DPC
DIALYSIS PATIENT CITIZENS

Improving Life Through Empowerment

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SUBMITTED FOR THE RECORD VIA WMSubmission@mail.house.gov

House Committee on Ways and Means Committee Chairman Jason Smith
Health Subcommittee Chairman Vern Buchanan
House Committee on Ways and Means Ranking Member Richard Neal
Health Subcommittee Ranking Member Llyod Doggett
U.S. House Committee on Ways and Means
Subcommittee on Health
1139 Longworth House Office Building
Washington, DC 20515

RE: HL-08 Health Subcommittee Hearing on Improving Kidney Health Through Better Prevention and Effective Treatment

Dear Chairmen, Ranking Members and Members of the Health Subcommittee:

We want to thank the Subcommittee for holding a hearing on kidney care issues. We are pleased that most of the challenges facing dialysis patients were aired at this hearing, and heartened that Members seem to understand the problems created by bundling innovative new drugs into a payment system designed for old staples. We would like to use this opportunity to highlight an issue that wasn't addressed in detail—schemes to deprive dialysis patients of their employer insurance coverage. I would also like to detail how the issue of bundled drugs impacts patients like me.

Dialysis patients are losing access to their health insurance as provider reimbursements are converted into hidden intermediary fees.

For about a decade, some aggressive and opportunistic vendors have been exploiting employers' frustration with dialysis costs to strip patients of their insurance coverage and charge employer health plans exorbitant fees. They purport to save money on health insurance costs but actually they take dollars earmarked to pay clinicians who wear scrubs and divert them to consultants who wear suits. Discrimination against dialysis patients has converged with an industry-wide trend of vendors converting a share of unrealistically high, seldom enforced "chargemaster" out-of-network billing into cash for themselves.

The vendors claim to be saving money for payers by unilaterally imposing lower prices. But, Catalyst for Payment Reform, an employer health policy collective, observes: "A substantial portion of the 'savings' achieved through reducing high OON charges is often recouped by TPAs or repricers, who sometimes serve as negotiators with OON providers, through what is called 'shared savings fees.' … typical shared savings fees charged by TPAs for services to reduce OON prices can range from 25-35% and sometimes up to 50% of the amount 'saved' between the billed charge and the ultimate payment. TPAs characterize these fees as ‘savings because the amount paid on an OON claim is less than the billed charge, therefore the employer “saved” the difference. However, the savings are only relative to what otherwise might be an unsubstantiated and/or outlandishly high price for a service.”

But dialysis repricing vendors like Renalogic differ from other repricers. Ordinary TPAs reprice claims from providers who chose to remain out-of-network. The dialysis repricers proactively remove facilities from the network so that they can execute the repricing and reap the spread pricing fees. This scheme is harmful to both the patient, who does not want out-of-network hassles, and the dialysis provider, which has already negotiated a reasonable network fee with the employer’s overall TPA. This is a money grab, pure and simple, preying on patients and on the less sophisticated employers.

Discovery in a Florida lawsuit against Renalogic confirmed that Renalogic charges a fee set at a percentage of the difference between dialysis clinics’ billed charges and the Medicare price, and not benchmarked to the much lower price negotiated between the clinics and the insurer/TPA whose network agreements Renalogic supplants.

For example, assume that a dialysis provider’s billed charges are $3,000 per treatment, its negotiated price with the underlying insurer was $1,200 per treatment, and the Medicare price is $300 per treatment; and Renalogic’s fee is 33% of the difference between the billed price ($3,000) and the Medicare price ($300) (.33 x $2,700 = $891). In this hypothetical, the employer plan would pay a total of $1,191, essentially equaling the price negotiated by the insurer. In such a scenario, the health plan saves nothing, but instead diverts much of its spending from the clinic providing life-sustaining treatment to a clever consultant.

As is the case with PBMs’ spread pricing, Renalogic is paid more when it refers the patient to the provider with higher list prices, a perverse incentive in the market. But the true intended effect of the arrangement is for the patient, frustrated by out-of-network hassles, to drop employer coverage and switch to Medicare.

Commercial insurance coverage is important to kidney patients for three reasons. First, many patients prefer generous employer plans over Medicare. Medicare has no dental or dependent coverage. AHRQ’s Quality and Disparities Report has identified 33 different measures on which better care is delivered through private insurance than public insurance. Importantly to ESRD patients, commercially insured patients receive kidney transplants at a higher rate than those covered by Medicare or Medicaid. Our own patient surveys have found higher satisfaction with employer coverage than with Medicare.

Second, the ESRD Medicare Secondary Payer law created an all-payer financing system for dialysis intended to compensate for penurious and inadequate Medicare reimbursements. Medicare payments typically cover the costs of care in high-volume, urban clinics but not in lower-volume or rural clinics. In some years, dialysis facilities in the aggregate have a net loss on Medicare payments. We are already seeing closures of scattered rural facilities; a widespread loss of commercial insurance funding could lead to retrenchment in access to care.

Finally, the entitlement of people with ESRD to enroll in Medicare regardless of age creates a perverse dynamic in the care of persons with chronic kidney disease. Non-elderly CKD patients are typically covered by commercial insurance. Most of these patients have costly comorbidities— e.g., about half of all dialysis patients have diabetes. Once an insured's CKD progresses to ESRD, the insurer may be able to offload that sick patient's expenses onto taxpayers. This means the insurer lacks the financial incentive to try to preserve the patient's kidney function as long as possible, or to prepare the patient for the CKD-ESRD transition by having a fistula created, educating the patient about home dialysis, or obtaining a pre-emptive transplant. By putting insurers on the hook for some dialysis costs, Congress gave them skin in the game—incentivizing employer health plans to detect CKD; treat it, often with drugs that are quite expensive; and smooth the transition to ESRD, eventually handing off a stable patient to Medicare. If employers no longer have a stake in kidney care—if they can simply hand over an incident patient to Medicare when he "crashes into" dialysis—they will no longer take steps to preserve kidney function or ensure a stable transition.

You may have seen the commercials on television advertising new drugs that preserve kidney function for diabetes and CKD patients. But nephrologists tell us that very few eligible patients get this medicine. We wonder if this is a result of the message the Supreme Court sent employers in the Marietta decision.

We are grateful to Rep. Mike Kelly for introducing the Restore Protections for Dialysis Patients Act (H.R. 2199). The bill reiterates Congress' intent, and the long-time understanding of plans, providers, and regulators up until recently, that plans may not shirk their responsibilities to kidney patients. We hope the committee will advance this bill this year.

Dialysis patients are missing out on new therapies because of rigid payment bundling.

It is important to understand that while dialysis treatments sustain life for people with kidney failure, they cannot replace all of the many functions of a healthy kidney. Patients rely on medications to address certain symptoms. As of January 1, 2025, all of these medications are included in the ESRD prospective payment system bundle and dialysis facilities are given the responsibility of dispensing them.

One of the conditions addressed by medications is phosphorus. Phosphorus is absorbed in the small intestines and stored in the bones. Healthy kidneys get rid of the extra amounts not needed in the body. Because unhealthy kidneys are no longer able to remove phosphorus from the blood and get rid of the excess in urine, high levels of phosphorus (hyperphosphatemia) is a problem for people with stage 4 and 5 kidney disease, especially stage 5, known as end stage renal disease.

Among the problems that high levels of phosphorus in the blood can cause are bone and heart problems that lead to hospital stays and in some cases, death; calcification or hardening of tissues when phosphorus and calcium form deposits in the heart, arteries, joints, skin or lungs that can be painful and lead to serious health problems; and pruritis (itching).

Until recently, the only treatment for high phosphorus was phosphate binders, large pills that must be taken in large quantities. Because I had a gastric sleeve done several years ago, the phosphorus binders expand in my now much smaller stomach. Then I can't eat. If I can't eat I miss out on all the other nutrients and vitamins you gain from eating. So I have battled with my phosphorus. I have tried all types of binders with not very good results. And all these years of uncontrolled phosphorus has caused calcium deposits throughout my veins, throughout my entire body, which complicates my eligibility for transplantation.

An innovative treatment for phosphorus is Xphosah, a phosphate blocker. I was prescribed and received this drug from my Medicare Part D plan until it was rolled into the ESRD bundle. It has worked well for me and I feel like if there was access to these new medicine years ago I would be on the transplant list or better yet would have a kidney by now. But because of an impasse between the manufacturer, Ardelyx, and CMS over the terms, Medicare no longer covers this drug. I am fortunate that Ardelyx is providing me with the drug for free for the time being, but this is not a sustainable solution for patients.

We agree with Ardelyx that the ESRD PPS as currently implement by CMS is ill-equipped to roll out new dialysis drugs. CMS has instituted a Transitional Drug Add-On Payment Adjustment (TDAPA) for new medications, but it has proven inadequate. New therapies need to be paid for separately in a sustainable manner.

Certain assumptions underlie payment bundling. Simply rolling together a number of related items and services does not suffice for a safe and efficient bundled payment.

First and foremost, a bundled payment is not safe for patients if there is significant variation in patients' needs. The bundle intentionally incentivizes providers to administer less treatment. This can be helpful if excessive treatment is wasteful or dangerous. But when some patients require more than the standard treatment, providers may default to the usual care to avoid the extra expense.

For years, kidney care relied on old and inexpensive drugs to address various conditions. It did not matter that not every dialysis patient has ESRD-related pruritic (itching) when the standard treatment was a Benadryl tablet that costs a penny. But the introduction of Korsuva, a drug to treat pruritis, changed that. The requirement that this drug go in the bundle has resulted in a de facto embargo of the medication. Empirical research has found a prevalence of moderate to severe pruritis among dialysis patients of 33 percent, but Korsuva has been dispensed to fewer than one percent of patients. CMS baked the artificially low take-up during the TDAPA period into the cake, adding a tiny amount to the bundle for the drug and locking in a depressed rate of utilization in perpetuity.

In my case, while most patients respond well to phosphate binders, I and many others do not. When the payment is fixed and Medicare treats me like the "average" patient, I become an expensive patient in the eye of providers. The experience under TDAPA is that we exceptional patients are not getting the new drugs.

Parsabiv is a new calcimimetic. During the 2019-2020 period, when a TDAPA add-on payment was made, 5,105 of 34,924 patients on dialysis (14.2%) received etelcalcetide each month, according to a study by Stuart M. Sprague of NorthShore University HealthSystem. After January 2021 when payment policy changed, only 217 of those patients (0.7%) were receiving etelcalcetide each month. Mean monthly PTH values increased from 483 pg/mL before the policy change to 544 pg/mL after the policy change. Among the 3,560 patients who discontinued etelcalcetide when the payment policy changed in January 2021, mean monthly PTH increased from 579 to 745 pg/mL. We understand that this remains the status quo today.

Bundling also assumes that there are consensus protocols followed by clinicians when it includes dollars for a particular intervention. That is not always how things work, especially when an intervention is new. In the kidney care world, the management of dialysis organizations determines protocols and formularies for each of their clinics. If fewer than all providers implement a new drug in their facilities, and CMS averages the take-up across all patients, the new component of the payment will only partially reimburse the treatment for the adopting clinics, and leave a windfall for clinics sticking to the status quo. This scenario appears to be in play for two current TDAPA drugs that are not being adopted profession-wide.

Finally, bundling assumes that savings from new protocols benefit the provider. The template for bundling has been the hospital inpatient prospective system. Up until the 1980s, hospitals simply sent Medicare a bill for the costs of a hospitalization. The hospital had no incentive to reduce the patient's length of stay or to get a low price for supplies if it could simply pass those costs on. In the bundled environment, hospitals are incentivized to manage stays efficiently, and to drive a hard bargain with their suppliers. If they succeed, they keep the difference between the bundled price and their costs. Patients are protected by the right to a real-time appeal of discharges.

But the gains from new protocols in the ESRD bundle don't go to providers. DefenCath is a catheter lock solution whose costs are borne by dialysis organizations while the benefits—reduced infections and hospitalizations—accrue mostly to patients and the Medicare HI Trust Fund. Vafseo, an oral HIF-PHI to treat anemia in dialysis patients, could reduce transfusions for patients who don't respond to ESAs, but that too is a benefit to patients and to Medicare, not to the bundle gatekeeper. In practice, the unit of CMS with responsibility for the ESRD PPS has scrutinized only costs within its silo, not costs to Medicare Part A and the program as a whole. Meanwhile, patients can't appeal a lack of access to a new therapy that their doctor hasn't prescribed and that they most likely don't even know about.

We now see a retreat by drugmakers from the kidney space. GSK recently filed with the FDA to remove Jesduvroq, an oral HIF-PHI, from the market due to the inadequate TDAPA and post-TDAPA reimbursement, meaning one fewer option for patients who don't respond to ESAs. Ardelyx, manufacturer of the drug Xphozah, has filed a lawsuit against CMS rather than accepting TDAPA with its perverse dynamics that all but preclude profitability, a blow to patients like me with inadequate response to phosphate binders or who are intolerant of any dose of phosphate binder therapy.

These are products on which many millions of dollars were invested to improve kidney care. This negative experience means venture capital is unlikely to make such investments in the future. But make no mistake, patients with these conditions are needlessly suffering today. To date, TDAPA has been an abject failure in protecting the most seriously afflicted among an already vulnerable population. In these circumstances, CMS has accepted or encouraged medical outcomes that have not developed organically, but ensued solely because of Medicare payment idiosyncrasies. We believe this constitutes interference with the practice of medicine banned under Section 1395 of the Medicare Act; but more to the point, it is a betrayal of patients living with a disfavored disease.

We urge the committee to advance H.R. 6214, the Kidney Care Access Protection Act (KCAPA), which would address these problems.

Sincerely,

Quiana Bishop

Quiana Bishop
Dialysis Patient Citizens Board President