

## The Role of the Networks

### How We Work for Patients

The End Stage Renal Disease (ESRD) Networks are companies that work under contract for the Centers for Medicare & Medicaid Services (CMS). There are 18 ESRD Networks throughout the country. ESRD Networks 8 and 14 work together as the Alliant Quality Kidney Collaborative (AQKC) to improve the quality of healthcare, and the quality of life for ESRD patients in Alabama, Mississippi, Tennessee, and Texas. Some of the ways we serve you include:

- Providing educational materials to patients and staff
- Working with dialysis facilities on projects to improve your care
- Investigating and resolving grievances
- Providing information about the different treatment options available to you
- Working with patients who are having a hard time keeping or finding a dialysis facility

If you would like more information, you can visit our website at <http://aqkc.org/>.

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## Rehabilitation: Getting Back to Work!

Vocational Rehabilitation (VR) provides many services to people to help meet their goals. VR may help you return to work, find a new job, provide retraining for a job, or go to school. Having rehabilitation goals and working towards them can improve your quality of life and restore your livelihood. For more information, speak with your social worker or contact your local VR program:

Alabama Department of Rehabilitation Services 1-800-441-7607  
<http://www.rehab.alabama.gov/>

Mississippi Department of Rehabilitation Services 1-800-443-1000  
<http://www.mdrs.ms.gov/>

Tennessee Department of Rehabilitation Services 1-800-270-1349  
<http://www.tennessee.gov/humanservices/topic/vocational-rehabilitation>

Texas Department of Rehabilitation Services 1-800-628-5115  
<http://www.dars.state.tx.us/>

## Treatment Options: Patient Story

### Leigh Anne Tanzberger



My story began at the age of 8; I was stung several times by a wasp. Three months later, oddly, I woke up 4 days in a row with puffy eyes. My mother, concerned, consulted my

pediatrician. After testing, he recommended I be hospitalized for further investigation. A new Pediatric Nephrologist associated with Tulane University Hospital & Clinic in New Orleans entered my case.

In the summer of 1978, I was diagnosed with FSGS (Focal Segmental Glomeruli Sclerosis) which is a rare auto-immune disease that scars the kidneys. The rate of progression of the disease was swift. Therefore, in December, 1979, I started hemodialysis with a shunt in my right ankle.

At this point, we began considering a renal transplant. My father was a possible match, but my mother was not and my siblings were too young. At that time, a new study at Tulane was researching if the blood of the living related donor was given to the recipient, would the recipient form any antibodies? We entered the study. My dad gave me his blood over a 3 month period. We set my transplant date for March 10, 1981. That day, my father was ill, and I had

fluid around my heart and as a result, was admitted. Unfortunately, we had to postpone the transplant. Later that day my parents were told that a pediatric kidney may be available. A family decision was agreed upon to go forward the next day with the cadaveric kidney.

The FSGS reoccurred rather quickly in the transplanted kidney. In January, 1985, after 4 years, I would have to return to dialysis. At that time, I was a freshman in high school. My nephrologist felt I would be a perfect candidate to try a new type of dialysis called peritoneal dialysis. I opted to begin CAPD (Continuous Ambulatory Peritoneal Dialysis) doing 4 exchanges of dialysate per day. My high school arranged for a study hall for me after lunch. My mom picked me up so I could go home to eat lunch and do my afternoon exchange. She then took me back for my afternoon classes. We did this for 3 1/2 years. When I graduated, I received a certificate of merit from President Ronald Reagan.

In order to live on campus during college, my parents arranged for a private dorm room. I had a closet in my private bathroom where I stored my PD supplies, which my parents delivered weekly to Loyola University in New Orleans.

In 1990, we moved to Medford, NJ. HUP (Hospital of the University of Pennsylvania) in Philadelphia, is where I found my new nephrologist. I would see him monthly. In 1992, my parathyroid levels were extremely high, so

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## Treatment Options: Patient Story Cont.

most were removed. During surgery, the surgeon at HUP observed some tissue that "just didn't look quite right". The tissue was removed and pathology showed papillary carcinoma or thyroid cancer. One week later to the day, I had my thyroid gland and surrounding tissue removed. Weeks later, I received radioactive iodine and, thankfully, I have since been cancer free.

In 1993, I graduated from Rutgers University School of Business in Camden, NJ. We moved back to New Orleans, and I worked several years using CAPD for 14 years. I lost my peritoneal cavity in 1999 due to a fungal infection. I also underwent a bi-lateral nephrectomy the same year. Meanwhile, I qualified and was listed on 3 transplant lists.

In 2001, I had implanted in my upper thighs, titanium LifeSites which I used as my accesses for 8 years. We moved to Houston in 2003. Soon afterwards in the fall of 2003, I had surgery where the surgeon nicked my colon. I became septic and after further abdominal surgeries, I was hospitalized for 63 days. Since that point, I have used an ileostomy bag and have been advised that attempting another transplant is not recommended. I now continue on hemodialysis.

I have, for several years, devoted myself as an

advocate for renal patients. I have served on several renal committees including ESRD Network of Texas, its Board of Directors (2009-2014), their Executive Committee (2009-2014) and currently the Patient Advisory Committee. Also, I am currently serving on the National Committee for NPFE-LAN along with the Renal Support Network WeKAN Committee. I also serve on a committee in Fort Bend County (FBC) which raises money for the FBC Women's Center for abused women and children.

Today, I have many medical challenges, the chief of which is, nephrogenic systemic fibrosis (NSF) which I contracted after having several MRI's with contrast containing gadolinium.

Everyone's stories and circumstances are different, but the underlying theme for all of us is the desire to help ourselves improve our quality of life and find out how to make better decisions about our individual lifestyles'. Being on CAPD, unlike hemodialysis, I was able to make all my classes in high school and college. It also allowed me to work full time for 6 years until I could no longer do peritoneal dialysis.

Remember, as Lori Hartwell has always said, "An illness is too demanding when you don't have HOPE".



**Like us on Facebook by searching for ESRD Network 8, Inc.!**

**On this page, you will find information on kidney friendly recipes, health tips, patient stories, and treatment choices.**

# The Grievance Process and You

If you are unhappy with the care or treatment you receive at your dialysis clinic or transplant center, you have the right to file a grievance. Here's how to file your grievance:



**FIRST**—talk to your nurse, doctor or social worker about the problem. There could be a simple explanation. Or, it may be possible for you and the clinic to work out a solution that could result in better care for you and other patients.



**NEXT**—if talking does not resolve the issue, or if you feel you cannot discuss your problem with the staff at your clinic, you can go directly to the regional administrator, or the corporate office of your dialysis company or transplant unit. The names and phone numbers of these contacts should be posted in the waiting room of your clinic.



**FINALLY**—if none of the above actions work, or if you feel your clinic or corporation cannot assist you, call your ESRD Network or State Survey Agency toll-free for help.

**NEW Toolkit:** The Dialysis Patient Grievance Toolkit is a tool designed BY patients FOR patients. It serves as a guide to help you understand the grievance process. You can get a copy of it from this website. <http://esrdnetworks.org/resources/toolkits/patient-toolkits>

To file a grievance, please contact Network 8, Inc. at 1-877-936-9260, [info@nw8esrd.net](mailto:info@nw8esrd.net), 775 Woodlands Pkwy, Suite 310, Ridgeland, MS 39157 and [www.esrdnetwork8.org](http://www.esrdnetwork8.org).

## Kidney Friendly Recipe

### Dijon Chicken ([www.nwkidney.org](http://www.nwkidney.org))

#### Ingredients

- 4 boneless chicken breasts
- 1/4 cup Dijon mustard
- 3 tablespoons honey
- 1 teaspoon lemon juice
- 1 teaspoon curry powder

#### Preparation

1. Put chicken in a pan.
2. In a bowl mix together other ingredients.
3. Brush both sides of chicken with sauce.
4. Bake in 350 degree oven for 30 minutes.

Nutrition Facts: Calories 189; Carbohydrates 49g; Protein 25g; Fiber 3g; Sodium 258mg; Potassium 454mg; Phosphorus 250mg



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