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THE KIDNEY CITIZEN

A publication of Dialysis Patient Citizens (DPC) Education Center



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PRESIDENT'S MESSAGE



I want to thank you for your continued support of Dialysis Patient Citizens (DPC) Education Center and our efforts to educate kidney disease patients to help improve their quality of life. At the same time, I want to give a special thanks to all of you who went one step further in supporting our affiliate organization Dialysis Patient Citizens by lobbying your state and federal policy makers last year to help us elevate the patient voice. Through your dedication and hard work, whether it be by coming to D.C. as a volunteer advocate or calling your Members of Congress to reiterate the concerns of dialysis patients, we were able to ensure policy makers heard our voice. It is imperative that in 2017 – and beyond – we continue to work together to protect kidney disease patients' access to quality affordable healthcare.

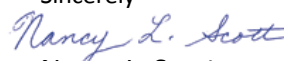
As I mentioned, with your assistance in 2016, we were able to secure huge victories for dialysis patients. First and foremost, last year we were able to finally get legislation enacted which will ensure dialysis patients are able to enroll in Medicare Advantage (MA) plans if they so choose. The 21st Century Cures Act was approved by Congress on December 7, 2016 and signed into law on December 13, 2016. This legislation, which addresses funding for the National Institutes of Health and makes regulatory changes to the U.S. Food and Drug Administration, also included a provision that would allow end-stage renal disease (ESRD) patients to choose MA plans starting in 2021. This is great for dialysis patients as MA plans often include benefits that are not offered in traditional Medicare, including case-management services that help to assess patients' needs, set health goals and provide ongoing support to patients. The MA program also limits a patient's out-of-pocket costs to \$6,700 per year, while Medicare beneficiaries with ESRD can face cost sharing of \$15,000 per year or more.

We also made big strides in elevating the importance of care coordination for dialysis patients. In June, bipartisan legislation was introduced to expand access to coordinated care for patients with ESRD. The Dialysis Patient Access to Integrated Care, Empowerment, Nephrologists and Treatment Demonstration (Dialysis PATIENTS Demonstration) Act would establish a demonstration program in which interdisciplinary teams provide holistic care to patients with ESRD under the leadership of a nephrologist. While this bill has not yet become law, we look forward to working with Congress on ways to further increase care coordination to improve patient care.

Having made such progress last year, we are now looking ahead to work for this year. Two main priorities once again focus on ensuring ESRD patients have access to affordable quality care. We will be working with our friends at DPC to ensure ESRD patients covered under Medicare have the ability to access a Medigap plan. Medigap policies are standardized, private insurance policies that cover costs not covered by Medicare, such as copayments and deductibles. We also want to protect kidney failure patients' ability to purchase private health insurance. With Congress looking to replace the Affordable Care Act (ACA), we need to make sure they preserve ESRD patients' access to private, and not just public, health plans and that these plans are affordable or allow patients to use charitable contributions to pay for them.

With so much going on in the healthcare world this year, be it replacing the ACA or reforming Medicare and Medicaid, we will once again be reaching out to you to ensure the voices of dialysis patients are being heard. It is vital we work together to protect access to quality care for all ESRD patients and I hope we can once again count on your support. ●

Sincerely



Nancy L. Scott

DPC Education Center Board President



A Peek at Upcoming Events

By **Kathi Niccum**, Ed. D.

As the new Education Director for the DPC Education Center, I bring years of experience both working with people who have chronic kidney disease and developing educational resources and programs. Even with my experience, though, I am always interested in hearing from you to learn what topics interest you and what type of information is still needed. We also appreciate all of you who participated in the DPC membership survey and shared your interests with us. Your voice is important to us in all that we do!

The topics that we plan to cover this year include items that you and various kidney patient committees have deemed important to kidney patients. And, we'll include additional subjects that have been in the news. In addition to the ongoing task of updating our web site (www.dpcedcenter.org), we will produce The Kidney Citizen four times in 2017 (we welcome your articles), and we will offer free monthly

educational sessions, such as, webinars that you can access through your computer, tablet or smartphone. Or, you can just listen to the sessions on your phone.

Some of you may be wondering what a webinar is. It is a combination of the two words – web and seminar. It is a way that people can gain information through a presentation, a class, or an information-gathering session over the internet. It might include a presentation with slides, a video, or some people might just listen to the session over their phones. During a live webinar, you can ask questions during the event.

We often have the educational sessions recorded so that you can listen to them later if you are unable to attend the session or if you want to listen to them again. You can access past recorded webinars by visiting www.dpcedcenter.org/education-seminars.

2017 SCHEDULE:
EASTERN STANDARD TIME

TOPIC

PRESENTER

4-12 AT 3 PM

RUSH[ED]- Living with Dialysis

Touring with Pitbull while on dialysis? David Rush didn't let his diagnosis stop him!

David Rush

David Rush is a platinum selling recording artist signed to Pitbull's label, Mr.305 inc. As a patient in center, home, transplant recipient and back to home David Rush truly knows what it means to live life while on Dialysis. As a Nxstage patient David took his machine on a 40 city world tour in 2009 with Pitbull as an opening act. In present-day David Rush is now married with two children after a successful transplant in November 2010 that was given to him by his brother. David went back to Home Hemodialysis in January 2017 when his transplant failed. He works now as a patient consultant and Advocate for Nxstage Medical while all still pursuing his dreams on a daily basis.

5-11 AT 3 PM

Depression and Kidney Disease: Coping with a Long-Term Illness

Life with a chronic illness can be a bumpy road with many hurdles to navigate along the way. Emotional ups and downs due to stress are common among people undergoing dialysis treatments. If you find yourself experiencing issues of depression, anxiety, fear and anger, you are having a normal reaction to stressful circumstances. And you are not alone in this. Yet, despite being surrounded by other people, a sense of isolation may arise. There are ways to address these normal feelings. This webinar will present some guidelines for coping with the array of emotions common to life with dialysis and chronic illness. You also will learn positive ways to manage the stress associated with a chronic illness.

Dr. Maureen O'Reilly-Landry, Ph.D. is a licensed psychologist and a member of the clinical faculty of Columbia University Medical Center. She is former Director of Psychological Services for Apollo Healthcare, a dialysis company dedicated to the psychological well-being of patients and their families. Dr. O'Reilly-Landry has worked individually with many dialysis patients, both in-center and as part of a home hemodialysis dialysis program, and has run support groups for dialysis patients. She writes about the psychological aspects of dialysis and medical illness and gives talks to groups of patients and staff. She edited the book, A Psychodynamic Understanding of Modern Medicine: Placing the person at the center of care (Radcliffe, 2012). Dr. O'Reilly-Landry maintains a private practice in New York City and is available for consulting to dialysis staff to teach them how to enhance the emotional well-being of patients and their families.

6-21 AT 3 PM

Travel Tips, Travel Sips, Travel Grub: Vacationing with kidney disease doesn't mean you have to take a vacation from health.

Learn how to successfully stay on track with doable and practical traveling tips.

Jessiana Saville, RD, MS, RDN, LD, CSR is a registered dietitian who has a blog and web site at www.kidneygrub.com

*Topics are subject to change please visit www.dpcedcenter.org for most current schedule

How to join:

visit www.dpcedcenter.org/education-call to be automatically redirected to the meeting room or you can dial in by phone at 1-877-399-5186 conference code: 433-459-5474

This May, Fill Out Your Patient Experience Survey and Send It In!

By **Jack Reynolds**, Dialysis Patient, Dialysis Patient Citizens (DPC) Board President

The month of May brings many familiar seasonal changes. For dialysis patients, May is one of two months each year that you are likely to receive in your mailbox Medicare's CAHPS survey that asks you to rate the care delivered by your dialysis center. This spring we are urging patients to make a special effort to open this envelope, fill out the survey, and mail it back (or answer the questions by phone, if you receive a phone call). Let me explain what the survey is for and why your participation in it is so important to maintaining the quality of dialysis care.

Medicare uses CAHPS surveys to rate patients' experiences with their health care providers. The different versions of the surveys also go to randomly selected patients discharged from hospitals, and also to health plan enrollees.

For ESRD patients, these surveys have two special uses:

Survey responses are now being counted by Medicare's ESRD Quality Improvement Program toward a clinic's total QIP score. That means there is money at stake for a clinic with low patient satisfaction.

Beginning in October, survey responses will be reported on Medicare's Dialysis Facility Compare website. That means that current patients are in a position to make recommendations to new patients on which center they choose to dialyze at. Before I go any further, let me emphasize an important fact about these surveys: they are 100% confidential. Your answers are anonymous and go directly to Medicare. Nobody at your clinic will know how you answered.

As you can imagine, the small size of a dialysis clinic poses some

complications for surveys relative to a hospital or health plan that serves thousands of people. To maintain confidentiality, Medicare does not report scores for clinics if they get fewer than 30 responses. For smaller clinics this means a large proportion of patients need to respond in order to get a rating. Unfortunately, the patient response rate is only 31%, and it's declining. (Medicare officials say declining response rates are a problem with all surveys, not just this one.)

Because there must be at least 30 responses from a facility for the results to count, results are only going to be available for 40-45% of facilities. That means that come October, your facility probably won't have a rating posted on the Dialysis Facility Compare website.

I know that responding to a survey is probably not your preferred way of spending free time. Nevertheless, I always answer and return this survey both times I get it each year. It typically only takes 10-15 minutes.

At Dialysis Patient Citizens, our mission is to give voice to patients, and these surveys are a very direct way of making your voice heard. It is not just about your care and your clinic, but about contributing to the overall improvement of our entire health care system. We know that once hospitals stood to lose money over poor patient satisfaction, they made immediate changes. The number one complaint was noise, and now hospitals make a special effort to keep their facilities quiet! I don't know what kind of improvements are potentially in store for dialysis facilities, but I'm confident that your response to the survey can only help. ●

The background of the page is a composite image. The top half features a microscopic view of numerous green, rod-shaped bacteria, some of which are clustered together. The bottom half shows a close-up of a person's hand being washed with white, foamy soap. The hand is positioned in the lower right corner, with the fingers slightly curled. The overall theme is hygiene and infection prevention.

Catheter Related Bloodstream Infections: Patient Basics

By **Michael Allon**, M.D. Department of Medicine, Division of Nephrology ,
The University of Alabama at Birmingham

More than 1.5 million people around the world are treated with hemodialysis, a procedure that involves filtering the blood to remove wastes, extra salt and water when the kidneys cannot perform these functions. For these people, hemodialysis is a lifesaving procedure. At the same time, it is important to be aware of preventable complications that can compromise the health of kidney patients like catheter related bloodstream infections. Dialysis patients are over 100 times more likely than other people to get a bloodstream infection from methicillin-resistant *Staphylococcus aureus*, a common antibiotic resistant bacteria¹, so it's worthwhile to learn more about these infections and how they happen.

Catheters frequently have bacteria coating their inside surface. From time to time, the bacteria inside the catheter are released into the patient's bloodstream causing serious infection. Every time a kidney patient comes to dialysis, they have to expose the catheter to the skin and needles. Each time there is the possibility of introducing an infection into the catheter, and this happens three times a week. The longer you have the catheter, the greater the risk of infection.

These infections can be small nuisances or become life threatening if allowed to spread throughout the body. Twenty-one to thirty-one percent of hemodialysis patients with certain bloodstream infections can develop complications such as an infected heart valve (endocarditis) or bone infection (osteomyelitis)². Patients with an *S. aureus* infection could require hospitalization for an average of 9-13 days.²

1 <https://www.cdc.gov/media/releases/2013/p0513-dialysis-infections.html>

2 <http://www.cdc.gov/dialysis/PDFs/collaborative/Intro-to-cdc-dialysis-collabroative.pdf>

The good news is that there is a lot that patients and caregivers can do to prevent these infections from happening. In April 2009, the Centers for Disease Control launched a collaborative project with dialysis centers across the United States to prevent bloodstream infections among dialysis patients. Guidelines were developed and implemented which led to a 32% decrease in overall bloodstream infections and a 54% decrease in vascular access-related bloodstream infections among dialysis patients.³ There are precautions you can take at home as well:

- Keep your catheter bandage clean and dry. If your bandage gets wet, notify your healthcare professional.
- Check your vascular access daily for signs of infection such as redness, pus and swelling. Notify your healthcare professional if you notice these signs.
- Make sure that all healthcare providers clean their hands with soap and water or alcohol-based hand sanitizer before and after caring for you or your vascular access site. If they think they did, ask them, don't be afraid to speak up.
- Follow your healthcare team's recommendations regarding diet, medication and dialysis treatments. Consume adequate amounts of protein, calories and nutrients to build your body's immune system.

In addition, there are several pharmaceutical products that may be useful in preventing catheter related bloodstream infections. These include application of an antimicrobial ointment to the exit site of the catheter and infusing an antimicrobial solution into the catheter lumen after a dialysis procedure.⁴

Researchers are exploring new tools to help prevent these infections. A number of doctors around the country are participating in a trial called LOCK-IT-100, testing whether an investigational new drug solution called Neutrolin could help to safely prevent catheter-related infections and blood clots when instilled into your central venous/dialysis catheter. More information about this trial and other ongoing studies to prevent and treat catheter related bloodstream infections can be found at www.clinicaltrials.gov.

Researchers, doctors, nurses, patients and caregivers can do a lot to prevent catheter related bloodstream infections. As these groups work together to refine techniques, we can make these infections more rare each year. ●

³ <http://www.nephrologynews.com/dialysis-bloodstream-infections-significantly-reduced-by-following-cdc-guidelines/>

⁴ [http://www.ajkd.org/article/S0272-6386\(04\)01078-9/abstract?cc=y](http://www.ajkd.org/article/S0272-6386(04)01078-9/abstract?cc=y)



Travel Doesn't Stop When Dialysis Starts

By **Andrew Conkling**, Hemodialysis Patient, DPC Education Center Board Member

Traveling while on dialysis can seem like a scary thought, but it doesn't have to be. Traveling can be very helpful to the psyche of a dialysis patient. Seeing family and friends is important, as well as taking relaxing vacations. You may also want to see new places that you may not have had the chance to visit before you were on dialysis. There should be something good to come out of dialysis, so look for it wherever you can.

Take a look at your bucket list: is travel a big part? If so, time to get to it! If nothing else, traveling allows you to see how other clinics are organized, which can help you understand some of the things that you see in your home clinic. You may even be able to make a few suggestions to your home clinic that you found worked better for you. I've been on in-center hemodialysis dialysis for twelve years now. With the help of an excellent social worker and a wonderful clinic staff I was encouraged to continue traveling as I had done before starting dialysis. It's very important to most patients to have as close to the same social or work life as they had before they started dialysis. I regularly take trips to the Gulf of Mexico or to the upper mid-west to visit family. These trips are long enough that they would not be possible to take without making arrangements for treatments where I will be going. I have also had the opportunity to travel to San Francisco and Washington D.C. with Dialysis Patient Citizens (DPC) to advocate for dialysis patients' rights on Capitol Hill, something that I wouldn't have been able to do if I could not travel.

I was of course apprehensive the first time. I started with short trips that only required one treatment, and locations that were close to home just in case. However, in short order I was taking longer trips both in distance and time. I've been in



clinics of all sizes and locations and the differences between clinics can be drastic. Being proactive in your care is the key. The more you know about your own treatments, the easier time you will have.

Now that we have the "why" taken care of, let's move on to the "how." Most clinics, no matter the company that owns it, have a social worker and a unit secretary. These two people are normally the people that will help you the most as you start your journey. In addition, both DaVita and Fresenius, the two largest dialysis providers, have websites and toll free numbers you can call to get help planning your travel. You may also find it helpful to check out the dialysis facility compare tool from Medicare.gov. This can be very helpful when deciding what clinic you may want to use, --but remember the star ratings are not the only indicator of care quality. Don't be alarmed if your destination has only one or two star-rated facilities. Use the ratings as a guide to ask questions before receiving treatment.

Decide where it is you want to go.

This may seem simple enough but some consideration must be made.

The bigger the destination, the



more choices you may have in where you receive your treatments. Also, if your destination is a tourist area, you may need to be flexible on where and when you receive your treatments. Tourist areas have large numbers of traveling patients, and while they try their best to fit your needs, you may need to bend some as well. For example, you may normally receive treatments on Monday, Wednesday and Friday early in the morning. If you are traveling, you may have to receive treatment on Tuesday, Thursday and Saturday in the afternoon. To avoid complications, make sure that whomever is helping you make the arrangements is clear on what days you are traveling to and from your destination so they may work with the destination to fit you in the best clinic for your needs.

Relationships with your home clinic staff and physicians are also very important. Your clinic staff and doctor will need to have your records sent to the travel clinic ahead of time. Most clinics that accept patients who are traveling will require at least a week's worth of flow sheets (the document your clinic uses to track your treatment information). They will also help to make sure that you receive any shots or tests you may need. Some states or clinic areas require that a traveling patient must have a tuberculous skin test within a year of travel. Your home clinic can administer that test and make sure records are sent to the travel clinic.

Travel can be a fun and a safe proposition if you plan and work together with your staff. Remember, it should be about you and your well-being. Staying informed during your normal treatments is very helpful so you know when something is not right while traveling. However, above all else, have fun! ●

Additional Resources for Travel:

Davita Travel Support-<https://www.davita.com/services/travel-support> or 1-800-244-0680

Fresenius Travel Services- <https://www.freseniuskidneycare.com/travel-services> or 1-866-434-2597

Dialysis Facility Compare- <https://www.medicare.gov/dialysisfacilitycompare/>





The Swiss Army Knife of the Plant Kingdom: The Coconut

by **Jessiana Saville**, RD, owner of kidneygrub.com

There are few foods as versatile as coconut. It is edible, drinkable, and wearable. It is currently one of the hottest food and health trends buzzing through grocery stores, restaurants, blogs, books, and magazines. It is touted as being able to whiten teeth, fight infection, clear acne, and solve a myriad of chronic diseases. There are so many health claims surrounding coconut at this time that it seems to be the holy grail of food. Food manufacturers have taken note of this.

Coconut is no longer just the packages of sweet white flakes in the baking aisle or your tropical drink next to the pool in the Bahamas. Coconut now can be readily found in all stores in a dizzying variety of products. Coconut sugar for your coffee? Check! Coconut creamer, too? Why, yes. How about some coconut chips for lunch with a coconut butter and jelly

sandwich and a cookie made from coconut flour? Yes, yes, and yes. Oh, and thirsty? We have coconut water, coconut milk, coconut milk beverage, and even coconut soda.

For patients with kidney disease, coconut is generally found on the “limit” list due to the high potassium content of more traditional coconut products made from the flesh or water (aka shredded coconut or coconut water). There are, however, a few coconut products that can be enjoyed. And, of course, a slew of new products to watch out for!

High Potassium Coconut Products – Don’t let the health hype give you hyperkalemia!

Bad news out of the way first! The potassium in coconut is found in the flesh and fluids of coconuts. The following chart shows some common coconut products and their potassium content. If you’re watching your potassium, these items

should be consumed in limited quantities. That doesn't mean none, but it does mean watching portion size. Culinary tricks, such as toasting your coconut, can help enhance the flavor and decrease the need for a large portion.

COCONUT PRODUCT/ SERVING SIZE	MILLIGRAMS OF POTASSIUM
SHREDDED COCONUT, 1 CUP	434 MG
COCONUT WATER, 1 CUP	404 MG
COCONUT MILK, 1 CUP (THE KIND IN A CAN)	467 MG
COCONUT CREAM, 1 CUP	780 MG
CREAM OF COCONUT, 1 CUP	~400-450MG
COCONUT BUTTER	N/A – THIS PRODUCT IS JUST PULVERIZED COCONUT FLESH SO IT IS SAFE TO ASSUME IT IS VERY HIGH IN POTASSIUM
COCONUT FLOUR, ¼ CUP	367 MG

Can-Do Low-Potassium Coconut Products for People with Kidney Disease:

Coconut Milk Beverage – milk replacement: Coconut milk beverage is marketed as a milk substitute. It should not be confused with coconut milk from the can (which is very high in potassium). It can be found nestled nicely among its other rectangular carton milk alternative friends, usually in the “organic” or “natural” aisle in a store. The So Delicious® coconut milk beverage rings in at 45 calories, 40 mg of potassium (compared to 366 mg in a cup of milk), and 15 mg of sodium (woohoo!). It does contain some phosphate additives due to the calcium and magnesium fortification, but otherwise fits in a kidney-friendly diet nicely. While coconut milk beverage fits the renal nutrition profile, flavor-wise it is disappointing. Despite my most vigorous shaking of the carton, the coconut flavor is very mild, almost non-existent. However, for a recipe calling for coconut water, this could be a reasonable substitute.

Coconut Sugar - Coconut palm sugar or coconut sugar is a variety of sugar made from sap that is extracted from the coconut tree. It has no flavor resemblance to coconut so if you're after a coconut flavor, coconut sugar won't do much for your recipe. Health-wise, it has the same carbohydrate profile as regular cane sugar although it is touted as having a low glycemic index. This means, if you're diabetic, it still will raise your blood glucose levels like sugar. It has the same potassium and phosphorus as regular sugar (which per 1 tsp serving is none),

so it is a green-light coconut product for those with kidney disease, though there doesn't seem to be any extra benefit to using it over other sugar products.

Coconut Oil: Coconut oil is a fat. It is specifically high in saturated fat, which has kept it on the “limit” list of many health organizations. There is a good deal of scientific debate about the whether or not coconut oil is “healthy” or not. This is a topic for another day. Nutritionally, coconut oil has no potassium, phosphorus, or sodium making it a reasonable choice for people with kidney failure. As with all fats, it should be used in moderation.

Coconut Extract: If you love coconut and have been limiting it due to its potassium content, then coconut extract is something to begin stocking in your cupboard. Like all baking extracts, a small amount (as in <1 tsp) goes a long way in creating a potent flavor. Coconut extract can be used in a variety of recipes to cut back

Coconut Milk Substitute: 1/3 cup rice or almond milk, 1 teaspoon cornstarch, 1/2 teaspoon coconut extract, 2 teaspoons oil. Combine milk, oil, and cornstarch in small saucepan. Stir constantly over high heat until mixture boils and thickens. Immediately pour into small bowl; stir in extract. Cool.

Great for use in curries or other sauces.

on coconut content while still maintaining a wonderful coconut flavor. It has no potassium or phosphorus in it.

Coconut Soda: Most coconut sodas on the market are





carbonated water with added flavor. As long as the product isn't a "sparkling coconut water," then this can be a great choice. Refresco Goya makes a coconut soda that is not only tasty, but low potassium, and free of phosphate additives.

How to make coconut a "can-do" food:

Love coconut? People with kidney failure can make coconut work for them with creativity. Coconut shrimp curry with a tall glass of sparkling coconut water and a slice of Aunt June's famous coconut cake is probably out. But, how about sprinkling 1-2 tablespoons of toasted coconut flakes on your oatmeal? Yes and double yes, since toasting makes the flavor really shine. Making a cake using coconut extract instead of vanilla extract? Absolutely. Mixing up a refreshing afternoon cocktail using coconut milk beverage, a touch of gin, lemon-lime soda, mint and strawberries? Most definitely. Making the renal diet work with coconut is definitely possible with a little culinary creativity.

Kidney Friendly Coconut Cake!

INGREDIENTS

For the Cake:

- 3 cup all purpose flour
- 2 cup sugar
- 1 Tbsp baking powder*
- 1 cup rice milk
- 1 cup butter*
- 2 tsp coconut extract
- 5 egg whites
- 1/4 cup coconut flakes, optional for garnish

For the Icing:

- 2 tablespoons all-purpose flour
- 1/2 cup rice milk
- 1/2 cup butter, softened
- 1/2 cup sugar
- 1 teaspoons coconut extract

INSTRUCTIONS

1. Preheat oven to 350° and grease 2 (9 inch) round cake pans. Line with parchment paper. Grease and flour parchment paper. Set aside.
2. Allow eggs whites to sit out at room temperature for 30 minutes before using.
3. In a small bowl, mix milk and coconut extract together. Set aside.
4. In a medium bowl, beat butter until creamy. Add sugar. Mix until light and fluffy. Add flour and baking powder, into the butter mixture, alternating with the milk and coconut mixture. Set aside.
5. Beat egg whites until stiff peaks form. Fold gently into cake batter. Pour into prepared pans. Spread with spatula to cover pans completely with batter.
6. Bake at 350° for approximately 30 minutes or until wooden tooth pick inserted in the center comes out clean. Place on cooling rack for 10 minutes then removed from pans, set cakes on cooling rack and discard parchment paper.
7. For the Icing: In a medium-size saucepan, whisk the flour into the milk until smooth. Place over medium heat and, stirring constantly, cook until the mixture becomes very thick and begins to bubble, 10-15 minutes. Cover with waxed paper placed directly on the surface and cool to room temperature, about 30 minutes.
8. In a large bowl, on the medium high speed of an electric mixer, beat the butter for 3 minutes, until smooth and creamy. Gradually add the sugar, beating continuously for 3 minutes until fluffy. Add the coconut and beat well.
9. Add the cooled milk mixture, and continue to beat on the medium high speed for 5 minutes, until very smooth and noticeably whiter in color. Cover and refrigerate for 15- 20 minutes. Use immediately!
10. Toast coconut flakes in oven for 7 minutes. Garnish with toasted coconut flakes.

***Recipe Notes:** To decrease phosphorus in your recipe use Ener-G Baking Powder substitute or $\frac{3}{4}$ tsp cream of tartar +1½ tsp baking soda.

*To decrease the fat and calories in the recipe you may also replace $\frac{1}{2}$ the coconut oil with applesauce

Nutrition Facts: 1/10 of cake

656 kcal, 85 gm carbohydrates, 32 gm fat., sodium 44mg, 6 gm pro, potassium 93 mg, phosphorus 74 mg,

*This is not a low calorie or low carb recipe. For patients with diabetes, consider a small portion or limit the amount of icing applied to the cake. ●

Insights Into Dialysis Patients From DPC's 2016 Annual Patient Survey

By **Jackson Williams**, Director of Regulatory Affairs and General Counsel, Dialysis Patient Citizens

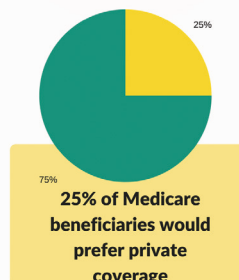
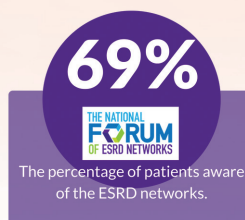
DPC conducts an annual survey of dialysis patients to guide our public policy priorities, benchmark your access to care, and identify challenges to living with end-stage renal disease. We frequently report findings to you in our newsletters, to the news media, and to policymakers in Washington DC and state capitals. The most recent DPC survey of 510 dialysis patients was conducted by research firm Ipsos during September 2016.

In general, the average DPC member has been on dialysis for 6.7 years, and 19% have been on dialysis for more than 10 years. One-third of our members who have not received transplants are on a transplant waiting list.

Here are our findings on specific topics covered in this past summer's survey.

Patient Engagement

A big trend in health care today is “consumerism,” in which patients are given more information about providers and urged to compare them based upon various quality indicators. Are dialysis patients—who interact with the health care system much more frequently than other consumers—more engaged in this aspect of their care? Our survey found not. The Medicare program has created a website called Dialysis Facility Compare, which reports several quality measures. Our survey found that only 11% of ESRD patients have gone to this website. This is the same percentage as members of the general public who have looked for online ratings of doctors and hospitals. Most of the ESRD patients who looked at the Dialysis Facility Compare website were simply curious about how their facilities compared to others, or were looking for



a facility to use while traveling. We found only a handful of people who used the tool to find a new clinic.

The year before, our survey asked dialysis patients if their doctors made their medical records available to them through an online “patient portal.” We found that ESRD patients use these portals at the same rate as consumers overall. One area where we believe ESRD patients are significantly more engaged than other patients is in awareness of Medicare complaint processes. Our survey found that 69% of ESRD patients know what the ESRD Networks are. There is no comparable data of non-ESRD Medicare beneficiaries’ awareness of the Quality

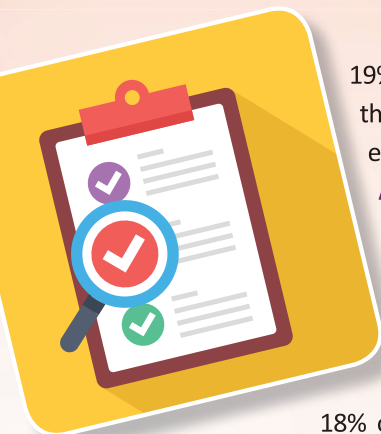
Improvement Organizations, the counterpart of ESRD Networks, but it is generally understood that public awareness of Medicare grievance procedures is very low.

Economics of Living With ESRD

While 54% of ESRD patients were employed at the time their kidneys failed, afterward only about 7% work full-time and another 5% work part-time. Full-time work is higher among patients on peritoneal dialysis (18%) or home hemodialysis (11%). Seventeen percent of transplant patients report working full-time.

Most patients report their employment status as “retired” (54%). Among reasons reported for being out of the workforce are not feeling well enough to work (50%), perceived inability to juggle dialysis treatments and a work schedule (28%) and fear of losing social insurance benefits (19%).

Thirty-five percent of ESRD patients reported receiving Social Security Disability payments. With regard to health care,



19% reported receiving assistance from the American Kidney Fund and 23% were enrolled in Medicaid.

Access to Oral Medications

Eighty-four percent of patients are prescribed an oral medication. Asked if they were unable, within the past 12 months, to obtain a prescription medication a doctor believed necessary,

18% of ESRD patients reported difficulty. The comparable percentage for the general public is 3%. The disparity may be related to the greater health care needs of dialysis patients, and to doctor-prescribed nutritional supplements that are not covered by Medicare Part D.

Satisfaction with Insurance Coverage

The DPC survey finds that most ESRD patients' preferences for insurance type match with their current coverage. However, a significant portion of patients would like to be able to choose another type of coverage.

While 74% of respondents have Original (fee-for-service) Medicare as their primary insurance, only 47% say that Original Medicare is their preferred choice. 25% of ESRD Medicare beneficiaries would prefer private options such as ACA coverage or employer coverage. 5% would like to enroll in Medicare Advantage.

Not surprisingly, patient views about Medicare and private insurance differ according to whether the patient's state guarantees access to Medigap coverage. Patients in states where Medigap is available to Medicare beneficiaries under 65 are more likely to express satisfaction with their Medicare coverage. Meanwhile, in the 25 states where Medigap is not available, patients are 50% more likely to express satisfaction with their commercial coverage, and more likely to desire the ability to enroll in Medicare Advantage.

We asked several questions from the Consumer Assessment of Health Plan Survey (CAHPS) to gauge patients' relative satisfaction with their coverage, which found that patients with commercial health insurance are more satisfied with their coverage than those enrolled in Medicare or Medicaid:

- A greater proportion of commercially insured dialysis patients rate their health insurance as the "best health insurance plan possible" than do those enrolled in Medicare.
- Medicare beneficiaries are more than twice as likely as private health plan members to report having trouble getting health care that they wanted or needed.
- Medicare beneficiaries are more likely than private health plan members to report difficulties in getting the specific medication they need, difficulty getting someone on the phone to answer questions, and delays in receiving care or treatment.

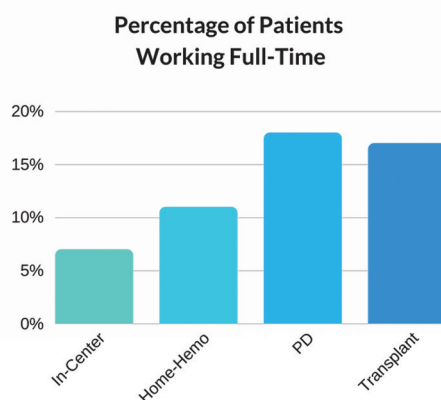
Home Modalities

Our surveys find that while about 74% of ESRD patients are informed about the option of home modalities, only 26% seriously consider it. For those within the 46 percent gap of patients who were informed but did not consider it, the most frequently cited (45%) reason for not considering it was the feeling of safety in a professionally-staffed clinic. But 37% of patients reported that they could not consider home hemodialysis because they had no one to help them.

Many in-center dialysis patients—about 72%—say they have made up their minds to continue receiving treatment at the clinic. But 20% say they would be willing to dialyze at home if they had a care partner. Among survey respondents who previously dialyzed at home but now receive treatment in-center, 18 percent stopped home dialysis because of care partner issues.

There is a gap in information given to ESRD patients about home dialysis related to their type of insurance

coverage. For home hemodialysis there is an information gap of 17 percentage points between patients covered by Medicare (77%) and Medicaid (60%). While 68% of ESRD patients overall are informed about peritoneal dialysis, the information gap is 14 percentage points between patients covered by Medicare (70%) and Medicaid (56%). And while 72% of ESRD patients overall are informed about transplantation, there is a 12 percentage-point information gap between patients covered by Medicare (76%) and Medicaid (64%). ●





In Harmony with Your Health through Music: Diabetes and More

By **Susan E. Mandel**, Ph.D., MT-BC

It is likely that you or someone close to you is living with diabetes because this serious health problem is on the rise in the U.S. and all around the world. We completed a three-year study of music therapy with people with diabetes at Lake Health in northeast Ohio and learned that participation in music therapy along with diabetes education can help you lower your blood pressure. "How?" you might be wondering. The answer is related to listening to preferred music to energize and relax you.

- What music excites you and gets you moving? Think about it and make a list of a few of your favorite energizing musical selections.

Try listening to your favorite energizing music to help motivate you to move and be active. Feel the beat and move your body in sync with the music. Tap your foot, clap your hands, sway your body. Now consider ways that you can increase your activity level. It can be as simple as parking a little further from the door and walking a few extra steps, or pushing a lawn mower instead of riding one. Let the music move you!

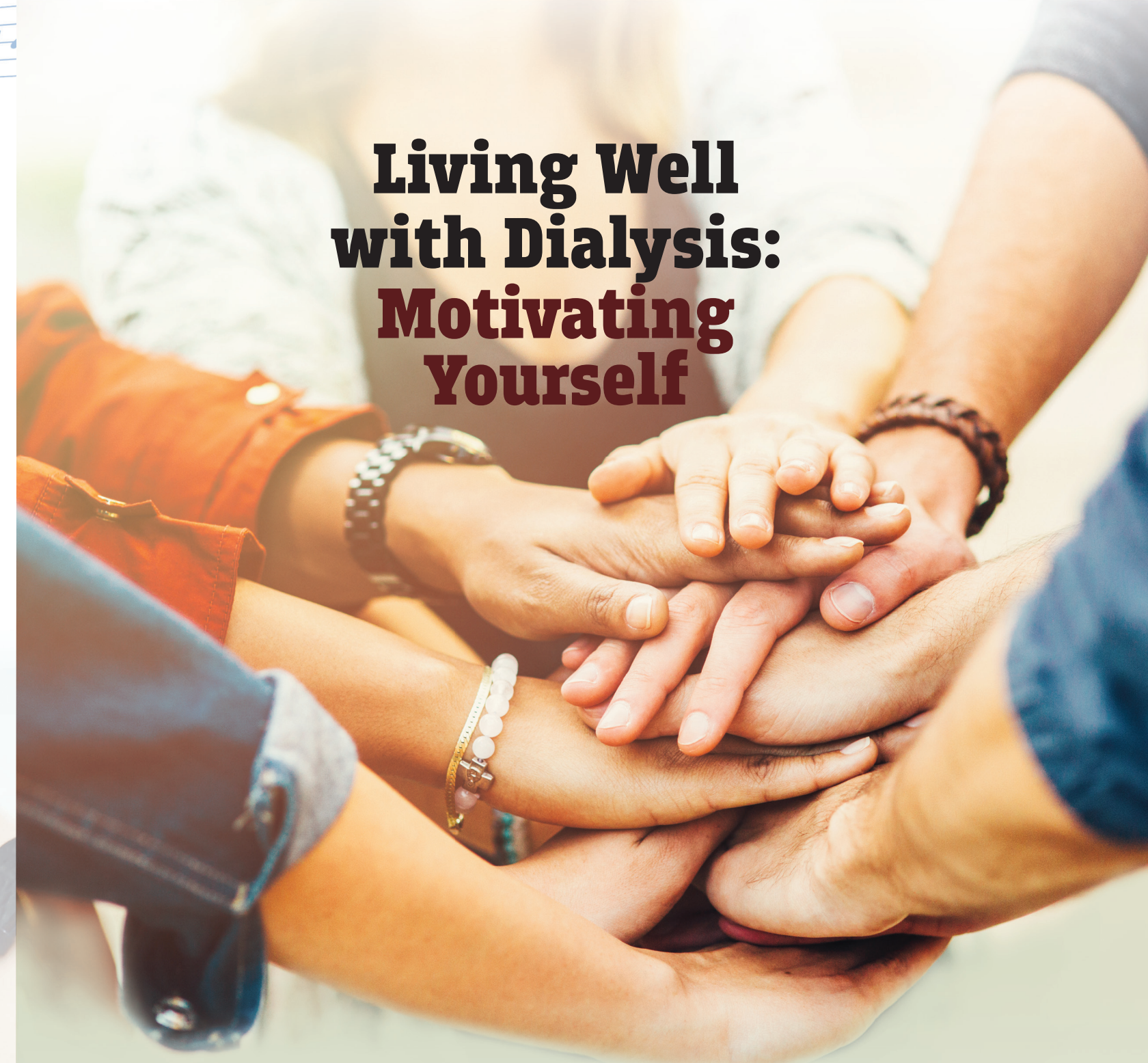
- Which music calms you down? Make a list of your favorite relaxing musical selections.
- Do you feel anxious before you go to your doctor to check in about your health? Do you experience stress at work and find it difficult to let it go? Do anxious thoughts keep you awake at night? These are all opportunities to listen to your favorite relaxing music. Take a few deep breaths as the music begins. Imagine that you are breathing in peaceful feelings and gently blowing out worry as you exhale. You may be surprised at the relief you experience after just a few minutes with your relaxing music. Once you experience how good it feels to let go with the music, you will probably want to listen more regularly.

Do you live with other health challenges? Do you want to learn more about how music can improve your health? I co-authored a self-help book with Dr. Suzanne Hanser, *Manage Your Stress and Pain Through Music*. This book, along with an accompanying compact disc recording, is available at many local libraries, as well as, for purchase online at various websites.

You may also want to connect with a board-certified music therapist who is a credentialed professional trained to provide evidence-based music interventions to help you manage your personal health. Music therapists work in many medical centers throughout the U.S. You can locate a music therapist in your area through the American Music Therapy website at: <http://www.musictherapy.org>

Karen was 60 years old when she participated in our music therapy study with patients with diabetes. Her systolic blood pressured dropped over 30 points from the day she started music therapy until she finished the program three months later. She talked about how music improved her well-being. *"Music therapy helped me realize the importance of music and how I can benefit from learning to relax while listening. I applied the deep breathing and mindset of being in a happy, warm, and relaxing environment. I haven't felt as stressed, even though there are a lot of stressful situations going on in my life right now. It helps me to stay focused and motivated and I will continue to enjoy all varieties of music while relaxing and exercising."* ●

Susan E. Mandel, PhD, MT-BC Dr. Susan Mandel is a board-certified music therapist, specializing in stress and pain management in medical settings. She works as a music therapy consultant to Lake Health, where she manages the music therapy program and researched music therapy in cardiac rehabilitation, diabetes education, integrative medicine, and the emergency department. Susan has also established two local music therapy hospice programs. Susan is on the faculty of the University of Phoenix School of Advanced Studies where she teaches research. Dr. Susan Mandel and Dr. Suzanne Hanser co-authored the book and accompanying CD, *"Manage Your Stress and Pain Through Music,"* published by Berklee Press. Susan and Daniel Kobiak recorded the CD, *"Harmony of Mind and Body: A MARI Experience."*



Living Well with Dialysis: Motivating Yourself

By **Teri L. Bourdeau**, Ph.D. ABPP, Clinical Assistant Professor of Behavioral Sciences and Director of Behavioral Health Services at Oklahoma State University

Whether you're new to dialysis or have been living with the routine for a while, it's easy to get stuck in a rut. Even if you feel like you have things under control, there might be areas of your routine that could use a reboot.

How do you know if you're stuck? One clue is to ask yourself if there are things you think are important that you're not doing. Maybe you have excellent eating habits, but don't exercise as much as you think you probably should. Maybe you never miss a dialysis appointment, but sometimes forget to take your pills.

When it comes to our health, few people do everything perfectly all the time. Most of us can find ways to do things a little bit better.

Unfortunately, you don't have control over the fact that you need dialysis. But you do have control over other aspects of your health. If you think of lifestyle changes as a long "to-do" list, they can easily feel overwhelming. But people who think of their sense of control as a gift are more likely to thrive.

Maybe you're ready to make changes today. Maybe you're just starting to think about making them in the future. Either



way, the first step to getting unstuck is to figure out why you're stuck. You may feel you don't have enough knowledge or information to make a change. Maybe you worry you don't have the skills or the support you need to do things differently. Maybe you're just not confident you can really change, and you're afraid to begin.

Once you understand your sticking points, consider sharing that information with your healthcare providers, psychologist, social worker, or other members of your treatment team. They can help you figure out the best ways to move beyond the logjam. Then you can start taking steps to tackle the goals that are important to you.

Lay the groundwork. Arm yourself with the tools you need before you start. Make sure you understand the medical reasons for making a change -- and how that change could help make your life better, both physically and emotionally. Enlist friends and family to support your lifestyle changes. If you believe something is important and you believe you can change it, you'll be more motivated to follow through.

Think about what motivates you. Some people make lifestyle changes in order to have more stamina or spend less time in the hospital. Some are motivated by the desire to see their grandkids grow up. Some just want to get their spouse to stop nagging them. It's helpful to make a list of pros and cons to clarify your reasons for making a change. Once you understand what you have to gain from a change, it's easier to make it happen.

Figure out what strategies work for you. You probably have a lot of experts in your life: physicians, nurses, dieticians, social workers, therapists. But you're the expert on you. Think about what works best to motivate you. Maybe you need people to check in with you frequently and hold you accountable.

Maybe you need rewards to encourage you to stick to your goals. Maybe you hate being told what to do -- or maybe you appreciate helpful suggestions. As you collaborate with healthcare providers and family members to set goals, it often helps to keep in mind that what works for other people might not work for you.

Set clear goals. When setting goals, experts recommend stating them in concrete, positive terms. "I'll exercise more" is a vague goal that's hard to achieve. It's almost always more effective to set specific terms for the goal, such as "I'll take a 20-minute walk each day." Instead of just saying you'll cut down on sweets, you might set a goal limiting yourself to, say, two desserts a week. The more specific you can be, the better.

Start low and go slow. When you make healthy lifestyle changes, it can be tempting to set big goals. For some people, big goals are inspirational. Usually, though, it's easier for people to break big goals into smaller steps. It can take time to establish a new habit, and the more we practice, the better we get. Think about setting a small, realistic target -- even something as minor as eating one extra serving of vegetables each day. Once that goal becomes a habit, it's easier to layer on new changes. You don't have to overhaul your life all at once to make progress toward a goal. Small steps can add up to big effects. By taking time to understand what's really important to you, and what steps will work best to lead you there, you'll set yourself up for success.

APA and DPC gratefully acknowledge Teri L. Bourdeau, PhD, ABPP, Clinical Assistant Professor of Behavioral Sciences and Director of Behavioral Health Services at Oklahoma State University, for her assistance with this article. ●



Dialysis Patient Citizens Wins Court Ruling Against Insurer Veto on ESRD Patients

By **Jackson Williams**, Director of Regulatory Affairs and General Counsel, Dialysis Patient Citizens

In a lawsuit filed by DPC against the Department of Health and Human Services, a federal court has blocked a regulation that would have given insurers veto power over ESRD patients' access to private coverage. The judge called the regulation, that could have forced dialysis patients off their current health insurance and jeopardized their access to care, "arbitrary and capricious."

In enjoining the regulation's enforcement, the U.S. District Court for the Eastern District of Texas held that the rule was 1) procedurally defective because HHS adopted it without first giving the public notice of it and seeking comment on it, and 2) "arbitrary and capricious" because HHS failed to consider the benefits of private coverage and ignored the disadvantages of adopting the rule.

The court concluded that the regulation cannot be

implemented because HHS "failed to consider the benefits of private qualified health plans and ignored the disadvantages of the Rule," including that "the rule would leave thousands of Medicare-ineligible ESRD patients without health insurance."

The court went beyond invalidating the rule on procedural grounds and questioned the policy itself.

"Congress has long recognized the importance of dialysis treatment for ESRD [end-stage renal disease] patients and has afforded patients the opportunity to elect coverage that best serves their needs," the opinion stated. The court added that, "For decades, ESRD patients have had the choice of selecting private insurance options over Medicare if those options better served their treatment needs. Private insurance is particularly attractive to ESRD patients with

families because Medicare does not provide coverage for spouses and dependents.”

“The court recognized the critical need to suspend enforcement of a harmful regulation that would give insurers illegal veto power over a patient’s ability to receive charitable assistance that helps them afford health insurance,” said Hrant Jamgochian, chief executive of Dialysis Patient Citizens (DPC). “CMS hastily released the rule without recognizing its harmful impact on patients’ ability to keep their current health plan.”

Advocates filed suit in January asking the court to suspend enforcement and invalidate the regulation. The suit was brought by DPC, which represents nearly 30,000 dialysis and pre-dialysis patients nationwide, and three major dialysis providers.

The complaint was against a regulation that would require dialysis providers to ensure that “issuers are informed of and have agreed to accept the third party payments.” The effect of the rule would be to prevent dialysis patients from obtaining charitable assistance to pay their health insurance premiums unless their insurer agreed to accept such payments.

“This discriminatory rule would single out dialysis patients for denial of basic patient protections by insurers that want to dodge their responsibility for covering the costs of potentially lifesaving care,” Jamgochian said. “The rule would also give insurers a financial incentive to restrict services and limit the treatment choices of dialysis patients who they are about to throw over to Medicare.”

Dialysis patients are eligible for Medicare at any age but can benefit from services offered in individual plans sold in the Affordable Care Act’s state health insurance exchanges. For example:

- Medicare has no out-of-pocket limit, unlike private insurance, and because ESRD patients under age 65 are prohibited in 23 states from buying Medigap coverage, they have unlimited liability in those states for the 20 percent of costs not covered by Medicare. Even in states where ESRD patients can purchase a Medigap policy, patients sometimes can buy only the most basic Medigap Plan, which still leaves a substantial portion of their expenses uncovered.
 - ESRD patients are more likely to obtain a kidney transplant if they have private insurance than if they are on Medicare. Research shows that ESRD patients with private coverage are almost three times as likely to obtain a transplant as those on Medicare. African-American ESRD patients with private coverage are roughly 14 times as likely to obtain a transplant as those on Medicare.
 - Private plans sometimes offer patients access to doctors, specialists and health care facilities that do not participate in Medicare.
 - Medicare does not cover dependents, a policy that could leave family members and caregivers uninsured.
- “The ban on discrimination against people with pre-existing conditions has strong bipartisan support,” Jamgochian said. “We call on the Trump administration and Congress to prevent this regulation from ever being implemented and ensure that dialysis patients have the same rights as everyone else to receive charitable help in keeping their health insurance and their access to lifesaving care.”
- The full opinion is available online at dialysispatients.org/patient-assistance. ●



Some of My Favorite Phone Apps

By **Daniel Iniguez**, Transplant Patient, DPC Education Center Board Member

Everyday smart phone apps are becoming more popular. They have become a way to gain more information quickly, to play games for fun, and to motivate us in a number of different ways. Health and diet apps are popular for many people. As a person with chronic kidney disease, in the last 5 years I've used apps that have their core focus on End

Stage Renal Disease (ESRD). It's nice to know that on the palm of your hands you can click on an app and do research on kidney disease. But they also don't replace your nephrologist; apps are just another platform or tools to bring you up to date.

Below are apps that I use and like:

iCHOOSE Kidney is a mobile application developed by Emory University. It is a risk calculator tool that both the health care team and patient with kidney disease can use. Its goal is to help patients make more educated treatment decisions. It shows estimates for a patient's risk of survival and death with treatment options such as dialysis and transplant. It provides a good starting point for talking to



your doctor when your kidneys are not going to be able to do their work on their own. The information you enter in the tool is secure, not saved, and is automatically cleared after each use.

You can also go to the web site at <http://www.ichoosekidney.emory.edu/> to learn more about the model and how it was developed.

Kidney News is a news magazine app of the American Society of Nephrology. It is geared towards kidney professionals and provides news, analysis, and resources. It gives information about topics such as research findings, policy changes, and emerging trends in nephrology. You also can go to the web site at www.kidneynews.org.

I would like an app that focuses on legislation where we could just get an alert and send emails to legislators to be an active advocate for our health and well-being.

What apps do you like and what app would you like to see developed? You can send your comments to info@dpcedcenter.org and put Apps in the subject line. ●

A person wearing a dark, textured robe is shown from the chest up, holding a large, glowing white sphere (a crystal ball) with both hands. The person's fingernails are painted a dark red color. The background is dark and out of focus.

Welcome to a new Administration, a new Congress, and an Unpredictable Healthcare World

By **Megan Beveridge**, Director of Congressional Relations, Dialysis Patient Citizens

If ever there were a time to have a crystal ball, now would be the time. With the change in any Presidential administration, one can expect broad changes which will impact economic sectors across the country from financial services, to education, and especially after this cycle, to healthcare. President Trump and Congressional Republicans, who now control both the House and the Senate, ran on the pledge to repeal and replace the Affordable Care Act (ACA), reform Medicaid, and protect Medicare – and while we are beginning to see steps toward these goals, the future of healthcare is incredibly unpredictable.

Here is what we do know. On day one of this Administration, President Trump issued an executive order titled “Minimizing the Economic Burden of the Patient Protection and Affordable Care Act Pending Repeal,” which instructs agencies to use their existing authority and discretion to reduce regulatory burdens associated with the ACA. The executive order appears to be deliberately vague as to its practical implications in order to

provide the Trump Administration maximum flexibility in rescinding and interpreting ACA regulations.

We also know in early January, Congress took the first steps towards repealing the ACA by beginning a budget reconciliation process. This is the same process Democrats used to pass the ACA and Republicans plan to include provisions to direct the appropriate committees of jurisdiction to craft legislation that would change the existing law’s taxing, spending, or debt limiting provisions. But before passing the first of likely two resolutions, Congressional Republicans want to have a replace plan ready to go. They were hoping to have that plan ready by the end of January but then that deadline was pushed to March and now it seems we may not see a replace plan until next year.

While Congressional Republicans continue to try to finalize a replace plan, we are beginning to see work on smaller steps they can take in the meantime. It appears the first step will be to stabilize the insurance market. Recently the Energy and

Commerce Committee held a hearing titled “Patient Relief from Collapsing Health Markets” which examined several bills they said give patients cost relief from Obamacare, tighten enrollment gaps, and protect taxpayers. The Energy and Commerce Committee has primary jurisdiction over reforming the private insurance market (which is the bulk of the ACA) as well as Medicaid. That same week, the Senate Health, Education, Labor, and Pensions (HELP) Committee held a hearing titled “Obamacare Emergency: Stabilizing the Individual Health Insurance Market.” Both hearings show a coordinated effort by both Chambers to make focusing on the insurance market a top priority.

We also know there are several looming deadlines Congress must address which oftentimes creates a vehicle to move other, more difficult, legislative proposals. For example, the debt ceiling deadline expired March 15, 2017. While the Treasury Secretary has said he would like to raise the ceiling sooner rather than later, he still faces an uphill battle with fiscal conservatives. At the same time, the current Continuing Resolution (CR) which funds the government is set to expire on April 30, 2017. Finally, the authorization for State Children’s Health Insurance Program (S-CHIP), which also includes funding for other organizations such as Community Health Centers, expires on September 30, 2017. All of these deadlines could provide opportunities for the movement of larger packages including reforms to the ACA.

As Congress works to replace the ACA, they also will be looking to reform Medicaid, the federal-state insurance plan that covers low-income people. As part of the ACA, 32 states have been able to expand their Medicaid programs in the hopes of providing basic coverage for more low income individuals. The main proposal supported by House Speaker Paul Ryan and Secretary Tom Price, is block granting Medicaid. Right now, Medicaid covers almost 75 million adults and children. Because it is an entitlement, everyone who qualifies is guaranteed coverage, and states and the federal government combine funds to cover the costs. Conservatives have long argued the program would be more efficient if states got a lump sum from the federal government and then managed the program as they saw fit. That is the core idea behind block grants which critics argue will cut funds to many states and ultimately cut care.

Finally, we may see some significant reforms to Medicare, the federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease (ESRD). As of now, the Medicare Trust Fund, which funds the majority of Medicare, is projected

to be insolvent by 2028. House Speaker Paul Ryan has put forward a plan for Medicare called “A Better Way”. Aside from repealing changes made by the ACA, this plan includes allowing more flexibility in benefits for Medicare Advantage plans, combining Medicare Parts A and B, gradually increasing the Medicare retirement age to match Social Security, and implementing a premium support model. President Trump, on the other hand, has been much more vague, saying he pledges to “modernize Medicare, so that it will be ready for the challenges with the coming retirement of the Baby Boom generation -- and beyond.” So, expect a lot of discussions and Congressional hearings on possible steps to protect the solvency of the Medicare Trust Fund for future generations. With Congress and the Trump Administration busy at work on replacing the ACA, reforming Medicaid, and protecting Medicare, we here at Dialysis Patient Citizens will be working for you. While we will always convey dialysis patients’ best interests to Congress, some of our main priorities moving forward will be ensuring kidney failure patients maintain the option to purchase a private insurance plan and the ability to use charitable assistance to pay for that plan if necessary. We also want to ensure all kidney failure patients covered by Medicare are able to purchase a Medigap plan to help pay for extra healthcare costs. Medigap policies are extra health insurance that you buy from a private company to pay for services that Medicare doesn’t cover. Right now only 30 states allow Medicare beneficiaries who are not yet 65 to purchase Medigap plans. This ability should be consistent for all Medicare beneficiaries.

So, with all of these changes being debated, we will need your help to ensure Congress does not forget about dialysis patients. Below is information on how to contact your Members of Congress and as always please feel free to reach out to us here at DPC if we can be of assistance. Healthcare is facing some unpredictable times, but your voice matters.

Call to Action

Take a moment to introduce yourself to Members of Congress now that the new session has begun.

Online:

Visit www.dialysispatients.org/take-action

Step 1: Click the issue labeled “Introduce Yourself to Members of Congress”, then hit Take Action

Step 2: Enter your email and zip code (your full address may be required to determine your representative)

Step 3: Add your personal story in the letter if you choose

Step 4: Click Send! ●



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