

The one Star News etter

A Newsletter for People with Chronic Kidney Diseases and Their Families

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Phone: 877-886-4435

www.esrdnetwork.org

Can I Work or Attend School and Still Dialyze?

Have you ever thought you couldn't have a fulltime job or continue your education because of your dialysis schedule? Well the good news is; many dialysis patients are able to create a functional work/life balance and still dialyze as usual. There are many benefits to maintaining employment or attending school while on dialysis. These could be obvious things like gaining more income, learning a new skill, providing services to your community or just socializing outside of the dialysis arena. Dialysis patients continue to be a vital part of an untapped and underserved population when it comes to the utilization of skills and knowledge in our community. There are many reasons why patients and their families tend to think they can no longer dialyze and work or attend school. Some reasons are thought to be an employer's inability to be flexible with work schedules and or job duties. Other reasons are patients' beliefs that they are unable to maintain a job or attend school and be on dialysis due to the side effects of dialysis, like being tired; well this simply is not true in every case. Last year more that 2,000 patients in the state of Texas worked full or part-time jobs and close to 400 patients attended school.

There are currently over 35,000 people on dialysis in the state of Texas, the number individuals working and attending school is far too low. It is important not only to take care of yourself physically but also mentally and socially. Staying actively employed and engaged in the learning process, has many day to day hidden benefits and at the same time helps foster personal growth. For example, people who work or volunteer are contributing a needed service to the community at large. These individuals can often look back and see value added to their lives as well as those they serve. However, working and/or volunteering are not the only ways of staying active in the process of life; learning is another avenue that patients can explore. There are many dialysis patients that have desires to learn. However, they have not tapped into the resources available to them to meet these challenging desires.

Well the time has come! The Network encourages you to contact your local Vocational Rehabilitation Services to explore new opportunities and ways they can assist you. Your Social Worker at your facility should have contact information that he/she can provide to you. Remember dialysis does not mean the end of a productive and fulfilling life, it simply means altering the plan and being open to exploring new goals. If you would like more information on Vocational Rehabilitation, please contact your facility Social Worker or your local Vocational Rehabilitation Services department. Network 14 also has a toll free patient telephone hotline @ 1-877-886-4435 if you need further assistance.



In this Issue

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- PAC info

It's my life and I have a right to choose!

As an ESRD patient, you should be educated annually by someone from your treatment team about the treatment options available to you. Treatment options include home dialysis, kidney transplantation, peritoneal and hemo dialysis and even the option of no treatment at all. Today's treatments for kidney failure allow you to participate in life and enjoy your family and friends. Dialysis is a life-saving treatment, but it is not a cure. Most people with kidney failure have other diseases or conditions that get worse over time. At some point, you could face failing health and as all people do, regardless of their health - the end of life.

Looking ahead can be overwhelming and scary to think about. But it helps to take control of your care by telling your health care providers and your family about your wishes and the type of care you want as your disease progresses. This also will make it easier for them to make decisions for you if you become too sick to make them yourself. Think of this as a gift you give to your loved ones. Many people on dialysis say they feel better knowing that they talked with their family or social worker about their wishes for the future. They say that they:

- Feel a sense of control over their future
- Have peace of mind
- Know they have made sure that they will be taken care of with dignity, through pain relief and other chosen treatment
- Feel they will be less of a burden to their family, who will not have to make difficult decisions on their behalf

All these decisions are called "**advance care planning**," which is simply planning for your care before you need it. When making plans, it is helpful to have an understanding of the progression of your illness, anticipated outcomes, and treatment options which include not doing dialysis. Your physician should participate with you in determining appropriate care for you and helping you to fully understand what your journey may be.

Your dialysis facility staff is ready to work with you to put some of these decisions in writing so you can have peace of mind about your future. You can always change any of your decisions later; they are not set in stone. If you would like more information about Advance Care Planning, someone on your treatment team can assist. In addition, Network 14 also has a toll free patient telephone hotline @ 1-877-886-4435 if you need additional assistance and there is information on our website www.esrdnetwork.org/patients/endoflife/advanced care planning and at <http://www.kidneyeol.org/>



Share Your Story!

The Network is always looking for patient stories for The Lone Star Newsletter. We need your stories in order to make a successful newsletter, pictures are always welcome as well. If you would like to submit a story or make a suggestion for the Newsletter please contact Andrea Fichtner at afichtner@nw14.esrd.net or call 1-877-886-4435.

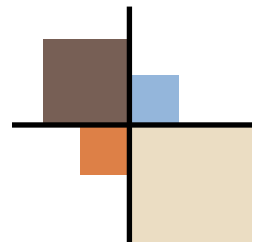
The Network is also recruiting more individuals for its PAC membership. If you are interested in becoming a PAC member look for more information on page 7.

Word Search

T N N Y G Y J V W B W C R P
B N L D Z H O V K P C L E K
U N A S U P W I Y H I F H R
U S G L A P D G F M H S A O
S X N S P N D R L P A T B W
I R P B E S I V H C A N I T
S O C Y F J N L W E V I L E
Y P T N E I T A P C Y A I N
L S Z B L O O D R I Y L T U
A E X P X R Y O Z T A P A N
I B A H O O V J S Z J M T B
D O Y P K J Q Y N Z I O I J
W F C J Z P N P S O Y C O R
X B Y F C R E N D S K G N F

Word Find

- Blood
- Complaints
- Dialysis
- Kidney
- Network
- Patient
- Rehabilitation



Complaints and Grievances



If I'm having a problem with my facility, what can I do?

It is always best to talk to someone at the facility that you trust as a first step. As a patient you have the right to file a complaint or grievance against your facility. If you feel that you are not being treated fairly or that staff is not doing what they should for patients during treatment time, you may contact the ESRD Network of Texas and speak with our Patient Services Department. Our goal is to make sure patients receive the best care possible from their dialysis and transplant facilities.

What happens when I call the Network to file a complaint or grievance?

The Network may decide to investigate the issue or may refer it to the State agency that handles complaints. Unless you give us permission to use your name, your name will not be used during the investigation. In 2009, the Network has received over **500 calls** from patients and/or facility staff regarding a wide range of issues. Some of the most common complaints were:

- Staff do not care about patients, do not treat them with respect and speak to them in a rude and negative manner.
- The facility schedules treatment times but does not stick to those times.
- The facility is discharging or 'firing' me without a good reason.
- The staff does not stay in their assigned areas during treatment.
- Alarms go off for a long time before the staff comes over to check the machine.
- The facility will not fax patient records.



The Patient Services Department will investigate your complaint and determine what plan of action should be taken for a timely resolution. The Patient Services Coordinator may make a visit to the facility, recommend additional staff training or do a patient survey to see if other patients are experiencing the same things that you are. Sometimes immediate action needs to be taken. In those situations the Network will send the complaint to the Department of State Health Services to investigate. The State may survey the facility and/or interview staff and patients.

What does the Network do with this information?

Every 3 months the Network reviews all the complaints and grievances that have been filed. If a facility has 3 or more complaints during a 3-month period or 4 or more in 6 months, the Patient Services Coordinator will contact the facility and make recommendations on how the facility can reduce complaints. Sometimes the Network will require the facility to develop an improvement plan that the Network will monitor for a period of time. The Network makes every effort to resolve complaints in a timely manner. If you, as a patient ever feel that you are not receiving the best experience of care, please speak with your facility administrator or call our Patient Services Department for assistance toll free @ 1-877-886-4435.

??? What to do if you have a complaint ???

If you are unhappy with the care or treatment you receive at your dialysis clinic or transplant center, or if you have a complaint about your care, you have the right to file a complaint.

Here's how to file your complaint:

- ⇒ First-try to talk to your nurse, doctor, or social worker about the problem. It is possible there is a simple explanation. Even if there is not a simple explanation, it may be possible for you and the clinic to work out a solution to the problem that could result in better care for you and other patients.
- ⇒ Next-if talking does not resolve the problem, or if you feel you cannot discuss your problem with the staff at your clinic, you can go directly to the regional administrator or even the corporate office of your dialysis company or transplant unit. The names and phone numbers of these people 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 help you, call one of the Toll Free numbers below for help.

Texas Department of State Health Services	or	The ESRD Network of Texas
(888)-973-0022		(877)-886-4435

If you contact the Network for help, WE CAN:

Give you names and phone numbers of people you can speak to at your clinic's corporate offices.

Give you information about Medicare regulations and your rights under Medicare.

Contact the clinic and conduct a *confidential* investigation into your complaint, which may include one or more of the following actions:

- Request medical records
- Interview staff members or patients and asking for details about a complaint
- If necessary, visit a clinic in person
- *Confidential* means we will not tell anyone at the facility or clinic your name, unless you give us permission to do so

If you contact the Network for help, WE CANNOT:

- Force a clinic or doctor to accept a patient.
- Guarantee you can choose which staff members put your needles in.
- Change or get involved in anything that has to do with personnel policies and procedures.
- Get a doctor, nurse or patient care technician "fired" or transferred.

Renal Friendly Recipes

Recipe from DaVita Inc.



Chicken and Vegetable Bake

Ingredients

- 1-1/2 pounds boneless, skinless chicken breast (fresh, not frozen) cut into bite-sized pieces
- 8-ounce bag medium-sized egg noodles
- one 10-ounce frozen carrots or 3 medium, fresh, cut julienne-style
- 1 medium onion, sliced
- 1 medium red pepper, chopped
- one 10-ounce box frozen, chopped broccoli, thawed and drained
- 1/2 cup unsalted chicken broth
- 1 teaspoon dry mustard
- 1/2 teaspoon black pepper
- 1/2 cup bread crumbs (plain or seasoned)
- 2 tablespoons butter or margarine, melted

Nutrients per serving

- Calories: 420
- Protein: 36 g
- Carbohydrates: 44 g
- Fat: 11 g
- Cholesterol: 120 mg
- Sodium: 178 mg
- Potassium: 567 mg
- Phosphorus: 359 mg
- Calcium: 94 mg
- Fiber: 5.1 g

Preparation

1. Heat oven to 350 °F.
2. Coat a 3-quart, rectangular baking dish with non-stick spray. Set the dish aside.
3. Cook noodles according to package directions omitting salt. Drain, rinse with cold water, and set aside.
4. Spray a large skillet with cooking spray and place over medium heat. Cook chicken pieces for 3 minutes or until chicken is no longer pink.
5. Transfer chicken to a large bowl.
6. Add onion, pepper, broccoli and carrots to skillet. Cook and stir until veggies are tender.
7. Dump veggies into bowl with chicken and stir in broth, dry mustard, pepper and noodles.
8. Spoon mixture into baking dish.
9. Mix bread crumbs and melted butter together. Sprinkle over chicken mixture.

Bake, covered, for 30 minutes. Uncover and bake an additional 30 minutes, until heated through.

Compare Dialysis Facilities in Your Area!

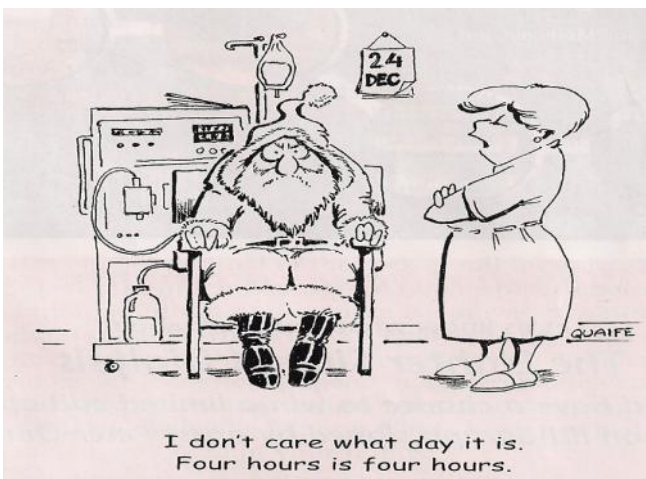
The **Dialysis Facility Compare** tool, located at www.medicare.gov/dialysis, is a tool to help you find dialysis facilities in your area. It has detailed information about Medicare-certified dialysis facilities and other resources for people with kidney disease. You can use this information to compare the services available and the quality of care provided by facilities in your area and around the country. Contact the Network for a flyer about how to use this valuable tool at **1.877.886.4435** Dialysis Facility Compare Website: www.medicare.gov/dialysis

Patient Advisory Committee Represents You!

The Patient Advisory Committee (PAC): Your “Voice” at the ESRD Network

To see the complete list of PAC members and the regions they cover, please visit our website at and click on **Patients** then click on **Patient Representatives**. We are currently looking for additional members to cover the following areas: West Texas, El Paso, East Texas and the Valley.

The PAC is a group of patients and care givers from around the state who give feedback to the Network staff and the Medical Review Board about issues that affect the care and quality of lives of patients. We want to have all regions of Texas covered by PAC members. If you are interested in joining this group, please send a letter of interest to the ESRD Network of Texas, attention: Andrea Fichtner or call the Network toll-free number at 877-886-4435.



Happy New Year from the staff here at the network!

Used with permission from Jazz Communications Ltd., publishers of *The Lighter Side of Dialysis* by Peter Quaipe. For more information or to obtain a copy, please visit www.lightersideofdialysis.com or call 1-866-239-3279.



A kidney suitable for transplant comes from 2 different sources: a living person or a deceased person. The living person may be a relative, friend, or an anonymous person. Some of the advantages of having a living donor is that the health of the living donor is better known, the evaluation can be more thorough, and the kidney tends to function immediately and longer. A kidney from a deceased donor may or may not function immediately and often does not last as long as the kidney from a living person. Regardless of whether the kidney is from a living person or a deceased person, the donor undergoes an extensive evaluation to make sure the kidney is a good one for the recipient.

A kidney good enough to give to a person with kidney disease is a scarce resource.
Don't Waste it !



Kidney Transplantation

What do you, the recipient, have to do to get a kidney?

First of all, you have to get financial approval from the transplant center. Once you have that, you will undergo an extensive evaluation to make sure you are a suitable candidate and have no problems that would interfere with the transplant. Transplant centers have specific tests that are done as part of your workup.



What is "UNOS" or "The List" and how does it work?

UNOS stands for the "United Network for Organ Sharing" and is the national computerized list of all patients waiting for a transplant. When appropriate, your name will be added to that list as well as to your local/regional list. When a kidney becomes available, the information from that deceased donor is entered into the UNOS data base and the UNOS computer matches that specific kidney with the next appropriate person.

Timely Tips

1. Keep all your appointments.
2. Keep your immunizations current.
3. Take your medications as directed.
4. Don't miss dialysis treatments or sign off early. (If you miss your medications or dialysis treatments now, the transplant center will think you'll do the same after you get your new kidney.)
5. **Plan ahead and save money for your transplant medications.**
6. You will be able to return to work after your transplant.
7. Keep fit and eat healthy.
8. Notify the transplant center of any change in your contact information. **WHY?** When a kidney that is right for you becomes available, the transplant center staff has only **ONE HOUR** to locate you and accept the kidney before it is offered to the next person on the UNOS list.

Texas Adult Transplant Centers

Texas Pediatric Transplant Centers

Austin
North Austin Medical Center

Dallas
Baylor University Medical Center
Medical City Dallas Hospital
Methodist Medical Center
Parkland Health & Hospital
University Hospital St. Paul

El Paso
Las Palmas Medical Center

Ft. Worth
Baylor All Saints Medical Center
Texas Health Harris Methodist

Galveston
University of Texas Medical Branch (UTMB)

Houston
Memorial Herman Texas Medical Center
St. Luke’s Episcopal Hospital
The Methodist Hospital

Lubbock
University Medical Center

McAllen
South Texas Transplant Center

San Antonio
Christus Transplant Institute
Methodist Specialty & Transplant Hospital
University Hospital Transplant Center

Temple
Scott & White Memorial Hospital

Tyler
East Texas Medical Center

Corpus Christi
Driscoll Children’s Hospital

Dallas
Children’s Medical Center
Medical City Children’s Hospital

Ft. Worth
Cook Children’s Medical Center

Galveston
University of Texas Medical Branch
Pediatric Transplant Center

Houston
Memorial Hermann Pediatric Transplant
Texas Children’s Hospital

San Antonio
Christus Transplant Institute
University Hospital Renal Transplant Services



A Patient’s story-

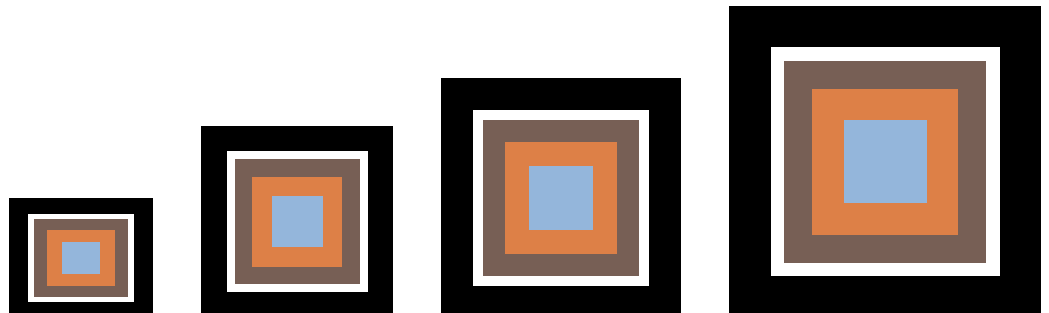
Fresenius recently told me that I am a member of a rather unique club. The Quarter Century Club. Now, while I am proud to be a member of that club, I do not wish it on my family and friends. It means I have been on dialysis for at least 25 years. For anybody who knows anything about dialysis, that is an accomplishment. In September 2010, Fresenius had 136,000 patients on dialysis in North America. Of that number 356 patients are members of “The Quarter Century Club”, with Texas having 55 members.

My name is Danny Knight. My journey started in the summer of 1975, when I had to take a flight physical for the Air Force. I am a certified Air Traffic Controller, but never got to land a plane. The Air Force found my disease the week after I graduated from ATC school and began the process of honorably discharging me. I fought the discharge but lost.

It took nine years for me to lose my kidneys. The Air Force told me that when the time came I would probably lose my life because there were not enough dialysis machines to go around. By the time I did need dialysis, thanks to great doctors and research, getting dialysis was not a problem. I had my transplant nine months later (September 1984) in Dallas. My team of physicians and surgeon gave me a second chance at life. I was able to work very physical labor at the United States Post Office and even had a third child, our gift from God, our daughter, Heaven Leigh. Her two brothers could not have been more excited.

I lost my transplant in August of 1998. I have been on hemodialysis since then. There are definitely ups and downs associated with dialysis. I listen to my doctors, I watch what I eat and keep track of my fluid intake. Overload is a real problem for the patient's heart. I know what the readings on my machine mean and keep well informed on my progress.

I have a good life. I keep busy and volunteer when I can for different groups. I now have six beautiful grandchildren, who remind me daily of what life is all about. My terrific family, friends, and church give me the strength and courage to keep fighting. With their help I plan to make the 30 year club, the 40 year club and who knows maybe the 50 year club. In the last 35 years I have been taken care of by many people some that I don't even know that have improved the life of all kidney patients, to all of you I say Thank You.





WHAT DID YOU SAY?

Doctors, nurses and other medical folks sometimes seem like they are talking a foreign language, don't they? Here's an easy thing to do if this happens to you. When someone is giving instructions and information that is really important about your health or a loved one's health too fast and in words you don't know, and you find yourself thinking, wait what did they say? Just ask 3 easy questions! Start out by saying, I can tell what you are saying is really important so I want to be sure I understand what you want me to know. **“Could you answer 3 quick questions for me?”**

1. **What is the main problem?**
2. **What do I need to do?**
3. **Why is it important for me to do this?**

You can also use these questions to repeat back things you are told by medical folks by saying, “Let me make sure I understand what you were telling me”.

1. I think you said the main problem is _____.
2. I need to do _____ to take care of the problem.
3. This is important to me because _____.

Here are some examples of how this would sound.

- I think you said this catheter is the problem. I really need to keep my appointment to see the surgeon to get a permanent vascular access. This is important to me because catheters cause serious infections that would make me very sick and might even cause death.
- I think you were saying my potassium is too high. I really need to stop eating so much fruit to get it down. This is important to me because high potassium can cause my heart to stop beating.
- I think you said I have too much fluid. I really need to drink less and eat less salt between dialysis. This is important because the extra fluid makes my heart like a water balloon and after awhile it won't be able to work anymore.
- I think you said my blood pressure is too high. I really need to get this new prescription filled and take it all the time. This is important because as high as my blood pressure is, I could have a stroke or heart attack.

TIP: Cut the three questions out from this newsletter and put them in your wallet or purse, then take them out when you see a doctor or other medical professional. Remember, just 3 easy questions to be sure you understand what is important for your health!

We Need NPR's

What is a Network Patient Representative (NPR)?

Each clinic is asked by the Network to appoint at least one **Network Patient Representative (NPR)** to be a contact person between the clinic patients and the Network. Some clinics have a Representative for each shift or each dialysis day. **We need more NPR's !** If you would like to be considered for the NPR position at your facility, speak with your social worker about the job.

Super Staff Award



In our next issue look for a nomination form to nominate any staff member for the Networks' super staff award. The super staff award is a certificate given to any employee that is nominated by patients for going above and beyond. If you would like to recognize them please keep them in mind for nominations in our next newsletter! This could be anyone from a nurse, doctor or a security guard. The Network will choose the top nominations, and those staff will receive a certificate from us and if a picture is taken with the certificate, we will post them in upcoming newsletters.

Bundling: It's here!



The world of dialysis is changing for companies because the Center for Medicare & Medicaid Services (CMS) is changing how it pays for dialysis and will begin a "bundling" payment system January 2011. The new system will replace the current system and change the rules for the reimbursement of outpatient ESRD related items and services that can be billed to Medicare separately by the dialysis facility. The new system will provide a single payment to ESRD facilities that will cover all the resources used in providing an outpatient dialysis treatment, including supplies and equipment used to administer dialysis in the ESRD facility or at the patient's home, drugs, laboratory tests, training, and support services. Some companies have chosen to make the change in January and others will use a 4-year phase-in (transition) period.

What does this mean for you as dialysis patient? As a dialysis patient you may see some changes to how services are rendered to you and an increase in your portion of the cost for your care. Dialysis providers will have the challenge of meeting quality care standards and needs of the patients and have a different payment system from Medicare. For example, dialysis providers used to be able to bill separately for some laboratory tests; but now this expense will be included in the cost of your dialysis treatment. **How does this impact you?** If you have 100% coverage there will be no financial impact; however; if you have Medicare only and must pay the 20% out of pocket coverage that many dialysis patients have, you may begin receiving a higher bill and companies may start enforcing payment if they did not in the past. In addition to having a set billing rate for dialysis treatments, starting in 2014, dialysis clinics will have to meet specific quality outcomes or they will lose money.

Things for you to think about and remember! 1. Keep a record of how you feel and let your doctor know. 2. Make sure that your dialysis facility knows all of the medications you are taking. 3. Ask your treatment team if and how your care will change because of the new bundling payment system. 4. If you notice a change in quality of care you are receiving let someone know! 5. Remember, you have a right to ask questions if you see things changing in your treatment and care!

Who We Are?

The End Stage Renal Disease Network of Texas (ESRD Network) is one of 18 agencies that work under contract with the Centers for Medicare & Medicaid Services (CMS) the federal agency that runs Medicare. Your ESRD Network, which provides support to the Texas dialysis and transplant community, is located in Dallas, Texas. The other 17 Networks are located regionally across the country. The Networks perform many important jobs for the dialysis and transplant community, including:

- Collecting and analyzing data about dialysis and transplant patients and their treatments
- Evaluating the quality of care and services provided to dialysis and transplant patients
- Supplying professionals with clinical information and data they can use to evaluate and (if needed) improve their services
- Maintaining a grievance procedure to investigate patient complaints about the quality of care provided by dialysis or transplant units

The Network is made up of several volunteer committees-the Executive Committee, Medical Review Board, and Patient Advisory Committee. Each committee is made up of patients and professionals. The committees provide guidance and support to help the Network meet its mission and goals.

Our Goals

To improve the quality of care for persons with ESRD and to make sure that this care is medically necessary, efficient, high quality and consistent with professional knowledge.

To provide CMS, the Texas Department of State Health Services, and the dialysis and transplant community with information and data related to the Medicare ESRD program and the ESRD population.

Resources and Important Numbers and Websites

Kidney School

www.kidneyschool.org

One of the BEST **resources** available for almost everything you need to know about kidney failure, dialysis and transplant. This site is organized into interactive, self-paced chapters.

Texas Department of State Health Services (TDSHS)

1-888-973-0022

www.dshs.state.tx.us

Medicare

Customer Service Line

1-800-813-8868

www.medicare.gov

Medicare Part D

Updates and Information

www.medicare.gov

American Association of Kidney Patients (AAKP)

800-749- AAKP

www.aakp.org

Renal Diet Information

www.mrsdash.com

www.andrew.cmu.edu/user/sorensen/

Bureau of Kidney Health

1-800-222-3986

www.dshs.state.tx.us/kidney

United Network of Organ Sharing (UNOS)

1-800-292-9547

www.transplantliving.org

American Kidney Fund

1-800-638-8299

www.akfinc.org

The Renal Support Network (RSN)

1-818-543-0896

www.renalnetwork.org

Modality/Treatment Options

www.homedialysis.org

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The End Stage
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Network Of Texas