

ESRD Patient News

Spring is Here

This edition of *ESRD Patient News* focuses on traveling while on dialysis. Spring is here and many opportunities arise to vacation or visit family as warmer weather arrives. We have the Top 10 dialysis-friendly cities, along with an article on your travel rights and an article about TSA Cares to help you travel better, with less stress.

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The Carlisle-Williams Foundation, Inc.

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Top 10 U.S. Cities for Dialysis-Friendly Travel

You *can* vacation while on dialysis. Here is a list of the top destinations for dialysis patients.

1. **Las Vegas.** The desert oasis is the number one requested travel spot for dialysis patients. From countless themed hotels and casinos, to the endless array of shows and world-class dining, Las Vegas is the ultimate playground for grownups.

2. **Orlando.** Walt Disney World®, Universal Studios Orlando® and SeaWorld Orlando® are just some of the exciting attractions to visit. Bask in the warm weather, take in views of the surrounding orange groves and enjoy the abundance of attractions in Orlando area.

3. **Myrtle Beach.** Noted as one of the premier coastal resorts on the East Coast, Myrtle Beach offers a fun selection of dinner theater shows, live music and casino cruises. Golfing, fishing, boating and windsurfing are a few of the outdoor activities Myrtle Beach has to offer.

4. **Houston.** Not only are the pick-ups and steaks big here, but so is the arts district! Houston's other attractions include the nation's largest wildlife refuge and the Space Center Houston.

5. **San Antonio.** Visit the place hailed as "The Heart of Texas." Take a step back into history when visiting the Alamo. Afterwards, stroll over the bridges of

the famous River Walk, with unique shops and authentic Tex-Mex cuisine. San Antonio has theme parks and major sporting events to entertain everyone.

6. **Chicago.** Chicago, meaning Wild Onion, is a city rich in colorful history, uniquely its own with so much to see and experience. From Wrigley Field to world-class shopping opportunities, you'll have a hard time choosing what to do.

7. **San Diego.** Whether killer whales or killer waves, San Diego is a thriller! This Southern California city packs an amazing amount of history, recreation and culture into its scenic bayside locale. With an abundance of lodging options to choose from, you'll never be far from the sights you want to see.

8. **Atlanta.** In Atlanta, American history meets modern times. After the Civil War, the capital of the Peach State became the center of the Civil Rights Movement.

Travel back in time by touring The King Center, and the house of author Margaret Mitchell. Explore the city's modern side by attending a sporting event, touring the CNN studios or visiting Coca-Cola.

9. **Virginia Beach.** Sandy beaches, historical places around every corner and plenty of outdoor activities make Virginia Beach one of the top destinations for people on dialysis. Whether you spend your time on the water or on the shore, Virginia Beach can cater to anyone's tastes.

10. **Los Angeles.** Play in the snow on the mountains in the morning, soak up the sun at the beach in the afternoon. Walk along the Venice boardwalk, or the Walk of Fame in Hollywood or participate in fair games at Santa Monica Pier. You could even spot a celebrity!

<http://www.davita.com/services/travel-support/travel-tips-and-articles/top-10-u.s.-cities-for-dialysis-friendly-travel/s/5733>



ESRD Patient News—a publication of The Carlisle-Williams Foundation, Inc.—informs our readers of issues important to management and understanding of their disease and to further the Foundation's mission of providing hope and support to ESRD patients. We welcome and encourage feedback through email (JanieC@esrd-patient-support.org) or by using the "Contact Us" form on the website. Thank you!

ESRD Patient News

Better Care, Earlier Diagnosis and Treatment of Related Conditions, are Improving Patients' Health



The Carlisle-Williams Foundation, Inc. provides free comfort bags for use during dialysis. They include items for education, entertainment, and warmth. To request one, simply fill out the request form on the website www.esrd-patient-support.org and click submit.

Fresenius Medical Care North America (FMCNA) celebrated National Kidney Month in March by recognizing recent progress in helping patients with kidney failure live longer, while reaffirming its mission to improve the quality of life of dialysis patients daily.

Data from the 2014 United States Renal Data System (USRDS) annual report suggests that while the total number of end stage renal disease (ESRD) patients in the United States continues to rise, at least part of that increase is the result of patients actually living longer. Likewise, the Peer Kidney Care Initiative's 2014 Dialysis Care & Outcomes report agrees that overall ESRD mortality rates have declined since 2004, noting that "declining mortality rates translate to longer lives, as illustrated by displays of gains in expected remaining life-times and deaths averted."

Healthcare experts attribute the increased longevity to earlier detection and treatment of chronic kidney disease (CKD) and timely patient referrals to kidney specialists. Better detection and care of risk factors such as diabetes and hypertension is also contributing to slower disease progression.

Fresenius Medical Care made significant achievements in en-

hancing the care of patients with kidney failure, including reducing both patient mortality rates and avoidable hospitalizations.

FMCNA is helping patients live longer by providing:

Exceptional care and the latest treatment options:

Home dialysis and in-center nighttime dialysis, for example, can provide health benefits by allowing longer and/or slower dialysis treatments. This gives patients the option of having more free time to continue working, or to enjoy their favorite activities.

Healthy Lifestyles initiatives: These programs, designed to encourage patients to stay active and follow a healthy diet, include consultations with renal dietitians and social workers on staff at each facility. Dietitians help dialysis patients learn how to eat a healthy diet while strictly limiting their intake of foods containing high levels of potassium, phosphorus, and salt, which can be harmful to them. FMCNA also has a partnership with celebrity chef Aaron McCargo, Jr. to create delicious dialysis-friendly recipes that inspire patients to enjoy eating while staying within their dietary guidelines.

Treatment Options Program: Offered regularly across the country and open to the

public at no cost, these programs provide valuable information about managing kidney disease. They help CKD patients and their families plan for and transition more smoothly to dialysis or organ transplants.

Innovative patient research: Through its global network of medical experts and clinical research, FMCNA strives to keep patients healthier, whether through more effective treatment of related conditions such as diabetes and cardiovascular disease, better management of anemia, or promotion of flu shots and other preventive care.

"Our physicians, nurses and other caregivers are extending the lives of dialysis patients and reducing hospitalizations by working as multi-disciplinary teams to provide excellent care both in and out of the treatment chair," said Franklin W. Maddux, M.D., FMCNA's chief medical officer and executive vice president for clinical and scientific affairs. "Our patient-centric approach to care and treatment is designed to help patients with end stage kidney disease live a better life."

<http://newsroom.fmcna.com/press-release/during-national-kidney-month-fresenius-medical-care-celebrates-progress-helping-patient>

Travel Rights for People on Home Dialysis

The Air Carrier Access Act (ACAA) of 1990 says airlines can't discriminate against people with disabilities, including PD and HHD patients. The law applies to U.S. and foreign flights. These rules cover your rights when you need an "Assistive Device" like a portable dialysis machine.

Your rights include:

- Not counting your dialysis machine as a carry-on item if it fits in the overhead bin or under the seat in front of you on the plane
- Help with stowing and retrieving your machine as a carry-on item
- Stowing your machine so it is one of the first things off the plane at the end of the flight, if you checked it as luggage
- Giving your machine priority over other bags if space is limited
- Baggage liability limits don't apply if the airline loses or harms your machine—they must pay for your machine based on the purchase price
- Not being asked to sign a waiver of liability for loss or damage

When you check a dialysis machine as luggage, some may try to charge a fee if you have suitcases plus a machine. Some will charge you if your machine weighs more than 50 lbs. Under the ACAA, the airlines are not allowed to charge you for your dialysis machine.

Right to bring your dialysis machine on a plane

Before you purchase a ticket, go to the airline's website to check the carry-on bag limitations. You can use that information to determine if your PD cyclor will fit on the plane or must go

as checked luggage. TheNxStage® System One used for HHD is too large to fit in any airplane cabin and can only go as checked luggage.

Plan to arrive at the airport two hours early; it takes time to talk to airline agents about travel with a dialysis machine.

Right to carry medications and syringes with you

To be safe, pack all medications in your carry-on. Airplanes don't have refrigerators, so if you have a drug that must be kept cold, ask your pharmacist how to package it for travel.

If you bring syringes, you must also bring along the drug you inject, such as insulin or EPO, with a professionally printed label that says what it is. There is no limit to how many empty syringes you can bring, as long as you also have the drug with you.

Get help at the security line

If it has been a while since you last flew, some things have changed, including what you're allowed to bring on a flight.

For a full list of what is prohibited in carry-on and checked bags, visit the Transportation Security Administration (TSA) website.

At the security line, if you need help to lift your cyclor onto the belt, ask for it. You may have an easier time if you bring the manual for your machine or a letter from your doctor to explain what it is.

If your PD catheter has the titanium adapter, or if you have an insulin pump, pacemaker, a steel plate in your body, a prosthetic limb or other hidden medical device, tell the security guard before you go through the metal

detector. Most airports will ask you to remove your shoes before going through the metal detector, so wear shoes that are easy to take off. If you set off the metal detector, the security guard will ask you to step aside for a more careful search.

Right to pre-board your PD cyclor

As an assistive device, a PD cyclor has priority for stowage. Be sure to measure it first so you know it will fit in an overhead bin. If you plan to bring your cyclor onto the plane, tell the gate agent and ask for help to get your cyclor on board and stowed if you need it. When boarding starts, the agent will ask for passengers who need assistance or extra time getting down the jet way to board.

Traveling with dialysate

If you do PD or use a NxStage machine for HHD, you'll need to bring dialysate on your trip. Plan ahead so your supply company can ship most of the boxes to where you will be staying. The airlines should also allow you to take a day or two of dialysate without a fee for extra or overweight luggage, but there will be a charge for more than that. All supplies must be in their original boxes, with the contents clearly labeled.

Better travel when you know your rights

Knowing your rights as a home dialysis patient, may make travel a smoother experience. If you do encounter any problems, you can report it to the DOT Disability Hotline at 1-800-778-4838.

<http://www.davita.com/services/travel-support>.

ESRD Patient News

Thousands With Disabilities To Get Rental Assistance

A new round of federal funding is expected to provide rental assistance to thousands of people with disabilities in 25 states.

Millions of dollars are heading to over two dozen states to help people with disabilities access community-based housing and support services.

Federal officials said this week that housing agencies in 25 states will each get a

share of \$150 million to provide rental assistance to those with disabilities.

The funding is expected to support nearly 4,600 households, including many people transitioning out of institutional settings, the U.S.

Department of Housing and Urban Development said.

The money is being made available through HUD's Section 811 Project Rental Assistance Program, which

provides housing assistance so people with disabilities can live independently in the community.

To qualify, state housing agencies must partner with local Medicaid and health and human services agencies to identify participants and ensure that long-term services and supports are in place so that they can live as independently as possible.

*TSA Cares
can help
you plan
for your
next trip.
Call 855
787 2227.*

Travelers with Disabilities and Medical Conditions—TSA Cares

TSA Cares is a toll-free help line (855 787 2227) to assist travelers with disabilities and medical conditions. TSA recommends that passengers call 72 hours ahead of travel for information about what to expect during screening. Travelers may ask questions about screening policies, procedures and what to expect at the security checkpoint. TSA Cares will serve as an additional, dedicated resource specifically for passengers with disabilities, medical conditions or other circumstances or their loved ones who want to prepare for the screening process prior to flying. Travelers may also request a Passenger Support Specialist ahead of time.

Contact TSA Cares Monday through Friday 8 a.m.-11 p.m. Eastern Time; weekends and Holidays 9 a.m.-8 p.m. Eastern Time. Travelers who are deaf or hard of hearing can use a relay service to contact TSA Cares or e-mail TSA-ContactCenter@tsa.dhs.gov.

When a passenger with a disability or medi-

cal condition calls TSA Cares, a representative will provide assistance with information about screening that is relevant to the passenger's specific disability or medical condition, or the passenger may be referred to disability experts at TSA.

A primary goal of TSA is to provide the highest level of security and customer service to all who pass through our screening checkpoints. Current policies and procedures focus on ensuring that all passengers, regardless of personal situations and needs, are treated equally and with the dignity, respect, and courtesy they deserve. Every person and item must be screened before entering each secure boarding area. All disability-related equipment, aids, and devices are allowed through security checkpoints once cleared through screening.

<http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions>

Anxious? How About Running Toward Your Anxiety?

Chronic conditions can bring all kinds of uncertainty to your life and humans don't always handle uncertainty well. So what do you do about those anxious feelings?

Coping with anxiety begins with how you think about anxious feelings and preparing for the anxiety that might come your way.

Accept that anxiety is part of life. Any day may bring reasons to feel anxious. Although you will probably experience anxious feelings, you don't have to be continuously overwhelmed with anxiety. It's normal, and you're not alone.

Lean in to your anxiety. Here's a mindfulness exercise for you. Visualize yourself hiding in your house with all the doors and windows locked and anxiety standing outside on the porch, pounding on the door to get in. Now imagine opening the door and saying: "Come on in, anxiety. Let's sit down and talk." If the anxiety is not going away on its own, you might as well see if the two of you can come to an understanding.

Look for the lesson. Is there something you can learn from those anxious feelings? Could some of the anxiety be a message from your mind that it's time to take better care of yourself or to make a change for the better in your life? Successful people often talk about how they use their anxiety to motivate themselves to work a little harder to be excellent. Clients living with chronic conditions often say that feeling a little bit anxious helps motivate them to stay compliant

with their treatment and self-care routine. Learning from it might help you reduce some anxiety.

Don't get anxious about getting anxious. Nobody likes being anxious. Some people dislike anxiety so much, they get anxious about the anxiety. They worry about how bad their anxiety might be, or create anxious stories about what might happen, about how they're going to cope with the anxiety. This creates more anxiety. Watch out for negative self-talk that helps to create more anxiety.

Talk to yourself. When anxious thoughts and feelings start building up in your mind, talk yourself off the ceiling. Remind yourself that it's normal to be anxious sometimes. Ask yourself what you can do to reduce your anxious feelings. When you stop fighting anxiety, you free yourself up to focus your energy on what you can do about it.

Calm yourself down. Think about what helps you when you're feeling anxious. Imagining a relaxing place like the beach? Taking a walk? Listening to music? Reading a book? It might help to put a toolkit together with calming techniques that work for you, and have it ready when you feel anxious.

Be proactive. Take a look at recent days when you have felt less anxious to find clues for how to avoid anxiety. Was there something you did or didn't do that day that might have helped you to have a more relaxed outlook? Were you compliant with medication? Following your diet? Staying active? In touch with supportive people?

One of the best ways to cope with anxiety is to avoid setting yourself up to feel that way by building anxiety prevention into each and every day. Again, apply the lessons that anxiety can teach you.

Talk to somebody. Get some perspective by sitting down with someone who can listen without judging or telling you what to do. Talk about what's making you feel anxious. Sometimes saying it out loud can help you see what's real and what's imagination. Ask for encouragement or even accountability if you want to make changes for the better.

Reach out for help if you need it. If you are feeling overwhelmed by anxiety, if it is interfering with your ability to do what you need to do to take care of yourself, or making it hard for you to make decisions, then it may be time to reach out to a mental health professional. Talk to your doctor if you aren't sure where to start. Don't go through this alone.

Anxious feelings are part of being human. Lean in to your anxiety. Listen for the lesson anxiety can teach you. And take good care of yourself.

<http://www.diabeticconnect.com/diabetes-information-articles/general/1614-anxious-how-about-running-toward-your-anxiety?>

This article has been edited. Click the above link for the article in its entirety.

Your mental health is as equally important as your physical health. Visit our website at www.esrd-patient-support.org for links to improving your mental wellbeing or email us.

The objective is to improve PD catheter performance by examining placement of the catheter

New research underway on peritoneal dialysis catheter placement

February 04, 2015

The North American Research Consortium (NARC), an arm of the North American chapter of the International Society of Peritoneal Dialysis, is reviewing results from a 29-question survey about catheter insertion practices in the U.S. and Canada.

NARC was developed after a meeting of ISPD members at Vanderbilt University in summer 2013. Funding from Baxter Health Care was secured in February 2014 to complete NARC's first study looking at catheter placement. The goals of the project are to quantify the variability in peritoneal dialysis catheter practices and outcomes in North American programs, identify key predictors of successful peritone-

al dialysis catheter outcomes, and establish a sustainable framework for ongoing quality improvement relating to peritoneal dialysis catheter practices.

Approximately 40 sites from Canada and the United States participated in the survey, which revealed "a high variety of techniques being used in surgical suites," to place peritoneal dialysis catheters, said Matt Oliver, MD, who presented initial findings from the surveys at the third annual symposium for the NAC ISPD during the Annual Dialysis Conference. The goal of the research is to review 1,000 catheter placements.

After the survey results were received, Oliver went back and asked questions among respond-

ers about details of the catheter placement. The research group wants to look at the relationship between the operator, who places the catheter, and the outcomes.

"We are also looking for ways to standardize outcomes" by reviewing peritonitis, tunnel infections, dysfunction of the catheter, exit site infections, leaks, etc., that is detailed in the survey. "One question is how we define the response 'works very well' for catheters," said Oliver. The survey results showed over 90% of the responders used that language to define catheter performance.

<http://www.nephrologynews.com/articles/110689-new-research-underway-on-peritoneal-dialysis-catheter-placement>

Diabetes and Diet

Dr. Cindy Haines of HealthDay TV

"Is your biggest meal breakfast, lunch or dinner? A small, new study found adjusting this diet pattern may help optimize metabolic control and prevent complications of type 2 diabetes.

The researchers recruited 18 people with the disease, who were between 30 and 70 years old. Body mass index ranged from healthy to obese. The participants were randomly assigned to follow one of two diets.

The B Diet contained the largest meal at breakfast, about 700 calories, and the smallest at dinner, about 200 calories. The D Diet contained the same number of calories, but flipped with the smallest amount of energy consumed at

breakfast and largest at dinner. Both had the same lunch levels.

On the 7th day, the researchers collected several blood samples before and after each meal. Two weeks later, patients were switched to the opposite diet plan and the tests were repeated.

The results showed that post-meal glucose levels were 20% lower and insulin levels were 20% higher in people on the B diet compared to the D diet.

One of the authors says these findings show that "a person's meal timing schedule may be a crucial factor in the improvement of glucose balance and prevention of complications in type 2 diabetes"

http://www.nlm.nih.gov/medlineplus/videos/news/Diabetes_Diet_022515-1.html



FDA authorizes first device to treat dialysis-related amyloidosis

March 09, 2015

The US FDA authorized use of Lixelle Beta 2-microglobulin Apheresis Column, the first device to treat dialysis-related amyloidosis.

Dialysis-related amyloidosis is a chronic, progressive condition caused by the buildup in the body of a protein called beta 2-microglobulin and is a complication of kidney failure. As beta 2-microglobulin builds up in the blood, deposits of the protein can form in the bones, joints and tendons causing painful and stiff joints, bone cysts that can lead to bone fractures, and torn tendons and ligaments. Beta 2-microglobulin deposits can also affect the digestive tract and organs, such as the heart and lungs.

Dialysis-related amyloidosis (DRA) most often occurs in patients with kidney failure, especially adults older than 60, who have been on hemodialysis for more than five years.

The Lixelle Column works by removing beta 2-microglobulin from the blood. It contains porous cellulose beads specifically designed to bind to beta 2-microglobulin as the patient's blood passes over the beads. The device is used in conjunction with hemodialysis, a treatment where blood circulates outside the body through a special filter that removes waste products and extra fluid. The clean blood is returned to the body. When the Lixelle Col-

umn is used, the blood passes through the Lixelle Column before it enters the dialysis filter.

The device may help patients who have developed symptoms related to the condition and may be especially useful for those patients who may not have access to extended dialysis therapies or who may not be eligible for a kidney transplant, the FDA said.

"While DRA affects only a small population of patients on dialysis, there are not many treatment options for these patients and some options may not be available to patients in all areas," said William Maisel, MD, MPH, deputy director for science, chief scientist and acting director of the Office of Device Evaluation in FDA's Center for Devices and Radiological Health. "The Lixelle Beta 2-microglobulin Apheresis Column may provide this patient population with an option for relieving some of the debilitating symptoms of DRA."

Data supporting the safety and probable benefit of the Lixelle Column include published clinical studies describing treatment of approximately 100 patients from Japan with DRA, and post-market safety data from approximately 200 patients in Japan where the device has been approved for use. The studies generally showed improvement in symptoms associated with DRA with use of the

device.

The most common adverse events associated with the device's use are temporary hypotension (low blood pressure) and a decrease in hematocrit. As a condition of the HDE approval, the company must conduct a postmarket study to gain more data on the benefits, risks, and adverse events in the U.S. population.

The FDA reviewed the Lixelle Column through the Humanitarian Device Exemption (HDE) pathway. An HDE is an application that is similar to a premarket approval application (PMA), but it is exempt from the effectiveness requirements that apply to PMAs. Devices are eligible for HUD designation if they are designed to treat or diagnose a disease or condition that affects or is manifested in fewer than 4,000 individuals in the United States per year. In order to receive HDE approval for a HUD, a company must demonstrate safety and probable benefit of the device, and that there are no legally-marketed comparable devices, other than a device approved under the HDE or investigational device exemption IDE, available to treat or diagnose the disease or condition.

<http://www.nephrologynews.com/articles/110759-fda-authorizes-first-device-to-treat-dialysis-related-amyloidosis>



“Dialysis-related Amyloidosis is a chronic, progressive condition caused by beta 2-microglobulin buildup in the blood.”

ESRD Patient News

Managing Your Health Care the Smart Way



If there is something we can help you with please contact us through the contact form on our website or email JanieC@esrd-patient-support.org.

Living with diabetes can present a host of challenges. One of them is managing all of your health care needs. You may have quite a few medical appointments as part of your schedule, which may be difficult to keep track of and tiring in itself. Add the need to make sure all your providers are on the same page and the challenge of understanding your diabetes care plan and it could be easy to feel a little overwhelmed.

However, there are ways you can manage your diabetes care that can take some stress off of you and help you follow your treatment plan to the letter.

What's your treatment plan?

The best place to start with managing your health care is figuring out where you are. So take out some paper and a pen and answer these questions:

- How many providers do you see? What are their names and specialties?
- What are the drugs you are on and their doses and frequency?
- What are your treatment goals right now? This could

include such things as a target range for your A1C, a reduction in your blood pressure or a few pounds of weight loss. Anything you have discussed with a provider as a good idea for your diabetes care should go in this category.

- Do you have access to your medical records? Do you know how to get them?
- Who would make decisions for you in a medical emergency? Is this person authorized to do so?

Write down anything else that strikes you as important about your diabetes care plan too. With this beginning document, you can better organize your health care.

Do your providers talk to each other?

If you have a few different care providers, as many people with diabetes do, make sure you've signed any necessary releases to allow them to confer with one another about your care. It will streamline things for your primary care doctor to be able to receive results of tests your endocrinologist ordered, for example – and prevent duplication of such

tests. If your providers all work in the same practices, chances are they do talk already. Make sure they keep you as up-to-date on your care and needs as they keep each other.

How can you be proactive?

Knowing about your treatment plan is half the battle, and you're already well on your way if you've answered the questions above. However, taking action on that knowledge is equally important if you want to see good outcomes from your diabetes care. Brainstorm ways you could be more involved in your care - whether that means getting serious about medication compliance, asking your doctor about things you don't understand, or beginning to track health data in an app or journal. The more involved you are in managing your diabetes, the better you will be able to collaborate with your providers and handle all the challenges diabetes throws your way.

<http://www.diabeticconnect.com/diabetes-information-articles/general/1671-managing-your-health-care-the-smart-way>