

THE PatientCitizen

IMPROVING OUR LIVES THROUGH EMPOWERMENT

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

DPC Members Organize Events during National Kidney Month in their Local Communities



We are happy to report that this March many of our devoted DPC members organized local events recognizing National Kidney Month and World Kidney Day to raise kidney disease awareness within their communities. Throughout the entire month, approximately 30 different events were held across the country by DPC members, including dialysis facility tours and meetings with Members of Congress, as well as kidney disease awareness walks and kidney health screenings. These National Kidney Month community events that DPC members continue to successfully host each year are great ways to educate new audiences about chronic kidney disease (CKD), DPC and how to better manage your kidney health.

Some highlights of the National Kidney Month activities by DPC Members included:

- Sixth Annual Fountain Hills, AZ Kidney Walk and Fundraiser, hosted by Patient Ambassador Ed Stizza, gathered local kidney care supporters and elected officials.
- Step Out & Give Life, Prattville, AL

awareness event, kidney screening and blood donation, hosted by Patient Ambassador Gary Barron, gathered over 400 local kidney care supporters.

- Bayfront Medical Center's World Kidney Day Celebration in St. Petersburg, FL, hosted together by Patient Ambassadors Janice Starling and Jeffrey Campbell, brought together renal professionals, physicians and local patients to raise kidney disease awareness.
 - Lunch and Learn, hosted by Patient Ambassador and DPC Board Member Mike Guffey at UMB Bank's national headquarters in Kansas City, MO, provided participants with general information on kidney health, dialysis and transplantation. The event was also broadcasted by video conference so other UMB branches could participate in the event.
 - Two day dialysis facility open houses and a "Kidney Disease Among Seniors" awareness event in Chicago, IL hosted by Patient Ambassador Shirley Nealy.
- "Local community involvement and education is an excellent way to ensure that our important messages are heard across the country and that new audiences are educated on how to manage their own kidney health," said Interim Executive Director Tonya Saffer. "On behalf of DPC, I would like to thank all of our dedicated members for their efforts in organizing these wonderful educational and awareness events during National Kidney Month."

President's Message

DPC Welcomes New Executive Director



Nancy Scott, Board President

We are proud to announce that Hrant Jamgochian, J.D., LL.M., formerly the Director of Health Policy for the United Way, has joined DPC as our new Executive Director. Hrant has extensive expertise in formulating and advancing effective health care policies at the national and state levels, having served as the



Hrant Jamgochian, Executive Director

lead health policy expert on United Way's public policy team. Hrant led the organization in supporting health care legislation and policies designed to advance United Way's goals in increasing the number of Americans who are healthy and avoid risky behaviors.

Hrant previously served as Director of Congressional and State Relations

for the American Pharmacists Association and as Director of Field and State Operations for the American Psychological Association, where he spearheaded a number of successful national advocacy initiatives and grassroots campaigns. He also previously worked at the Armenian Assembly of America, where he led the organization's membership, grassroots and public relations activities.

Hrant's experience in advancing effective health care policies, his background in leading and growing membership organizations, and his passion for helping improve others' quality of life will be tremendous assets to our organization as he takes the reins in leading DPC. Please join us in welcoming Hrant!

DPC Says Goodbye to Tonya Saffer

As we welcome Hrant, we also say goodbye to Tonya Saffer, who has served in a variety of roles at DPC since she started with the organization in 2006, including Project Manager, Deputy Director, and, most recently, Interim Executive Director. Tonya will be taking a new role at Avalere Health, where she will work with the company's numerous clients to develop strategies and solutions to improve access to quality health care. It's with a heavy heart that we see Tonya leave, but we wish her the best with her new endeavors.

On a personal note, I am excited to begin serving a two-year term as DPC's new Board President, taking

over the reins from Myron Zayon. Having worked in education for 25 years as a teacher and a principal, Myron has been a passionate and effective advocate on behalf of DPC's members and the entire kidney community. We thank him for his dedicated service to our organization, as he plans to remain on the Board of Directors, but devote additional time with his family and volunteer efforts within his community in Baltimore, Md.

During my time serving with DPC as its Board Vice President and Education Chair, I have been fortunate to meet many of you directly, to visit with lawmakers in Washington to advocate for supportive kidney care legislation, and to testify before policymakers about the impact that certain policies could have on dialysis patients like us. As some of you know, I am also a registered nurse, an ordained minister and an in-center hemodialysis patient. I believe that all of these experiences and perspectives will allow me to successfully represent you – DPC's members and the heart of our organization – as we continue to grow and advance our education and advocacy reach.

I am eager to get started in my new role as President, and I look forward to working with all of you this year as we strive to improve all dialysis patients' quality of life.

Nancy Scott, President
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Former President's Welcome



Looking back, I am extremely grateful for the experiences I have had serving as DPC's Board President, the progress we have made together as a united patient community, and the friendships I have made with many of you in undertaking these efforts during my term. It has truly been a privilege to serve you.

As I now pass the baton to Nancy Scott, our new DPC Board President, I am excited to see what will happen next for our organization under such a well-regarded and talented leader. With Nancy's diverse background in nursing, education, advocacy, and the ministry, she is extremely well-positioned to continue to move DPC forward as a strong and credible patient-led organization working to improve all dialysis patients' quality of life.

I look forward to staying engaged with DPC as a Board member and remaining involved with advancing our education and advocacy programs. I congratulate Nancy and wish her the best in this new role, as I wish each of you the best in our pursuit of improving kidney care together.

Patient Ambassador Profile: Tom Fossa

Tom Fossa of Claremore, Oklahoma was rushed to the hospital on his 70th birthday. Those in the emergency room initially thought he had been in a car accident due to his badly bruised face, but Tom explained that something must be wrong with his kidneys because just two months prior, he was diagnosed with kidney disease. On that day, February 14, 2009, he was diagnosed with end stage renal disease (ESRD). After spending four days in the intensive care unit, Tom was released from the hospital and faced with his new diagnosis: kidney failure.

When Tom was told his kidneys had failed, he thought he was dying. The optimistic, lively, spirited man was crushed when he first realized he would be sitting in a dialysis chair three times a week for five hours a day. However, he has come to realize that he can continue a full life while on dialysis and that he could be a positive example for his fellow patients.

This is exactly why Tom chose to become a DPC Patient Ambassador – to rid dialysis patients of fear by encouraging them to make the best of the time they spend at dialysis. He tries to make them laugh, asks them if they have any questions, gives them his home telephone number and lets them know that if they need anything they can come to him and he will provide them with an answer - even if that means going to the local library to look it up. Although he only dialyzes three times a week, Tom is often in visiting patients for the remainder of the week.

After volunteering at his local hospital for 10 years, Tom knew that his diagnosis would not mean that his volunteer days were over. When he learned of DPC, Tom decided to join because he wanted to help others. "I find it so re-



Tom Fossa

warding to help a brother or sister out; what I get out of it is priceless," Tom said. "It's the most rewarding thing I've ever done. I should be thanking them for the feeling that they give me."

Originally from New York, Tom now lives in Claremore, Oklahoma with his wife of 50 years, whom he met on a blind date, and their son. He loves music of all kinds and made his passion, ice skating, his career. He spent 38 years as a lithographer, printing materials for Olympic figure skaters.

In his tenure thus far as a Patient Ambassador he has hosted dialysis facility tours for Claremore Mayor Flo Guthrie, Oklahoma state Senator Sean Burrage and Oklahoma state Representative Marty Quinn. His additional contributions to kidney disease awareness include having an article, "Dialysis to Music," published in DaVita's Lifelines magazine, as well as facilitating and raising awareness about kidney disease by having his experiences featured in publications in the The Tulsa World and The Claremore Progress during National Kidney Month.

Learn about Alport Syndrome



Alport Syndrome is a rare genetic kidney disease affecting an estimated 1 in 5,000 people that causes progressive kidney deterioration and profound hearing loss. The majority of those affected by Alport Syndrome are young men who require dialysis or a kidney transplant by their early 20s. The Alport Syndrome Foundation was launched in 2007 as a grassroots effort by families affected by the disease to provide a support community linking patients, medical providers and the scientific research community. The Foundation has grown to become an international presence in outreach, education and research of Alport Syndrome, and in 2010, it hosted the first-ever International Alport Syndrome Symposium for Physicians, Researchers and Families. In 2011, the organization has already raised \$100,000 for research funding.

Alport Syndrome is caused by genetic mutations that affect the type IV collagen family of proteins. Type IV collagen is a major part of important tissue structures called basement membranes that are present in all tissues including the kidney, inner ear and eye. Generally, Alport Syndrome affects males more than females because 80 percent of the time the disease is passed on by a mutation on the X chromosome (called X-linked Alport Syndrome). Males only have one X-chromosome whereas females have two X chromosomes. In females, the normal X chromosome buffers the effect of the mutated gene. The other 20 percent of Alport Syndrome patients have the autosomal recessive or autosomal dominant form of the disease where males and females are equally affected.

The primary symptom of Alport Syndrome is blood in the urine, which is

usually so small that it's hard to detect. As the disease progresses, additional symptoms occur, such as protein in the urine and high blood pressure. Progressive scarring of the kidney leads to eventual renal failure and the need for dialysis or transplantation. Hearing loss is estimated to affect 80 percent of males with X-linked Alport Syndrome and may be the first indication of the progression of the disease.

The diagnosis of Alport Syndrome is performed using the standard methods common to nephrologists along with genetic testing, which is available for all genetic types of the disease. However, the disease is often not diagnosed early unless the family has had a previous diagnosis of Alport Syndrome.

"Many of us have been told we have Familial Nephritis or benign Thin Basement Membrane Disease only to be later diagnosed with Alport Syndrome. Early diagnosis is crucial, as there are

medications that are being used to prolong kidney function, and the data shows the sooner these medications are started the longer the life of the kidney," says Sharon Lagas, President of the Alport Syndrome Foundation. "My two boys are affected by Alport Syndrome and they started on ACE inhibitors when they were around five years old, and they are now teenagers and still have full kidney function. My brother lost his kidneys at the age of 16, and I am hoping these medications will give us more time than he had before kidney failure."

The Alport Syndrome Foundation works to empower patients and their families with information and resources and to increase awareness of the disease in our communities. The Foundation is coordinating 5Ks for Healthy Kidneys in Kentucky, Arizona, Utah and Illinois to raise funds and awareness. For more information on the Foundation, Alport Syndrome, and the 5Ks for Healthy Kidneys please visit www.alportsyndrome.org.



Ask a Dietitian

Jeanette Morgan, MHA, RD, LD

The Ask a Dietitian column will return in our June issue. Please let us know what questions you have.

Each quarter DPC's Education Committee Member and renal dietitian Jennette Morgan answers CKD patients' questions about their diet in our Ask a Dietitian column. Past questions Jen has answered have included, "If I am a dialysis patient how can I get the protein I need? How can I follow a renal friendly diet on a budget?"

Do you have a question for Jen that you would like answered in this column? These questions can help you not only to navigate nutrition requirements needed to improve your health, but they can also benefit thousands of other patients. If you have a question you would like answered in an upcoming issue of the Patient Citizen please email, write or call us.

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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. DPC continues to advocate for the prevention of cuts to Medicaid reimbursement so that important health care services for kidney patients are maintained. The following state updates are all accessible on our State Advocacy and Resource web page at <http://www.dialysispatients.org/patient-assistance-state-advocacy>. DPC has submitted comments and encouraged patient emails to lawmakers on these issues.

Arizona



The Arizona Senate Finance Committee has passed a budget, which could negatively impact dialysis patients who rely on Medicaid coverage. It has still yet to go before the full House and Senate for a vote. However, if passed, it would reduce Medicaid reimbursements to health care providers by five percent and would give the state Medicaid office authority to eliminate Medicaid coverage of non-emergency medical transportation, which includes transportation to dialysis appointments.

An initial five percent reduction to Medicaid was already applied in March 2010. While kidney transplants and kidney/pancreas transplants are still covered, pancreas-only, lung and

liver transplants are no longer covered by the state Medicaid program. Heart transplant coverage was only cut for non-ischemic heart disease.



California

While proposed reductions to MediCal and caps on certain patient services were avoided, the California legislature

has passed into law the restriction of MediCal coverage of oral nutritional supplements for individuals 21 years of age and older to only those patients who are tube fed. This may hurt patients who rely on oral nutritional supplements to maintain proper nutrition. We are in the process of determining exactly how this will affect kidney patients.



Missouri

Good news! Funding for the Missouri Kidney Program (MoKP) has been restored in the proposed budget. The Missouri state House of Representative's original proposal was to cut \$2 million from the program. MoKP is a non-Medicaid, state-funded program that provides financial aid for low-income persons who have kidney dis-

ease. This issue still has to go before the full legislature for vote. DPC is advocating to keep funding for MoKP where it is so that patients are not hurt who are reliant on the program's services for prescription drug costs, transportation, and supplemental



insurance premiums, among others.

Nevada

The Nevada governor's proposed budget for their next two-year

period includes a 15 percent reduction in Medicaid payments to dialysis providers specifically. The state budget is not set to be finalized for a couple months still, so it does leave opportunity for revisions to this proposal to be made. However, if it stands, specifically cutting from Medicaid reimbursement to providers would likely lead to dialysis provider downsizing or cuts to services, which in turn could lead to reduced access to care for patients.



New York

New York is looking to cut state Medicaid by two percent and to eliminate Medicaid coverage of nutritional supplements for individuals 21 years of age and older. This restriction may hurt patients who rely on oral nutritional supplements to maintain proper nutri-

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Ask a Pharmacist

QUESTION: Some deodorant says not to use if I have kidney disease? Is there any deodorant out there that is safe for kidney patients?

Antiperspirants are designed to combat underarm odor by reducing sweat. Aluminum is the active ingredients in antiperspirants. It has been used in these products safely for more than 100 years. These aluminum salts act as temporary plugs that block the sweat glands and keep you from sweating. The FDA requires all antiperspirants containing aluminum to carry a warning label for people with kidney disease. The warning advises those with kidney disease to talk to their doctor before using the antiperspirant.

Since aluminum is one of the most commonly found elements on our planet, we are exposed to it every day in the food we eat, the water we drink and bathe in, and even the air we breathe. This aluminum can be absorbed by your body through your gastrointestinal tract or through your skin. When you use an antiperspirant, small amounts of aluminum can be absorbed through your skin. It has been estimated that the amount of aluminum absorbed from antiperspirants is much less than the amount absorbed from food and water.

In a person with normal kidneys, the accumulation of aluminum from antiperspirants is very low and has no known health effects. However, people with advanced chronic kidney disease (people with Stage 4 or Stage 5 CKD who have less than 30 percent of their original normal kidney function) may not be able to remove this aluminum from their bodies, resulting in high aluminum levels.

Unfortunately, aluminum salts are the only active ingredient approved by the FDA for use in antiperspirants. However, deodorants do not contain aluminum. While most people use the term antiperspirant and deodorant interchangeably, they are not the same. Antiperspirants work to stop sweating completely. Unlike antiperspirants, deodorants allow your body to sweat, while they work to kill the bacteria that cause the sweat to smell.

Aluminum-free underarm deodorants are readily found in your local health-food store, and may also be found in your supermarket or health and beauty aid stores. One example of such a product is Tom's of Maine Long Lasting Natural Aluminum Free Deodorant Stick.

The kidney experts at the American Society of Nephrology have suggested that everyone with severe Chronic Kidney Disease talk to their doctor before using an antiperspirant. Please contact your doctor if you have any doubts about whether this warning applies to you.

Reference

American Society of Nephrology. Antiperspirant Warning Questions and Answers http://www.asn-online.org/facts_and_statistics/Antiperspirant%20Warning%20QAs.pdf (Accessed 3/15/2011)

Each quarter we ask a pharmacist to answer questions dialysis and pre-dialysis patients have about medications. If you have a question for a pharmacist that you would like answered in an upcoming issue of the Patient Citizen please email, write or call us.

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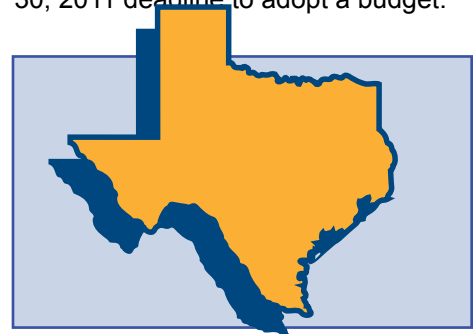
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tion, and overall Medicaid cuts may lead to dialysis provider downsizing or cuts to services, which in turn could lead to reduced access to care for patients.



Pennsylvania

The Pennsylvania Department of Health's Chronic Renal Disease Program (CRDP), which provides health coverage for vital services to people suffering from chronic kidney disease, has had its full \$6.779 million budget restored in the state's current budget proposal. The program's services include life sustaining medications, treatments and associated services for dialysis patients. The state has a June 30, 2011 deadline to adopt a budget.



Texas

On September 1, 2010, Texas reduced Medicaid reimbursement for providers by one percent. However, current budget proposal discussions indicate that there may indeed be further cuts to the state Medicaid program. Additionally, in the past Texas has directed up to \$368,600 per year of fees from health care facility licensing to go to regulating ESRD facilities. With the proposed budget, this money for regulating

Advanced Practitioners: An Important Member of your Kidney Care Team

by Sue Cary, RN, MN, NP, CNN

You see many people in the Hemodialysis unit or in the Peritoneal Dialysis clinic. You know your patient care technician, your nurse and your doctor, but you may not know some of the other very important caregivers in your facility that are often part of the health care team taking care of you! They go by many different names: Physician Assistants (PAs), Nurse Practitioners (NPs) and Clinical Nurse Specialists (CNNs). Collectively, they are referred to as Advanced Practitioners (APs), and they work with your kidney doctors to make sure you receive the best possible medical care. The APs have special training and have passed national tests. They can make changes to your dialysis prescription, refer you to other health professionals, and write prescriptions. The AP works under the direction of your kidney doctor.

These APs are most often found doing the weekly rounds at the dialysis units. Most of them come to the dialysis unit regularly (can be 1 to 3 times a month). They review the dialysis orders (directions that tell the nurses how to set the dialysis machine for you) and make any needed changes. They review your lab values and may change your orders. They look at and adjust your dry weight (target weight) and also work with you in taking care of your dialysis access and monitoring any changes in the flow or the look of the access.

APs make rounds and adjust prescriptions for peritoneal dialysis patients. You may see them at the nighttime dialysis units, on home visits for bed-bound patients, or at the local nursing home dialysis unit. They may also see you and take care of you at the hospital dialysis units. Most of them are also “on-call”

for your dialysis unit. When the nurses have a problem or a question, they may call your AP. APs help with the care plan meeting, the time when your entire kidney team (your advanced practitioner, nurses, dietitian, social worker and nephrologist) all get together to discuss your care. They often are who you turn to when you have general health questions which do not involve your kidneys. They know about heart disease and birth control, thyroid disease and diabetes, colonoscopies and kidney transplant...the list goes on and on.

The NP, PA or CNN is there to help you with your kidney disease, medicines, or any part of your treatment.

Special thanks to Jane S. Davis, RN, CRNP and Kim Zuber, PA-C, MSPS in their assistance in providing information for this article.

DPC State Events

On September 28 and November 9 of last year, Dialysis Patient Citizens (DPC) hosted first-of-their-kind End Stage Renal Disease (ESRD) Summits in Huntington Beach, CA and Austin, TX respectively. These events highlighted the benefits that expanded access to home dialysis could have on patients' quality of life, as the well as the financial benefits to each state if patients become better educated about their dialysis options.

Each event brought together patient speakers who offered their personal dialysis experiences, practicing nephrologists and clinicians who offered clinical data and public policy officials



Texas State Representative Elliot Naishtat

who spoke about California and Texas public programs and legislation. Noteworthy speakers included California state Senator Curren Price, Regional Director of Centers for Medicare Services Herb Schultz, Texas state Representative Elliot Naishtat and Texas

DSHS Kidney Health Care Program administrator Lisa Genna.

In addition to these ESRD Summits, DPC recently hosted a “Kidney Health and Disparities” awareness event, also in Austin, TX, on March 14, 2011. The event brought together members of the Texas state Senate Hispanic Caucus to discuss kidney health disparities among minority populations and focused on increasing patients' access to options in their care.

We would like to thank our co-hosts DaVita and Baxter for helping us hold these events, which highlighted the benefits of expanding kidney disease awareness and helped states keep the needs of kidney patients in mind as they work to address budget shortfalls.



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