

A Patient's Perspective on Advancing American Kidney Health Initiative

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Introduction

On July 10, 2019, President Trump signed an Executive Order—Advancing American Kidney Health (AAKH)—that will significantly change the administering of kidney care. Kidney disease was the ninth leading cause of death in 2017. Hence, it is somewhat surprising and disappointing that not since President Nixon signed Public Law 92–602, a Social Security bill, on October 20, 1972, has kidney disease received such support from the presidential level. The bill Nixon signed contained a provision that anyone with ESKD will be covered by Medicare. The backstory to Public Law 92–602 is that advocacy by Shep Blazer, Vice President of the National Association of Patients on Hemodialysis (NAPH) and others, who testified before the House Ways and Means Committee on November 4, 1971, motivated Congress. Shep Blazer testified while connected to a functioning artificial kidney machine.

Hence, patient engagement from decades ago informs my perspectives. The NAPH became the American Association of Kidney Patients (AAKP). As President of the AAKP, I work tirelessly with legislators on Capitol Hill and many of the leaders of the Executive Branch to help frame the context of changes in health care that would benefit patients with kidney disease. It was with a great deal of pride that members of the AAKP attended the announcement of AAKH at the Ronald Reagan International Building. Patients with kidney disease throughout the country basked in newfound hope. However, hope is not a strategy. As I listened to the lofty goals articulated in the Executive Order, I immediately started thinking about implementation. A good strategy, which I believe is the underpinning of the AAKH initiative, can be harmed by poor execution.

The AAKH initiative is comprehensive and addresses the entire kidney continuum. The realignment of incentives encourages health care professionals to focus on aspects of kidney disease that align better with quality of life and wellbeing for patients. For patients, realignment of incentives translates to a longstanding AAKP motto, which is early identification of kidney disease, slow the progression, educate the patient, explore a pre-emptive transplant, select an appropriate dialysis modality, and

aggressively pursue a transplant. The AAKH initiative has three high-level goals (1), which are

1. reduce the number of Americans developing ESKD by 25% by 2030,
2. increase the number of new (incident) American patients on home dialysis or transplantation to 80% by 2025, and
3. double the number of organs available for transplantation by 2030.

The AAKH initiative brings together the various programs and efforts already underway within the many agencies under the purview of Health and Human Services (HHS). The goals mentioned above are aspirational and hard to argue with the need identified in each target.

The AAKP National Strategy

As we celebrate our 50th anniversary, the AAKP is more relevant than ever before. My predecessor, Paul Conway (Immediate Past President, currently serving as Chair of Public Policy and Global Affairs) and I developed a National Strategy in 2014. The objectives of the National Strategy are to elevate the voice and presence of our patients to the national level. The National Strategy builds on the AAKP's original mission of educating and advocating patients with kidney disease. We included patient engagement as part of the AAKP's mission so that we could define patient engagement from a patient perspective. For example, Shep Blazer dialyzing on the floor of the House Ways and Means Committee is a form of patient engagement at the highest level. Education of patients and advocating for patients are foundational pieces of the puzzle of the successful implementation of the AAKH initiative. No doubt, with new incentives to nudge health care professionals toward focusing on specific metrics to achieve desired outcomes, I highlight the dichotomy that often exists between patient preferences and health care preferences. The Standardized Outcomes in Nephrology-Hemodialysis consensus workshop (2) indicated that a large number of evidenced-based clinical outcomes were varied but not patient centered. Timing matters, with the increased level of patient engagement, changes to the traditional dialysis facility business model brought about by new

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entrants with resources focusing on home dialysis options, and increased innovation along the kidney continuum making the kidney arena more attractive. New entrants into the dialysis industry include CVS Health, Somatus, and Cricket Health. These businesses bring scale and innovation to the dialysis industry, with each firm focusing on home dialysis.

The AAKH initiative requires physician leadership. An industry in transition requires vision and commitment. The notion that pre-emptive transplants, increases in home dialysis, and more living donors are not feasible in our current system is not acceptable. The President's Executive Order, if aggressively implemented, will change the current policy. As patients, we intend to support health care leaders who embrace the gift handed to them from the Centers for Medicare and Medicaid (CMS) and think kidneys first and if not available, let us get you home for dialysis (3).

Let us take a look at each of the goals, and consider strategies discussed among patients that can facilitate the achievement of the goals.

Goal 1: Reduce the Number of Americans Developing ESKD by 25% by 2030

Patients need an earlier diagnosis, which is critical to reducing the number of Americans developing ESKD. Diabetes and hypertension are the number 1 and number 2 causes of kidney disease. The AAKP has advocated for a change in how we educate patients about kidney disease. We ridiculed those who supported the idea of paying primary care physicians specifically for diagnosing kidney disease. The CMS is implementing the Primary Care First Model, which incentivizes primary care physicians for the total cost of care, moving away from fee for service (4). Considering the number of patients who crash into dialysis, I suggest that this is a very achievable goal.

One of the crucial aspects of the AAKH initiative is leveraging resources from across HHS. The AAKP has mobilized patients through our ambassador program to assist in the continued education of patients. Ambassadors attend meetings and conferences sponsored by the federal agencies engaged in addressing kidney disease issues. The AAKP ambassadors are highly engaged and educated patients and care partners dedicated to carrying out the mission of the AAKP—to educate and advocate. Peer to peer interaction allows patients to share knowledge acquired at different venues and their personal experiences with new patients. Effective patient education is very nuanced. Unfortunately, there is a difference between funded education programs and effective education programs.

Goal 2: Increase the Number of New (Incident) American Patients on Home Dialysis or Transplantation to 80% by 2025

The success achieved in goal 1 will ultimately strengthen this goal. The key to the successful implementation of this goal is education. Increasing the number of American patients on home dialysis cannot be accomplished under the dominate dialysis facility business model. We must change the business model to one that emphasizes a transplant first and home dialysis second approach. An outside-in approach, whereby we put the emphasis

on what is best for the patient and build out the infrastructure to support this strategy, requires a drastic change away from the current business model. For the record, I received excellent care during my time at an in-center hemodialysis facility. However, I did not have any options presented to me, because I crashed into dialysis from the emergency room.

The belief expressed by a few in the kidney arena that forcing patients to do home dialysis takes away a patient's choice is a false notion. People, in general, have a fear of the unknown. The thought of a patient doing home dialysis elicits fear of the unknown. Hence, there is a need for early identification of kidney disease, slowing the progression, and educating the patient. Only 12% of patients are offered home dialysis, with approximately 33% made aware that peritoneal dialysis is an option. Moreover, we need to encourage a change in physician behaviors to inspire them to prepare and refer more patients for home dialysis (5).

Goal 3: Double the Number of Organs Available for Transplantation by 2030

The third goal is perhaps the most ambitious goal of the President's Executive Order. I serve on the Scientific Registry for Transplant Recipients (SRTR) Visiting Committee. The role of the SRTR Visiting Committee is to advise the SRTR on issues, such as analytical methodologies to support Organ Procurement and Transplantation Networks (OPTNs), methods used in simulated allocation methods, and other similar matters. The United Network for Organ Sharing manages the OPTN. The OPTN establishes policies that govern all organizations working in organ donation and transplantation. The 58 Organ Procurement Organizations (OPOs) connect with 254 transplant hospitals for distribution and procurement of organs.

The legal, regulatory, and policy background adds to the level of complexity to increasing available organs. I received a transplant 13 years ago from a living donor. After I reviewed the challenges in using the system, I was relieved to receive a kidney from a living donor. On the basis of a review of current literature on kidney transplantation, I submit that we can do better. The obvious way to increase available organs is to decrease the number of kidney discards. What are the best practices in other countries? Researchers in France theorize that, by accepting organs from older patients and patients with comorbidities, the United States could use 62% of kidneys currently discarded (6). Although France has a very different health care system, such a significant difference merits analysis. We need to revisit the current policy and apply best practices of the more successful 58 OPOs to all of the OPOs with discard rates above a targeted percentage. We should consider input from patients with kidney disease, the beneficiaries of transplants, in establishing acceptable metrics.

Proposed Solutions

Congressional support is needed to achieve the AAKH initiative. In short, our legislators need to take action. Initial steps include the following:

- pass the Living Donor Protection Act (H.R. 1224/S. 511),
- pass the Comprehensive Immunosuppressive Drug Coverage Extension Act (when introduced), and

- support the goals of the AAKH initiative by (1) increased funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to provide continuity for projects, such as the Kidney Precision Medicine Project, and (2) increased funding for the American Society for Nephrology (ASN)/HHS Kidney X Initiative.

The AAKP will continue to collaborate with >75 stakeholder organizations at all phases of the kidney continuum to address goals of the AAKH initiative. A few of the AAKP's strategic roles include leadership positions with the NIDDK's Kidney Precision Medicine Project and the APOL1 Long-Term Kidney Transplantation Outcomes Network Initiative, the Food and Drug Administration's Patient Engagement Advisory Committee, the Centers for Disease Control and Prevention's Making Dialysis Safe Coalition, the ASN's Kidney Health Initiative, the Health Resources and Services Administration's SRTR Visiting Committee, the Transplant Roundtable, and Quality Insight's Renal Network 5. Targeted leadership positions facilitate the assertion of the patient voice at appropriate levels.

The AAKP is marshaling its collaborative efforts under the overarching idea of the Decade of the Kidney. The AAKP announced the Decade of the Kidney at its June 20, 2019, National Policy Summit in Washington, DC. Awareness of the Decade of the Kidney has accelerated since President Trump's signing of the AAKH initiative and the AAKP's accompanying joint statement of support for the Trump Administration's kidney actions by the AAKP leaders President Richard Knight and Chair of Policy and Global Affairs Paul T. Conway. If we are to achieve the lofty vision outlined in the President's Executive Order, we must further engage patients with kidney disease and accept them as equal partners in our efforts to defeat kidney disease. The Decade of the Kidney has begun.

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Disclosures

Mr. Knight is a former patient on hemodialysis who received a kidney transplant approximately 11 years ago. He is President of

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