



February 28, 2018

The Honorable Jason Smith  
118 Longworth House Office Building  
Washington, DC 20515

The Honorable Earl Blumenauer  
1111 Longworth House Office Building  
Washington, DC 20515

The Honorable Cathy McMorris Rodgers  
1314 Longworth House Office Building  
Washington, DC 20515

The Honorable Tony Cárdenas  
1510 Longworth House Office Building  
Washington, DC 20515

Dear Representative Smith, Representative Blumenauer, Representative McMorris Rodgers, and Representative Cárdenas:

On behalf of the American Society of Nephrology (ASN) and the American Association of Kidney Patients (AAKP), thank you for your commitment to improving the lives of the 40 million Americans affected by kidney diseases, including more than 680,000 Americans with kidney failure.

ASN represents more than 18,000 physicians, scientists, nurses, and other health professionals dedicated to improving the lives of people with kidney diseases. The society's membership includes approximately 90 percent of the nephrologists in the United States. ASN is a not-for-profit organization dedicated to promoting excellence in kidney care and ensuring access to patient-centered high-quality care, regardless of socioeconomic status, geographic location, or demographic characteristics.

With more than 120,000 patient and caregiver members, AAKP is America's largest and oldest fully independent kidney patient organization. AAKP's mission is to educate patients about kidney diseases and to help preserve their freedom to wisely choose which life-saving treatment best aligns to their aspirations, including full-time work and a career.

ASN and AAKP appreciate your recognition of the significant challenges facing individuals with kidney diseases and kidney failure as well as your commitment to improving their lives. Our organizations were both grateful for the opportunity to provide input on the draft Dialysis PATIENTS Demonstration Act of 2017 (H.R. 4143), and we commend your efforts to collaborate with our organizations and the rest of the kidney community to refine and further improve the legislation. However, as described below, ASN and AAKP are unable to support the legislation.

We appreciate the emphasis in the bill on creating a demonstration project to test an integrated care model to increase care coordination. As staunch proponents of the move towards value-based care, we believe that increasing care coordination for patients with kidney diseases—including those with kidney failure—is essential to provide better care for people with these complex needs. ASN and AAKP believe the model proposed in H.R. 4143 offers elements with the potential for:

- **Improving patient care via reduced hospitalizations**, a serious event from patients' perspective and one of the costliest aspects of the Medicare ESRD program.
- **Enhancing care coordination** by requiring a range of integrated care strategies.
- **Increasing access to social workers and dieticians**, which current research shows improves long-term patient outcomes.
- **Improving access to transportation services**, a current challenge for many patients that, if resolved, could help improve adherence, outcomes, and quality of life.

However, ASN and AAKP remain concerned about the possibility of unintended consequences and risks associated with foundational aspects of the PATIENTS Act. These potential risks include:

- **Restricting patient choice** by automatically enrolling patients in the model and not permitting them to move from an ESRD Integrated Care Organization's preferred network to its open network after a 75-day period. Additionally, patients must wait a full year to make any of the permitted changes, regardless of their care experience.
- **Exacerbating existing silos of care** by excluding patients with earlier kidney diseases and missing critical opportunities to slow or prevent progression to kidney failure as well as improve patients' lives and avoid more costly care.
- **Excluding transplanted patients from the model**. Not including the optimal therapy for most patients as a treatment option within the model runs contrary to national efforts to encourage more transplantation as a means of improving patient health outcomes and lowering overall costs to taxpayers.
- **Infringing on the patient-physician relationship and disrupting care** by prohibiting nephrologists who are not part of preferred networks from caring for their patients receiving care in units owned by an ESRD Integrated Care Organization participating in the model.

ASN and AAKP believe that the potential beneficial elements for patients receiving dialysis in the PATIENTS Act could be achieved in more effective ways that minimize or eliminate the potential risks and unintended consequences described above. As such, ASN and AAKP are unable to support H.R. 4143 at this time.

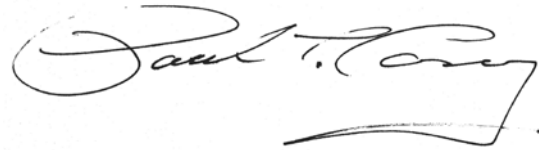
However, we remain grateful for your ongoing commitment to improving the lives of the millions of Americans with kidney diseases and kidney failure. We look forward to continuing the dialogue, and to working together in future endeavors to achieve the important and shared goals of improving the health outcomes of patients who currently suffer from kidney disease and those yet to be diagnosed.

Again, thank you. ASN and AAKP would be pleased to discuss these comments, and the society stands ready to assist in any way. Please feel free to contact ASN Director of Policy and Government Affairs Rachel Meyer at (202) 640-4659 or at [rmeyer@asn-online.org](mailto:rmeyer@asn-online.org) or Richard Knight, AAKP Vice President and Chair of Public Policy at (240) 508-2552 or at [rk.reslend@gmail.com](mailto:rk.reslend@gmail.com).

Respectfully,

A handwritten signature in black ink, appearing to read "Mark Okusa". The signature is fluid and cursive, with a long horizontal stroke at the beginning.

Mark Okusa, MD, FASN  
ASN President

A handwritten signature in black ink, appearing to read "Paul T. Conway". The signature is cursive and includes a large, sweeping flourish at the end.

Paul T. Conway  
AAKP President



February 28, 2018

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

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

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

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

Dear Senator Young, Senator Nelson, Senator Heller, and Senator Bennet:

On behalf of the American Society of Nephrology (ASN) and the American Association of Kidney Patients (AAKP), thank you for your commitment to improving the lives of the 40 million Americans affected by kidney diseases, including more than 680,000 Americans with kidney failure.

ASN represents more than 18,000 physicians, scientists, nurses, and other health professionals dedicated to improving the lives of people with kidney diseases. The society's membership includes approximately 90 percent of the nephrologists in the United States. ASN is a not-for-profit organization dedicated to promoting excellence in kidney care and ensuring access to patient-centered high-quality care, regardless of socioeconomic status, geographic location, or demographic characteristics.

With more than 120,000 patient and caregiver members, AAKP is America's largest and oldest fully independent kidney patient organization. AAKP's mission is to educate patients about kidney diseases and to help preserve their freedom to wisely choose which life-saving treatment best aligns to their aspirations, including full-time work and a career.

ASN and AAKP appreciate your recognition of the significant challenges facing individuals with kidney diseases and kidney failure as well as your commitment to improving their lives. Our organizations were both grateful for the opportunity to provide input on the draft Dialysis PATIENTS Demonstration Act of 2017 (S. 2065), and we commend your efforts to collaborate with our organizations and the rest of the kidney community to refine and further improve the legislation. However, as described below, ASN and AAKP are unable to support the legislation.

We appreciate the emphasis in the bill on creating a demonstration project to test an integrated care model to increase care coordination. As staunch proponents of the move towards value-based care, we believe that increasing care coordination for patients with kidney diseases—including those with kidney failure—is essential to provide better care for people with these complex needs. ASN and AAKP believe the model proposed in S. 2065 offers elements with the potential for:

- **Improving patient care via reduced hospitalizations**, a serious event from patients' perspective and one of the costliest aspects of the Medicare ESRD program.
- **Enhancing care coordination** by requiring a range of integrated care strategies.
- **Increasing access to social workers and dieticians**, which current research shows improves long-term patient outcomes.
- **Improving access to transportation services**, a current challenge for many patients that, if resolved, could help improve adherence, outcomes, and quality of life.

However, ASN and AAKP remain concerned about the possibility of unintended consequences and risks associated with foundational aspects of the PATIENTS Act. These potential risks include:

- **Restricting patient choice** by automatically enrolling patients in the model and not permitting them to move from an ESRD Integrated Care Organization's preferred network to its open network after a 75-day period. Additionally, patients must wait a full year to make any of the permitted changes, regardless of their care experience.
- **Exacerbating existing silos of care** by excluding patients with earlier kidney diseases and missing critical opportunities to slow or prevent progression to kidney failure as well as improve patients' lives and avoid more costly care.
- **Excluding transplanted patients from the model**. Not including the optimal therapy for most patients as a treatment option within the model runs contrary to national efforts to encourage more transplantation as a means of improving patient health outcomes and lowering overall costs to taxpayers.
- **Infringing on the patient-physician relationship and disrupting care** by prohibiting nephrologists who are not part of preferred networks from caring for their patients receiving care in units owned by an ESRD Integrated Care Organization participating in the model.

ASN and AAKP believe that the potential beneficial elements for patients receiving dialysis in the PATIENTS Act could be achieved in more effective ways that minimize or eliminate the potential risks and unintended consequences described above. As such, ASN and AAKP are unable to support S. 2065 at this time.

However, we remain grateful for your ongoing commitment to improving the lives of the millions of Americans with kidney diseases and kidney failure. We look forward to continuing the dialogue, and to working together in future endeavors to achieve the important and shared goals of improving the health outcomes of patients who currently suffer from kidney disease and those yet to be diagnosed.

Again, thank you. ASN and AAKP would be pleased to discuss these comments, and the society stands ready to assist in any way. Please feel free to contact ASN Director of Policy and Government Affairs Rachel Meyer at (202) 640-4659 or at [rmeyer@asn-online.org](mailto:rmeyer@asn-online.org) or Richard Knight, AAKP Vice President and Chair of Public Policy at (240) 508-2552 or at [rk.reslend@gmail.com](mailto:rk.reslend@gmail.com).

Respectfully,

A handwritten signature in black ink, appearing to read "Mark Okusa". The signature is fluid and cursive, with a long horizontal stroke at the beginning.

Mark Okusa, MD, FASN  
ASN President

A handwritten signature in black ink, appearing to read "Paul T. Conway". The signature is cursive and includes a large, sweeping flourish at the end.

Paul T. Conway  
AAKP President