



# ESRD PATIENT NEWS

The Carlisle-Williams Foundation, Inc.

Volume 4, Issue 4

## Entring and Carlisle-Williams Foundation Partnership

Entring, LLC has partnered with the Carlisle-Williams Foundation to donate sample packs of Nephure for inclusion in our free patient support bags.

As a public charity dedicated to improving the quality of life for dialysis patients, we provide an ESRD support package that is filled with educational resources and comfort items they can use during dialysis and hospital visits.

“One of the foundational pillars of our company is education. We are committed to raising awareness about oxalates and providing resources to help educate people on their kidney health,” said Helena Cowley, co-founder and CEO of Entring. “From the very first time I spoke with Janie at the Carlisle-Williams Foundation, I knew it was a good fit. We are excited to partner with them in educating their patients about kidney health.”

In addition to donating sample packs of Nephure, educational material for the support bags, including a Low-Oxalate Shopping Guide and Oxalate-Packed Foods to Avoid, is also supplied.

“We continuously seek better ways to serve dialysis patients.

While looking at improvements and innovations in the kidney health space, I was thrilled and excited to learn about this new product,” stated Janie Carlisle, President and Founder of the Carlisle-Williams Foundation. Nephure stood out to me as the perfect addition to our ESRD support bag as it complements our efforts to educate di-

alysis patients on nutrition. We look forward to a continuing relationship with Entring.”

Nephure is the first-to-market enzyme product offering flexibility to people with oxalate-related nutritional limitations.

Entring, LLC, specializes in enzyme-based products that provide consumer-friendly choices for people with nutritional limitations. As a subsidiary of the research and development organization, Captozyme Inc., Entring’s products are backed by more than 60 years of combined experience in biochemical engineering, including extensive research on innovative approaches for kidney health.

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*ESRD Patient News, a publication of The Carlisle-Williams Foundation, Inc., informs our readers of issues important to management and understanding of their disease and furthers the Foundation’s mission of providing hope and support to ESRD patients. We welcome and encourage feedback. Email [JanieC@esrd-patient-support.org](mailto:JanieC@esrd-patient-support.org) or “Contact Us” on the website. Thank you!*

# ESRD Patient News

## Medicaid expansion linked to reduced mortality among dialysis patients



***We provide links to clinical research trials on our website. Check them often as new trials are constantly being added. It's a great opportunity to have a voice.***

PROVIDENCE, R.I. — In the first three years of Medicaid expansion due to the Affordable Care Act (ACA), the number of patients with end-stage kidney disease who died within a year of starting dialysis decreased in states that expanded Medicaid compared to non-expansion states, new research found.

In the study - published in JAMA and led by Brown University researchers, Trivedi and colleagues tracked more than 230,000 non-elderly patients with end-stage renal disease (ESRD) between 2011 and 2017. In January 2014, 25 states and the District of Columbia extended Medicaid to non-elderly residents with incomes at or below 138 percent of the poverty level, while 25 states did not.

In Medicaid expan-

sion states, the number of patients who died within the first year of beginning dialysis — defined in the study as from the 91st day to the end of the 15th month of dialysis treatment — decreased from 6.9 percent prior to expansion to 6.1 percent after expansion, a total reduction of 0.8 percentage points. In non-expansion states, the mortality rate was 7 percent from January 2011 to January 2014 (prior to ACA) and 6.8 percent from January 2014 to March 2017, a reduction of 0.2 percentage points.

Not only did the researchers compare death rates before and after expansion, they also compared rates between states that expanded Medicaid and states that did not. This method gave the researchers two layers of

comparison — before 2014 versus after and expansion states versus non-expansion states — for determining whether the differences were associated with Medicaid expansion, Trivedi said.

The adjusted absolute reduction in mortality in expansion states versus non-expansion states was 0.6 percentage points. Since ESRD affects more than 100,000 Americans each year, 0.6 percentage points equals hundreds of deaths annually, Trivedi said.

Trivedi says that more research is needed to determine exactly what caused the decrease in deaths, but the study suggests expanded insurance coverage, which provided better access to care, was the key factor in reducing mortality among this group. Medicaid ex-

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pansion reduced the rate of ESRD patients without insurance by 4.2 percentage points, primarily through Medicaid coverage.

Multiple factors may have contributed to the reduction of mortality among patients with ESRD. “Medicaid may have resulted in better adherence to treatment sessions, normally three times a week, because it eliminated co-payments of about \$150 per week. On the other hand, because out-of-pocket medical payments were reduced, Medicaid may have also improved patients’ finances, thereby improving health. More research may be essential to unravel this,” according to Shailender Swaminathan, lead author and an adjunct assistant professor at Brown.

Medicaid expansion also improved pre-dialysis care for kidney disease, as indicated by the surgical placement of a fistula or graft before beginning dialysis, Trivedi said. Fistulas and grafts are less likely to become infected than temporary venous catheters, and in expansion states there was an increase of 2.3 percentage points in the number of patients beginning dialysis with a fistula or graft.

Trivedi would like to monitor the long-term effects of Medicaid expansion on end-stage kidney disease mortality and incidence rates. It is possible that increases in insurance rates due to Medicaid expansion could lead to better recognition, treatment and management of diabetes and hypertension, the two

key underlying causes of kidney disease, ultimately reducing the number of people who develop ESRD, he said.

“Our study suggests that there are significant mortality reductions in patients with end-stage renal disease, who have substantial medical needs, in the states that expanded Medicaid,” Trivedi said. “We’re studying a central question in health policy: To what extent does expanded health coverage save lives?”

He added that the results may apply beyond patients with kidney disease to others with serious chronic conditions, but more research is needed.

*The National Institutes of Health (grant R01DK113398) supported this research.*

*Visit <https://news.brown.edu/articles/2018/10/dialysis> to read the entire article.*

**Handling foods safely is much more than throwing away expired milk or washing your fruits and vegetables. While these actions are important, there are several more common food safety mistakes that can result in major consequences.**

# ESRD Patient News

## Living Well on Dialysis-Take Charge of Your Emotions

**ESRD and dialysis are manageable with the right tools and the right support. You can take control of your emotional and physical health to live a full rewarding life.**

Successful dialysis treatments mean focusing on your physical, mental and emotional health. By taking charge of your emotional health, and accepting help when you need it you can live a rewarding life on dialysis.

### **Rollercoaster Emotions**

Dialysis requires significant time and effort—time spent traveling to and from appointments and receiving treatment, time and work to carefully monitor diet and fluid intake.

It is not unusual to experience a flurry of emotions. These can range from an initial reaction of shock or denial to numbness, anger, sadness, worry, and guilt.

For those who knew dialysis was likely in their future, there could be a feeling of relief now that they have started. Hopefulness, anxiety and fear are also common.

As you adjust to the dialysis routine, you should start to feel more like yourself again. And as you continue on with your life, there are steps you can take to manage sadness, worry and stress.

### **Managing Stress and Negative Feelings**

**Maintain the activities that bring positivity.** As much as possible, keep up the hobbies and interests you had before dialysis, even if you have to adapt them to your dialysis schedule or health condition. If possible, continue working—the ADA provides workplace accommodations that can help with this. Socialize with friends. All of these activities tend to create a happier and healthier life on dialysis.

**Educate yourself—this is a major focus of The Carlisle-Williams Foundation.** Gather information and ask questions to help you understand the dialysis

treatment and the lifestyle changes that go along with it. Keep a list of questions and bring them to your doctor appointments. Keep a notebook of important information with all your medical information in one place—also add this info to your smartphone.

**Stay connected to other people.** Reach out for support from family and friends. Be open with them about what you're experiencing and how you're feeling—there's a link on our website that provides words for expressing emotions. Don't be afraid to ask for help and explain to others what you need.

Seek additional support by joining a support group for people on dialysis. There is comfort when you connect with others who are going through the same things you are.

**Take a deep breath.** Relaxation exercises such as meditation and

## Living Well on Dialysis-Take Charge of Your Emotions

gentle forms of yoga, as well as prayer can help lower stress levels. (We are looking for patients who are interested in participating in a pilot wellness program.

Contact us if you would like to participate). Consult with your physician about what forms of exercise are safe and appropriate for you.

**Give back.** Be helpful to those you love, volunteer your time or do charitable work can help remind you that you have valuable skills to offer, even if you can no longer work.

**Seek professional help.** When dealing with a chronic illness, it's easy to get stuck in negative thought patterns. Psychologists, social workers and other mental health professionals can help you take control of those negative thoughts and adjust to the unique challenges of dialysis.

It's normal to feel sad while adjusting to the

changes that dialysis brings. For some people, the sadness lingers and can lead to depression and anxiety. This is common in people with chronic illness.

You might need extra help managing your emotions if you notice you are:

- Feeling hopeless
- Often very stressed or worried
- Sleeping more or less than you used to
- Frequently irritable with family and friends
- Withdrawing from people or activities you used to enjoy
- Doing things you know aren't healthy, like skipping medications
- Making excuses for not following doctor's recommendations

If you're concerned about your emotional state or your stress levels, there are people who can help. The doctors and mental

health professionals at your dialysis clinic are trained to discuss these concerns with you and help you manage them. They can also provide you with resources and referrals to local mental health providers in your community that can help.

People undergoing dialysis can safely take some antidepressant medications. However, non-drug options may also be effective, either alone or in combination with medications. Studies have found that exercise and cognitive behavioral therapy (CBT) can successfully treat depression in people with chronic kidney disease. CBT can help identify ways that you are stuck and help you gain control over negative thoughts, unhelpful behaviors, and begin to feel like yourself again.

*This information was compiled from a resource developed jointly by the American Psychological Association (APA) and Dialysis Patient Citizens Education Center.*

# ESRD Patient News

## Gift Ideas for the Dialysis Patient

A kidney diet is an important part of a dialysis patient's day. Kitchen tools and accessories make great gifts for cooking at home.

**Great gifts for any occasion include many items in our flagship ESRD Dialysis Support Bag...blanket, pill container, socks. Here are some more great gift ideas that any dialysis patient will appreciate.**

- ⇒ *Cooking for David: A Culinary Dialysis Cookbook* by Sara Colman and Dorothy Gordon – This book, co-authored by a DaVita® dietitian, details how dialysis patients can modify their favorite foods to be kidney-friendly.
- ⇒ Spice rack filled with spices – Lowering sodium in the kidney diet is important, so give a spice rack loaded with yummy spices, such as cinnamon, cumin, curry powder, dried oregano, garlic powder, ground ginger, lemon pepper, Mrs. Dash®, paprika, tarragon or thyme.
- ⇒ Hot air popcorn popper – Popcorn is a healthy snack for a person on dialysis, so make it fun for him with this kitchen appliance.
- ⇒ Herb growing kit – Fresh herbs are a delicious addition to many dishes. Basil, chilies, mint, parsley, rosemary and sage are just a few you can give.
- ⇒ Ice pop molds – To help curb thirst and regulate fluid intake, a person on dialysis can make her own ice pops. Instead of the usual rectangular shape, browse a specialty store or the Internet for ice tray molds in different shapes.
- ⇒ Insulated lunch bag – Does the dialysis patient in your life go to school or work? She can pack a kidney-friendly lunch in her own lunch bag. An Internet search for “lunch bags” gives an array of websites that sell colorful and uniquely-designed lunch totes.
- ⇒ Measuring cups or food scale – A kidney diet needs to be monitored closely, so measuring food and beverages is important. Purchase a set of measuring cups and spoons or a food scale. Home goods stores sometimes feature models in assorted colors.
- ⇒ Slow cooker – For a cold winter's day, a meal made in a slow cooker can be comforting and easy. DaVita.com features numerous slow cooker recipes.

## Your Wellbeing Journey

With the right attitude, the road to achieving your goals, managing your disease and enjoying a better quality of life gets easier.

- ◆ Seeing the positive aspects of your life is an essential component of happiness.
- ◆ Focus on positive self-talk. When something goes well, take time to appreciate it and be excited about more good things to come in the future. Look for positive ways to cope with negative situations.
- ◆ Be thankful each day and look forward to what lies ahead.
- ◆ Make goals. Map out the steps to achieve them.
- ◆ Pump up your heart. Aim for at least 30 minutes of moderate physical activity five days a week or more. Breaking activity sessions into 10-minute intervals can add up to your 30 minutes for the day.
- ◆ Finding your balance: Only eat as many calories as you burn.

Reducing stress matters for your overall health—both physical and mental. Here are a few tips for relaxing and letting stress melt away.

- ◆ Take a walk and breathe in some fresh air
- ◆ Listen to soothing music and allow your body to move with the sound.
- ◆ Practice recharging and savoring the moment through meditation, deep-breathing exercises, or whatever else brings you to a place of calm.
- ◆ Laugh. You can chase away stress with a good laugh. Even a simple, genuine smile has been shown to help offset tension and negative thoughts. Watch a funny movie or show, read humorous comics, or a funny book. Call or visit a friend who is always good for a laugh. Be willing to laugh at yourself.
- ◆ Spend time with your friends—especially the ones who are spontaneous, funny, and positive.
- ◆ Cook up your favorite meal in the kitchen. Try a new renal-friendly version of your favorite meal.
- ◆ Get out and about—see a movie, sporting event, show, or go to dance club or a museum.
- ◆ Be generous—good deeds help you feel good about yourself while lightening your spirit.
- ◆ Practice mindfulness—listen actively, let go of judgment, live in the moment.
- ◆ Reach out—enjoy the good company of your social support network.
- ◆ Take care of yourself—eat and sleep well, exercise regularly, go out with friends, and make room in your life for things you enjoy.



# ESRD Patient News

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The Carlisle-Williams  
Foundation, Inc.

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## 2018 Annual PB Dialysis Charity Race

The Annual PB Dialysis Trail Run fundraiser was held in Mohegan Park in Norwich, CT on Sunday, November 25. This annual fundraiser raises money we need to continue providing ESRD dialysis support packages for kidney failure patients free of charge. The funds from this year will help us supply packages to all the dialysis patients at Wakefield Dialysis Clinic in Rhode Island in fulfillment of a request from 2016.

The Foundation traditionally responds to individual dialysis patients; who, after receiving their packages, tell the social worker, dietitian or facility manager and suggest getting them for everyone. We love that our clients appreciate the value of our services and we want to be able to continue providing the packages to every patient who requests one.

We have plans to conduct a pilot program for providing emotional and mental wellness tools to dialysis patients to see if this makes a positive difference in their overall wellbeing. Additional fundraising efforts are underway to help bring this project to fruition. **If you are interested in participating in this pilot, email [wellnesspilot@esrd-patient-support.org](mailto:wellnesspilot@esrd-patient-support.org).** We are looking to have two options: a telephone group counseling session; and an online app that employs meditation, games and acts of kindness to build positivity and resilience.

Volunteers are always needed to help with fundraising events, social media efforts, awareness marketing and outreach to dialysis patients. Please use the contact form on our website if you are interested in volunteering. Additionally, if you are a dialysis patient - or know one - please complete the Patient Survey on our website to request a support bag.

Thank you to our volunteers (special thanks to Lorine Blouin and Rose-Andree Meeker), Board members - Debbie Williams Glover, Esther Doele, Kim Joffrion Howell, and Jamie Jones; registrants, participants, sponsor - **Entring, LLC, City of Norwich Parks & Recreation Department and SNERRO Timing LLC** - all who contributed to our success. See you next year.

Many thanks also to our donors for making this a success - **Charlotte Knights, 36 Town Restaurant & Grille, Tavolo Restaurant, Foxwoods Resort Casino, First Wok, Work Happiness Method - Stella Grizont, Olde Tymes Restaurant, Hair Cuttery, Janytra Brooks Messer, Debbie Williams Glover, International Tennis Hall of Fame, Wachusett Mountain Ski Resort.**