DPC
DIALYSIS PATIENT CITIZENS

Improving Life Through Empowerment

June 12, 2024

Chair Lampton, Vice Chair Barhorst, members of the Ohio House Insurance Committee:

My name is Elizabeth Lively, Eastern Region Advocacy Director for Dialysis Patient Citizens. DPC is a patient-led non-profit organization dedicated to improving dialysis citizens' quality of life through education and advocacy.

While most individuals become eligible for Medicare by turning age 65, those under-age 65 with a diagnosis of End Stage Renal Disease (ESRD) or ALS have expedited access to Medicare coverage. ESRD and ALS are the only two diseases in federal statute that provide a fast track to Medicare Part A and B. (42 U.S.C. §426-1 and §426(b)(h)).

What does the dialysis patient population look like? Dialysis patients comprise an extremely vulnerable population. In Ohio, more than half of the under-age 65 End Stage Renal Disease (ESRD) population is on Medicaid, with both Medicare and Medicaid coverage -- called dual-eligibles. Dialysis patients need either multiple weekly dialysis treatments or a kidney transplant to stay alive. There are no other treatment options. Further, kidney disease and dialysis disproportionately impact communities of color. According to the US Renal Data System, African Americans are 3 and a half times more likely to have kidney failure; while Hispanics, Asians and Native Americans are 1 and a half times more likely.

I am testifying in support of HB 400, which will provide access to affordable Medicare Supplement (also called Medigap) policies for these Medicare eligible individuals under the age of 65. Under current Ohio statute, Medigap policies are not available to under-age 65 eligible Ohioans. This legislation focuses on a small group of Ohioans who are on Medicare, but not on the state's Medicaid program, called non-duals.

The number of non-dual Ohioans under-age 65 with a diagnosis of End Stage Renal Disease is around 2,700. HB 400 would add these 2,700 individuals to the larger Medigap pool of nearly 614,000 Ohioans age 65 and older, representing a de minimis 0.4% of the overall Medigap risk pool.

Why is this legislation needed? To provide these Ohioans with financial security, protect the state's Medicaid program and enable Ohioans to gain access to kidney transplantation.

Let us look first at why financial security is important. Medicare only covers 80% of the cost of patient care, leaving the remaining 20% -- which has no cap – the patient's responsibility. For dialysis patients, their out-of-pocket costs can be as high as $18,000 a year. Medigap coverage helps patients pay for these expenses, so less people struggle with impossible decisions like whether to pay their medical bills, buy food or pay rent.

However, many are forced to make the incredibly difficulty decision to give up their hard-earned assets to qualify for Medicaid. This makes the State of Ohio the secondary payer of these medical bills, and once a person is on Medicaid, there is no going back. To qualify for Medicaid, you cannot have cash over $2,000 but can keep your primary residence exempt up to $688,000, personal property, burial plots and irrevocable funeral plans. There is also a 5-year look back for asset transfers. Imagine yourself having to make this hard decision to spend down your assets to qualify for Medicaid, especially when HB 400 creates another option.

There are about 6,000 Ohioans with End Stage Renal disease who are under-age 65. Over 3,400 or 56% of this group are on the state's Medicaid program. HB 400 can help protect the Medicaid program by providing affordable Medigap policies, offering a better option to the remaining 2,700 under-age 65 Ohioans needing help to cover their out-of-pocket medical costs, saving the Medicaid program millions of dollars. Why should the state Medicaid program help subsidize private insurers by forcing Ohioans to spend down assets to save themselves from financial ruin? Just because dialysis patients are not yet age 65.

Medigap provides access to life-saving and life-changing kidney transplantation. While not all dialysis patients medically qualify for transplant, it is the optimal therapy as it provides patients with a higher quality of life with most transplant patients able to re-enter the workforce, providing for their families and supporting their communities. Without secondary coverage, like Medigap, most transplant centers will not list patients for transplants as they must have the ability to cover the 20% deductible for surgery and medical care needed to support the health of their new kidney.

With Indiana just passing affordable Medigap legislation for those under age 65, they join the other Ohio boarder states of Kentucky and Pennsylvania, who have similar legislation in statute. The reality is that most people wanting a kidney transplant get listed at multiple transplant centers in order to help expedite their transplant. Ohio has eight kidney transplant programs, and under-age 65 patients from Kentucky, Indiana and Pennsylvania can literally jump ahead of Ohioans and get their transplants because they have access to affordable Medigap coverage.

HB 400 includes the premium protection formula of "same as age 65," meaning that under-age 65 individuals cannot be charged a premium higher than those who are age 65. This proven premium protection formula has been in place in Kansas since 1999, which has a robust Medigap market for all age groups with more than 45 insurers writing plans.

What will this cost? Will adding around 2,700 End Stage Renal Disease patients (the group insurers say is the most expensive) to the larger 614,000 Medigap pool drastically increase insurance premiums for seniors? DPC commissioned an independent, third-party actuarial firm – Health Management Associates (HMA) – to look at the data and determine what will happen to overall premiums.

Actual Medicare claims data was analyzed, and HMA determined that – if insurers chose to raise their rates – the impact would be 0.5% on the overall premium pool or an increase of around $1.00 a month – less than a cup of coffee.

Medicare Advantage plans are not a good option for this patient population. Out-of-state transplant centers will be out-of-network for MA plans, and the immunosuppresant drug prior authorization process can delay transplant or drug administration, or require less effecacious medications. Many Medicare Advantage plans do not cover the 20% out-of-pocket costs.

HB 400 provides the opportunity for this committee and the Ohio legislature to recognize that Ohioans should not be discriminated against just because they got sick before they turned 65 years old. The diagnosis of End Stage Renal Disease will not magically disappear when these individuals turn age 65. They need help now to obtain some measure of financial security and access to kidney transplant as they continue to combat this disease which has no cure – dialysis treatments or a kidney transplant are the only two therapies that help combat kidney failure. I am asking for your yes vote on HB 400. Thank you.

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Dialysis Patient Testimony
Porothea Dennis, constituent of House District 6

My story begins back in the 1990s with a diagnosis of gestational diabetes during pregnancy. Twenty years later, a diagnosis of hypertension led to a heart attack and stroke that damaged my kidneys, requiring dialysis treatments. During my hospital stay, I lost my job and my employer-based insurance coverage. While I was able to get COBRA coverage, it was expensive, and my friends helped me with the premium payments. COBRA is temporary, but with my diagnosis of End Stage Renal Disease, I qualified for Medicare coverage. I also qualified for Social Security Disability payments, but because my benefit payments were too high, I did not qualify for Medicaid. I was stuck in between and could not afford the 20% out-of-pocket coverage or pay the high Medigap premiums as I was under the age of 65. If not for the American Kidney Fund, I would not have had access to Medigap coverage as AKF paid my monthly premiums. The payments were extremely high and there was no way that I could have afforded the premiums on my own.

I agreed to accept a high-risk kidney with Hepatitis C, which moved me to the top of the transplant list. I also needed an 8-week dose of antiviral medication immediately after the transplant surgery. This therapy is extremely expensive -- $15,000 for the 8-week drug therapy – and I received help from the HealthWell Foundation to pay for this drug, which cured the kidney from Hep C.

Having Medigap coverage helped me get on the active kidney transplant wait list, and I received a new kidney in August of 2021. But there is a catch with qualifying for Medicare before turning age 65 and getting a kidney transplant, as Medicare stops 3 years post-transplant.

In August of 2022 – one year later – I went back to work and now have health insurance coverage through my employer. My one remaining out-of-pocket cost is about $70 a month for my anti-rejection medications that keep my kidney healthy.

My journey has been hard and not as easy as for those who are age 65 and can get affordable Medigap coverage. Because Ohio does not have laws in place that protect those under age 65, I had to use a patchwork quilt of coverage and accept charity to ultimately get my transplant. The financial pressures of dialysis are huge, and there are about 2,700 Ohioans like me who need your help to get affordable Medigap coverage. I took the risk of accepting a high-risk kidney to get to the top of the transplant wait list so I could get back to work and get affordable health insurance coverage. I urge you to support HB 400 so others can have better financial security and access to life-changing kidney transplantation.