

October 23, 2018

The Honorable Todd Young
US Senate
400 Russell Senate Office Building
Washington, DC 20510

The Honorable Bill Nelson
US Senate
716 Hart Senate Office Building
Washington, DC 20510

The Honorable Dean Heller
US Senate
324 Hart Senate Office Building
Washington, DC 20510

The Honorable Michael Bennet
US Senate
261 Russell Senate Office Building
Washington, DC 20510

Dear Senators Young, Nelson, Heller, and Bennet:

I am writing to you today on behalf of Dialysis Patient Citizens (DPC), America's largest patient-led kidney disease organization representing 33,000 dialysis patients and their family members. I first want to thank you for your efforts to improve care for dialysis patients by introducing the *Dialysis PATIENTS Demonstration Act* (H.R. 4143 / S. 2065). The PATIENTS Act, as its name suggests, puts dialysis patients first by providing additional support that can help break down barriers to care that patients on dialysis face. The teams of nephrologists, nurses, social workers, dialysis providers, and others empowered by the PATIENTS Act would be able to better coordinate a patient's care without limiting patient choice or infringing on the patient-physician relationship.

While I believe the patient-centered support of the PATIENTS Act would be an undeniable improvement over the system in place today, there are others in the kidney care community who have expressed concerns and even opposition to the legislation, despite the Ways and Means Committee making multiple changes to the legislation to address their concerns. I do not doubt that all members of the kidney care community have the best interest of patients at heart, but I fear that misunderstandings about the legislation are fueling misdirected opposition. I would like to address the points raised by members of the community that I feel deserve clarification and correction.

- The PATIENTS Act does not limit patient choice in any way. Much like an Accountable Care Organization, patients are aligned to the demonstration based on where they have chosen to receive dialysis care. After alignment, patients keep all Medicare part A and B benefits, and retain their right to see any Medicare provider. The PATIENTS Act then builds on Medicare fee-for-service by providing beneficiaries with additional support from an interdisciplinary care team, and makes optional supplemental benefits available for those beneficiaries who wish to elect them. If patients choose not to participate in the PATIENTS Act demonstration, they have multiple opportunities to opt-out of the program, and at any point could decline to interact with the PATIENTS Act care team and continue accessing their Medicare benefits as they do today. In fact, this legislation provides dialysis patients with the choice of receiving integrated care vs. continuing in our current fragmented care delivery system, an important step as care coordination is currently not an option for most ESRD patients. Also, while dialysis patients will become eligible for Medicare

Advantage in 2021, this demonstration gives patients the choice of staying in Medicare FFS and receiving the benefits of integrated care without having to enroll in MA

- Patients retain access to all currently available Medicare transplant surgeons and transplant programs. The delivery of transplant-related services appropriately remains in the hands of transplant professionals. These services, along with all Medicare A and B benefits, would be paid for by the PATIENTS Act Organization according to Medicare rates. Organ acquisition costs, the most significant cost incurred during transplantation, would be paid directly by Medicare FFS. While the PATIENTS Act changes financial accountability for covered services, patients and their nephrologist are still responsible for all treatment decisions, including those related to transplantation.
- The latest version of the legislation includes several transplant-focused quality measures that Organizations must report to the Health and Human Services (HHS) Secretary, to Congress, and to the public. The transplant-focused quality measures are in addition to those that dialysis facilities must currently meet as a condition for serving Medicare beneficiaries. Organizations will be required to meet certain standards on these quality measures, which will be developed with input from nephrologists and transplant providers. Organizations that fail to meet these quality standards will face contract suspension or termination. No other program for dialysis patients offers such strong transplant related consumer protections.
- The PATIENTS Act will complement the long-awaited choices for ESRD beneficiaries to access integrated care. While ESRD patients continue to be barred from electing most MA plans until 2021, Congress should promote more models to expand access to integrated care and to test what programs work best for patients, their families, and providers. The PATIENTS Act also aligns with Medicare's broader shift from volume to value by encouraging providers to participate in value-based care, creating incentives for providers to care for their patients holistically and take accountability to reduce health care costs.
- The legislation includes a number of guardrails to ensure the program is improving quality and reducing costs before the demonstration could be expanded. The Secretary must also certify that expansion of the demonstration would not deny or limit Medicare coverage or benefits for the dialysis patient population. Finally, the legislation also calls for studies by HHS and the Medicare Payment Advisory Commission to regularly monitor the impacts of the demonstration, including specifically on access to transplantation.

The protections and benefits outlined above should make clear to all stakeholders that the PATIENTS Act would create a positive change in the care for dialysis patients without sacrificing patient choice or negatively impacting the role of physicians and other providers. The proposed model creates a differential opportunity to improve patient experience and satisfaction by making individualized care planning a centerpiece of the care strategy, and by using transparent, public reporting to hold providers accountable for high quality care. Dialysis patients face an enormous set of challenges in navigating the fragmented, fee-for-service health care system that predominates today, and deserve access to more programs that can help promote better communication and care coordination between their multiple providers and improve their care.

Thank you again for your efforts to improve the lives of dialysis patients. I applaud you all for your efforts to engage with the community and continue to strengthen the legislation as you have. Please let me know if there is any assistance that I may provide in order to advance this important legislation for our patients.

Sincerely,

A handwritten signature in black ink, appearing to read "Hrant Jamgochian". The signature is fluid and cursive, with a prominent initial "H" and a long, sweeping underline.

Hrant Jamgochian, J.D., LL.M.
Chief Executive Officer
Dialysis Patient Citizens