

OPINION & EDITORIAL

Dialysis patients need Congress to restore medical coverage protections

Jean Cullen

Pennsylvania's congressional delegation must hold the health insurance companies accountable for leaving Americans with kidney failure behind. Across Pennsylvania and the country, many patients with kidney failure are being denied the level of health coverage they need and deserve. They need Pennsylvania's members of the U.S. House Ways and Means Committee — Mike Kelly, R-PA, Lloyd Smucker, R-PA, Brian Fitzpatrick, R-PA, and Dwight Evans, D-PA, to work together to stop them.

Following a recent Supreme Court decision, private insurers have more leeway to deny patients with kidney failure the coverage they deserve by rolling back benefits and its reimbursement rates, imposing an enormous medical and financial burden on those just coming to terms with their diagnosis. There's a bill making its way through the House that would address this issue called the Restore Protections for Dialysis Patients Act.

Thankfully, Congressman Kelly introduced the bill and Representative Fitzpatrick has cosponsored the bill, but Evans and Smucker have not. They should both cosponsor the bill, and all of Pennsylvania's congressional delegation should work together to advance it in the House of Representatives. Doing so would protect America's vulnerable kidney patient population.

End Stage Renal Disease (ESRD), or kidney failure, sweeps up most who have it. Ellen Bluestone, a previously healthy Pennsylvania, learned she had kidney disease from a routine blood test. Ellen had to quickly turn her life upside down to adapt ESRD patients like Ellen must adapt their busy lives to accommodate dialysis — it's a long, three-to-four-week, hospital-long treatment that filters patient's blood in the dialysis — while waiting for a kidney transplant. Approv-

The DeVal faculty does not offer a music major but its music department has always been an active part of the school and it encourages local residents to participate. On its website, the school invites students to join its musical groups: "Share your love of music by participating in one or more of our bands, including Symphonic, Jazz, Chorus or the Summer Community Music program. These bands give you the opportunity to practice and perform alongside faculty, staff and members of our local community."

I attended a concert in the new Broad Commons Park across from Doylestown Borough Hall last week. My son Gene was playing in the Community Band for the first time — he's a longtime lover of band music and local bands, dating back to the pit orchestra and the marching band in high school, and even elementary and middle school bands.

It was a balmy evening, cool and breezy, a pause in the July heat wave. Children were running through the courtyard fountain and climbing the Fort Hill Castle model in the playground. The Doylestown Heat opened the show with "Basic Straight Ahead" and "Sparkly," jazz standards. The Community Band followed with oompah pieces like "Semper Paratus" (Always Ready, the Coast Guard anthem) and the theme from "Hogan's Heroes." The bands held their summer concerts on the old Bucks County Courthouse lawn until last year, when they moved to the new park. Master of Ceremonies Ed Lisowski believes it's taking some time for locals to get used to the new venue.

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The bands will play their final summer concert at 7 p.m. Thursday, Aug. 1 and the Heat will wind up the season with a solo performance Aug. 8.

Russo Music and the Bucks County Symphony Orchestra sponsored the summer concerts. Many of the band members will pick up their instruments again in the fall, to join in the music with DeVal's students.

In 2022, Harris was instrumental in the re-authorization of the Violence Against Women Act (VAWA), which included a provision named "Keeping Children Safe From Family Violence Act," also known as "Kayden's Law."

Yet, in spite of this special provision in VAWA, which requires an evidentiary hearing during child custody proceedings to vet allegations — both new and old — of abuse, the mothers in Pennsylvania, and in other states, are failing miserably in their quest to get a judge to hear their dire concerns about the safety of their children during custody litigation.

Given that many judges respond with more deference to mothers' pleas for protection of their children from abuse by the other parent, mothers are sometimes penalized with the loss of custody for bringing claims of abuse to the attention of the court.

A passionate supporter of civil rights, Harris is my best person

imate 20,000 Pennsylvanians rely on dialysis to survive. Only about 1 in 5 people with ESRD in Pennsylvania receive a transplant each year, so dialysis remains the necessary option for most patients.

A sudden ESRD diagnosis brings immediate stress. Like anyone else, ESRD patients have job, families, and responsibilities. What ESRD patients require most of all is stability, especially during those tumultuous first months of care.

Many ESRD patients are happy if they can keep their job and continue to work while beginning dialysis treatment. However, many employees provided private insurance plans have taken advantage of the Supreme Court decision that makes it easier to limit coverage for dialysis patients. And while dialysis patients may lose access to the benefits they need, they rarely complain to their employer, because they simply want to keep their jobs and provide for their families despite their complicated and exhausting health condition.

Some dialysis patients are lucky enough to have private insurance that actually does provide adequate health coverage, and they appreciate the advantages of private insurance, as a primary payer, over Medicare. In those cases, private insurance will provide a broader array of treatment options, covering more medications and visits to specialists. It allows families to maintain continuity of coverage, and enrollees are far less likely to report issues receiving the care they need. Further, private insurance improves the chances that an ESRD patient will receive a kidney transplant. The sad reality is that patients without sufficient coverage remain lower on the transplant waiting list than many other patients.

By law, all dialysis patients must eventually transition to Medicare.

However, because of concerns about financial stability and trans-

plant access, Congress previously guaranteed that dialysis patients could keep their employee-provided private insurance for the first 30 months of care. That way, dialysis patients could continue working without the additional stress of financial instability.

The Supreme Court's decision opened the door for private insurers to discriminate against dialysis patients and effectively push these patients off the plan and onto Medicare prematurely. That's unfortunate, because Medicare provides more limited care options and it only covers 80% of treatment expenses. If new dialysis patients suddenly lose their insurance, they must quickly find ways to account for the 20% that Medicare doesn't cover. In states without affordable supplemental insurance plans, patients must deal with piling medical debt. Representatives Kelly, Smucker, Fitzpatrick, and Evans can unite to prevent such an unacceptable state of affairs in the rich state of Earth.

Struggling dialysis patients are depending on our representatives to hear their voices. Pennsylvanians and Americans all across the country with dialysis suddenly find themselves in health insurance situations that fail to meet their needs — though no fault of their own. Fitzpatrick, Smucker, Evans and Kelly can, in their capacity as members of the Ways and Means Committee, continue building momentum for the Restore Protections for Dialysis Patients Act. This legislation would allow Pennsylvanians beginning dialysis to keep their existing private insurance for the first 30 months of care. I'm grateful Representative Kelly introduced the bill and Fitzpatrick cosponsored it. I strongly urge the rest of Pennsylvania's representatives to support it too. I hope that they can get this done.

Jean Cullen lives in Telford Township.

Kayden Mancuso's story can help Kamala Harris in Pennsylvania

Amy Neustein and Michelle Ellis

Mothers in Pennsylvania and elsewhere, have been suffering a brutal fate at the hands of the American family courts as they beg judges to protect their children from abusive fathers. Their demographic mix is broad. They range from educated non-educated, rich to poor, and Black to white.

Kamala Harris can help these mothers by speaking up for them. And she would certainly earn their vote in the presidential race.

Last month, major television networks and print media around the world covered the tragic story of 3-year-old Ellie-Obi Lestino, who was recently killed while on a visit with her father, and subsequently tossed into a San Francisco Bay Area recycling center. The father was found to have subsequently committed suicide.

This tragedy was preventable. The mother, Dr. Chrystal Obo, a Stamford Clinical Instructor in Pediatric Radiology, had implored the court over a two-year custody dispute to order supervised visitation for the father because of his "increasingly erratic" behavior and his becoming "progressively unstable," according to court papers filed by the mother.

A similar tragedy gripped Pennsylvania when Kayden Mancuso, a 7-year-old Bucks County girl, was struck by her father three times in the head with a dumbbell and died in a murder-suicide. The Pennsylvania Legislature passed a bill in honor of Mancuso. Equally important, her tragic fate became known to Vice President Harris.

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to champion the cause of Pennsylvania mothers, and mothers in other states too, whose civil rights have been woefully violated in the demonizing climate of family courts that sacrifice children to the perils of instability and/or the whims of one other parent. As vice president, Harris can call Attorney General Merrick Garland today and request that the Civil Rights Division of the U.S. Department of Justice investigate the egregious civil rights violations suffered by mothers in the family courts post-haste.

She would surely win the vote

of the Pennsylvania mothers and elsewhere, and save the lives of children. It would also do her critics who complain of a monopoly of her message on abortion rights, by broadening her platform to include "Mothers' Rights."

Sociologist Amy Neustein co-authored "From Madness to Maternity: Why Mothers are Runaway from the Family Courts — And What Can Be Done About It." She resides in Fort Lee, NJ. Michelle Ellis authored "The Hostage Child." She resides in Pilesville, Md.

Tanks in exclamation
The excess blood in their words.
Bew-huh

A crash ion the clouds
The methods of her touch

The merriment of youthful chases

Wishful woes

Rapid roads leathered in their hair

Sunken planes

Lodges of sun in the layered smoke

Putzing in his yellow minotur

Pins & needles

The scattered battle lines

Calling cards

The broken blush

Handwriten bushings on the wall

Bloodied breeze

A stream of sange in the sapphire

Rose to tragedy

The valley between people

The debonair of a sunless highway

Fight or flight

Broken light

In honor of the young

The pink coral has tattooed to their guns

it's not a dream child

The movements of a nightmare

Called them by the roadside

There's no distractions at the bottom of a river

Tristan Butterig is a singer-songwriter, musician and poet. He has released seven collaboration albums titled "Bubbles On The Ceiling" (2018), "Einstein's Garage" (2018), "Paint Job 33" (2018), "Roar of Time" (2009), "Cosmos Colossal" (2020), "House of Hair" (2021) and "Jack of Habits" (2021). He resides in Bucks County.

Tristan's Corner is curated by Bucks County Poet Laureate Emeritus Tom Mallouk and supported by a grant to the Bucks County Herald Foundation made possible by Mary and Dee Ann Woodall.

To submit a poem for consideration, email it to Heraldpoetcorner@gmail.com. If the poem has been previously published, please say where it first appeared.



BRIDGET WINGERT

Flutes perform with the Doylestown Community Band.

Bridget Wingert: Happy to Be Here

A 70-year tradition beckons local musicians



but in many ways, it's a better venue. It has free parking, lots of space, and an irresistible sense of summer sounds.

Lisowski's been the MC for 31 years and he expects to keep going for a while. His involvement with the band may be mundane only by French horn player Cindy Carson, who has been a member for 38 years.

Lauren Ryals adds a professional touch as she conducts the Community Band. Last Thursday, she directed six tubas, three flutes, four french horns, four clarinets, three trumpets, three trombones, a couple of drums, and maybe a keyboard (couldn't see). Ryals holds a bachelor's degree from the University of Colorado at Boulder, a master's in music education from VanderCook College of Music in Chicago and a Ph.D. from Temple University. She grew up in Littleton, Colo. and she's exploring the East Coast.

On the DeVal faculty since spring 2023, Ryals directs all of the musical groups. She also teaches a class that covers varied topics related to music, possibly musicology or music history.

"In Bucks County it seems that at every corner you turn there's a band," she said. "I was honored to be asked to conduct the Central Bucks Band. It's awesome to meet the people in Doylestown."

Ryals enjoys working in a multi-generational setting the bands offer and she's currently researching music education, looking through a trauma-informed lens, especially focusing on war veterans.

At the beginning of July, Ryals sent a message to the community musicians: "I am honored to have been asked to direct the summer band and humbled by the invitation to work with all of you. Community music ensembles and multi-generation musical playing is not only my musical passion but my life's work."

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ANGELIQUE WINGERT

David O'Neill, leader of the Doylestown Heat sings along with a song from the 1950s.