

THE Patient Citizen

IMPROVING OUR LIVES THROUGH EMPOWERMENT

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DPC is a 501(c)(4) non-profit organization governed by dialysis patients.

DPC Patient Advocates Storm Capitol Hill



In September, DPC Patient Ambassadors and the Board of Directors traveled to Washington, DC to meet with their Members of Congress and discuss legislative issues important to the 31 million Americans with chronic kidney disease.

Participants from 21 states came to the nation's capital for a multi-day trip that included a congressional briefing, training session and culminated

in a day of meetings on Capitol Hill. DPC organized the event in an effort to raise awareness with Members of Congress about the unique needs of end stage renal disease (ESRD) patients.

Each DPC member met with his/her U.S. Senators and Representative to discuss several policy priorities for the kidney disease community. DPC

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See inside for a patient column on the Washington DC Fly-In.

President's Message: *Take the Time to Recognize Someone Special*



Nancy Scott,
Board President

We all know that special someone who goes above and beyond to make a difference in the lives of others. Within the dialysis community especially, heroes are all around us. During this holiday season, as we all reflect on the year that was, please take the time to recognize that special someone who works each day to make a positive impact in the lives of those around them. Show your appreciation by nominating someone deserving for the DPC Hero award.

The DPC Hero campaign strives to tell the many heartwarming stories about patients, their families and caregivers, and others in the community who make a difference in

the lives of dialysis patients. A DPC hero is anyone who is making a difference and helping others within the dialysis community. A hero can be a nurse or technician who goes the extra mile for patients; a local volunteer; a patient who is beating the odds; or a family member who is a constant cheerleader.

As a recipient of the DPC Hero award myself, I cannot express how much it means to be recognized by your community. DPC is counting on all of you to capture the good deeds you see every day and identify the heroes among us.

Nancy L. Scott

If you are interested in nominating a DPC Hero, contact our office at 1-866-877-4242 or dpc@dialysispatients.org.

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members asked their representatives to support the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2011, legislation that will extend Medicare coverage for anti-rejection drugs beyond the 36-month limit to the life of the transplant.

The Attendees also discussed ways the federal government can save on Medicare spending by ensuring dialysis patients have equal access to private health coverage in the new health insurance exchanges. Such common-sense measures will improve patient access and help with the long-

term fiscal outlook of the county.

As part of the week-long event, DPC advocates also joined representatives from the National Kidney Foundation and Baxter to host a congressional briefing called "Dialysis 101." The event, held in conjunction with the Congressional Kidney Caucus, featured a presentation on the basics of kidney disease and dialysis followed by a patient panel. The three-member panel, which included DPC Board President Nancy Scott and new Board Member Christina Esposito, shared their personal stories with kidney failure and highlighted several key topics of importance to the greater kidney community.

Federal Issue Spotlight



While DPC is actively advocating on behalf of dialysis patients on a variety of issues, one of our top policy priorities is ensuring medication access for all CKD and ESRD patients. As part of that campaign, we encourage all DPC members to contact their Members of Congress about new legislation that will make a positive impact in the lives of many ESRD patients. The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2011 (H.R. 2969/ S.1454) is legislation that will extend Medicare coverage for the anti-rejection drugs necessary for transplant recipients. Currently, for those who qualify for Medicare due to their ESRD diagnosis, Medicare only covers immunosuppressive drugs for 36-months after the transplant. This bill will extend that coverage to the life of the transplant. This critical legislation will help patients secure the medications they need to prevent the early rejection of their transplants and reduce the number of beneficiaries who return to Medicare-funded dialysis after organ rejection.

Patient Perspective: My Trip to Washington DC

By: Devon Osborne, DPC Patient Ambassador

On September 13, I along with about two dozen other patients traveled to Washington, D.C. to represent Dialysis Patient Citizens (DPC) and lobby Congress for the passage of the "Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2011." We also worked to assure that dialysis patients continue to have access to private insurance in the design of the new health insurance exchanges which are part of the Affordable Care Act (ACA). In addition, we extended invitations to the staff and Legislators to visit our local treatment centers to meet patients, caregivers and providers.

The first day culminated with dinner where the group of DPC activists from all over the US gathered. Eating family style was the perfect opportunity to form the bonds needed in the fast and furious days ahead. I met Ike and Flossy from Mississippi along with Jack from Iowa, and Angela from South Carolina. By the end of the meal we were all good friends.

The second day started very early at the DaVita K-street Dialysis Center. The regular patients kindly come in at 2 a.m. so us "out-of-towners" can take their 6 a.m. slots. By noon, we were back at the hotel for lunch followed by a Congressional Briefing on Capitol Hill with legislative aides. That evening our training began. Soapbox Consulting prepared us for the next day's lobbying activity. We had three objectives. One, to lobby for the immunosuppressive legislation we were supporting; two, lobby for continuation of private insurance coverage in the new health insurance exchanges that are part of the ACA; and three, to invite the Legislators and/or staff to visit local dialysis centers in their district. For each Legislative visit, this would be our "agenda".



Devon and Senator Kay Bailey Hutchison

Thursday, September 15th started with a brief photo session on Capitol Hill where the morning sun bathed the Capitol Dome in a glow of soft, yellow light then we divided into small groups. Our group consisted of Kristi, Shelley and I from Texas, Tom and Roy, representing Oklahoma, along with our guide Jessica from DPC. With our timetables in hand, we set out for the Russell Senate Office Building for our first visit of the day with Senator James Inhofe of Oklahoma.

In the course of the day, we met with

Senators Inhofe and Coburn (OK), the Health Legislative Aide (HLA) for Senator Kay Bailey Hutchison (TX), Senator John Cornyn's (TX) HLA and Congresswoman Kay Granger's (TX) HLA. The HLA's are the "movers and shakers" when it comes to getting legislation through Congress so their attention was appreciated.

The trip was a chance of a lifetime, and in those sixty short hours I went from being a simple dialysis patient standing in the security line at Dallas-Fort Worth (DFW) Airport to an experienced political activist.

Ask a Dietitian

Jennette Morgan, MHA, RD, LD

What traditional holiday foods can I eat while sticking to my renal diet?



The holidays can be a challenge when it comes to sticking to your renal diet. Not only are some holiday foods

high in phosphorus or potassium, but everyone has a tendency to overindulge, which can lead to high fluid gains when you have kidney failure. The key to enjoying the holidays is moderation. If there are some holiday foods that are usually considered a no-no that you simply cannot skip, pick the one or two that are your favorites, and keep the portion of those to about 1/2 of a cup. Fill the rest of your plate with items that are OK for renal diets. For those of you who take a phosphorus binder every time you eat, don't forget to do so at these celebrations! And of course, if you have any questions, or want to enjoy something and are not sure if you should, ask your dietitian.

Foods/Ingredients that are OK to enjoy:

- Turkey
- Roast beef
- Pork roast
- Duck
- Goose
- Venison
- Deviled eggs
- Cocktail meatballs
- Molded salads/jell-o molds
- Macaroni salad
- Green salad
- Broccoli
- Cauliflower
- Sweet peas
- Green beans/string beans
- Onions
- Carrots
- Cabbage
- Mustard greens
- Cranberry sauce
- Pickles **
- Yeast rolls/dinner rolls
- Brown and serve rolls
- White Rice
- Homemade stuffing made with white bread crumbs**
- Homemade gravy **
- Hot apple cider
- Mulled cider or wine
- Sparkling apple cider
- Sparkling grape juice
- Wine or champagne
- Jell-O
- Sugar cookies
- Butter cookies
- Apple pie
- Cherry pie
- Lemon pies
- Cool whip
- Candy canes
- Marshmallow-Rice cereal bars
- Pineapple
- Lemonade

Foods to Limit:

- Ham
- Self-basting turkey
- Yams /sweet potatoes
- Butter beans
- Blackeyed peas
- Collard greens
- Corn
- White potatoes/mashed potatoes (OK if potatoes are soaked first)
- Potato salad
- Canned gravy
- Gravy made from mix
- Corn bread
- Corn bread stuffing
- Self-rising flour
- Biscuits
- Macaroni & cheese
- Cream of mushroom soup
- Cream of chicken soup
- Cocktail smokies
- Nuts
- Pumpkin pie
- Sweet potato pie
- Pecan pie
- Mincemeat pie
- Chocolate
- Fudge
- Gingerbread cookies
- Peanut brittle
- Cheesecake
- Red velvet cake
- Fruitcake
- Eggnog
- Beer

** These items may be high in sodium, so please limit your portions



Make Your Getaway!

By Contributing Writer and PD Patient Jim McFarlin

Stevenson's novels include Treasure Island and Kidnapped, so it would appear his travel experiences were mixed at best. If you relish the rejuvenating, life-changing excitement of journeying throughout the U.S. or visiting exotic foreign lands and you have Chronic Kidney Disease (CKD), you may think your "great affair" has to end due to your continual need for dialysis. Guess what? Not so! Keep your bags packed, buddy, because with your doctor's permission and some advance planning, patients with CKD can maintain an active travel lifestyle.

I know. I am a professional writer (as you surely could tell by my stylish and witty prose above) who has to travel frequently for interviews and editorial meetings. When offered a choice of dialysis options, I consciously selected self-administered Peritoneal Dialysis (PD) because I thought it would offer the greatest flexibility in terms of when and where I could dialyze. But it really doesn't matter which form of dialysis you're using, traveling requires organization, scheduling and packing an extra suitcase or two. I have determined that I am horrible at all these things. But like they say in the weight-loss infomercials, if I can do this, anybody can.

First and most important, consult your physician and/or dialysis nurse for approval and advice on traveling. They know a little more about all this than you do and can offer some valuable assistance. They will not, however, under most circumstances, book your flights or hotel rooms. Some things you must do on your own.

You cannot possibly begin soon enough to make travel arrangements.

Because I'm frequently on the go, I am almost constantly in a state of preparation. In fact, I live in Illinois, which is known as "The Preparation State." But if this is your first excursion with dialysis, even if it's only a brief trip, you should consider starting the process up to a month in advance with so many new details to absorb – even longer if you're heading for a hot-spot destination like Florida, Las Vegas, New York or Canada.

If you're on Hemodialysis (HD), you can reserve a space at a treatment center near where you'll be heading. ("Seat for one, please.") Your regular dialysis facility or social worker can be a huge help in making your accommodations. Medicare and private insurers generally will pay their usual portion of dialysis treatments you receive away from home.

Your dialysis center can also forward your dialysis prescription and other vital records to the facility you'll be visiting. But to be on the safe side, carry copies of your medical information with you and call ahead to the new center to confirm they have all the particulars they need on you and that they've actually heard of you before. And just like at home, whatever you do, don't be late for your appointment!

For PD you can arrange to have dialysis solution and other supplies drop-shipped to your destination with several weeks' advance notice. I often stay at a friend's condominium when I'm working in Detroit and was delighted to learn that supplies can be delivered to private residences as well as hotels and resorts. (Probably less delighted than my friend, who has to receive and manage the deliveries

"For my part, I travel not to go anywhere, but to go," the author Robert Louis Stevenson once declared. "I travel for travel's sake. The great affair is to move."

until I return.) If you are staying at a hotel, be sure to call ahead and let them know you're expecting important medical supplies that need to be stored in a dry, clean area away from direct sunlight and placed in your room upon your arrival. Politely suggest that the hotel staff probably will need a dolly. And a truss.

When I'm driving to my location, I usually just throw some cases of dialysis solution in my trunk. Well, more accurately, I place them in my trunk. Those suckers are heavy! And I always take at least one more box than I'll need in case of unexpected leakage.

So keep your passport up to date and start planning your next getaway. Even with CKD, you can travel, even for travel's sake. Get your move on.

This article and others like it are available at www.livenow.info



Ask a Pharmacist

QUESTION:

What over the counter medications should I be careful about with my kidney disease?

Over the counter medications, vitamins, and supplements can be purchased from the pharmacy, health food store, or even your grocery store without a prescription. Because these drugs are so easy to obtain without consulting a healthcare professional, it is often assumed that they are absolutely safe. However, like all drugs, these products have side effects and may interact with each other, or with prescription drugs. Some of these medications may be unsuitable for people with chronic kidney disease.

Here are some examples of common over the counter medicines that should be avoided in people with Chronic Kidney Disease:

Motrin/Advil (ibuprofen), Aleve (naproxen): These drugs can worsen the function of damaged kidneys, by causing an allergic reaction known as interstitial nephritis, and by decreasing the blood flow inside the kidneys.

Aluminum and Magnesium Containing Antacids: If used by people with chronic kidney failure, antacids containing aluminum can lead to too much aluminum in the blood. The risk of magnesium toxicity increases with kidney failure, when the kidney loses the ability to remove excess magnesium. Magnesium-containing laxatives and antacids have been associated with magnesium toxicity.

Decongestants: Cough medicines contain decongestants such as ephedrine or pseudoephedrine (Sudafed). These decongestants may raise blood pressure. Many people with chronic kidney disease also have hypertension.

People living with kidney disease are at a higher risk of these reactions and interactions, since many drugs are eliminated by the kidneys. It is very important for patients with CKD to use caution when taking any over the counter medications. Always

consult your kidney doctor and your pharmacist before taking any over the counter medications.

Reference

Pham K, Hirschberg R. *Global Safety of coxibs and NSAIDS. Curr Top Med Chem* 2005; 5: 465-473.

Xing JH and Soffer EE. *Adverse effects of laxatives. Dis Colon Rectum* 2001; 44: 1201-9.

HAVE A QUESTION

for a pharmacist you think would be helpful to kidney patients and would like to see it published in the Patient Citizen?

Please email to DPC at dpc@dialysispatients.org or mail it to us at 900 7th Street NW, Suite 670 Washington, DC 20001

Dialysis Patient Protections Under the ADA

Many DPC members may be unaware that there are various protections outlined in the American Disabilities Act (ADA) that safeguard ESRD patients from discrimination at work. The ADA became law on July 26, 1990 to protect millions of Americans living with physical and mental impairments that limit their ability to perform one or more major life activities. Dialysis patients, due to the fact that their kid-

ney disease limits their body's ability to function optimally, are able to take advantage of many of the protections outlined in the ADA.

Title I of the ADA prohibits employment discrimination of persons with disabilities who want and are qualified to work, but are in need of reasonable accommodations to participate in the workforce. Examples of reasonable accommodations include modification

of existing facilities for easy access and use, job restructuring, work schedule modification, and position reassignment, among others.

Many dialysis patients find work schedule modification and job restructuring to be beneficial as they navigate working full or part-time while undergoing dialysis treatments. These benefits often allow patients to undergo treatment at scheduled times, on-site

or off-site, depending on their dialysis modality. Job restructuring can reduce difficulties following and in-between treatment sessions while ensuring business needs are being met.

Title I of the ADA also prohibits employers from asking applicants about the existence, nature and/or severity of their disability, including their ESRD diagnosis. However, be aware that employers are permitted to ask applicants about their ability to perform specific job functions. Dialysis patients should not be harassed in the workplace for their disability and an employer cannot fire or discipline disabled individuals for asserting their ADA established rights.

Although employers are required to be mindful of the personal health and needs of their employees, it is ulti-



mately the responsibility of individuals to advocate for themselves. An employer cannot accurately determine an individual's unique workplace needs without input, so workers covered under the ADA should not hesitate to start the discussion with

their employers. Accommodations vary depending upon the needs of the individual applicant or employee, so speak with your employers about what workplace changes suit your individual case. These conversations with one's employers should begin early-on and be maintained as adjustments are needed.

For additional information on the Americans with Disabilities Act and how it impacts you or someone you know, please refer to the U.S. Department of Justice, Americans with Disabilities Act homepage at <http://www.ada.gov/>. If you have questions about your ADA rights in the work place, you can also contact the Equal Employment Opportunity Commission (EEOC) at 1-800-669-4000 or online at <http://www.eeoc.gov/>.

State Round-Up

Arizona: The state saw CMS accept a \$4 co-payment for taxi rides to non-emergency



medical appointments in Maricopa and Pima counties, a \$3 fee for parents and childless adults who fail to give 24-hour notice for missed

appointments in Maricopa and Pima counties, and 60 days of health benefits for people who have lost federal disability coverage in the last month. CMS rejected the state's plan to cap eligibility for parents earning 75% to 100% of the poverty level, to require beneficiaries to re-enroll every 6

months rather than annually, and to charge a \$50 fee for smokers.

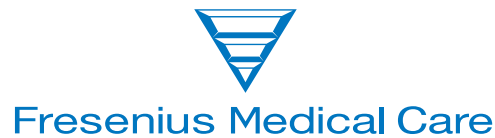
California: The state has restricted coverage of oral nutritional supplements for adults enrolled in Medi-Cal, but DPC has received a letter from the Department of Health Care Services that patients with kidney disease and a co-morbidity mal-absorption diagnosis who require specialized elemental or semi-elemental enteral nutrition products may still receive Medi-Cal coverage of these products.



New York: The state has restricted coverage of oral nutritional supplements for those enrolled in the state's Medicaid program. The state has released regulations regarding this issue and DPC has submitted comments to the state's Department of Health on the importance of these supplements to dialysis patients.



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