

THE Patient Citizen

IMPROVING OUR LIVES THROUGH EMPOWERMENT

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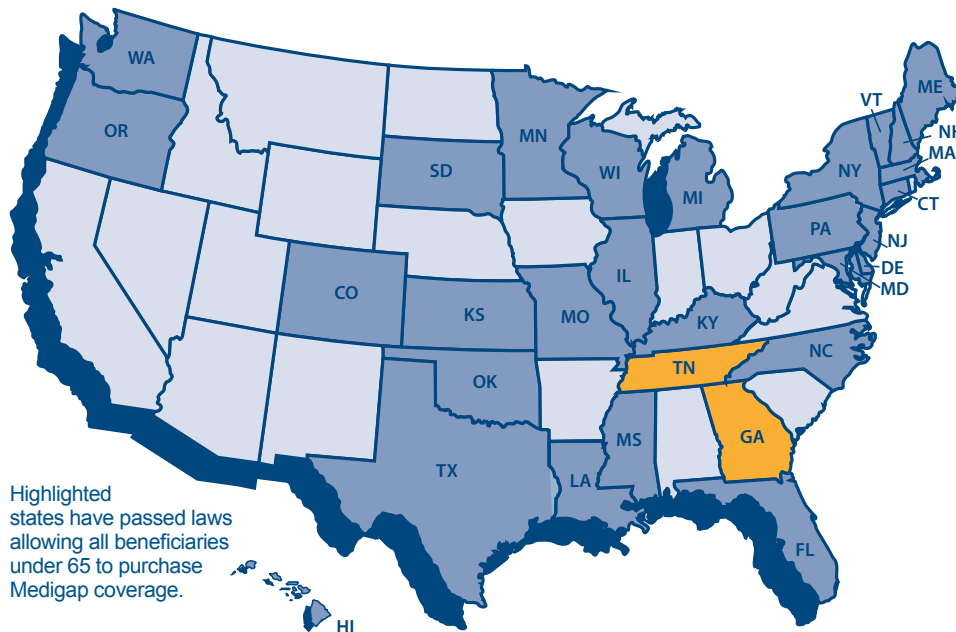
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Medigap Victories – Georgia and Tennessee

Recently, both the Georgia and Tennessee state legislatures have passed legislation to allow all Medicare beneficiaries, regardless of age, the ability to purchase optional Medigap supplemental insurance plans. This is a tremendous victory for DPC but more

(ESRD) benefit. Fortunately, Medicare covers the majority of patients' medical costs – 80 percent. However, patients are left to cover the remaining 20 percent, which include costs such as medical deductibles and co-pays. Many patients have access to additional



importantly, the passage of Medigap coverage in Georgia and Tennessee is a victory for individuals on dialysis.

These states join Florida, which passed similar legislation in 2009, and 28 other states in a step towards providing equality in coverage to all Medicare beneficiaries. Thankfully, dialysis patients are unique in that no matter what their age, they are eligible to qualify for Medicare under the program's end stage renal disease

insurance to help them cover these expenses. This type of secondary insurance may be in the form of a private or employer pay plan, or it could be provided through state Medicaid assistance. For ESRD patients age 65 and older, Medicare coverage allows them to purchase Medigap, a supplemental insurance to assist them with covering their out-of-pocket expenses. Unfortunately, federal law does not allow

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

President's Message

The Value of Patient Advocacy



Federal and state policies have a huge effect on kidney care and dialysis patients. Yet, lawmakers may not

realize the impact that their decision making can have on kidney patients or even know the number of dialysis or pre-dialysis constituents in their states or districts. That is why it is so important to let lawmakers know how certain issues will impact you, as a kidney patient who is their constituent.

There are many different ways to be an advocate. This month, for example, we are encouraging patient leaders to invite their legislators to their dialysis centers. Seeing the dialysis process often helps lawmakers better realize the needs of ESRD patients. However, advocacy hap-

pens whenever you take the time to voice your opinion. It can be as easy as calling or writing your legislator's office in support of an issue. We can help you.

Patients should work together to generate support for the issues that are most important to all dialysis patients. This is why Dialysis Patient Citizens (DPC) has established advocacy priorities based on our members input. A sampling of issues in existing legislation that would benefit from advocacy activities include: allowing dialysis patients under 65 the opportunity to purchase Medigap plans, helping protect military veterans' access to quality care, and guaranteeing lifetime immunosuppressive drug coverage for kidney transplant patients.

For your legislators, meeting an individual impacted by these issues and/or receiving a personalized message from constituents about matters they

consider important can go a long way towards helping them make decisions that are beneficial to you. Your legislators want to help. It's up to us, the patients, to tell them how. So, please do not hesitate to let your representative lawmakers hear from you directly. Patient advocacy is very important.

If you have any questions about advocacy, need assistance getting started, or would like to become a patient advocate, please call DPC toll free at 1- 866- 877-4242 or visit our website at www.dialysispatients.org. Thank you and stay well!

A handwritten signature in black ink that reads "Myron Zayon".

Myron Zayon, President
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California Living Donor Registry

On Thursday, June 3rd, the California Senate approved SB 1395 in an attempt to create the nation's first altruistic (living) organ donor database. The bill still needs to pass the House of Representatives to be implemented into law by the state of California, but it has the Governor's support. There are currently over 21,000 Californians waiting for an organ transplant. Of them, 17,000 are specifically waiting for kidneys. The altruistic donor database would be the first registry of

living donors in national history. Living donors are living individuals who are willing to donate organs like their kidneys and portions of their liver.

The bill would also work to simplify current organ donor registration efforts for Californians to become organ donors upon death. The California Department of Motor Vehicles would have each person interested in becoming a deceased organ donor mark "yes" or "no" in order to complete the

application for a new license, renewal or identification card. Donate Life reports that approximately 25 percent of those applying or renewing a driver's license or identification card sign up to be deceased donors.

Simplifying the deceased donor registry and including a living donor database is expected to increase the number of organ donations, helping to reduce wait times for those waiting for a transplant.

Patient Ambassador Profile: Kendra Deike

Plainfield, Iowa, native Kendra Deike was born with congenital nephrosis, a genetic disorder caused by a defect in the protein nephrin, which is essentially a lack of filters in the kidney. Her parents knew that something was not right when she was born. She had considerable fluid retention and swelling, but visited multiple doctors before she was finally diagnosed at the University of Minnesota.

Kendra is now 32 years old, has been on dialysis for 24 years, and has received three kidney transplants. She received her first transplant from her father when she was four years old, which lasted for four years. Her second transplant lasted only two short weeks, and her most recent transplant from the University of Iowa lasted two years.

Today, Kendra dialyzes in-center three times a week and takes a proactive role in promoting education about both chronic kidney disease (CKD) and end stage renal disease (ESRD) within her local community. Most recently, Kendra was featured in a local television news segment to inform the public about risk factors for kidney disease as well as the importance of living a healthy lifestyle. She encourages those suffering from CKD or ESRD to get involved in the dialysis community and become an active participant in their dialysis care.

Kendra has managed to live an extremely active lifestyle in spite of her kidney failure. She works full-time at Farm Bureau Financial Services as a Licensed Insurance Producer and, in May of 2010, she graduated from Upper Iowa University with a Masters in Business Administration in Organizational Development. She also makes it a priority to stay educated on the issues that are affecting dialysis



Kendra Deike

patients. She feels that it is important to remind those suffering from kidney disease and kidney failure that if they take care of themselves and listen to their doctors, they can continue to live a full and happy life. "Dialysis does not define me. It is just one little piece of who I am," says Kendra of the role dialysis plays in her life.

Kendra learned about Dialysis Patient Citizens through her dialysis center. "It was important for me to join DPC

because people are not aware of the issues that affect dialysis patients and some people do not even understand what dialysis is," says Kendra.

This year, Kendra traveled to Washington, D.C. with DPC for World Kidney Day to talk to Members of Congress about the issues that are affecting dialysis patients. "As a dialysis patient, it is important to me to advocate for myself as well as those who are not able to," adds Kendra.



Ask a Dietitian

Jeanette Morgan, MHA, RD, LD



Summer Foods for the Renal Diet

Summer is a time of abundance when it comes to fresh foods. From backyard gardens and roadside stands

to cookouts at parties and family reunions, food seems to be at the center of many summer activities. The question for many dialysis patients is, "How can I follow my renal diet and not feel left out of all of the fun?" The following suggestions can help you navigate these occasions and enjoy them in moderation along with everyone else.

Fresh from the Garden

Fruits and vegetables have a high fluid content so always keep your portions of these foods small. Individuals undergoing peritoneal dialysis can choose from an even wider variety of fresh garden vegetables than what is listed below. Check with your dietitian for details.

- Cucumbers
- Green Beans (string beans, pole beans)
- Yellow Summer Squash
- Zucchini
- Grapes
- Onions (all types – yellow, white, sweet, green and red)
- Eggplant
- Bell Peppers
- Hot Peppers
- Cabbage
- Cauliflower
- Carrots
- Berries (strawberries, blueberries, blackberries, raspberries)

Great Main Dishes for a Picnic in the Park

Try any of these plain or as a sandwich in hamburger buns or sliced white or sourdough bread:

- Chicken Salad (Try a recipe with sliced grapes or chopped apples for variety)
- Tuna Salad
- Egg Salad
- Pulled Pork BBQ (choose vinegar or mustard-based sauce) *
*BBQ is a higher sodium selection, so limit portion size.

What to Grill at Your Next Cookout

- Hamburgers (skip the tomato slice & cheese)
- Steaks
- Ribs
- Chicken
- Shrimp & Scallops
- Tuna Steaks
- Salmon Fillets
- Kabobs (Choose from chicken, shrimp, beef, pork, lamb, red & green bell peppers, onions, mushrooms, hot peppers, pineapple, yellow squash, zucchini, eggplant)

Drinks to Ease the Summer Heat

Be sure to keep your fluid limits in mind when pouring a glass of these:

- Iced Tea (Add sliced lemons or lemon juice for extra flavor)
- Lemonade (Add a splash of cranberry juice for flavor & color)
- Lemon-lime soda or Ginger Ale (Add a scoop of sherbet to make a cool float!)

Great Sides for that Picnic or Cookout

- Macaroni or other Pasta Salad

- Deviled Eggs
- Cole Slaw
- Fruit Salad (choose from the following: canned fruits, canned mandarin oranges, pineapple, grapes, fresh cherries, strawberries, blueberries, blackberries, raspberries)
- Watermelon (lower in potassium than other melons, but still high in fluid, so do not overdo it with your slice!)

Vegetable Salads. Choose from:

- All types of lettuce
- bell peppers
- celery
- onions
- cucumbers
- carrots
- cauliflower
- shredded red cabbage
- sliced boiled eggs
- sliced apples
- sliced strawberries
- canned pineapple
- canned mandarin oranges

Top your salad with homemade vinaigrette made with Dijon mustard, olive oil & balsamic vinegar.

What's For Dessert?

- Gelatin Molds made with canned fruit cocktail*
- Sherbet or Gelato*
- Pie (blueberry, apple, cherry, strawberry)
- Lemon Bar Cookies
- Crispy Rice Cereal Bars
- Trifle made with pound cake or angel food cake, mixed berries & whipped topping

* These items should be counted towards your daily fluid limit.

Hurricane season is upon us. Do you and your family have a disaster plan in place?



Disaster preparedness is important for everyone. Everyone should have an evacuation plan, plenty of clean water and food supplies, and knowledge of how to get in touch with your friends and loved ones in the case of a weather emergency. For dialysis patients there are even more preparedness measures needed. You may be surprised to know that most local and state governments do not have a disaster preparedness plan that accounts for the special needs of dialysis patients. Therefore, it is extremely important that you take responsibility to prepare for a potential disaster.

Below are some general tips to help you be prepared for an emergency situation:

- Keep a list of all your medications in your wallet.
- Carry a list of your doctor's phone numbers and the number to your dialysis facility with you.
- Talk to your dietitian about an emergency diet plan. In an emergency you may not be able to get your regular dialysis treatment. Adhering to a stricter diet can help manage the risks involved if your dialysis treatment is delayed due to an emergency. You should start your emergency diet as soon as an emergency situation occurs.
- Have a plan for dialysis at an alternate location. In the event you may need to evacuate or your dialysis clinic is unable to open, you should know which other dialysis facilities to contact to make arrangements for your treatment.
- Keep an emergency supply of dialysis friendly food, clean water, medical supplies, flashlight, batteries and anything else you may need in the event of an emergency. Keep these items together so they can easily be packed into a bag if you need to evacuate.
- If you do either home hemodialysis or peritoneal dialysis at home, contact your power and water companies prior to a pending emergency situation in order to register for special priority in the event of lost power and water to your home.

For more detailed information on what you can do to prepare for an emergency please call DPC toll free at 1.866.877.4242 or visit our emergency preparedness web page at: <http://www.dialysispatients.org/emergency-and-disaster-preparedness-for-dialysis-patients>.

The Kidney Community Response Coalition (KCER) has also established a toll-free number that is activated during a widespread emergency or disaster (other times you will only hear a recorded message). They can be reached at 1.888.33.KIDNEY (888.335.4363). Please call this number after you have tried to get in touch with your dialysis provider.



Ask a Pharmacist

Is it safe to use herbal supplements if I have Chronic Kidney Disease?

As a chronic kidney disease (CKD) patient, you may have considered the use of herbal products to help stay healthy. The use of herbs has become extremely popular over the past ten years, creating to a \$4.1 billion supplement industry. The popularity of herbs may be due to several factors: they can be purchased without a prescription, a belief that “natural” products are safer and the knowledge that many of our modern drugs are derived from herbs.

However, very few of these herbal supplements have been studied specifically in people with kidney disease. Even if a product is safe for healthy people, it may not be safe for someone with CKD, and could possibly cause you harm. Healthy kidneys remove toxins from your body. When your kidneys don't work well, you can't get rid of these toxins, and they can build up in your body. Therefore, you need to be very careful about using these supplements.

Before using any herbal supplement, it is especially important for people with CKD to know if the product:

- Is filtered out by the kidneys
- Makes blood clots progress more quickly or not
- Raises blood pressure
- Affects potassium levels

Some herbs that act as diuretics may cause kidney damage. These include bucha leaves and juniper berries. Supplements that contain Uva Ursi and parsley capsules may also cause side effects. Many herbs can interact with prescription drugs, including product containing St. Johns Wort, echinacea, ginkgo, garlic, ginseng, ginger, and blue cohosh. It is important to consult with your doctor or your pharmacist before taking any herbal supplements.

References

National Kidney Foundation. Use of Herbal Supplements in Chronic Kidney Disease. <http://www.kidney.org/atoz/content/herbalsupp.cfm> (Accessed 3/13/10)

American Association of Kidney Patients. Herbal Products That May Cause Further Damage to the Kidneys <http://www.aakp.org/aakp-library/herbal-products-that-damage/> (Accessed 3/13/10)

Kidney School. Module 15: Alternative Treatments. http://www.kidneyschool.org/mod_15/mod15_01.shtml (Accessed 3/13/10)

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Medicare beneficiaries under age 65 to purchase Medigap. Yet, thirty-one states have voted to enact statewide legislation providing ESRD and disabled patients under age 65 with this opportunity.

By helping patients avoid having to spend down their personal assets and turn to Medicaid for support, enhanced Medigap policies are saving millions of dollars for state Medicaid programs. For instance, as a result of passing Medigap legislation this year, the state of Georgia is estimated to save \$20 million over the next five years.

DPC members have turned out in great numbers to support statewide Medigap legislation. For example, DPC member and dialysis patient Eric Edwards attended a Georgia Senate committee hearing this February to help show support for Medigap legislation and its benefit for younger ESRD patients. Like many other patients in the state, due to expensive co-pays, Edwards has sometimes been forced to put off visiting his physician – and for some patients, such a delay in treatment can lead to complications in care. In Georgia, Eric's and other DPC members' voices were heard, which helped sway the state legislature to pass the bill this year with overwhelming support.

DPC and our members are continuing to look at other states where Medigap access would benefit patients under age 65. In addition, we are pushing for federal legislation that would allow for dialysis patients in every state to purchase Medigap coverage. Our belief is that every patient should have the ability to access the medical care they need without having to bankrupt themselves and their families. We will continue our work to help all patients have the ability to purchase affordable Medigap policies.



New Project Manager—Ben Wislinski

Ben Wislinski, a South Carolina native with a passionate interest in improving kidney

care by strengthening public programs, joins DPC as Project Manager. Ben received his Bachelor's degree

from Randolph-Macon College and recently graduated with a Master in Public Administration degree from the George Washington University.

His political and health care advocacy experience has been shaped by internships for the U.S House of Representa-

tives' Majority Whip, Jim Clyburn and for a retiree health care nonprofit, the Alliance for Retired Americans. Prior to joining DPC, Ben worked as a strategic consultant for the Student Conservation Association to help grow the organization. He looks forward to working with members to do the same at DPC.

Become a Patient Ambassador

Make a real difference for yourself and fellow dialysis patients

Be an advocate for dialysis patients and their families in the largest dialysis patient organization in America. If you are a dialysis or pre-dialysis patient, or the family member of a patient, with a passion for helping to improve people's lives, we want to invite you to become a DPC Patient Ambassador.

As a DPC Patient Ambassador you will make a significant difference in the lives of dialysis patients by advocating on their behalf. You will accomplish this by:

- Building relationships with state and federal politicians through letters and meetings
- Creating partnerships with caregivers and implementing programs to help improve the quality of patient care
- Promoting DPC to other patients to encourage membership - the more members we have the stronger our voice
- Educating patients about public policy issues that may affect them

You can do as much or as little as you like. If you can commit to doing one of the tasks listed above that is enough to be a DPC Patient Ambassador. It does not have to take a lot of time, and we're here to help you by

providing training, tools, materials and talking points.

Can you use your time on dialysis to be a DPC Patient Ambassador?

Some DPC Patient Ambassadors find they are able to accomplish a lot while on dialysis. As far as a time commitment, we ask for 15 minutes before or after dialysis once a week, one hour a month for a conference call and one hour a month reviewing information.

Some of tasks you would perform as a DPC Patient Ambassador include:

- Scheduling dialysis center tours or meeting with local or national politicians
- Bringing programs to your dialysis center that help create a stronger patient-caregiver relationship
- Telling fellow patients about joining DPC and giving them applications
- Organizing letter writing campaigns with patients



- Handing out education materials to patients
- Arranging for local newspapers, radio and television stations to do a dialysis story

How you can become a DPC Patient Ambassador

If you have a dedication to improve the quality of life for dialysis patients through education and advocacy, we invite you to apply to become a DPC Patient Ambassador. Please see below.

**Please complete a
DPC Patient Ambassador application
at <http://www.dialysispatients.org/patient-ambassadors>,
or call toll-free 1-866-877-4242.**



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