

Do Not Distribute – Note That Updates Are In Green

**2019 National Kidney Foundation District Meeting
Policy Talking Points**

**Please note that you don't have to use all the talking points, these are given to you to help guide your conversation with your legislator and their staff. You also may not have time to cover all three asks. They are placed in order of importance.*

Introduction

- Introduce yourselves – your name, city and state, and organization you represent.
- Thank you for taking the time to meet with me (us).
- Chronic Kidney Disease (CKD) is a national health priority.
- Tell them what CKD is and what kidney failure is.
- When our kidneys fail permanently, known as end-stage renal disease (ESRD), we must rely on either dialysis or a kidney transplant to survive.
 - Dialysis is most commonly provided in a clinic three times a week for four hours per treatment, but some patients are able to do their dialysis at home daily for a shorter period of time.
 - Some of us who were fortunate enough to have received a kidney transplant from a deceased or living donor had many challenges and barriers to getting that transplant.
- When kidney disease progresses, we are at higher risk of heart complications, complete kidney failure, and early death.
- **Over 37 million American adults** have kidney disease, but 90 percent don't even know they have it because it is under-diagnosed, even among people at the highest risk such as those with diabetes and hypertension.
- Kidney disease is the 9th leading cause of death in the U.S. and is growing in prevalence.
- Medicare spends approximately \$114 billion annually caring for individuals with CKD – much of these costs could have been avoided if kidney disease was caught earlier.

Story time!

- Share your stories about CKD/living donation/caregiving, how this has impacted you, your family, and friends.

NKF, CKD Resources, and You

- Remember that this is a primary focus of your district meeting!
- Talk to them about how you can be a resource for their staff to learn about CKD, resources in the area, and answer constituents' questions they may need assistance with.
- (You or NKF Staff) Tell your legislator about the National Kidney Foundation, resources available to constituents, and its activities and impact in your region. Did NKF help you? – if so, use that as an example. (if you need information, contact Andrew or Kelli to put you in contact with your local office).

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- Tell them about upcoming NKF events and ask if they would like to participate to learn more about CKD, to meet kidney patients, living donors, and their supporters, and hear their experiences. (if you need information, contact Andrew or Kelli to put you in contact with your local office).

National Kidney Foundation Policy Priorities

- We are also here today to talk to you about three of our policy priorities:
 - The Living Donor Protection Act - Preventing life, long-term care and disability insurance companies from discriminating against living organ donors and codifying that living organ donors are eligible for FMLA benefits.
 - Extending Medicare coverage of immunosuppressive medications for kidney transplant recipients
 - Increased funding for federal programs supporting CKD research, kidney disease awareness and early detection and living donation.
- Talk about CKD in your state. Examples from our materials:
 - Number of Medicare CKD patients diagnosed.
 - Number of patients on dialysis.
 - Patients on the transplant waitlist in your state or nationally.
 - Patients who died while waiting for a kidney in your state or nationally.
 - Number of patients who received a transplant in 2018 in your state or nationally.
 - How many patients were added to the waitlist in 2018 in your state or nationally.
 - Number of living donors in your state or nationally.

Living Donor Protection Act (S. 511/H.R. 1224)

- We must also protect our heroes, living donors, who have selflessly given the gift of life by donating their kidney (or other organs).
 - Discuss how many people are on kidney waitlist (US – approximately 95,000), how many died while waiting in 2018 (US – 3,700), and how many living donors there are nationally or in state (US – a third of transplants are by living donors, nearly 6,400 in 2018).
 - We need to expand the pool of living donors to help meet the demands of the waitlist. We also need to ensure that they do not suffer economic loss for helping save another's life.
 - Some donors have faced discrimination obtaining or affording life, disability, or long-term care insurance in the form of higher premiums or non-coverage based solely on their status as a living donor. There are no current federal legislative protections to prevent discrimination in these three types of insurance.
 - In a 2015 study by Johns Hopkins University of 1,046 kidney transplant patients, of the 186 donors who changed or initiated life insurance after donation, 46

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(25%) reported difficulty obtaining their desired coverage; 23 (12%) were denied altogether, 27 (15%) were charged a higher premium, and 17 (9%) were told they had a preexisting condition because they were kidney donors.

- Some fellow advocates have had this happened to them or know of others who have had it happen
- To donate an organ, living donors must meet strict health standards and are often in better health than the general populace.
- The life expectancy of kidney donors is similar to that of non-donors, perhaps even longer.
- 11 states have passed versions of the LDPA: Arizona, Arkansas, Colorado, Idaho, Illinois, Kansas, Maine, Maryland, New York, Oklahoma, and Oregon. If you are from one of these states, you can mention that the state legislature and governor support this legislation and you hope that the federal legislator(s) will follow their leadership.
- In addition, donating a kidney requires time away from work during the surgery and recovery. This can put someone's job at risk. These situations are not fair and can discourage someone from donating. While rare, some donors have lost their job after donating to save another's life.
 - Last year, the Department of Labor issued a regulatory opinion letter clarifying that they consider FMLA to cover living donation. This was a regulatory victory but is not law. (note: FMLA does not apply to businesses with fewer than 50 employees).
- Removing barriers to donation can result in more people being able to donate. Each Medicare patient who is removed from dialysis saves Medicare approximately \$55,000 per year, while vastly improving their quality of life.
- **The Ask: Please co-sponsor the Living Donor Protection Act which prohibits insurance companies from denying or limiting life, disability and long-term care insurance to living donors and from charging higher premiums. The bill also ensures living donation is covered under the Family and Medical Leave Act (FMLA), helping to protect their jobs while recovering.**

Extension of Immunosuppressant Medication Coverage by Medicare

- Kidney transplant recipients must take immunosuppressive drugs for the life of their transplant, or they increase the risk of losing their kidney.
- Medicare pays for the transplant but Medicare eligibility for non-aged or non-disabled beneficiaries ends 36 months post-transplant, leaving many recipients struggling to find affordable coverage.
 - This extension of Medicare benefits is limited to immunosuppressive drugs and impacts only those without other health insurance with this benefit.

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- A recent report by the Centers for Medicare & Medicaid Services, Office of the Actuary, says that \$300 million would be saved over ten years if Medicare were to cover these anti-rejection drugs for the life of a kidney recipient.
- Some people are denied, and other refuse, a transplant because they cannot afford these medications after Medicare coverage ends.
- If a transplant recipient loses the kidney, he or she has to go back on the wait list for a kidney transplant and go back on dialysis.
- A patient on dialysis costs Medicare \$89,400 per year but immunosuppressive drugs costs Medicare only \$2,300.
 - The HHS report, released in May, proves that extending Medicare coverage of immunosuppressive drugs for transplant patients beyond the current three years post-transplant not only saves lives but saves money. The report shows extending the coverage would result in an accumulated savings of approximately \$73 million over ten years.
- **The Asks: When introduced, please co-sponsor legislation to extend immunosuppressive medication coverage indefinitely.**

Federal Appropriations for CKD Research and Support Programs

- In addition, there is still much research that needs to be done on CKD, including on the genetic causes of kidney diseases like Alport Syndrome, Polycystic Kidney Disease, FSGS, and IgA Nephropathy as well as additional factors that increase risk of progression to kidney failure.
 - Despite the large investments the Federal Government makes into treating people with kidney failure, investment in research to treat kidney disease is very low.
 - Additional investment in research and programs to improve early detection, slow kidney disease progression, and improve access to kidney transplantation are cost-effective strategies to improve lives and lower future healthcare costs.
- **The Asks: Please contact your colleagues on the Appropriations Committee and support increased funding in Fiscal Year 2020 for CDC's Division of Diabetes Translation's (DDT) CKD Surveillance Project; the Health Resources and Services Administration's (HRSA) Division of Transplantation and Bureau of Primary Care; the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); and KidneyX, the Kidney Innovation Accelerator.**
- We thank you for your time today and look forward to following up with you on these issues.
- We will send you PDFs of all materials and a copy of the photo (which you will take after the meeting with the staff/legislator).