



Andrew Fullerton
National Kidney Foundation

The Birth of a Bill



116th CONGRESS
1st Session

H. R. 1224

To promote and protect from discrimination living organ donors.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 14, 2019

Ms. NOZEM (for herself and Ms. HERRERA BUSTILLOS) introduced the following bill, which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Oversight and Reform, House Administration, Education and Labor, and Financial Services, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To promote and protect from discrimination living organ donors.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

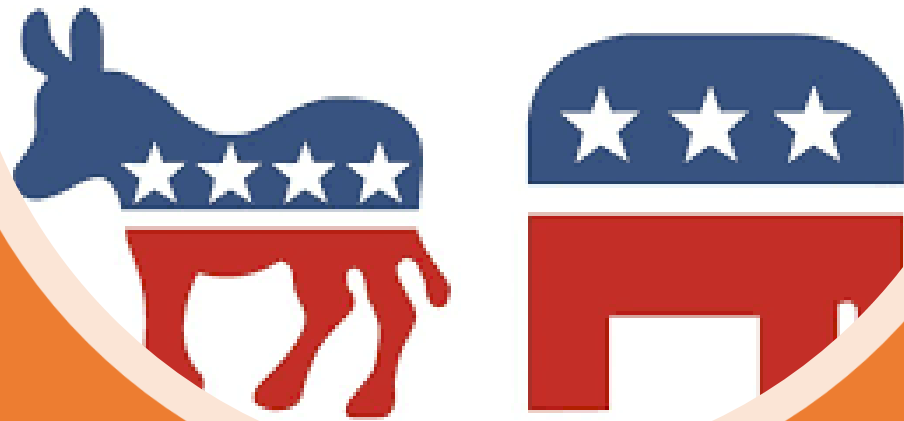
This Act may be cited as the "Living Donor Protection Act of 2019".

SEC. 2. PROHIBITION ON DENIAL OF COVERAGE OR INCREASE IN PREMIUMS OF LIFE OR DISABILITY INSURANCE FOR LIVING ORGAN DONORS.

NKF
Election Center

Vote.Kidney.Org

- Find out who is running for federal office in your area!
- Links to find out how to register for absentee ballots
- Some tips for voting safely if you must go in-person
- Requirements to vote, such as required IDs for first time voters

A screenshot of the National Kidney Foundation's website page titled "Healthy Voting in Election 2020". The page features a map of the United States with state abbreviations. Below the map is a dropdown menu labeled "-- Select a State --". There are two social media sharing buttons: "SHARE ON TWITTER" and "SHARE ON FACEBOOK". To the right of the map is a "KEY DATES" section with a table of election-related events.

NATIONAL KIDNEY FOUNDATION.

KEY DATES

14 SEP	DE Absentee Ballot Request Deadline (Primary)	15 SEP	DE Absentee Ballot Return Deadline (Primary)
18 SEP	SD In-person Absentee Voting Begins	20 SEP	VT Early Voting Begins

Healthy Voting in Election 2020

SAFE VOTING BY MAIL

SAFE VOTING IN-PERSON EARLY AND ON

Appropriations Funding

ASK: \$10 million for Kidney Risk Campaign

One of the key goals of the Administration's July 2019 Advancing American Kidney Health (AAKH) initiative is a public awareness campaign to enhance kidney disease awareness, educate clinical professionals and spur innovation by entities serving the kidney disease community.

NKF has launched the *Are You the 33%?* campaign and is seeking a \$10 million appropriation to support our work in reaching at-risk Americans.

The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (S. 3353/H.R. 5534)

Why?

- Kidney recipients who are non-aged/disabled receive Medicare coverage of immunosuppressants for only 36 months post-transplant.
- Patients risk their transplant by skipping doses, splitting their pills, or are forced to make difficult choices between paying for basic necessities or for medicine they need to prevent losing their transplant.
- Others may not qualify for a transplant because they don't have the financial resources to cover post-transplant care, including immunosuppressive drugs.

What Does it Do?

- Extends Medicare coverage of immunosuppressive drugs for the life of a kidney transplant, beyond the 36-month post-transplant cut-off currently in place covering these lifesaving medications.
- A preliminary CBO estimate shows \$70 million would be saved over ten years.

What Next?

- Have your friends and family write Congress here: <https://advocacy.kidney.org/>
- Write to your contact in your Representative's office to ask them to co-sponsor or thank them for co-sponsoring.

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

What does it do?

- Prohibits discrimination in benefit levels, pricing, and issuance of life, long-term care, and disability based solely on their status as organ donors.
- Codifies that FMLA covers living organ donation.

Why?

- In a 2015 study by Johns Hopkins University of the 186 donors who changed or initiated life insurance after donation, 46 (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.

Momentum!

- 19 Senators and 80 Representatives are co-sponsors in Congress
- State versions passed: Arizona, Arkansas, California, Colorado, Idaho, Illinois, Kansas, Maine, Maryland, New York, Oklahoma, and Oregon
- More in the works!



Role of the Patient Advocate

- Better kidney health policy isn't possible without your involvement
- You're not a professional lobbyist – good!
- Humanizing the facts and figures
- The unique and lasting power of personal stories

Join The Kidney Advocacy Committee

REPRESENT

the full spectrum of the kidney disease community.

INFLUENCE

kidney disease public policy.

EDUCATE

others on issues related to chronic kidney disease, organ donation and transplantation.

COMMUNICATE

the kidney community's stories, questions and concerns by talking to healthcare stakeholders.

ENGAGING

stakeholders their community.



Apply to become an advocate:

<https://www.kidney.org/advocacy/kidney-advocacy-committee>



FOLLOW US!

ADVOCACY IN ACTION
BLOG

<https://nkfadvocacy.blog/>

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