

#### News

# **Press Releases**

# **Bacon and Nadler Reintroduce Legislation to Protect Organ Donors**

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### **Bacon and Nadler Reintroduce Legislation to Protect Organ Donors**

**Washington** – Today, Representatives Don Bacon (NE-02) and Jerrold Nadler (NY-12) reintroduced the *Living Donor Protection Act* bill package to protect the rights of living organ donors. The *Living Donor Protection Act* is introduced as a two-bill package in the House, H.R. 4583, the *Living Donor Protection Act* and H.R.4582, *the Living Donor FMLA Protection Act*. The bills, taken together, are identical to last session's Living Donor Protection Act and S.1552 introduced in the Senate this session.

"Our state is fortunate to have Nebraska Medicine, which has a robust living donor kidney exchange program, performing more kidney chains which involves anonymous donors donating to someone without a compatible living donor, than almost any hospital nationwide. However, some living donors are discriminated against when it comes to rates and provision



"Every year, thousands of Americans die while waiting on an organ transplant, yet potential organ donors still face barriers that punish them for trying to selflessly save a life. Insurance discrimination and the threat of job loss can make it economically impossible for potential donors to move forward with donation and these roadblocks are costing lives," said **Representative Nadler**. "Congress must do everything in its power to remove deterrents to organ donation, which is why Congress must pass the *Living Donor Protection Act* bill package."

Organ donation saves thousands of lives every year, but burdensome roadblocks often stop individuals from becoming living donors. The *Living Donor Protection Act* bill package would protect living organ donors and promote organ donation in three easy, low-cost ways:

- 1. Prohibits life, disability, and long-term care insurance companies from denying or limiting coverage and from charging higher premiums based only on donor status;
- 2. Amends the Family and Medical Leave Act of 1993 to specifically allow private and civil service employees to use FMLA leave to recover from donation surgery; and
- 3. Directs HHS to update their materials on live organ donation to reflect these new protections and encourage more individuals to consider donating an organ.

Currently, there are over 103,000 people on the national transplant waiting list, with almost 90,000 people on the kidney transplant list. The average wait time for a kidney transplant is about three to five years, and during that time, many patients become too sick to receive a transplant or die—13 people die each year waiting for an organ transplant. Receiving an organ from a living donor can shorten this wait time and ultimately allow the best chance for long-term success. Unfortunately, studies have found that up to one in four living donors report discrimination in the rates and provision of life insurance and disability insurance, and they can struggle to receive time off from work to complete their donation and recovery. Reducing barriers to living organ donation and educating potential donors on the protections provided to them under law will help to promote living organ donation and save the lives of those waiting for a transplant.

The *Living Donor Protection Act* is endorsed by Alport Syndrome Foundation, American Association of Kidney Patients, American Council of Life Insurers, American Heart Association, American Kidney Fund, American Liver Foundation, American Nephrology Nurses Association, American Society of Nephrology, American Society of Pediatric Nephrology, American Society of Transplant Surgeons, American Society of Transplantation, Dialysis Patient Citizens, Global Liver Institute, IGA Nephropathy Foundation, International Society of Glomerular Disease, Kidney Transplant Collaborative, National Kidney Foundation, NephCure, the Nonprofit Kidney Care Alliance (NKCA), North American Transplant



rnational Organization (TRIO), and Renal Physicians Association.

"On behalf of all kidney patients, organ donors and American taxpayers, the American Association of Kidney Patients salutes U.S. Senators Tom Cotton and Kristen Gillibrand and U.S. Representatives Don Bacon and Jerrold Nadler for introducing the bipartisan *Living Donor Protection Act* so that living organ donors will no longer face the Hobbesian choice of saving an innocent human life at the risk of losing insurance coverages that provide economic security and peace of mind to their families and loved ones. The time is now for America to transcend high-cost, high-mortality dialysis care as the default solution for people living with kidney failure and to encourage greater living organ donation and greater transplant opportunities for all Americans in need of a life-saving organ," said **Edward V. Hickey, III, President, American Association of Kidney Patients.** 

"Life insurers are committed to helping people access the financial protection they want and need for themselves and their families. The *Living Donor Protection Act* will help ensure that organ donors can continue to access life, disability income, or long-term care coverage, while upholding fair underwriting standards. Most importantly, it will safeguard those who selflessly give the gift of life through organ donation," said **David Chavern, President and CEO, American Council of Life Insurers.** 

"The selfless individuals who give the gift of life by donating a kidney should not face discrimination by life, long-term care, or disability insurers. This legislation would be a significant step in efforts to encourage more living donors and reduce the kidney transplant waiting list by providing the protections that living donors should receive for their lifesaving actions," said **LaVarne Burton, President and CEO, American Kidney Fund.** 

"No child or adult should die waiting for a liver transplant. We must work together to increase living organ donation, and the *Living Donor Protection Act* provides a tangible path forward by removing key barriers for those willing to give the gift of life. We are so grateful to Representatives Bacon and Nadler for their extraordinary leadership and commitment to advancing living donor transplantation, which will help thousands of liver patients throughout the country," said **Lorraine Stiehl, CEO, American Liver Foundation and caregiver to a transplant patient.** 

"ASN commends the re-introduction of the *Living Donor Protection Act* and accompanying Living Donor FMLA Protection Act, critical legislation which will remove barriers that discourage living donors from providing the life-saving gift of a kidney transplant. Americans who are considering becoming living donors deserve more support than the current system provides for them, and ASN believes the *Living Donor Protection Act* and accompanying



"On behalf of the American Society of Transplantation (AST), representing a majority of the nation's transplant medical professionals, our Society strongly applauds and endorses the reintroduction of the *Living Donor Protection Act* (LDPA). AST is grateful for the ongoing and steadfast leadership of Representatives Bacon, Nadler and Senators Cotton and Gillibrand to protect transplant patients and strengthen living donation. The LDPA is a patient-focused bill seeking to remove policy barriers that might otherwise prevent an individual from providing a lifesaving donor organ. AST greatly appreciates this bipartisan, bicameral, and patient centric legislation. We look forward to working with you to advance the LDPA in this 119th Congress," said **Dr. Jon Kobashigawa, MD, President, American Society of Transplantation.** 

"On behalf of more than 2,000 transplant surgeons and professionals, the American Society of Transplant Surgeons (ASTS) enthusiastically commends the champions of the *Living Donor Protection Act* (LDPA) for their unwavering commitment to saving lives. As a tireless advocate for this legislation since its inception—and a proud partner in shaping its recent progress—ASTS is thrilled to see the momentum continue following the bill's strong bipartisan support in the 118th Congress. With a preliminary CBO score of zero, there is no better time for Congress to act. Passing the LDPA will provide vital, commonsense protections for living donors and remove unnecessary employment and insurance barriers to giving the ultimate gift: the gift of life," said **Ginny L. Bumgardner, MD, PhD, American Society of Transplant Surgeons.** 

"Global Liver Institute strongly supports the *Living Donor Protection Act* as an essential step to save lives by making the donation process affordable for living donors and protecting their employment. This bipartisan legislation was a collaborative effort, reflecting the policies determined most important to support living donors as determined by organ donors, liver and kidney patients, the insurance industry, transplant professionals, nephrologists, advocacy organizations and disease professionals. We look forward to its final passage in the 119th Congress," said **Larry Holden, President and CEO, Global Liver Institute.** 

"Living donors are heroes demonstrating compassion and generosity, and they are also rigorously screened individuals at the peak of health. Our family, friends and neighbors who choose to give the gift of a kidney enable thousands of Americans per year to resume a life where they can fully contribute to society, the economy, and their families rather than being limited by the life-support stopgap of dialysis. The ISGD enthusiastically endorses the *Living Donor Protection Act*," said **Laurel Damashek, Executive Director, International Society of Glomerular Disease and living donor kidney transplant recipient.** 

"We applaud Representatives Bacon and Nadler for their continued leadership on the *Living Donor Protection Act*. Taking this new approach of splitting the bill to ensure a smoother

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Congress to pass this legislation quickly," said **Kevin Longino**, **CEO**, **National Kidney Foundation and a kidney transplant recipient.** 

"As nonprofit dialysis providers, kidney transplant is an ideal outcome for many of our patients and legislation to protect and support living donors is critical to our patient-centered mission," said **Monica Massaro, Executive Director, Nonprofit Kidney Care Alliance.** 

"Polycystic kidney disease currently has no cure, and for many of the 600,000 patients living in the US, organ transplantation becomes their best path forward when kidney function declines. Living donors don't just extend lives—they reduce strain on our health care system and save taxpayer money by helping patients avoid dialysis. Yet needless barriers disincentivize many from stepping up to help. The *Living Donor Protection Act* is a commonsense, bipartisan solution that will ensure living donors are protected, not penalized, for their generosity," said **Susan Bushnell, President and CEO, Polycystic Kidney Disease (PKD) Foundation.** 

"As a pioneer in transplantation since performing New York State's first living donor kidney transplant in 1963, The Rogosin Institute believes that kidney transplantation is the ideal treatment for patients with end-stage kidney disease. We are proud to wholeheartedly endorse all components of the *Living Donor Protection Act*. Importantly, the Act will remove barriers to donation such as insurance uncertainty and financial insecurity. Rogosin extends our thanks to the bipartisan members of Congress supporting this critical legislation. We thank Congressmen Bacon and Nadler for championing the *Living Donor Protection Act*," said **The Rogosin Institute.** 

"Living organ donors save people's lives and should be able to give the gift of life without fear of insurance discrimination or financial retribution, especially as they recover from surgery. The *Living Donor Protection Act* rightfully protects these selfless individuals from this. Thank you, Sens. Cotton and Gillibrand and Reps. Bacon and Nadler for your bipartisan leadership and for standing up for living organ donors," said **Maureen McBride, Ph.D., CEO, United Network for Organ Sharing.** 

The text of the bills can be found here and here.



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