

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 Hero: Loretta deVries



Loretta deVries

DPC Hero Loretta deVries has been involved in the kidney community for many years as a devoted caregiver to her husband and is now spreading her support throughout the kidney community in South Florida.

Fourteen years ago, Loretta's beloved husband, Johan deVries, a former diplomat, passed away at the age of 69 after many years of struggling with diabetes and renal failure. Loretta's involvement in her husband's treatment opened her eyes to many of the problems within the dialysis community at that time. She became aware of many patients receiving dialysis who had little or no resources for receiving proper nutrition at home – making them even sicker.

In 1996, Loretta started The Dialysis Food Foundation of South Florida –

the only foundation of its kind in the country – in honor of her late husband with the hope of bringing a solution to ensuring dialysis patients receive the nutrition they need. Eligible patients for this program, receive kidney-healthy foods each week at no charge. To date, the foundation has served thousands of meals to patients who otherwise would not have been eating the proper food or not eating at all.

The cost to feed one patient is less than \$4 a day. For more information on how you can sponsor a patient, please call 305-937-2598 or visit www.dialysisfoodfoundation.org.

Transplantation 101–

DPC will hold a call for our membership on Wednesday May 26th at 2:00 PM Eastern Time (11:00 AM Pacific/Arizona, 12:00 PM Mountain, 1:00 PM Central) to talk about kidney transplants. Our Guest Speaker will be Gigi Spicer, RN the Director of Kidney Transplant Services at the Virginia Transplant Center. This call will be limited to the first 250 people who register. In order to register, you must be a current member of DPC and a dialysis patient or family member of a patient. To register please email us at dpc@dialysispatients.org or call us toll-free 1.866.877.4242

State Round Up

Most states are still facing budget deficits, and more Medicaid cuts are looming. Many state legislative sessions are winding up, and states are looking for ways to balance their budgets while still providing necessary services to residents. This often means states are looking to non-emergency transportation and Medicaid for savings.

DPC, and other members of the kidney community, are working to minimize the impacts these potential funding cuts could have on individuals on dialysis. In addition, DPC continues to work toward the passage of Medigap legislation—which increases patient access to care while saving states money by reducing the number of individuals that must spend down their assets to become Medicaid eligible.

Arizona

Arizona is facing one of the nation's largest state budget deficits. Last year, it cut Medicaid reimbursement rates, and this year, Arizona is on track for additional cuts in Medicaid and non-emergency transportation, often used to transport dialysis patients.

In an attempt to save the state \$5 million over five years and ensure patients have access to dialysis treatments, DPC held an Arizona Dialysis Day on February 25 to encourage the availability of Medigap insurance for all Medicare beneficiaries. Advocates from across the state met in Phoenix to speak to their elected officials about the need to pass Medigap legislation. Rep. Nancy McClain and Senator Rebecca Rios addressed the advocates and provided words of encouragement. In addition, Senate President Robert Burns recognized DPC advocates and provided his colleagues with an overview of the Medigap issue. Unfortunately, due to forces outside of our control, the Arizona Medigap bill will not pass in 2010. However, bill sponsors have indicated their willingness to reintroduce the legislation in 2011 and again

build momentum for its passage next year.

California

The Sacramento Regional Transit District, is facing a budget shortfall. In an attempt to save resources, it has proposed stopping weekday bus/rail service at 7pm and all service on the weekends.

Since many dialysis patients use public transportation to get to and from their dialysis treatments, these provided comments to the Regional Transit District and provided comments at the public hearing. Changes are scheduled to go into effect on June 20.

Georgia

In February, the Georgia Senate unanimously passed legislation that would allow all Medicare beneficiaries, the opportunity to purchase Medigap policies. In mid-April the Georgia House Insurance Committee passed the Senate bill. The next step is passage by the full House and signing by the Governor.

South Carolina

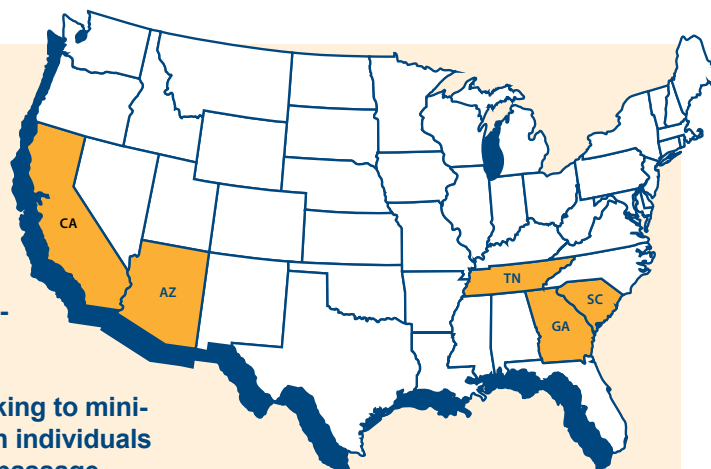
In February, DPC Patient Ambassador Angela Lattimore testified before

a subcommittee of the Senate Banking and Insurance Committee about her experience on dialysis and how the lack of access to supplemental insurance coverage has restricted her ability to access needed care.

On March 3, following a positive vote from the Senate Subcommittee, DPC and NKF hosted a Kidney Day at the Capitol with over 50 advocates from across the state. On March 11, the full Senate Banking and Insurance Committee voted 9-2 in favor of allowing all Medicare beneficiaries the option to purchase Medigap insurance. The bill will now move to the full Senate.

Tennessee

Two bills have been filed in the Tennessee State Legislature that could benefit dialysis patients under age 65. Senate Bill 3164 and House Bill 3717 would allow all Medicare beneficiaries the option to purchase supplemental Medigap insurance regardless of age. On March 22, the Senate Commerce Committee voted unanimously to support Senate Bill 3164. The next step is a hearing before the full Senate.



President's Message

DPC Members Celebrate National Kidney Month and World Kidney Day



This year DPC joined with the National Kidney Foundation, the American Society of Nephrology, and the American Kidney Fund to host national events in recognition of World Kidney Day. Approximately 20 DPC Board Members and Patient Ambassadors flew to Washington, DC to engage in these events that focused on bringing awareness to kidney disease during National Kidney Month and World Kidney Day.

On March 10, DPC co-hosted a reception on Capitol Hill for Members of Congress and Congressional staff. We were honored to have two celebrity guests, Grizz, from the hit NBC television series 30 Rock, who is currently a dialysis patient and Lorenzo Alexander, a player for the Washington Redskins attend the event. In addition, several Members of Congress stopped by to demonstrate their support.

The following day - March 11, World Kidney Day - DPC participants and medical professionals from the dialysis community traveled to Capitol Hill to share their personal journey with

kidney disease and increase lawmakers' awareness of kidney disease.

In addition, DPC members held a variety of events celebrating World Kidney Day and National Kidney Month in their hometowns (read about these on page 5). In each of these instances, DPC thanks our members for making these important events such a success.

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Health Awareness Months: Help Prevent Others from Needing Dialysis

Dialysis patients across the country are dedicated to ensuring their friends, family and members of their communities do not ever have a need for dialysis. If you didn't get a chance to participate in an awareness event during March, there is still time. Education is needed all year long in order to help prevent and delay the progression of kidney disease. The months of April and May provide unique opportunities for you to create attention around kidney health.

April is designated as both National Minority Health Month and National Donate Life Month. African Americans are 3.6 times more likely to have kidney failure, Hispanic Americans and Native Americans are almost twice as likely to develop kidney failure

compared with the general population, and Asian Americans are also at an increased risk for kidney failure. Additionally, in 2007 – the most recent year of available data – there were over 72,000 people waiting for a kidney transplant with 17,513 individuals receiving a transplant that year. Thirty-five percent of people waiting for a kidney transplant are African Americans.

May is National High Blood Pressure Education Month. Hypertension – or persistent high blood pressure – is the second leading cause of kidney failure. People with persistent high blood pressure should ensure they have their kidney function checked and learn to control their blood pressure.

To continue raising awareness about Chronic Kidney Disease, consider holding an event in your local community and inviting media to attend, or write a letter to the editor of your local newspaper about these important health awareness months and the importance of protecting kidney health. Dialysis Patient Citizens has helpful educational information you can distribute at your awareness event and tools to help you write a letter to the editor. We can also assist you with ideas for your event or tips for outreach to your local news station. You can find a list of educational resources on our website at www.dialysispatients.org/education or you can call us toll-free at 1.866.877.4242 for assistance with your activity or event.

Ask a Dietitian

Jeanette Morgan, MHA, RD, LD



QUESTION: How can I stick to my dialysis diet when I don't have a lot of money for groceries?

RESPONSE: With so many choices available and limited time in your schedule, it can be difficult to select the right food options for your kidney health and for your wallet. Use the following suggestions to help you eat more healthfully, while also saving money. As always, it's best to consult with your dietitian on what works with your particular dietary needs.

Getting the right amount of protein is important. Here are some inexpensive protein options:

- Canned tuna (use for tuna salad over salad greens or in a sandwich)
- Canned salmon (try it on grits, or make salmon croquettes)
- Eggs (make egg salad, or try them boiled, deviled, scrambled, fried or poached)
- Inexpensive fish such as whiting
- Dark meat chicken (such as thighs and leg quarters)
- Chuck roast
- Wild game such as deer, rabbit and pheasant (this can be inexpensive if you or someone you know hunts regularly)
- For a protein boost, add plain or vanilla whey protein powder to oatmeal or cream of wheat

**Note: Cheaper cuts of meat tend to be tougher and will soften up if they are stewed.

Vegetable Values

- Frozen vegetables are less expensive and are low in sodium.
- Stick with in-season produce when buying fresh.
- Check your local farmers market for additional options.

Tips For Saving Money on Groceries

- Always check the weekly sales for good deals on meat.
- Look for items reduced for quick sale when you are at the store.

- Buy store brands instead of name brands whenever available.
- Check your local warehouse store to see if meat is cheaper pound for pound.
- Don't waste money on junk foods that don't have many nutrients such as chips, cookies, and candy.
- If you're feeling really ambitious, create a spreadsheet of prices at the different stores in your area so you can see who offers the best prices overall.
- Grocery shop once every two weeks and stick to your shopping list. The more often you go to the store, the more likely you are to buy things you really don't need.
- Prepared foods such as frozen dinners tend to be overpriced and high in sodium and phosphorus; stay away from these. Prepared foods from the deli are also much more expensive.
- Avoid food fads such as pomegranate, açai, and noni juice. These foods are expensive and often poor choices for renal patients.
- Buy lettuce by the head rather than pre-chopped bags, which are more expensive pound for pound.
- Avoid eating out or picking up fast food. It is almost always cheaper to eat food cooked at home.

Healthier (And Cheaper) Fast Food Options

While it is cheaper to eat at home, the occasional meal out is some-

times necessary. Remember that most fast food is high in sodium, so even the choices listed here should not be eaten frequently.

McDonald's

- Plain Hamburgers (without cheese or bacon)
- Chicken Nuggets
- Filet-o-Fish Sandwiches
- Egg McMuffin (without cheese)
- Sausage McMuffin (without cheese)

Wendy's Super Value Menu

- Crispy Chicken Sandwich
- Chicken Go Wraps
- Chicken Nuggets
- Double Stack Burger (without cheese)

Burger King Value Menu

- Whopper Jr. (without cheese or tomato)
- Chicken Tenders
- Spicy Onion Rings
- Spicy Chick'n Crisp Sandwich

**Note: Since fries are not a kidney-friendly option, you can skip the meal deals and order tap water as your beverage, which will also lower your total bill.

Use this information as a guide, but it should not replace the advice of your renal dietician. You should limit the amount of foods that you eat that are high in phosphorus, sodium and potassium.

DPC Members Organize Variety of Local Events During National Kidney Month

In March, DPC members coordinated local kidney disease awareness events in recognition of National Kidney Month. Through these events, DPC members educated new audiences about chronic kidney disease (CKD), DPC and how to better manage your kidney health.

DPC members who held events in their communities included: Ethellena Headspeath (Des Moines, IA), Laura Musgrove (Miami Gardens, FL), Ed Stizza (Fountain Hills, AZ), Diane Brisbane (Brooklyn, NY), Shirley Nealy (Chicago, IL), Barry Palleson (Lawrenceville, GA), Harry Hartford (Rossford, OH), Lawrence Winston (San Bernardino, CA), Flossie Lewis (Moss Point, MS), Kimberly Stuart (Smithtown, MO), Angela Lattimore (Seneca, SC), Melanie Bengé (Marion, NC), Jacqueline Williams (Fort Worth, TX), Belinda Wood (Bicknell, IN), Lucy Coronado (Fort Worth, TX), Melinda Bearpaw (Hot Springs, AR), Wanda Stuart (Christiansburg, VA), Janice Starling (St. Petersburg, FL), Azim Abdullah-Bey (East Point, GA), Sharon Secor (Oviedo, FL), Terrence Bristow (Ashburn, VA) and Jeanette Weadon (Flagstaff, AZ).

Activities by DPC members included:

- Approximately 25 DPC members traveled to Washington, D.C. for the



Belinda Wood with her World Kidney Day poster

World Kidney Day fly-in event held with the National Kidney Foundation.

- Ed Stizza of Fountain Hills, AZ organized an annual kidney disease awareness walk and fundraiser
- Lawrence Winston of San Bernardino, CA held an event at his dialysis facility
- Shirley Nealy of Chicago, IL hosted an awareness event at her home for members of the community

- Barry Palleson of Lawrenceville, GA and Flossie Lewis of Moss Point, MS coordinated events at their churches
- Angela Lattimore of Seneca, GA distributed information at a local golf tournament
- Lucy Coronado of Fort Worth, TX hosted a 70's party at her dialysis facility
- Janice Starling of St. Petersburg, FL coordinated educational events at her local hospital
- Diane Brisbane of Brooklyn, NY held an event at her neighborhood senior citizens housing center
- Ethellena Headspeath of Des Moines, IA distributed information at an area grocery store
- Laura Musgrove of Miami Gardens, FL; Harry Hartford of Rossford, OH; Melanie Bengé of Marion, NC; Jacqueline Williams of Fort Worth,

TX; Melinda Bearpaw of Hot Springs, AR and Sharon Secor of (Oviedo, FL) set up displays and handed out information at their dialysis facilities

- Jeannette Weadon of (Flagstaff, AZ) set up a display at her local mall

Thank you to all our DPC members and Patient Ambassadors for their work during World Kidney Day and National Kidney Month.



Ask a Pharmacist

What is a good laxative that is OK for dialysis patients?

Constipation is a very common problem in dialysis patients, affecting 63 percent of hemodialysis patients. There are several reasons for this. Many people on dialysis (like many others who are not on dialysis) do not have enough fiber in their diet. Restrictions on fluid intake, certain fruits (patients on a potassium restriction), and decreased level of activity can all contribute to constipation. Regular use of aluminum containing phosphate binders may also worsen constipation.

It is important for dialysis patients to stay regular and avoid constipation. People with End Stage Renal Disease have a greater risk of developing complications from constipation, such as diverticulitis or perforations. If you are on peritoneal dialysis, you may have problems with your exchanges if constipation occurs.

The general approach is to get more daily activity. Then a bulk or hyperosmotic laxative can be used, such as psyllium (Metamucil) or polyethylene glycol (Miralax). Bulk-producing agents cause the stool to be bulkier and to retain more water, as well as forming a lubricant, making it easier for the intestines to move it along. They should be taken with plenty of water. Bulk-producing agents have the gentlest of effects among

laxatives and can be taken just for maintaining regular bowel movements. Hyperosmotic laxatives draw water back to your colon, replacing what was lost, and allow you to have a normal, easy and complete bowel movement.

Stool softeners, such as docusate (Colace), may also be used. These drugs enable additional water and fats to be incorporated in the stool, making it easier to move along. However, they are not always effective in dialysis patients. The use of stimulant laxatives such as bisacodyl (Dulcolax) should only be used on a short term basis, since they can cause hypokalemia.

There are a multitude of laxatives and their effectiveness varies from person to person. Each person has to find, hit or miss, the best regimen for himself or herself. However, treatment of constipation in dialysis patients differs from others' treatment in that dialysis patients should not take magnesium containing medications, such as milk of magnesia and other similar laxatives.

Lippincott Williams and Wilkins, Philadelphia Pa, 2009. Principals and Practice of Dialysis. Fourth Edition, William L. Henrich. Chapter 24 Gastrointestinal Complications in End Stage Renal Disease. Pg 425.

This activity is supported with an education grant provided by



CKD Corner – New Medicare Education Benefit

If you have been diagnosed with Chronic Kidney Disease (CKD) Stage IV and are on Medicare, there is a new benefit available to you. You now have the right to receive up to six Kidney Disease Education (KDE) sessions covered by Medicare Part B that will help you learn more about taking control of your disease and help you make informed decisions about your future treatment. These session topics include delaying the need for dialysis, preventing complications due to toxic waste buildup that can occur as kidneys fail, and explanation of treatments available (including kidney transplants and all dialysis options such as peritoneal dialysis, home hemodialysis, and in-center hemodialysis) and how they work

By taking an active role in your care, learning more about your disease and preparing yourself for future treatment you can improve your outcomes and be an active partner in your care. Talk to your nephrologist about this education benefit or call Medicare for more information at 1-800-Medicare.

Patient Ambassador Profile: Maria “Tina” Robinson



“Tina” Robinson in Washington, D.C.

Forty-eight-year-old Maria (“Tina”) Robinson of Statesboro, GA, was diagnosed with systemic lupus erythematosus at the age of 15. Systemic lupus erythematosus, commonly referred to as “lupus”, is a chronic inflammatory disease that occurs when the body’s immune system attacks its own tissues and organs, including the kidneys. Throughout her high school

years and into early adulthood, Tina and her doctors closely monitored her creatine levels and were able to maintain her kidney function for many years. However, at the age of 33, Tina went into kidney failure and was forced to begin dialysis treatments.

Although Tina has been on dialysis for 15 years, she still takes her three-

days-a-week hemodialysis treatment very seriously. Since Tina was diagnosed with kidney disease, she has had five cousins suffer from diabetes and kidney failure who have passed away, and she believes that all of them could have survived if they had been educated on the risk factors associated with kidney disease and the importance of treatment and following doctors’ orders.

It has always been very important to Tina to educate herself about dialysis. By keeping herself informed, working with her nephrologist, and living a healthy lifestyle, she has been able to maintain a fairly normal life. The most difficult adjustment that Tina had to make after starting dialysis was quitting her full time job with the Board of Education due to her health conditions.

However, Tina has not let dialysis stop her from helping and educating others. Six years ago, she began volunteering for her local dialysis facility, DaVita East Georgia Dialysis, as a set up technician.

Tina learned about DPC through her dialysis facility and was nominated to be a DPC Patient Ambassador. “It was important to me to join DPC in order to help other dialysis patients to help themselves,” said Tina.

Through DPC, Tina has traveled to Washington, DC twice to speak with lawmakers about kidney disease issues and participated in several DPC Patient Ambassador leadership seminars across the country. She has also arranged for both Senator Johnny Isakson and Congressman John Barrow to come and tour her local facility to help raise awareness about CKD and ESRD issues.

Thanks to our Sponsors



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