

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.

World Kidney Day Count Down!

March is National Kidney Month, and March 11th is World Kidney Day. World Kidney Day (WKD) is a global health awareness campaign. The international campaign focuses on the importance of our kidneys and reducing the impact of kidney disease and its associated health problems worldwide. During the month of March, we encourage you to participate in this important day by educating your local community about kidney disease. One way you can do this is to hold an awareness event at a local organization you belong to, a community center or place of worship. DPC has educational materials you can hand out about preventing kidney disease. Another great way to alert others to the need to protect their kidney health is to share your personal story of living with kidney disease. The more awareness we bring to our communities the better the chance we have at reducing the number of new people afflicted with kidney failure.

You can also reach out to your fellow dialysis patients and help them better manage their health to lessen the impact kidney failure has had on their lives. You can encourage them to take the first step by becoming a member of DPC. You can also share DPC's educational tools with them.

If you are interested in hosting a World Kidney Day event in your community or your dialysis clinic, please visit our website at www.wkdaction.org or contact us toll free at 1.866.877.4242. Below is a list of educational tools available for free on the DPC website

or you may ask us to mail them to you by emailing us at dpc@dialysispatients.org or giving us a call.

PUBLIC AWARENESS TOOLS

Articles:

- What is Chronic Kidney Disease (CKD)

One-Page Educational Sheets:

- High Blood Pressure and CKD
- Diabetes and CKD
- Number of Dialysis Patients by State

About DPC Tools:

- One-Page Fact Sheet
- Membership Application

KIDNEY FAILURE EDUCATIONAL TOOLS

Articles:

- Treatment Options
- Albumin
- Low Blood Pressure and Dialysis
- Potassium Problems

One-Page Fact Sheets:

- Kidney Health Disparities
- Basic Facts about Kidney Disease
- Managing your Anemia
- Dialysis Diet on a Budget
- Immunizations

Brochures:

- The Power of Iron
- Phosphorus and Medications

President's Message

Dialysis Patient Citizens Mourns the Loss of Micah Naftalin

Dialysis Patient Citizens Board of Directors Vice President and Leader for Advancement of Kidney Care

It is with a heavy heart, we inform you that Micah Naftalin – the Vice President of the Dialysis Patient Citizens (DPC) Board of Directors – passed away unexpectedly on December 23rd, 2009. Micah was one of the founding members of the



served as a liaison to the White House and Congress and represented the United States in numerous international human rights.

Previous to his leadership and prominence with

DPC Board of Directors, and his continued involvement and contributions to DPC were inspirational and will be deeply missed. As an End Stage Renal Disease (ESRD) Patient, Micah was dedicated to expanding the outreach of DPC and knew the trials dialysis patients face first hand.



Micah Naftalin

As Micah stated, "We need to make sure that our community of patients is not lost in the noise."

Among other achievements, Micah was a prominent leader in the fight for the religious and human rights of Jews in the former Soviet Union. Beginning in 1987, Micah served as the National Director of the Union of Councils of Jews in the former Soviet Union. The Union of Councils is the largest independent grassroots organization advocating for Jews and human rights in the former Soviet Union. In his role as National Director, he

the Union of Councils, Micah practiced as a lawyer; served as a Congressional Aide to Congressman Carl Elliot of Alabama; held title of Chief Council for the U.S. House of Representatives Select Committee on Government Research; and worked as a Senior Policy Analyst for the National Academy of Science, the National Academy of Engineers, and the National Research Council. Additionally, Micah was appointed to Deputy Director of the U.S. Memorial Holocaust Council where he aided in the early development of Washington DC's Holocaust Museum.

During his lifetime, Micah positively affected so many people with his passion and outreach as an advocate. Micah will be dearly missed as a member of the DPC family, and we express our most heartfelt condolences to his friends and families.

DPC Submits Comments on Behalf of Dialysis Patients to Medicare

As you may be aware, Congress has required the administrators of Medicare to reimburse dialysis facilities for administering treatments, medications and laboratory tests into one payment. On September 15, the Centers for Medicare and Medicaid Services (CMS) released a proposal for public comment on how they believe the new payment system should work. If implemented, many of the changes CMS proposed will alter how patient care is provided. This is why DPC worked to ensure patients were heard during the 90 day comment period. Working closely with the patients on the DPC Board of Directors and receiving comments from individual patients, DPC wrote and submitted a comment letter to CMS on December 15, 2009. CMS will read and acknowledge all comments they receive before releasing their final rule this year. Below is a summary of the suggestions DPC made to improve the new bundled payment system that will begin in select facilities in 2011 and in all facilities by 2014.

In the proposed bundle, CMS has included dialysis medications patients typically receive through their pharmacy. They have proposed paying only \$14 per patient per treatment for these medications – far short of what dialysis facilities will have to pay to ensure patients get the medications they are prescribed. This may impact where patients receive medications and reduce access to certain medica-

State Roundup: Medigap

Last year, the kidney care community experienced a tremendous legislative victory in Florida. With the passage of the Alonzo Mourning Access to Care Act, Medicare ESRD patients are now able to buy Medigap supplemental insurance plans to help pay for their co-payments and deductibles. Prior to this act, Medicare ESRD patients in Florida were not afforded the same benefits as traditional Medicare beneficiaries. Many patients who were unable to afford their Medicare co-pays and out-of-pocket costs were forced to spend down their income in order to qualify for Medicaid, and others were postponing going onto transplant lists due to concern over being able to pay for needed post-surgery medications.

Florida became the 29th state to allow Medicare ESRD patients the ability to purchase Medigap plans.

In 2010, DPC will work with the kidney care community on both the federal and state level to help ensure that Medigap coverage is available in additional states. If you would like

to provide your personal story and possibly help expand Medigap coverage to others, please contact DPC. Specifically we are looking for:



- ESRD patients under age 65 who are struggling with paying their medical bills
- ESRD patients under age 65 who have had to "spend down" their assets to qualify for Medicaid assistance
- ESRD patients under age 65 who are waiting to go onto the transplant list due to an inability to pay for the necessary post-surgery medications
- ESRD patients age 65 or over who previously struggled with their bills prior to reaching Medigap qualification

If you are interested in participating in this program please contact us at dpc@dialysispatients.org or toll-free at (866) 877-4242.

tions. If CMS must include these drugs in the new payment system, DPC recommended that they fully fund them and monitor changes in patients' access to drugs and outcomes related to the medications. DPC stressed the importance of ensuring that patients are able to get the medications prescribed by their nephrologists that result in the best outcomes. Additionally, many patients are likely to face increased co-payments and out of pocket expenses in order to access the same drugs they currently have now. DPC encouraged CMS to not shift Medicare costs in a way that results in a greater financial burden to patients.

Similarly, access to laboratory tests may also be complicated. Unless a list of laboratory tests that will be included in the new payment system is defined, patients may have to see multiple doctors to get lab tests drawn. DPC recommended CMS define a list of lab tests that will be included and ensure patients can continue to have their lab tests ordered by their nephrologist and drawn during dialysis.

Other areas of the proposed bundled payment may also reduce access to care and further increase disparities in care, particularly for patients who need more medications and services than the average patient. The way patients' anemia is managed and the amount of EPOGEN® patients receive may also change. DPC asked CMS to ensure their final payment system protects all patients' access to care and optimal treatments.

Training for home dialysis is another issue which will be improperly paid for under the proposed changes. In order to ensure home dialysis programs are widely available to patients who are interested in learning to do dialysis at home, DPC recommended CMS pay for home dialysis training for those who decide to use home therapies.

DPC 2009 Year in Review

2009 brought an unprecedented new focus on our nation's health care which included the introduction of comprehensive health care reform legislation as well as numerous policy proposals anticipated to impact kidney patients. Amid all the debates about these proposals in Washington, D.C. and beyond, Dialysis Patient Citizens (DPC) and our members stepped up to ensure that our voices were heard on key issues.

On a national level, DPC members spoke out on the proposed End Stage Renal Disease (ESRD) bundle, gave testimony at the Centers for Medicare and Medicaid Services (CMS) ESRD Town Hall Forum and successfully advocated for additional funding for the new Chronic Kidney Disease (CKD) IV education benefit. DPC members also made their presence felt in their home states and in their communities through Congressional visits, letters, briefings, online action and more. We thank you, our members, for continuing to help us advocate for

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improved quality of care and quality of life for all kidney patients. We look forward to another successful year together in 2010!

Our 2009 achievements include: Membership Activation

- Total membership of 22,056, including membership in 50 states
- Expanded number of Patient Ambassadors to 392, including membership in 42 states
- Provided new Patient Ambassador Leadership Seminars (PALS) – advanced training on advocacy and community leadership
- Launched Ambassadors Coordination Together (ACT) in four states – a program to facilitate collaboration among Patient Ambassadors residing in the same states.

Federal Advocacy

- Sent more than 2,200 e-mails to Congress
- Coordinated 126 visits with lawmakers
- Participated in Congressional briefings

Community Partnership

- Co-hosted World Kidney Day reception with lawmakers and staff on Capitol Hill with the American Soci-

ety of Nephrology (ASN), National Kidney Foundation (NKF) and Kidney Care Partners (KCP)

- Held a World Kidney Day “fly-in” event with NKF and ASN
- Led initiative to send patient organization letter to CMS requesting an Open Door Forum on the ESRD proposed payment system

Regulatory Activity

- Provided oral testimony at the CMS ESRD Town Hall Forum
- Provided written comments to CMS on the proposed ESRD bundle
- Successfully lobbied for additional funding for the new CKD IV education benefit

State Advocacy

- Coordinated with DPC members on state advocacy initiatives in Arizona, California, Washington, Florida, South Carolina, Maryland, Texas and Hawaii
- Hosted an Arizona Dialysis Day to educate lawmakers about the effects that would result from Medicaid cuts to dialysis care
- Established a tailored online advocacy tool to support Medigap legislation in Florida



Member Education And Community-Building

- Translated core educational materials into Spanish
- Distributed new educational pieces on immunizations and the flu
- Released an updated educational booklet, “The Power of Iron”
- Expanded upon the popular “Ask a Dietician” educational offering
- Launched the “Ask a Pharmacist” educational offering
- Published as an expert source in kidney trades Renal Business Today
- DPC Patient Ambassadors provided first-hand education to members of their community during local kidney screenings

Dialysis Patient Citizens Online Community

The Internet is a great way to stay up to date with Dialysis Patient Citizens (DPC). Aside from the newly remodeled DPC website, DPC can send out Advocacy Alerts or our monthly eNewsletters to your email account. In addition, DPC is on Facebook and Twitter.

What is Facebook?

Facebook is a social networking site. You can register for free and have your own online profile. With this profile you can interact with DPC. When DPC thinks something is of interest to patients to know, we post the informa-

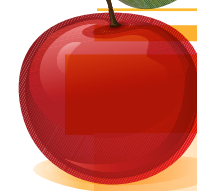
tion on Facebook. Once we have posted the information, you can read it from your online profile. You can become Facebook friends with fellow dialysis patients, friends or family members across the country. Facebook is a great way to interact with DPC and keep on top of key issues in the kidney care community. You can find us by typing Dialysis Patient Citizens into your Facebook page search bar.

What is Twitter?

Twitter is another social networking site. On Twitter, you can post up 140 characters about anything you

want. DPC tweets about Chronic Kidney Disease (CKD) and what we are doing as an organization. On DPC’s twitter page you’ll be able to find facts about CKD and about the progress DPC is making in the kidney community.

We hope that if you are able you will join our online efforts to improve the quality of care for kidney patients. Don’t forget to sign up for our Advocacy Alerts and monthly eNewsletters on the DPC website: www.dialysispatients.org. We hope we’ll be hearing from you soon on the Internet.



Ask a Dietitian

QUESTION: Sometimes I feel ungrateful if someone cooks me a meal I can’t eat because it’s off my diet — or like a burden if my family has to spend extra time or money at the grocery store for me. How can I accept the help I need and still stay on this renal diet?

ANSWER: Remember, the last thing people helping you want is to undermine your healthy goals. They will appreciate you explaining your nutritional needs and why you need to follow a special diet.

If someone offers to prepare a meal for you, explain that your renal dietitian has designed a menu plan specifically for you. Be sure to have the recipes handy, along with a grocery list that your dietitian can provide you.

Also remember, it took some effort for you to learn about your dietary needs, so ask your renal dietitian to provide any easy-to-understand resources you can share.

In general, remind those helping you that reading food labels can reduce anxiety about buying the right items.¹ Nutrition facts labels make it easier to

spot added ingredients that your renal dietitian may have recommended you limit, such as:²

- Phosphorus
- Potassium
- Sodium
- Calcium

Simple tips like choosing canned vegetables with labels that say “no salt added” or “low sodium” can help reduce confusion and cost.³

If you’re feeling up to it, go along with a friend or family member to do the shopping. With temptations in every aisle,⁴ you can use the moral support to stick to your approved list and your budget.⁵

The reward? You’ll have more confidence in your support system, and they’ll be glad to see you feeling better because of staying on your meal plan.⁶

- 1 Martin C. The Supermarket Safari. AAKP Web Site. http://www.aakp.org/print-version/dsp_library_art.cfm?art=348. Accessed November 12, 2009. P. 1, para 1, lines 2-5.
- 2 Davita. Supermarket shopping tips for those with kidney disease. <http://www.davita.com/diet-and-nutrition/c/896>. Accessed November 12, 2009. Page 2, paras 4-6.
- 3 Bosch R. Budget meals on the dialysis diet. Davita Web site. <http://www.davita.com/diet-and-nutrition/lifestyle/a/2567>. Accessed November 12, 2009. P. 1, para 4.
- 4 Davita. Supermarket shopping tips for those with kidney disease. <http://www.davita.com/diet-and-nutrition/c/896>. Accessed November 12, 2009. Page 1, para 1, lines 1-2.
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- 6 Davita. Supermarket shopping tips for those with kidney disease. <http://www.davita.com/diet-and-nutrition/c/896>. Accessed November 12, 2009. Page 1, para 1, lines 3-6.

Provided thanks to an Educational Grant from Shire



Dialysis and Exercise

Exercise can be a great therapy for dialysis patients. Exercise can provide many natural health benefits including increased energy, comfort and health outcomes. Dialysis patients often think that because of their treatment they cannot exercise or that exercise might be dangerous; however, exercise is possible for dialysis patients. In fact, if done correctly, exercise can improve the health of dialysis patients, but you should always check with your doctor before beginning an exercise program.

These are just a few health benefits that exercise can offer:

- More energy, mobility, and vitality
- A stronger muscle structure

- Better health outcomes - including reduced blood pressure and chance of heart attack
- Mood enhancing endorphins

How do you start if you haven’t been active for a while? If you haven’t exercised for a while and are worried about straining your muscles or cardiovascular system, a good start would be flexibility training. This would include stretching or holding your body in different positions to engage and strengthen certain muscles. Stretching is a great low-intensity, low-impact form of physical activity for beginners. Simply stretching provides health benefits including:

- Increased mobility and range of motion

- Decreased stress
- Improved circulation

When you begin exercising, just remember to take things slow. A regular workout routine will take time for your body to adjust to. You shouldn’t try to do more than you are capable of or feel frustrated if you can’t complete something. Remember that any increase in physical activity is a step in the right direction.

Note: Always remember to consult your physician before changing anything that could affect your dialysis treatment – including beginning an exercise regime. Some medical conditions may make it hazardous and unsafe for patients to engage in physical activity.



Ask a Pharmacist

QUESTION: Do I need to take my phosphorus binders even if I don't eat anything? My prescription says to take them three times a day.

People living with Chronic Kidney Disease (CKD) tend to have high levels of phosphorous. It is estimated that 70 percent of the 1.5 million dialysis patients worldwide will develop high phosphate levels.¹ Levels of phosphate in the blood rise because the kidneys are not excreting excess phosphate in the urine. High phosphate levels can make you feel itchy and can lead to complications such as heart disease and bone damage.²

Treatment includes eating a diet low in phosphates. Dialysis may also help remove some of the excess phosphate from your body, but dialysis and diet is usually not enough to control your phosphate levels. This is where phosphate binders come in. Phosphate binders are medicines that help keep your phosphorous in balance. Some common phosphate binders are listed below.

- Aluminium hydroxide (Alucaps)
- Calcium carbonate (Calcichew, Titalac)
- Calcium acetate (Phosex, PhosLo)
- Lanthanum carbonate (Fosrenol)
- Sevelamer (Renagel, Renvela)

Phosphate binders should always be taken with food because they only work if taken with foods containing phosphate. Binders work like a sponge, soaking up phosphorous from the food you eat. They work in your digestive tract, before the phosphorus has a chance to be absorbed. It defeats the purpose of the binder if they are not taken with food. In fact, some may

even make you nauseous if taken on an empty stomach. Therefore, you should not take phosphate binders if you don't eat anything.

However, it is important have a balance and nutritious diet and to take your medicine exactly as your doctor tells you. Phosphorus can cause a lot of damage and make you sick if it builds up in your body, so be sure to take your full phosphate dose with every meal.

1. Norris KC. Toward a new treatment paradigm for hypophosphatemia in chronic renal disease. *Dial Transplant* 1998; 27 (12) : 767-773.
2. American Association of Kidney Patients. Norris, K. Phosphate Binders: What Are They And How Do They Work? http://www.aakp.org/print-version/dsp_library_art.cfm?art=306 (Accessed December 9, 2009)

QUESTION: If I eat something very high in potassium and begin to experience high-potassium symptoms, is there a drug I can take to lower my serum potassium?

Hyperkalemia (high blood potassium levels) is common in people with CKD. The amount of potassium in the blood is controlled by the kidneys. For people with kidney disease, potassium levels can build up to high levels in the blood. This is called hyperkalemia and can be dangerous for the heart. Potassium-rich foods should be limited for those on hemodialysis because potassium builds up between dialysis treatments and can cause problems such as weakness, muscle cramps, tiredness, irregular heartbeat and worst of all, heart attack.

Mild hyperkalemia usually does not produce symptoms while severe hyperkalemia can cause serious symptoms such as weakened pulse, slow heart-beat or muscle weakness. If you experience any of these symptoms you should seek immediate medical care.

Hyperkalemia can be treated in several different ways. Dialysis is the primary path for removing potassium in patients with renal disease. As the kidneys lose their function, they are unable to remove potassium from your body. Although dialysis removes potassium from the body, it can build up between treatments. Other treatments can include a low potassium diet, or oral, intravenous or inhaled medications.

For kidney disease patients, having too much potassium can be a serious problem. It is important to maintain a low potassium diet and to monitor your potassium regularly. If you experience symptoms of hyperkalemia you should seek immediate medical care. As always, please speak to your nephrologist if you feel you are experiencing symptoms of hyperkalemia.

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- Emedicine Health. Hyperkalemia http://www.emedicinehealth.com/hyperkalemia/page3_em.htm (Accessed December 10, 2009)
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This activity is supported with an education grant provided by AMGEN

Patient Ambassador Profile: Barbara Alvarez



Barbara Alvarez

DPC Patient Ambassador Barbara Alvarez was diagnosed with End Stage Renal Disease (ESRD) in 1999. Since she did not have hypertension, diabetes or any other complications that typically lead to kidney failure, her diagnosis was very unexpected. Barbara began dialysis at the time of her diagnosis and remained on dialysis until 2007 when she had a kidney transplant. After her transplant failed two years later, she began dialysis once again.

Today, Barbara dialyzes in-center three

times a week and takes an active role in educating those in her community about Chronic Kidney Disease (CKD). Most recently, in October, she volunteered with DPC at the DaVita Kidney Awareness Run/Walk in her hometown of Long Beach, California. At the event, she visited with the health fair attendees, telling them more about the risks, impact and treatment options for CKD and ESRD.

"Unfortunately, I didn't know that I had kidney disease until I had reached the point for needing dialysis, so I am always glad to take the opportunity to help educate others in my community about the common risk factors present for kidney disease and to encourage them to get tested if they are at risk," said Barbara of her experience.

Barbara learned about DPC through

her dialysis facility. Since she was very outgoing, had a positive attitude and interacted well with the other patients, her facility thought she would make an effective Patient Ambassador.

Through DPC, Barbara and her husband have traveled to Washington, DC to speak with their Congressman about kidney disease issues, and she has spent a good deal of time with patients in her area to help educate them about CKD and ESRD issues.

"It was important to me to join DPC in order to promote overall CKD awareness, especially in African American women," said Barbara. "I am the face of kidney disease since it is so much more common in minorities, and I am proud to act as a positive influence and an educator to those in my community."

2010 Changes to DPC's Board

We think of the DPC Board of Directors as a family. Like many families, DPC has been lucky to have some new additions this year but was also saddened when other members left. This year, two Board Members retired from the Board.

Patricia Orna

A DPC Board Member since 2005, Patricia Orna served in many leadership capacities for the organization. In addition to being a Board Member, Patricia served as DPC's second President and as Treasurer. A Peritoneal Dialysis (PD) patient, Patricia helped guide DPC through many important organizational developments including our name change and transition to our Washington, DC headquarters. Patricia will continue to be active with DPC while focusing on her career and her health.

Malaysia Scott

Malaysia Scott served on the DPC Board of Directors for two years. Having experienced most modalities and eventually a kidney transplant, Malaysia brought tremendous knowledge about dialysis to the Board. A resident of Alabama, Malaysia helped focus DPC's activities and educational programs on rural dialysis populations.

As sad as we were to have these two great members retire, we are as equally pleased to welcome a new member to the DPC Board Family.



Martin Wienshienk

A mathematician and engineer for almost 50 years, Martin Wienshienk has taken the same analytical mindset and applied it to the challenges that face ESRD patients. A former home

hemodialysis and nocturnal dialysis patient in Scottsdale, AZ, Martin received a kidney transplant in April 2009. His transplant has not dampened his desire to provide support for those still in treatment. Martin has served as a DPC Patient Ambassador, participated as a patient member of the Medical Review Board for CMS Network 15, developed education material for dialysis patients, served as chair for a local support group, and assisted other ESRD organizations in developing comments regarding ESRD legislation.

We enthusiastically thank Patricia and Malaysia for their service to DPC and the dialysis patient community and welcome Martin. The DPC Board family is always looking to grow. If you are interested in joining the Board of Directors, please contact DPC for an application. While Board membership is open to anyone, we do put a focus on having current dialysis patients on the Board of Directors.

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