



**The Honorable Larry Bucshon, MD; Member, U.S. House of Representatives (IN);
Co-Chair, U.S. Congressional Kidney Caucus**

Remarks made during the AAKP 5th Annual Policy Summit

Transcription

Thank you very much, Ed, for the kind introduction.

And Ed, I would like to congratulate you on your election announced on Veterans Day as the new president of AAKP. This is an important moment of opportunity for the kidney community.

And I think having a U.S. Marine Corps veteran and former congressional staffer leading the largest kidney patient organization is absolutely terrific.

I also extend my congratulations to Ms. Jennifer Jones, AAKP's newly elected Vice President, and another U.S. Marine Corps veteran who served three combat tours in Iraq and one in Afghanistan.

Thank you both for your service to America and to the kidney community.

It is a sincere honor to appear before AAKP today at your 5th National Policy Summit.

For over 50 years, AAKP has maintained a proud legacy of fighting for greater patient choice, preservation of the doctor/patient relationship, and policies that support innovation and the ongoing employment of patients.

I appreciate the work AAKP is doing to educate patient consumers and allies across the kidney community on key policies that may impact patients and their families, as well as innovations in kidney medicine.

Patient consumers have the greatest stake in the decisions made by Congress and within federal agencies about kidney care.

This makes your insights and voices, as both patients and taxpayers, extremely valuable.

I appear before you today as co-chair of the Congressional Kidney Caucus, but also, as a cardiothoracic surgeon and as a longtime patient advocate.

As a doctor, I know and understand the challenges so many of you have faced while managing chronic kidney disease and kidney failure.

I have spent many hours in consultations with patients and families, and many hours providing lifesaving care to my patients.

My work in Congress, and for kidney patients, is informed by these experiences and memories.

I realized that kidney disease is not simply a medical issue. It is an employment, workforce, and economic security issue as well.

It is important to me that we find ways for these patients to maintain employment when they are physically able.

I am pleased to be joined in these efforts by my Congressional Kidney Caucus Co-Chair and friend, Representative Suzanne DelBene from Washington.

I know that many of you watching today are involved in the University of Washington's research efforts relating to kidney cancer and the development of an artificial kidney.

In 2019, AAKP called the coming decade, The Decade of the Kidney™.

And I agree.

I am encouraged by the new generation of kidney related diagnostics, devices, and drugs moving from the research stage to clinical trials and through the FDA regulatory process.

This great progress in fighting kidney diseases would not have been possible without investments in kidney science and research through the U.S. Department of Health and Human Services, including the National Institutes of Health, as well as the Department of Veterans Affairs, and the Department of Defense's Congressionally Directed Medical Research Program.

Recognition must also be extended to private sector investors and drug companies that have made substantial investments in kidney science and research.

In many circumstances, they have done so because they understand innovations in kidney medicine are now a top priority across the U.S. Congress and the federal government.

Make no mistake about it. Advances in care innovations for kidney patients, both here in the United States and across the globe, would not be possible without the sustained involvement and ingenuity of companies operating in the free market.

Government alone cannot create and maintain the momentum needed to achieve long-term changes in kidney treatment and patient outcomes without the private sector.

So as AAKP considers key issues in kidney policies at your 5th Annual Policy Summit, allow me to highlight to the patient community several things I think are very important to maintain the momentum towards greater innovations in kidney care.

First, I encourage all kidney patients through AAKP and other patient organizations to expand your engagement with the new and existing companies in the kidney space.

These companies need your unique insights, and they need patients to be actively involved in research and clinical trials.

Second, patients should take every opportunity to raise their voices as new products enter the regulatory process of the FDA.

The FDA has done a fine job of creating mechanisms for patients to share their insights. And AAKP's past president, Paul Conway, a 42-year kidney patient, was recently selected by FDA to serve a second term as the chair of the FDA's new Patient Engagement Advisory Committee for Medical Devices.

Federal regulators need to be fully informed of the unique burdens kidney patients face.

Third, I encourage kidney patients and AAKP to keep a very close eye on issues of payment for, and patient access to, new therapies that are being made available to slow kidney disease progression and to stop kidney failure.

If these therapies are not being made available through CMS or insurers, you must raise your voices to payers and keep Congress informed of unnecessary barriers to access.

The American taxpayer pays billions of dollars every year to support status quo dialysis therapy and the accompanying high costs of disability unemployment caused by kidney disease.

This is not a sustainable situation for either the patient community or the taxpayer.

It makes absolutely no sense to invest taxpayer funds in innovations that forestall kidney failure if the patients who are most at risk cannot access these drugs.

This is an important issue to me and the Congressional Kidney Caucus, and that is why I sincerely appreciate AAKP's active public support for two pieces of legislation aimed at increasing patient access to therapies.

Your support for the "Improving Seniors Timely Access to Care Act" to reform the prior authorization process and the "RAISE Act" to increase access to anemia treatments has been vitally important to Congressional efforts.

I appreciate your work on these and other issues.

On a final note, I salute AAKP's efforts to organize patients in over 90 countries across the globe to support the rapid development of artificial kidneys through an international consortium.

Many patient leaders and fellow legislators in Europe and other nations share our vision of creating more treatment choices for patients awaiting lifesaving organ transplants.

We are working hard to increase organ donation in America, but I believe further development of artificial organs will also help save lives.

These technologies must be encouraged because they will also create new industries and new jobs.

They will also lead to better opportunities for kidney patients to remain fully engaged in society.

I congratulate the patient advocates of AAKP for their leadership and teamwork across the global kidney community and look forward to more progress in this arena.

Thank you once again for the opportunity to join with you today.

It is a sincere honor to work with the kidney community on policies that save lives through greater innovation.

I look forward to working with AAKP advocates throughout the coming year.

Thank you once again, Ed, for your service to the nation and the kidney community.

I know AAKP will remain a very trusted and active force for good under your leadership.