

## **OPINION**

## Presidential order calls on transforming kidney disease treatment

Updated: Sep. 12, 2019, 2:42 p.m. | Published: Sep. 12, 2019, 2:42 p.m.

By Cutessa Bourge, Kidney transplant recipient Ann Rayburn, Kidney donor

By Guest Authors **Cutessa Bourge**, kidney transplant recipient

and Ann Rayburn, kidney donor

There is a silent disease targeting Americans, a disease that will continue to grow in presence as the prevalence of obesity and diabetes continues to rise. Nearly 37 million Americans are affected by kidney diseases, and more than 726,000 Americans suffer from complete kidney failure, causing them to rely on dialysis or a kidney transplant.

Of those who experience kidney failure, 35.4% receive little or no prekidney failure care by a nephrologist or kidney doctor. Patients are taken to emergency rooms and being told that they need to immediately receive a transplant -- a therapy they must get in a 100,000- person line to receive -- or start on intensive dialysis – a therapy with worse outcomes than all but four of the most deadly cancers -- in order to have a chance of survival. We have witnessed first-hand the toll kidney disease has had on Americans, a toll that has gone unrecognized for nearly 50 years. Recently, President Donald J. Trump signed the executive order on Advancing American Kidney Health. This historic Executive Order is the first major transformation of the kidney care system since 1973 when the Medicare End-Stage Renal Disease Program was launched.

The executive order demands that we as a nation fundamentally shift our health care system to pay not for kidney sickness but for kidney health through three ambitious goals that will improve the lives of kidney disease patients:

1. Lower the number of patients who develop kidney failure.

2. Improve the quality and quantity of therapies available to Americans with kidney diseases.

3. Increase the number of kidneys available for transplant.

Most of the patients waiting on a kidney transplant currently rely on the generosity of a deceased kidney donor.

To accomplish goal number three, we encourage everyone to register to be a donor with Legacy of Hope, Alabama's Organ and Tissue Donation Alliance, at <u>www.LegacyofHope.org</u>. Legacy of Hope's efforts to eliminate the organ waitlist by shepherding the gift of life to those in need of organ and tissue transplants strongly aligns with the executive order. The executive order also encourages the development of new and innovative therapies, such as the creation of an artificial kidney to improve the lives of Americans with kidney failure, who today rely on dialysis - an arduous, costly therapy that has not fundamentally changed in decades. It also highlights KidneyX, a public-private partnership between the Department of Health and Human Services and the American Society of Nephrology, as the most promising vehicle to accelerate desperately needed innovation in kidney care. KidneyX aims to improve the lives of the millions of Americans affected by kidney diseases by accelerating the development and commercialization of innovative products across the spectrum of kidney care including prevention, diagnosis, and treatment. KidneyX achieved early progress through its inaugural prize competition, Redesign Dialysis, which asked innovators to begin developing next-generation dialysis products.

As a public-private partnership, KidneyX relies on funding from both public and private sources. The private sector has already committed the first \$25 million and the House of Representatives has appropriated funding for KidneyX for fiscal year 2020. The Senate must now act and members must do their part to provide the necessary \$25 million for KidneyX.

Senator Richard Shelby, is the chairman of the Senate Appropriations Committee, and therefore in a critical position to secure FY 2020 appropriations for KidneyX. We call on Senator Shelby to work with his Senate colleagues in a bi-partisan manner to address the needs of the 645,665 patients with kidney diseases in Alabama and across the nation.

The President took a historic step by signing Executive Order on Advancing American Kidney Health, which challenges the nation to change how we tackle kidney diseases. On behalf of the patients with kidney diseases, we count upon Senator Shelby to lead his Senate colleagues to follow the President's historic leadership and fund this priority.

Signed by Cutessa Bourge, an Alabama kidney transplant recipient and an Alabama Ann Rayburn, kidney donor.

## <u>source</u>