April 9, 2018

Honorable Ed Hernandez, O.D.
Chair, Senate Health Committee
State Capitol
Sacramento, CA 95814

Re: SB 1156 (Leyva) – Oppose – Dialysis Patient Citizens

Dear Mr. Chairman:

With 29,000 dialysis patient members, over 4,000 of whom reside in California, Dialysis Patient Citizens (DPC) is the nation's largest patient-led organization representing individuals with end-stage renal disease (ESRD). On behalf of California's 84,500 ESRD patients, I am writing in opposition to SB 1156, which threatens continuity of insurance coverage for kidney patients receiving assistance from the American Kidney Fund (AKF). I would like to provide some context for understanding the role that charitable assistance plays in buttressing America's all-payer system of funding dialysis care, how it assists individual ESRD patients with the costs of their care, and the important policy considerations promoted when ESRD patients are able to maintain commercial health insurance coverage.

SB 1156 loosely parallels an interim final rule issued by the federal Center for Medicare and Medicaid Services (CMS) in December 2016. That rule, which was enjoined by a federal court and never took effect, was based upon mischaracterizations of the impact of private insurance coverage on dialysis patients' access to transplantation. The federal judge who reviewed this rulemaking under the Administrative Procedures Act found that the agency adduced no evidence to support this justification, and acted arbitrarily and capriciously in trying to restrict patients' access to commercial coverage. We are therefore disappointed to see the introduction of SB 1156 which, like the discredited rule, requires disclosure to insurers of confidential information about ESRD patients supported by AKF, and is also justified by the same rhetoric relied upon by CMS in its aborted rulemaking.

The intent of SB 1156 appears to be to preclude ESRD patients who have lost their jobs from continuing on their commercial insurance after they become eligible for Medi-Cal or Medicare. As will be explained below, these are two separate circumstances that need to be analyzed separately; however, many of the considerations favoring continuity of coverage are the same.

I. The availability of commercial insurance has significant benefits to ESRD patients.

The Social Security Act assures people whose kidneys fail that if they like their health plan they can keep it for at least for 30 months. This is often referred to as Medicare Secondary Payer

(MSP) provision,[1] or 30-month "coordination period," and was clarified through the regulatory process as extending to exchange plans.[2]

Further, dialysis treatment is an "essential health benefit" (EHB) under California and federal law. While most individuals with ESRD become eligible for Medicare coverage, under the Social Security Act, ESRD patients are entitled to keep their group health insurance for at least 30 months. As such, the group health plans that become benchmarks for a state's EHB—including the Kaiser small group HMO plan that is California's benchmark—cover dialysis services, and their EHB benchmark designation extends this 30-month coverage mandate to the individual market.

The option to maintain private health coverage is important to ESRD patients for several reasons.

First, DPC's Membership Surveys, conducted by the IPSOS international research firm, find that dialysis patients prefer private coverage. We asked several questions from the Consumer Assessment of Health Plan Survey (CAHPS) to gauge relative satisfaction with their coverage. We found:

- 77 percent of patients rate their private health insurance as the "best health insurance plan possible," compared to 71 percent for Medicare.
- Medicare beneficiaries are more than twice as likely as private health plan members (13% versus 5%) to report having trouble getting health care that they wanted or needed.
- Medicare beneficiaries are more likely than private health plan members to report difficulties in getting the specific medication they need, difficulty getting someone on the phone to answer questions, and delays in receiving care or treatment.

Second, there is a significant financial advantage for dialysis patients to keep their private coverage. The Medicare program is extraordinarily popular with the American public, and we often hear advocates of universal health coverage call for "Medicare for All." Those who are not familiar with the Medicare program may wonder, why would a dialysis patient prefer commercial coverage to Medicare?

The reason is Medicare's structure, enacted in 1965 to mimic the indemnity-type health insurance that prevailed five decades ago. As a fee-for-service program, Medicare makes no insurer or provider organization accountable for patient outcomes, so no entity coordinates care to prevent avoidable complications. Further, Medicare retains a 1960s-era cost sharing structure with patients responsible for deductibles and co-insurance equal to about 20% of the cost of care. This is far less generous than employer or ACA health coverage, and most seniors buy Medigap supplemental coverage to ease this burden. In fact, the "Medicare for All" proposals put forward by Senator Bernie Sanders and the Center for American Progress do not retain Medicare's cost sharing structure—they change it significantly by requiring little or no cost sharing.

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[1] 42 USC 1395y

[2] 45 C.F.R. § 155, 156, and 157

According the Bureau of Labor Statistics, the average private health insurance plan has an actuarial value of 88.9 percent, significantly higher than Medicare's 80 percent. Health maintenance organizations—which are not available to ESRD patients through Medicare—have an average actuarial value of 91.8 percent. We further note that Medicare Savings Program assistance is not as generous to low-income patients as are subsidies in the exchanges for patients with income between 100% and 200% of the poverty line. For persons earning between $11,000 and $23,000 a year, the ACA guarantees that exchange health plans cover at least 87% of average medical expenses. Importantly, under the ACA, private health insurance plans have out-of-pocket maximums; fee-for-service Medicare does not. It is crucial for dialysis patients' financial well-being that they retain equal access to private health insurance, especially in a state like California that does not give under-65 patients access to Medigap supplemental coverage.

Finally, and most importantly, if a patient can lose coverage when his or her chronic kidney disease (CKD) progresses to end-stage renal disease (ESRD), an insurer has a perverse financial incentive not to take all possible measures to preserve the patient's kidney functions. This is because CKD typically accompanies other co-morbidities, often making CKD patients more expensive than other enrollees. Some of the drugs that preserve a patient's kidney function are quite expensive. While insurers such as Blue Shield of California have complained about the high costs of dialysis care, many CKD patients have to hope that those costs are greater than the costs of organ-preserving treatments so that insurers' incentives align with their health needs and reflect the social costs of kidney failure. If an insurer could off-load those expenses onto the Medicare program it will root for the patient's kidneys to fail sooner rather than later.

Further, an insurer with no financial stake in a patient's well-being after onset of ESRD has no incentive to smoothly manage the transition from CKD to ESRD by obtaining a preemptive transplant if possible, creating a fistula for safe dialysis access, and educating the patient about kidney failure in advance so he doesn't "crash" into dialysis, resulting in infections and hospitalizations.

These perverse incentives are not present when plans must pay for renal dialysis for at least 30 months before Medicare becomes the primary insurer. And only a commercial insurer has both the incentive and the capability to properly prepare a CKD patient for ESRD. The "Optimal ESRD Start" program pioneered by Southern California Kaiser Permanente represents the most sophisticated effort to date to manage the CKD-ESRD transition. It is no exaggeration to say that most of the innovations in integrating kidney care have come through the efforts of private payers, and not from the Medicare program.

You may have seen recent news reports about CVS entering the dialysis business. The CVS business model will be to use its data resources to identify CKD patients who are likely to lose their kidney function; intervene with education and access site preparation; and persuade patients to use newer, simpler home dialysis modalities that CVS is developing. This new model has the potential to create a great deal of consumer welfare—fewer complications during the CKD/ESRD transition, and lower costs overall because home dialysis patients have lower medical costs. It is important to note that the CVS business model only works in the context of continuous commercial coverage before and after kidney failure. There is no way that CVS (or a

partner payer, such as Aetna, with which CVS is merging) could reap the downstream savings from the upstream investment and interventions if the patient moves to Medicare before the 30-month coordination period expires. As such, the Committee must understand that if SB 1156 becomes law, CVS is unlikely to bring its dialysis innovations to California, and certainly not for under-65 patients.

The grim reality is that the right to maintain private coverage for 30 months beyond kidney failure would be illusory for many patients if not for the assistance in paying premiums offered by the American Kidney Fund. Kidney patients who've paid into the health insurance pool for decades as relatively healthy enrollees will too often, upon reaching ESRD, be unable to continue working and pay for insurance when they are most desperate to draw upon its benefits. AKF assistance performs a dual role of helping needy individuals and incentivizing commercial insurers to provide quality kidney care.

II. Proponents of SB 1156 advance spurious justifications for the bill.

We also want to respond to some comments that the bill's sponsor made in a press release. "SB 1156 protects patients by creating safeguards so that they are not caught up in schemes where they may lose their health insurance," Senator Leyva said in her release, which further suggests that enrollment in commercial coverage "is not in the best interest of the patient [and] results in… disruption in care and is being imposed upon consumers even though these patients are eligible for public coverage like Medicare or Medi-Cal." This echoes one of the discredited assertions adduced in response to CMS' 2016 Request for Information about "steering" of ESRD patients that were repeated in the preamble to the resulting December 2016 Interim Final Rule.

The source of the disruption/loss of coverage canard was a comment letter CMS received from Teri Browne, a professor of social work who is a prominent advocate for reducing racial disparities in kidney transplantation. Prof. Browne's hypothesis as we understand it (and she did not lay it out explicitly) is that AKF assistance has moved the transition from commercial coverage to Medicare coverage from the time of initial kidney failure to the time of transplant because AKF ceased making commercial premium payments after the transplant takes place, leaving patients to either pay the commercial premiums on their own or enroll in Medicare.

Initially we note that AKF has changed its policy and no longer ends its subsidies immediately following transplant (unless the transplant takes place in the last quarter of a coverage year). But even before that change, the transition between commercial insurance coverage and Medicare coverage at the time of transplant has been fairly seamless for patients. We urge you to review this article from the Medicare Rights Center, which operates a national Consumer Helpline that counsels 20,000 patients each year. https://www.medicareinteractive.org/get-answers/medicare-covered-services/medicare-and-end-stage-renal-disease-esrd/coverage-of-immunosuppressant-drugs-and-vitamins The Center advises ESRD patients that Medicare will cover immunosuppressive drugs so long as they are enrolled in Medicare Part A at the time of transplant; and that if they are not so enrolled, they have one year to enroll retroactively. We presume the Center has not encountered problems with these transitions because it weighed in

with a response to CMS' Request for Information supporting ESRD patients' ability to choose between commercial coverage and Medicare.

Prof. Browne's most specific complaint about the coverage transition at the time of transplant is that a patient receiving premium assistance will be "stuck" paying premiums on his or her own when the AKF assistance ends, e.g., the patient would need to pay a Blue Shield premium of $300-400/month. Left unsaid by Prof. Browne is that if this patient had enrolled in Medicare at the time of kidney failure, he or she would have had to pay the Medicare Part B premium (currently $134 per month) and Medicare Part D premium (~$36 per month). The average ESRD patient waits 3.6 years for a transplant and is entitled to coverage in a commercial health plan for 30 months. We estimate that AKF assistance saves the average ESRD patient $5,100 in Medicare premiums, as well as coinsurance obligations in Medicare that usually exceed the out-of-pocket maximum in a commercial health plan. It is not clear to us how a patient could be worse off having to pay Medicare premiums beginning at the time of transplant than he or she would be paying these premiums beginning at the time of kidney failure.

Senator Leyva's release also suggested that ESRD patients in commercial coverage may experience "higher out-of-pocket costs." We presume this was a reference to patients who are eligible for Medicaid, which has only nominal cost-sharing. From an overarching policy perspective, the same considerations supporting continuity of care from commercial coverage before and after kidney failure apply to patients eligible for Medi-Cal as well as to those eligible for Medicare; however, there are competing considerations unique to Medi-Cal eligibles because of the nominal cost sharing. We do not favor routine enrollment of Medi-Cal recipients into ACA commercial coverage, although there may be circumstances, such as where a patient is unable to get an appointment with a vascular surgeon due to low Medi-Cal reimbursements, in which an individual patient may be better off with commercial coverage.

Ultimately, the fallacy to arguments that consumers are being "steered" to commercial insurance is very simple: Congress, when it passed the Medicare Secondary Payer law, made the 30-month commercial coverage period mandatory for insurers but optional for consumers. If Congress had believed that consumers would not have voluntarily asserted this right, it would have made the 30-month period mandatory for consumers as well, lest its policy objectives be left unmet. Obviously, Congress expected that a significant proportion of ESRD patients would perceive an advantage to maintaining commercial coverage, and our survey data bears that out.

Please let me know if I can provide further information.

Respectfully submitted,

Jackson Williams
Director of Regulatory Affairs