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and DIALYSIS PATIENT CITIZENS, INC.

UNITED STATES DISTRICT COURT

CENTRAL DISTRICT OF CALIFORNIA

SOUTHERN DIVISION

JANE DOE, *et al.*

Plaintiffs,

v.

XAVIER BECERRA, *et al.*

Defendants.

Case No. 8:19-cv-02105

DECLARATION OF HRANT JAMGOCHIAN IN SUPPORT OF MOTION FOR A PRELIMINARY INJUNCTION

Date: December 9, 2019
Time: 8:30 a.m.
Place: Courtroom 9D

I, Hrant Jamgochian, declare as follows:

1. I am the Chief Executive Officer of Dialysis Patient Citizens ("DPC"). I am over 18 years of age. I have been the CEO of DPC since April 2011. I have previously served as the Director of Health Policy for the United Way Worldwide, as Director of Congressional and State Relations for the American Pharmacists Association, and as Director of Field and State Operations for the American Psychological Association. I have a Juris Doctorate (J.D.) from Catholic University and a Master of Laws (LL.M.) in Global Health Law from Georgetown University Law Center. I have personal knowledge of the facts set forth herein except as otherwise stated. I could and would testify truthfully about the matters contained herein.

DPC's Mission Combatting End Stage Renal Disease

2. DPC is a non-profit educational and social welfare organization operating under section 501(c)(4) of the Internal Revenue Code. Our mission is to improve the quality of life of patients with End Stage Renal Disease ("ESRD") and chronic kidney disease ("CKD"). We empower patients with kidney disease through a variety of advocacy and education efforts.

3. ESRD is a chronic, painful, irreversible, and potentially fatal illness. When a patient has ESRD, her kidneys are no longer capable of filtering waste and toxins from her blood. ESRD is also associated with a host of comorbidities, most notably diabetes, cancer, heart disease, and anemia. More than 700,000 people in the United States have ESRD, and each year, there are more than 100,000 new ESRD diagnoses in the United States.

4. To survive, an ESRD patient must either obtain a kidney transplant or undergo dialysis. Dialysis is a medical process that filters waste and excess fluid from a patient's blood. The typical dialysis patient requires three dialysis treatments per week, each lasting four to five hours. Dialysis is the only way, absent a kidney transplant, to keep an ESRD patient alive, and it exacts a tremendous toll. Dialysis

is expensive, stressful, and time-consuming. The demands of dialysis treatment mean that ESRD patients often have difficulty keeping their jobs. Further, the prevalence of depression or anxiety among ESRD patients is approximately four times higher than that of the general adult population.

5. DPC is a patient-led organization. Our by-laws require that the President, Vice President, and the majority of the Board of Directors to be current dialysis patients. DPC's membership is restricted to patients with kidney disease and their family members. We have more than 28,000 members nationwide and 4,587 members residing in California. Our 2016 Membership Survey found that 87% of our members with kidney disease are on dialysis and that 11% have received kidney transplants.

6. Our Membership Survey also found that the average DPC member with ESRD has been on dialysis for 6.7 years, and that 19% have been on dialysis for more than 10 years. One-third of our members who have not received transplants are on a transplant waiting list. The average waiting period for a DPC member to receive a kidney transplant is between three and seven years.

7. DPC is demographically diverse, as ESRD disproportionately afflicts racial minorities. Fifty-three percent of our members are white, 30% are African-American, and 4% are Hispanic.

8. Because dialysis patients must receive frequent, lengthy treatments, they have difficulty staying employed. Fifty-two percent of our members are retired, and another 26% are unemployed. As a result, a large portion of our members have very little income. Two-thirds of our members have received some form of financial assistance to help make ends meet.

9. Our members receive coverage from multiple sources, including Medicare, Medicaid, and private coverage. However, even with insurance, dialysis treatment is expensive. Accordingly, 23% of our members have received assistance from the American Kidney Fund ("AKF") to help them pay for their premiums,

including premiums for Medicare and Medicaid.

AB 290 Will Interfere with Congress's Objectives

10. During my work with DPC, I have become familiar with federal laws related to dialysis. Understanding these statutes is essential for DPC to conduct its mission and effectuate informed policymaking that best serves the needs of dialysis patients.

11. Some of the most important federal provisions related to dialysis are found in the Medicare Secondary Payer Act ("MSPA"). Based on my role with DPC and my legal training, I am familiar with the MSPA, its purposes, and its legislative history. Congress had three objectives when it enacted the MSPA. *First*, Congress designed the MSPA to allow a dialysis patient to keep her private insurance coverage if she elects to do so. Accordingly, there is no requirement that an ESRD patient must leave her health plan. (Doing so would, in fact, make receiving a kidney transplant more difficult if not impossible.) *Second*, Congress intended insurance providers to contribute to the cost of dialysis coverage. From 1973 until 1981, Medicare bore the entire burden of paying for dialysis for ESRD patients. The MSPA inverted this state of affairs by mandating that private insurers cover ESRD patients for the duration of the "coordination period," which was originally 12 months and is now 30 months. *Finally*, Congress sought to mitigate perverse incentives. Without the coordination period, unscrupulous insurers would be financially incentivized to allow patients with CKD to deteriorate to ESRD, thus foisting those patients and their costly dialysis needs onto Medicare. AB 290 will interfere with all three of Congress's objectives.

AB 290 Will Cause Irreparable Harm to DPC and Its Members

12. Based on my close working relationship with AKF and information I have learned from DPC members, I know AKF has already curtailed its charitable work to avoid liability under AB 290. Most notably, AKF has ceased providing new dialysis patients with premium assistance in California because the new grants

would not be "grandfathered" under the terms of AB 290. It is my understanding that, by the end of the year, AKF must either provide premium assistance that complies with the terms of AB 290 or else stop providing premium assistance in California entirely.

13. If AKF stops providing premium assistance in California while this suit is litigated, DPC and its members will be irreparably and irreversibly harmed.

14. It is imperative that ESRD patients have access to dialysis treatment, as missing even one treatment can mean death. In my experience, providing patients with affordable and reliable insurance coverage is the best way to ensure that they receive the dialysis treatments they need at regular intervals. However, quality health insurance coverage is expensive. The average annual premium for employer-sponsored health insurance in 2019 was $7,188 for single coverage. Very few ESRD patients are be able to pay for such coverage without assistance. Therefore, AKF's premium assistance program is critical to ensuring dialysis patients have access to the treatment they need. If AB 290 is allowed to go into effect while this lawsuit is litigated, however, it will disrupt, or even terminate, the insurance coverage of many of DPC's members.

15. Because many of DPC's members cannot afford their insurance coverage without assistance from AKF, these patients will lose their current insurance. DPC members who have private insurance coverage due to AKF's assistance will no longer be able to afford that coverage. Upon losing AKF's financial assistance, these members will be forced to shift to Medicare or Medicaid, provided that they qualify for those programs and can afford to pay the associated copayments. For DPC members who cannot afford to move to public insurance options, the alternative is no insurance at all.

16. Based on my knowledge and experience, there are many reasons why an ESRD patient could prefer to maintain commercial coverage rather than immediately enroll in Medicare. For instance, Medicare does not offer coverage for

dependents, does not offer dental coverage, and does not have an out-of-pocket maximum. According to our Membership Survey, patients on Medicare were more than twice as likely to report having trouble getting the health care they wanted or needed compared with patients on private health insurance plans. We also found that Medicare beneficiaries were more likely to report difficulties in getting the specific medications they needed, more likely to report having difficulty getting answers to their questions, and more likely to experience delays in receiving care or treatment. For these reasons, DPC members strongly prefer to maintain their private insurance coverage when they can afford to do so. Likewise, a public insurance option like Medicare is far preferable to no insurance coverage at all.

17. Some DPC members may be able to afford their current insurance coverage, but only as a result of great personal financial sacrifice. As stated above, more than three-quarters of DPC's members are either unemployed or retired and thus have very low incomes. If forced to pay for their own insurance premiums without AKF's assistance, these DPC members would likely have to forego other essentials in order to continue receiving their dialysis treatments.

18. Further, dialysis patients who change insurance coverage frequently lose their places on kidney transplant waiting lists. Even in the best of circumstances, DPC members typically wait anywhere from three to seven years to receive a kidney transplant. If AB 290 is allowed to go into effect, it will jeopardize DPC members' access to life-saving kidney transplants through even further delay. These members will also be forced to spend even more time receiving dialysis treatment, and at great physical, financial, psychological, and emotional costs.

19. The effects of AB 290 will expand well beyond lost insurance coverage. From my experience at DPC, I know that our members suffer constant stress and anxiety about their health care needs and expenses. Many of our members have told me that paying for their dialysis treatments is already the largest source of stress and anxiety in their lives. AB 290 will only exacerbate the fears of DPC members due

to the uncertainty it will cause, to say nothing of the increased financial burdens it will place on them.

20. AB 290 will also have less immediate, but no less irreparable, long-term effects on DPC's members in California. In order to be economically viable, dialysis providers charge patients who have private insurance coverage higher rates than patients who have Medicare or another public insurance option. Based on my knowledge and experience, it would not be possible for dialysis providers to offer the level of access and quality of treatment that dialysis patients require if the dialysis providers received only the current Medicare reimbursement rate from all patients. But AB 290 will mandate that dialysis providers will receive only the Medicare reimbursement rate for most patients in California.

21. Based on my knowledge and experience, AB 290 will therefore force dialysis providers to close existing clinics. This will only worsen DPC members' access to dialysis treatment. The closure of even one dialysis clinic in California will have ripple effects on DPC's members and will burden them with additional costs, transportation time, anxiety, and uncertainty, as well as lowering the quality of care at the dialysis clinics that do remain open by foisting additional patients upon them.

22. Similarly, based on my knowledge and experience, AB 290 will discourage dialysis providers from opening new clinics in California. Because ESRD is becoming increasingly common due to the country's aging population, it is imperative that dialysis providers continue to open new clinics to meet the growing need for dialysis treatment. As stated above, there are more than 100,000 new ESRD diagnoses ever year in the United States. However, AB 290 will create an

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impediment to dialysis providers opening new clinics in California. This will further limit our members' access to critical dialysis treatment.

I declare under the penalty of perjury and the laws of the United States that the foregoing is true and correct this 7th day of November 2019, at Washington, District of Columbia.

HRANT JAMGOCHIAN