-800-705-2630
ProGraf; KF506 (Fujisawa)	1-800-477-6472
Sandimmune; Cyclosporin; Neoral (Novartis)	1-800-257-3273
SangCya; generic cyclosporine (SangSat)	1-877-264-7828

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AAKP Convention Notes

This convention was a first for me and I was excited to attend. This meeting was in Phoenix, Arizona. This was the 30th anniversary of the American Association of Kidney Patients and they chose an appropriate theme for this year's convention, "*On the Dawn of a New Millennium.*" There was a diverse group at this year's convention including patients, spouses, doctors, nurses, and clinical workers.

From the opening ceremonies on Friday, September 3 until the closing moments on Sunday, September 5 the topics presented at this year's convention were different. This year's topics ranged from ESRD in the Managed Care Environment to New Issues in Transplantation. There were also chances to speak to some of the experts about some of the topics being discussed.

There were several sessions that I believe had information worth bringing back to share with you. The first of these was "**Cardiovascular Disease: Don't Go Breaking My Heart.**" Dr. George R. Aronoff, who is Professor of Medicine and Pharmacology at the University of Louisville School of Medicine, moderated this session. He gave some valuable information concerning dialysis and cardiovascular disease. He believes that there needs to be a coordination of treatments for both renal and cardiac patients. Dr. Aronoff told of a patient that had escalated blood pressure

while on hemodialysis. The medical staff then concluded that the patient was losing cardiac medications during dialysis.

Dr. Aronoff also believes that dialysis patients should also have lower cholesterol because heart

by Carl Nettleton

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"I was fortunate when I was hired for my current position. I was on CAPD and my employer knew about my disease. I started hemodialysis a few months after I was hired, so my employer has treated me well. The Tribe knew about ESRD as most Indians know someone on dialysis. I realize not every dialysis patient can work, but I know that I feel better physically and emotionally because I am working."

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3. Annual National Kidney Foundation's Constituent Council Program to be held November 6, 1999 in Miami Florida. Registration fee is \$15. If you need more information or a registration packet, please call the National Kidney Foundation at 1-800-622-9010 or at their website www.kidney.org. Topics to include: Exercise and a Healthy Attitude, Sexuality, Adequacy & NKF-DOQI, Coping Issues, Organ Donation, Self-Empowerment, transplantation: Options & Facing Medical Challenges.

Oklahoma Indian Tribe Vocational Rehabilitation Contacts

Apache Tribe of Oklahoma- Delrona Strong (405) 247-7494
 Cheyenne/Arapaho- James Ahtone (405) 422-1178
 Cherokee Nation- James Ballard (918) 458-4415
 Chickasaw Nation- TBA (580) 436-0553
 Choctaw Nation- Randy Hammons (580) 326-8304
 Delaware Tribe- TBA (405) 247-2448
 Muscogee Creek Nation- Dr. Sandra Choney (918) 758-1910

State Vocational Rehabilitation Offices

Arkansas Rehabilitative Services (800) 330-0632 or (501) 296-1629
 Louisiana Rehabilitation Services (800) 737-2958 or (504) 925-4985
 Oklahoma Rehabilitation Services (800) 845-8476

ATTENTION PATIENTS

The Patient Advisory Committee (PAC) is looking for patients interested in serving as At-Large members. The PAC is the VOICE of the patients for Network 13. They are involved in patient education through Kidney Concerns and the Speakers Bureau, they provide feedback from a patient perspective on Network 13 Quality Improvement Projects and special projects. This opportunity provides you with the ability to assist the direction of Network 13 in addressing patient concerns and the state of dialysis and transplantation. Make Your Voice Heard. If interested contact Patrick Murphy, Patient Services Coordinator, at Network 13. The phone number is 1-800-472-8664 extension 3011.



KIDNEY KONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for WINTER/JANUARY. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

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