



RENAL ROUNDUP

For Patients in the Intermountain End-Stage Renal Disease Network (ESRD Network #15)

WINTER 2011

Work and Dialysis

The Importance of Support: How My Family, Friends and Dialysis Caregivers Help Me Be Successful

By Positive Thinker
Sparks, NV

My family and I had a major change in our lives when we found out that my kidneys had failed. We went from doing whatever we wanted at any time, to being on a tight schedule. I know that going to dialysis and working 40 hours a week is a hard thing to do, but it is possible. It helps to have a flexible employer allowing you to work different hours each day to be able to get to dialysis on time and make it to all the doctor appointments. It also helps having helpful and supportive friends and family to help with household chores and the children. My children are an absolute joy in my life but at ages 7 and 10, they are very involved in sports and after school activities and I definitely need help. So my Mom is able to watch them before and after school, help with homework and take them to after school activities. My husband picks up the children and gets home to cook dinner so that when I get home we are able to have some family time. He is also great about making sure I get all my protein in! I also have a great team of doctors and the wonderful employees at Liberty Dialysis to help



remind me of how to stay on the right track. With all this support, I am able to keep my head up and stay very positive. I am able to take control of my health and not let my health take control of me!



Ticket to Work

The goal of the Ticket to Work Program is to assist beneficiaries in obtaining employment and working toward financial independence. The Social Security Administration issues Tickets to beneficiaries with disabilities. The program is a free and voluntary service. It is available for people with disabilities ages 18 through 64 who are receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits. To learn more about the Ticket to Work Program, visit: www.socialsecurity.gov/work or call MAXIMUS toll-free at **1-866-968-7842** or **1-866-833-2967** for TTY. For more work related resources go to our website at www.esrdnet15.org and click on "For Network #15 Patients" and then click on "Vocational Rehabilitation."



Living the Dream with Dialysis

My name is Juan Casteneda and I was born in southern California to parents that emigrated from Mexico. My childhood was difficult because I came from a poor family. However, even though I started out with limited means I improved my life by enlisting in the military. Over my twenty-three years of service in the military I became a Vietnam and Iraq veteran. Additionally during my service, I married a wonderful woman who blessed me with a great son who earned degrees in engineering and is currently continuing his education.

After I retired from the military I spent some time employed at different jobs. I was hired as the Quality Manager where I worked long arduous hours while also maintaining my cleaning business. It was during this time that I experienced kidney failure. I kept working at my job and maintaining my business even though I was fighting depression. After a short bout with depression, I realized how blessed I was. I am currently serving as a consultant responsible for managing a company's quality management system. Even though my time with kidney failure has been hard, I have been able to continue my ability to work. I wondered why I was fortunate to be working and a contributing member to society and came up with the following inspiration for Kidney Dialysis:

- K** **Kee a positive attitude**
- I** **Inspire those around you**
- D** **Determination leads to success**
- N** **Never give up**
- E** **Every day is a new day to share your thoughts and experiences**
- Y** **You are responsible for being happy**

- D** **Demonstrate that you can still compete and challenge yourself to succeed**
- I** **Intent new ways to continue working**
- A** **Always have a positive disposition**
- L** **Live the dream and remind yourself of how blessed you are**
- Y** **You are still important**
- S** **Seek friendship and fellowship**
- I** **I will benefit from my own hard work**
- S** **Selfishness contradicts success**



***Make note of our
toll-free number:
1 (800) 783-8818***



New to Dialysis: My Perspective on Work and Peritoneal Dialysis

By Kristin Shelley

I am a 26 year old female who was diagnosed with IgA Nephropathy less than 3 years ago. I didn't know that from the time of my diagnosis to only four months ago, I would have to make a decision on the type of dialysis that best fit my lifestyle.

The informative videos that the doctors have you watch made dialysis look like it would be a piece of cake. But let me tell you, those videos did not prepare me for the reality.

Making the decision as to which type of dialysis was the most appropriate choice for me came easier than other things. Peritoneal dialysis was the only one that made sense to me. My financial needs were an important factor in determining which dialysis I would use. I knew I needed to keep working, not only for financial security and health insurance, but also my sanity.

Juggling work and peritoneal dialysis is definitely feasible. I do one dialysate exchange while at the office each day by combining my two 15-minute breaks into the 30 minutes needed to complete the exchange. The exchange may take longer, perhaps up to 45 minutes, for other people using peritoneal dialysis.

Sunday evening is a large part of making my week run smoothly. I pack a week's worth of dextrose bags and supplies. This way when Monday morning rolls around

I am ready to go. The only supplies I do not have to bring with me every day are the heparin and syringes. The days I have fibrin in the dialysate bag are the days the heparin and syringes are needed. As these items are not needed daily, there are times I have forgotten them. Some days your mind is moving a mile a minute and remembering everything is near impossible. These are the days everyone is plagued with sometimes.

The difficulty of juggling my schedule while ensuring I do the best job I possibly can and make all of my doctor appointments is nearly unexplainable. But it as a daily struggle that is absolutely attainable.

If life was a piece of cake and I had my choice, working part time while doing dialysis would be a no brainer, but that is not an option for me. By the end of the day I am drained, stressed and exhausted and I sometimes wake up drained. But I wake up every morning alive and there is nothing more I could ask for. We must take each day step by step and tell ourselves this is beatable.

I am writing this in hopes that my experience may help others understand work and dialysis better. This is not an easy journey. However, it is the journey my life has taken me, as well as one you may have to take. And with every day I am stronger mentally and emotionally and it is ok to let out a cry here and there. We are all human.

State Vocational Rehabilitation Agencies

Arizona

<https://www.azdes.gov/main.aspx?menu=32&id=1984>

Colorado

www.cdhs.state.co.us/dvr

Nevada

www.detr.state.nv.us

New Mexico

www.dvrgetsjobs.com

Utah

www.usor.utah.gov

Wyoming

www.wyomingworkforce.org/vr

Have a look at our web site and save it in your Favorites!

www.esrdnet15.org

Intermountain End-Stage Renal Disease Network
(Network #15) Contact Us

For Network #15 Patients
For Network #15 Providers
About Network #15
Info for New Dialysis Facilities
Disaster Resources
Pandemic Influenza
Conditions For Coverage

What is End-Stage Renal Disease, "ESRD"?
ESRD is irreversible kidney disease which requires treatment with an artificial kidney (dialysis) or a kidney transplant for a person to maintain life and health. ESRD is the only disease which entitles an individual to Medicare benefits (with some minimum requirements).

What is the Intermountain ESRD Network?
The Intermountain ESRD Network (Network #15) is a federally mandated, nonprofit Colorado corporation that contracts with the Centers for Medicare & Medicaid Services (CMS) to implement the ESRD Network program in its six-state area: Arizona, Colorado, Nevada, New Mexico, Utah, and Wyoming.

The mission of Network #15 is to facilitate the improvement of quality of care provided to ESRD patients. Network #15 is also charged with the collection and validation of information about, and treatment of persons with ESRD.

What is Included on This Web site?
This Web site contains information that is most relevant to ESRD patients (For Network #15 Patients) and ESRD professionals (For Network #15 Providers) within Network #15. For more detailed information about Network #15, including demographics info, and a copy of our most current Annual Report (pdf), please visit the About Network #15 section of our Web site.

For general ESRD program objectives and highlights please see the End-Stage Renal Disease Program Overview (ver. 4) on the Forum of ESRD Networks at www.esrdnetworks.org, or the National End Stage Renal Disease Network Coordinating Center (NCC).

If you have additional questions after browsing through our Web site we encourage you to email.us, or contact us at:

Intermountain End-Stage Renal Disease Network, Inc.
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The opinions and conclusions expressed are those of the authors. They do not necessarily reflect CMS policy. The authors assume full responsibility for the accuracy and completeness of the ideas presented.

Have A Problem?



For treatment or facility problems talk to facility staff members first (social worker, head nurse, administrator, or doctor); then, follow the steps of the facility's grievance procedure; if the problem remains and is about quality of care, you may contact us at:

ESRD Network #15

165 South Union Blvd., #466
Lakewood, CO 80228

1 (800) 783-8818

Email: info@nw15.esrd.net

OR

You may contact your State Health Department:

AZ: (602) 364-3030

**CO: (303) 692-2904 or
1 (800) 886-7689**

NV: 1 (800) 225-3414

**NM: (505) 476-9027 or
1 (800) 752-8649**

**UT: (801) 538-6158 or
1 (800) 662-4157**

WY: (307) 777-7123



The Benefits of Volunteering

Volunteering is when you give your time to help another person, group, or cause. There is a long list of possible advantages to those who volunteer: a happier outlook on life, a sense of connection with others, an increase in energy, and decreased feelings of loneliness, depression and helplessness. Volunteering can also add structure to your daily life, provide opportunities to focus on the needs of others while taking a break from your own problems, and also may lead to employment opportunities.

To find volunteer opportunities check your local paper for volunteer listings, call your local community center or senior center, or go to www.volunteersolutions.org.

