

# ESRD Patient News

The Carlisle-Williams Foundation, Inc.

Volume 7, Issue 4

## Another Year Begins—Happy 2023

Amazing as it seems, here we are at the end of another year. If you are like me, this year has gone by quickly even with a lot of challenges, sadness, triumphs and successes it still went quickly. I suppose they all do.

Here at The Carlisle-Williams Foundation, we were pleased with the amount of financial support we received this year, especially with our Giving Tuesday campaign and end of year gifts. We are not sponsored or funded by any national organization or corporate entity, so 100% of our support come from donations from individuals and charitable-minded groups like the Westerly Rotary and Charter Oak Community Bank who provides matching funds during their community drive for their account owners, and Cigna who provides matching funds to their employees

throughout the year through the Benevity platform.

Again, this year, we were unable to have our 5K PB Dialysis Run as we settled into a new location in another state. We are very much looking forward to finding an ideal location for the event in 2023—perhaps even a beach run since we are in the Ocean State. Please feel free to make suggestions OR to volunteer. You can visit us at our website—[www.esrd-patient-support.org/volunteer](http://www.esrd-patient-support.org/volunteer)—to sign up for volunteer events. You can also find us on the Benevity platform.

Thank you again to all our supporters, to our clients—our dialysis patients, and to all those who follow us on facebook or linkedin and spread the word about the Foundation. Let us know how we can help YOU.

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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 [Editor@esrd-patient-support.org](mailto:Editor@esrd-patient-support.org) or “Contact Us” on the website. Thank you!*

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## Researchers Create Metric to Predict Mortality in Persons on Dialysis

The new metric is calculated according to the ratio between phosphorous and normalized protein catabolic rate. Further, investigators noted that the metric enables improved phosphorus monitoring.

“Lowering serum phosphorus in people on hemodialysis may improve their survival. However, prior studies have shown that restricting dietary protein intake, a major source of phosphorus, is associated with higher mortality,” Dana Bielopolski, MD, PhD, from the Harold Simmons Center for Kidney Disease Research and Epidemiology in the division of nephrology and hypertension at the University of California, and colleagues wrote. They added, “Our objective was to combine the two, protein consumption and phosphorous levels, in one novel parsimonious metric and assess the relative contribution of each to mortality in people on maintenance hemodialysis (MHD).”

From a total of 1,737 facilities operated by a large dialysis organization in the U.S. between Jan. 1, 2007, and Dec. 31, 2011, researchers evaluated 63,016 patients on hemodialysis a year after initiation. All patients had reported data of phosphorous and normalized protein catabolic rate (nPCR) in the first 90 days of treatment. Follow-ups occurred in three 91-day intervals.

Based on the calculated values, patients were grouped into five categories. Group 1 consisted of sick patients with high phosphorus and low nPCR, and group 5

consisted of patients with low phosphorous and high nPCR.

Patients in group 1 were young, more likely to be women and initiated dialysis therapy with a catheter. Those in group 5 were older, used a permanent access and were less likely to be hypertensive.

A 1-year follow-up revealed an increase in calculated value correlated with improved survival. Additionally, residual kidney function did not impact mortality associations in accordance with the calculated value.

“The relationship of nutritional status and mortality in people on maintenance hemodialysis is multifaceted and involves multiple influencing factors. Scaling people on MHD according to R value might provide the clinician insight into nutritional status that will mandate intervention and direct the intensity,” Bielopolski and colleagues wrote. “People scoring low on the R value are being persistently attacked by two competing threats to their survival — they have low nutritional status as indicated and a high phosphorous level. This combination is the result of not only low compliance to medical therapy and dietary counseling but also of a high inflammatory state.”

To read the complete article, visit <https://www.healio.com/news/nephrology/20220708/researchers-create-metric-to-predict-mortality-in-patients-on-dialysis>

## Underrepresented Persons on Dialysis Report Unmet Existential and Supportive Care Needs

Based on a study conducted by University of Washington School of Medicine, Catherine Butler, MD, MA found that minority groups with kidney disease are less likely to receive important types of kidney care compared with non-minority patients and tend to have poorer health outcomes. “The reasons for these patterns are multiple and complex, but certainly coping with kidney failure is an intensely psychologically and socially challenging experience, and psychosocial wellbeing is likely a major contributor to health outcomes,” She added that the researchers wanted to better understand whether minority groups felt that they were receiving sufficient support for their psychological and existential needs.

The survey included 997 English-speaking adults receiving maintenance dialysis between April 2015 and October 2018 who care from one of 31 nonprofit dialysis facilities in Seattle, WA or Nashville, TN.

Participants reported ethnicity and responded to prompts about palliative and end-of-life care.

Unmet needs reported included wanting to learn about treating pain of kidney disease, wanting to learn about treating symptoms of kidney disease, wanting someone to talk with about the meaning of life and finding peace of mind, wanting help in sharing thoughts and feelings with those close to them, and finding spiritual resources.

Additional reported unmet needs were wanting help in coping with sadness, finding meaning in life, finding hope and overcoming fears, wanting to learn about relaxa-

tion or stress management and that they would like to have someone to talk to about their care plan and treatment options for the future.

“Coping with kidney failure and treatments like dialysis can be incredibly psychologically and socially challenging. Gaps in existential and supportive care needs among Black and Asian American, Native Hawaiian or other Pacific Islander groups suggest that the health care system needs to be better designed to support these populations in coping with their disease,” Butler told Healio. “If we don’t pay attention to these supportive care needs, other types of treatment that we tend to focus on — medications, diet, dialysis, etc. — are not going to be nearly as helpful.”

Butler added, “The next step is to dive into more detail about reasons for these gaps in care and opportunities to improve. While there may be opportunities to improve individual patient-physician interactions, perhaps more importantly, these results signal system-level gaps in care for minoritized racial groups of people with serious illness. This observation aligns with a broader movement to understand how health care system processes may perpetuate structural racism and to identify ways to rebuild our system.”

To read the complete article, visit <https://www.healio.com/news/nephrology/20220718/underrepresented-patients-on-dialysis-report-unmet-existential-and-supportive-care-needs>

## For Profit Dialysis Facilities Correlate with Increased Time to Wait-listing Transplant

Pediatric patients who received care at for-profit dialysis facilities experienced significantly longer time for placement on the waitlist and receipt of a kidney transplant compared with those who received care at a nonprofit facility.

“Studies have shown that receipt of maintenance dialysis at profit facilities was associated with lower rates of transplant and worse survival among adults with end-stage kidney disease,” Sandra Amaral, MD, MHS, from the Children’s Hospital of Philadelphia and University of Pennsylvania, and colleagues wrote. They added, “This study examined the association between the profit status of U.S. dialysis facilities and the amount of time it took for pediatric patients with End Stage Kidney Disease (ESKD) to be placed on the waiting list and receive a transplant.”

The study included 13,333 patients younger than 18 years old who initiated dialysis between 2000 and 2018 in United States facilities. Data were derived from the U.S. Renal Data System. 60% were treated at a nonprofit facility, 27% at a profit facility and 13% switched facilities with status. Moreover, 75% of the group were registered on the wait list during the study and follow-up period and 69% received a kidney transplant.

Analyses revealed that during a median follow-up of 0.87 years, the occurrence of wait-listing at profit facilities was 36.2 per

100 person years and was 49.8 per 100 person years at nonprofit facilities. Similarly, a median follow-up of 1.52 years revealed the incidence of kidney transplant, whether living or deceased donor, was also lower at profit facilities than at nonprofit facilities, 21.5 vs. 31.3 per 100 person-years, respectively.

One possible explanation offered in an editorial, by Mary B. Leonard, MD, MSCE, and Paul C. Grimm MD, from Stanford University School of Medicine, was that the substantial association between likely reflects greater clinician experience with the special needs of pediatric patients with ESKD and their families, as well as more robust facility-level processes and structures needed to care for these vulnerable patients.

They added, “Improving access to kidney transplants, availability, and outcomes for underrepresented groups with ESKD will require collecting national surveillance data on early steps to identify and overcome patient-level, clinician-level and system-level barriers to kidney transplants. These efforts also should include measures of interdisciplinary pediatric nephrology expertise. Pediatric patients may be a small part of the national transplant equation, but they have the most to gain.”

To read the complete article go to <https://www.healio.com/news/nephrology/20220809/for-profit-dialysis-facilities-correlate-with-increased-time-to-waitlisting-transplant>

## Medicare Expenditures Could be Reduced by Increased PD Use

“National policy reforms are focusing on promoting the use of Peritoneal Dialysis (PD). These are in part due to the expectation that peritoneal dialysis is less costly than in-center hemodialysis,” Kevin F. Erikson, MD, MS, associate professor of medicine at Baylor College of Medicine, told Healio. “We examined Medicare expenditures in similar patients starting these two dialysis modalities in order to see if peritoneal dialysis is actually less costly for Medicare. We also examined whether differences in cost have persisted over time as more patients are being put on PD.”

Analyses revealed hemodialysis had 69% higher estimated intravenous dialysis drug costs, 35% higher estimated rehabilitation expenditures and 34% higher estimated expenditures other than dialysis resulting in 11% higher costs than home-based PD. Data were derived from a study in the *Journal of American Society of Nephrologists*.

In a retrospective analysis, researchers evaluated Medicare beneficiaries aged at least 67 years who started in-center hemodialysis or PD between 2008 and 2015.

Specifically, researchers measured annual expenditures for up to 3 years after dialysis initiation to find if differences in Medicare costs across dialysis modalities persisted as more patients began PD.

Using propensity scores, researchers matched 8,305 patients initiating PD with 8,305 patients starting hemodialysis.

Researchers identified a total of \$108,656 spent for hemodialysis and \$91,716 for PD, a cost difference that did not significantly differ over time. Analyses revealed hemodialysis had 69% higher estimated intravenous dialysis drug costs, 35% higher estimated rehabilitation expenditures and 34% higher estimated expenditures other than dialysis, resulting in 11% higher costs than home-based PD. Additionally, the estimated intravenous drug costs decreased by \$2,900 per patient-year in hemodialysis from 2008 to 2014 vs. \$900 per patient-year in PD.

“Our findings are important because they suggest that Medicare expenditures could, in fact, be reduced by a shift towards more use of PD,” Erikson told Healio. “This study was informative but also raised several questions. We are currently conducting additional investigations into cost differences between these two dialysis modalities.”

*For more information, go to <https://www.healio.com/news/nephrology/20220822/medicare-expenditures-could-be-reduced-by-increased-peritoneal-dialysis-use>*

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## National Early Warning Score Performs Well with Kidney Failure Patients on Hemodialysis

Using systolic blood pressure, respiratory rate, temperature, pulse oximetry, heart rate, use of supplemental oxygen and level of consciousness, the National Early Warning Score (NEWS) points-based clinical decision tool performs better among patients with kidney failure than other hospitalized patients, according to a research letter published in *Kidney Medicine*.

Joanna Cavalier, MD, from the department of medicine at Duke University, and colleagues wrote. “Early warning scores have been examined in kidney transplant recipients, but their use in patients with kidney failure treated with maintenance hemodialysis has only been examined as subpopulation analyses in larger studies.”

The research was to determine the effectiveness of the NEWS tool among patients on maintenance hemodialysis who were hospitalized in 2019 at an academic medical center with more than 1,000 beds using data from electronic health records. Death while on the medical or surgical floor or escalation of care to the ICU served as the primary outcome.

The researchers used last known vital measurements to mimic continuous monitoring by calculating the NEWS in 2-hour intervals. Predictive performance of the time-varying risk score, stratified by kidney failure status was measured during the next 12 hours.

In total, researchers identified 28,905 admissions during the study period. Of these

admissions, 1,343 were patients with kidney failure on maintenance dialysis.

Analyses revealed the NEWS better predicted ICU transfer or mortality in 12 hours among patients with kidney failure vs. patients without kidney failure. In vital signs analysis researchers observed high systolic blood pressure tended to be relatively protective against decompensation in patients with kidney failure and a high heart rate was more predictive of decompensation among patients with kidney failure.

“This study is the first to establish that the widely used NEWS not only performs well in patients with kidney failure on maintenance dialysis, but better than in other hospitalized patients,” Cavalier and colleagues wrote. They added, “Given the NEWS’s predictive performance in this patient population, a customized early warning score for patients with kidney failure on maintenance dialysis is not necessary. Institutions can use the NEWS to reliably help predict decompensation in patients with kidney failure on maintenance dialysis.”

*To read the article in its entirety, visit <https://www.healio.com/news/nephrology/20220629/the-national-early-warning-score-performs-well-among-patients-with-kidney-failure>*

## Kidney Donations from Deceased Donors with COVID-19 Seen as Safe

Kidney transplant recipients do not contract COVID-19 from accepting a kidney donation from a COVID-19-positive deceased donor, according to data published in the *Journal of Urology*.

In a retrospective review, the Cleveland Clinic transplant team examined data for 55 patients who received a kidney donation from 34 deceased donors with COVID-19 between February 2021 and October 2021. All donors tested positive for COVID-19 within a median of 4 days of organ donation.

Analyses and follow-ups revealed no kidney transplant recipients contracted COVID-19 from the transplant. The team concluded in this initial retrospective review that a kidney donation from a COVID-19-positive deceased donor is safe.

Healio interviewed study author Alvin Wee, MD, MBA, the program director for the kidney programs at Cleveland Clinic, to further discuss the study findings.

Healio: Can you describe the study?

Wee: We conducted a retrospective review of 55 patients and 34 COVID-19-positive deceased donors. In this series, about two-thirds of donors died from what was not COVID-related, but turned out to be COVID-19 positive, while the remaining donors died from COVID-19. All patients had good kidney function. There was no difference in our immunosuppression management postoperatively. COVID-19 PCR tests were conducted 7 to 10 days after the transplantation.

Healio: What are the clinical findings of this study?

Not one of the recipients contracted COVID-19 after receiving a kidney transplant from a COVID-19-positive deceased donor. All kidney graft functions are excellent. We have one patient who died from his comorbidities. He never tested positive during the whole post-transplant follow-up.

Healio: Are other organs able to be transplanted, or just kidneys?

Wee: We have also utilized livers from COVID-19 deceased donors. There are some reports of utilized hearts.

Healio: If a recipient is infected with COVID after the transplantation, will the infection be more severe than if the recipient received an organ from a deceased donor without COVID?

Wee: That will require further research. With this study, we focused on answering the question of whether or not the transplantation would be as safe a transplantation from a healthy deceased donor.

Healio: What are the next steps for this research?

Wee: We conducted a follow-up study that included more than 100 kidney transplant recipients who got their organ from a COVID-positive donor and compared these to recipients who did not. It has been recently submitted for publication. One thing I can share is the outcomes are excellent and promising.

*For the full article, visit <https://www.healio.com/news/nephrology/20220517/qa-kidney-donations-from-deceased-donors-with-covid19-seen-as-safe>*

### Resources for Persons on Dialysis

Clinical Trials - <https://clinicaltrials.gov/search?recr=open&intr=dialysis>

Traveling while on dialysis - <https://www.kidney.org/atoz/content/traveltip>

Planning for Emergencies - <https://www.kidney.org/sites/default/files/docs/disasterbrochure.pdf>

Emergency Meal Planning - <https://www.freseniuskidneycare.com/treatment/disaster-preparation>



STARTING  
TODAY I NEED  
TO FORGET  
WHAT'S GONE,  
APPRECIATE  
WHAT STILL  
REMAINS, AND  
LOOK FORWARD  
TO WHAT'S  
COMING NEXT