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# Transplant Times

Organ Transplant Awareness Program
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March 2023

Promoting Organ Donor Awareness; Supporting the Transplant Community
Support Group: Friday, May 5, 2023, 1:00 - 3:00 pm
4505 Chadwick Rd NW, Albuquerque 87120
505.948.4099

#### Greetings!

Once again the Living Donor Protection Act has been introduced in Congress. It is really important that this legislation gets passed so that more people will receive a life-saving transplant. I have included all the information about the bill. Senators Ben Ray Lujan and Senator Martin Heinrich, still need to sign on. The New Mexico Kidney walk will take place on June 4th, please see enclosed flyer. I have received many calls about the support group, including one from a social worker at University of Colorado Hospital. I am looking for a meeting room in the Paseo Del Norte/I-25 area. If you know of a possible venue, please call me 505.948.4099. Congratulations to all those who are graduating this month!





HAPPY TRANSPIANTAVERSARY!

Robert Golding Venae Warner 1st Liver Transplant Liver Transplant May 23, 2014 May 24, 2011 9 yrs 12 yrs

### Statement from Lorraine Stiehl, Chief Executive Officer, American Liver Foundation

"On behalf of nearly 100 million Americans affected by <u>liver disease</u>, we applaud the reintroduction of the *Living Donor Protection Act of 2023*, which will help protect living organ donors from discrimination in insurance and ensure living donors can take time off for organ donation and recovery under the Family and Medical Leave Act (FMLA).

American Liver Foundation is so grateful to Congressman Jerrold Nadler (D-NY) for reintroducing the *Living Donor Protection Act* and to the bi-partisan co-sponsors championing this effort on Capitol Hill: Senators Kirsten Gillibrand (D-NY) and Tom Cotton (R-AR) and Representatives Troy Balderson (R-OH), Rep. Lisa Blunt Rochester (D-DE), Jim Costa (D-CA), John Curtis (R-UT), Diana DeGette (D-CO), Mariannette Miller-Meeks (R-IA), and Gregory F. Murphy, M.D. (R-NC).

Each year, 2,000 liver patients in the United States die waiting for a <u>transplant</u> that never comes. Even more are removed from the waitlist because they become too sick to undergo transplant surgery. As <u>fatty liver disease</u> becomes more common in the U.S., more people will progress to liver failure and require a transplant.

It is crucial that we work together to remove barriers to living organ donation so that more liver patients have access to a life-saving transplant whenever they need it. We encourage all Members of Congress to support the lifesaving *Living Donor Protection Act*."

## **About the American Liver Foundation**

The American Liver Foundation is the nation's largest non-profit organization focused solely on promoting liver health and disease prevention. The American Liver Foundation achieves its mission in the fight against liver disease by funding scientific research, education for medical professionals, advocacy, information and support programs for patients and their families as well as public awareness campaigns about liver wellness and disease prevention. The mission of the American Liver Foundation is to promote education, advocacy, support services and research for the prevention, treatment and cure of liver disease. For more information visit <u>liverfoundation.org</u> or call:1 800 GO LIVER (800-465-4837).

[~117H1255]

	(Original Signature of Member)
118TH CONGRESS 1ST SESSION  H.R.	
11.14.	<del></del> -
To promote and protect from discrin	nination living organ donors.
IN THE HOUSE OF RE	PRESENTATIVES
Mr. Nadler introduced the following Committee on	

## A BILL

To promote and protect from discrimination living organ donors.

- 1 Be it enacted by the Senate and House of Representa-
- $2\ \ tives\ of\ the\ United\ States\ of\ America\ in\ Congress\ assembled,$
- 3 SECTION 1. SHORT TITLE.
- 4 This Act may be cited as the "Living Donor Protec-
- 5 tion Act of 2023".

1	SEC. 2. PROHIBITION ON DENIAL OF COVERAGE OR IN-		
2	CREASE IN PREMIUMS OF LIFE OR DIS-		
3	ABILITY INSURANCE FOR LIVING ORGAN DO-		
4	NORS.		
5	(a) Prohibition.—Notwithstanding any other provi-		
6	sion of law, an insurer shall not deny coverage, cancel cov-		
7	erage, refuse to issue, determine the price or premium for,		
8	or otherwise vary any term or condition of a life insurance		
9	policy, disability insurance policy, or long-term care insur-		
10	ance policy for a person based solely, and without any ac-		
11	tual, unique, and material actuarial risks, on the status		
12	of such person as a living organ donor.		
13	(b) Enforcement.—A State insurance regulator		
14	may take such actions to enforce subsection (a) as are spe-		
15	cifically authorized under the laws of such State.		
16	(c) Definitions.—In this section:		
17	(1) DISABILITY INSURANCE POLICY.—The term		
18	"disability insurance policy" means a contract under		
19	which an entity promises to pay a person a sum of		
20	money in the event that an illness or injury resulting		
21	in a disability prevents such person from working.		
22	(2) Life insurance policy.—The term "life		
23	insurance policy" means a contract under which an		
24	entity promises to pay a designated beneficiary a		
25	sum of money upon the death of the insured.		

1	(3) LIVING ORGAN DONOR.—The term "living	
2	organ donor' means an individual who has donated	
3	all or part of an organ and is not deceased.	
4	(4) Long-term care insurance policy.—	
5	The term "long-term care insurance policy" means	
6	a contract for which the only insurance protection	
7	provided under the contract is coverage of qualified	
8	long-term care services (as defined in section	
9	7702B(c) of the Internal Revenue Code of 1986).	
10	SEC. 3. CLARIFICATION OF ORGAN DONATION SURGERY AS	
11	QUALIFYING AS A SERIOUS HEALTH CONDI-	
12	TION UNDER FMLA.	
13	(a) Private Sector Employees.—Section 101(11)	
14	of the Family and Medical Leave Act of 1993 (29 U.S.C.	
15	2611(11)) is amended by inserting "(including recovery	
16	from surgery related to organ donation)" after "physical	
17	or mental condition".	
18	(b) Federal Civil Service Employees.—	
19	(1) Definition.—Section 6381(5) of title 5,	
20	United States Code, is amended by inserting "(in-	
21	cluding recovery from surgery related to organ dona-	
22	tion)" after "physical or montal condition"	
23	tion)" after "physical or mental condition".	
	(2) Relationship to organ donor leave.—	
24		

1	employee who takes any part of the 12-week period
2	of leave under subsection (a)(1) to serve as an organ
3	donor (including recovery from surgery related to
4	organ donation) shall substitute, for as much of that
5	part as possible, any leave available to the employee
6	under section 6327.".
7	SEC. 4. UPDATING OF EDUCATIONAL MATERIALS ON THE
8	BENEFITS AND RISKS OF LIVING ORGAN DO-
9	NATION.
10	(a) Educational Materials.—
11	(1) REVIEW AND UPDATING.—Not later than 6
12	months after the date of enactment of this Act, the
13	Secretary of Health and Human Services (in this
14	section referred to as the "Secretary") shall review
15	and update materials related to living organ dona-
16	tion in order to educate the public on—
17	(A) the benefits and risks of living organ
18	donation; and
19	(B) the impact of living organ donation on
20	the access of a living organ donor to insurance.
21	(2) Information on statutory changes.—
22	Such updating shall include information on the
23	changes made by sections 2 and 3 of this Act.
24	(b) Methods of Updating.—In carrying out sub-
25	section (a), the Secretary shall update, as appropriate—

1	(1) Public Service Announcements previously
2	provided by the Secretary;
3	(2) publicly accessible websites (such as
4	organdonor.gov, or a successor website) that are
5	maintained by the Secretary and that contain infor-
6	mation and resources regarding living organ dona-
7	tion; and
8	(3) other media determined appropriate by the
9	Secretary.



## 2023 ANNUAL MEMBERSHIP FORM

Name		
Address		
City	StateZipCode	
Phone #	Cell Phone	
Email address for organization communication	ns only	
I would prefer to receive the ne	wsletter electronically.	
\$15 Individual membership	\$25 Family membership	Oonation
All contributions are tax deductible		
Please make checks payable and mail to:	PO Box 37217 Albuquerque, NM 87176	
	Albuquoi quo, Alli or 170	
Candidate: Organ/Tissue Type:	Date Listed//	
<b>Recipient:</b> Organ/Tissue Type:	Date Received//	
2 <sup>nd</sup> transplant date –month day year:/		
Donor/member of a Donor Family: Dor	nor Name Organ/Tissue	Туре
Transplant date -month/day/year:/	lI	
Friend of OTAP		
Opportunities - Please check all that apply:		
I would like to volunteer: promotional events	fundraising events	
Personal information such as phone number	and addressmay be shared with others.	
I would like to be a reader for the scholarship awa	ard	
Suggestions		

Representatives Nadler, Balderson, Blunt Rochester, Costa, Curtis, DeGette, Miller-Meeks, Murphy, Senators Gillibrand and Cotton Introduce Bipartisan, Bicameral Legislation to Protect Organ Donors

WASHINGTON, D.C., April 27, 2023

WASHINGTON, D.C.- Today, Congressman Jerrold Nadler (D-NY), Congressman Troy Balderson (R-OH), Congresswoman Lisa Blunt Rochester (D-DE), Congressman Jim Costa (D-CA), Congressman John Curtis (R-UT), Congresswoman Diana DeGette (D-CO), Congresswoman Mariannette Miller-Meeks (R-IA), Congressman Gregory F. Murphy, M.D. (R-NC), and joined by Senator Kirsten Gillibrand (D-NY) and Senator Tom Cotton (R-AR), introduced the Living Donor Protection Act to protect the rights of living organ donors.

Organ donation saves thousands of lives every year, but unnecessary red tape often stops individuals from becoming living donors. *The Living Donor Protection Act* 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 for living organ donors;
- 2. Amends the Family and Medical Leave Act of 1993 to specifically include living organ donation as a serious health condition for private and civil service employees; 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.

"When an organ donor decides to donate one of their organs to someone else, they aren't just saving someone's life—they're making one of the most selfless, difficult decisions anyone could ever make. The last thing they need in the midst of that challenging process is to be confronted by needless roadblocks or insurance discrimination," **said Representative**Nadler. "These roadblocks can make it economically impossible for potential donors to make that choice and, simply put, they are costing lives. April is National Donate Life Month, and I'm proud to introduce the Living Donor Protection Act to bring awareness to this issue and knock down these needless barriers to lifesaving organ donation."

"We must do more to remove the barriers that keep Americans from life-saving organ donations," **said Senator Gillibrand.** "The bipartisan Living Donor Protection Act would help ensure that individuals who are willing to save someone's life through organ donation can do so without worrying that they'll face harsh repercussions, like insurance discrimination or job loss. Enshrining these protections for donors will help save lives, and I will keep working with my colleagues across the aisle to finally pass this commonsense legislation."

"A close family friend of mine is a kidney transplant recipient, saved through the blessing of organ donation," **said Representative Balderson.** "I am proud to be among the 52 percent of

Ohioans registered to donate the gift of life. This bipartisan legislation is about offering hope for the more than 100,000 Americans - and their loved ones - awaiting their lifesaving transplant."

"Being an organ donor saves lives and Congress should do everything in our power to ensure that those who have chosen selflessly to be a donor are not penalized," **said Representative Blunt Rochester.** "That's why I'm proud to join my colleagues in introducing the bipartisan and bicameral Living Donor Protection Act."

"Donating an organ is a selfless act and Congress should ensure that generous individuals making a living donation are not penalized," **said Representative Costa.** "As Co-Chair of the Organ and Tissue Donation and Transplantation Awareness Caucus, I'm proud to support the Living Donor Protection Act to remove barriers to organ donations and help save lives."

"Donating a kidney – and saving a life – is an admirable thing for someone to do," **said Representative Curtis**. "Under no circumstances should an individual be denied insurance coverage because of this surgery and I am proud to work with folks in Utah, particularly Bruce Tippets in Vernal for his advocacy in the patient community and for bringing this to my attention and fix this oversight."

"The decision to become a living organ donor is one of the most difficult decisions a person can make," **said Representative DeGette.** "We should be doing everything we can to help those who are willing to step up to help someone else in need. This legislation will provide our living organ donors the protections they deserve and ensure no one is ever punished for providing the gift of life to someone else."

"Donating an organ is a selfless sacrifice, and our legislation will ensure these donors aren't met with unnecessary burdens which can deter, or event prevent, someone from going through with a procedure," **said Representative Miller-Meeks.** "In implementing these protections, our hope is to make it easier for donors who are eager to help save lives."

"I am proud to reintroduce the Living Donor Protection Act today with my colleagues," **said Representative Murphy.** "As a former transplant surgeon, I know the importance of supporting living organ donors who have sacrificed to help their fellow man. This legislation would break down barriers for individuals who want to make the selfless choice to give others another chance at life."

"Red tape shouldn't prevent organ donors from giving someone a new chance at life," **said Senator Cotton.** "This legislation will encourage more donors to volunteer by protecting them from denial of coverage, higher insurance premiums, and job loss."

"No human being should be forced to choose between becoming an organ donor to save another life and the real risk of losing current or future life or disability insurance coverage, and financial security, solely because of their selfless humanitarian act. We thank Congressman Nadler and all bipartisan co-sponsors for responding to the real world experiences of organ donors, transplant recipients and patients awaiting a life-saving organ transplant by offering legislation that protects living organ donors and removes a long-standing barrier to greater donation." - Ed Hickey, President of the American Association of Kidney Patients (AAKP)

"People who give a part of themselves so that someone else can live represent the best of us. They not only deserve praise and gratitude, but they also deserve to be protected for their altruistic act. The Living Donor Protection Act ensures that these donors will have the same access to life, long-term care, and disability insurance as everyone else and will remove barriers related to taking time off from work, ultimately allowing for more living organ donations. The American Kidney Fund fully supports this legislation, and we are hopeful for swift enactment."- LaVarne A. Burton, President and CEO of the American Kidney Fund

"The American Liver Foundation applauds the reintroduction of the Living Donor Protection Act by Congressman Nadler. This legislation will offer much needed protections for living donors who are considering donating a portion of their liver to help save another person's life. We urge Congress to pass this act and provide a vital safeguard for those individuals who step up to provide the gift of life. We thank Congressman Nadler for his leadership on this crucial issue." - Lorraine Stiehl, CEO of the American Liver Foundation

"ASN commends the re-introduction of the Living Donor Protection Act, vital legislation which will remove barriers that discourage living donors from providing the life-saving gift of a kidney transplant. Living donors deserve more support than the current system provides for them, ASN believes the Living Donor Protection Act is a critical first step to achieve this goal."- Michelle Josephson, President, American Society of Nephrology

"On behalf of the thousands of transplant surgeons we represent, we eagerly applaud these Congressional leaders for introducing the Living Donor Protect Act (LDPA)." Chapman added, "As a stalwart champion of LDPA since its inception and an instrumental group in recent improvements to the legislation, ASTS knows that now is the perfect time for Congress to enact into law these commonsense employment and insurance protections to assist living donors in giving others the gift of life." - Will Chapman, MD, President of the American Society of Transplant Surgeons (ASTS)

"On behalf of the American Society of Transplantation (AST), representing a majority of the nation's medical professionals engaged in the field of solid organ transplantation, the Society commends Reps. Nadler, Costa, Curtis, Balderson, DeGette, Miller-Meeks, and Murphy on introducing the Living Donor Protection Act (LDPA). This bill is critical in removing barriers to living organ donation, prohibiting certain discrimination in insurance, and codifying protection for living donors under the Family and Medical Leave Act (FMLA). The AST strongly supports and endorses the LDPA legislation as well as the steadfast leadership and support of Reps. Nadler, Curtis, Balderson, Miller-Meeks, and Murphy." - Dr. Josh Levisky, MD, MS, FAST, FAASLD, American Society of Transplantation President-Elect

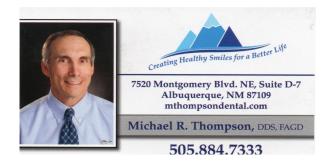
"There is a critical shortage of deceased organs for transplant in this country. To fill that gap, Congress must do everything possible to promote living donation. We applaud our Congressional champions for reintroducing the Living Donor Protection Act and for recognizing the critical need to support living organ donors." - Kevin Longino, CEO of the National Kidney Foundation and a transplant recipient

"The PKD Foundation applauds our bipartisan champions in Congress for re-introducing the Living Donor Protection Act (LDPA). For people with polycystic kidney disease, transplant is the gold standard of care. As the only organization in the U.S. solely dedicated to finding treatments and a cure for polycystic kidney disease, we are proud to endorse this legislation to encourage living organ donation and shorten the transplant waiting list." - Susan Bushnell, President and CEO of the Polycystic Kidney Disease Foundation (PKDF)

"The Renal Physicians Association is overjoyed to see a bill that for many years served as one of our legislative priorities to once again be introduced. Our patients with ESRD know the ideal pathway to a higher quality lifestyle is only through a kidney transplant. Unfortunately, with only a limited number of deceased donor organs available, these courageous, committed and compassionate living donors serve as an invaluable key to longer and better quality of life for our patients. We cannot afford to allow any hardships from providing this altruistic gift become a barrier in the process. This bill acknowledges that our country honors our living donors and stands behind them in appreciation for their sacrifice." - Keith Bellovich, President of the Renal Physicians Association

The bill has support from numerous groups that advocate on behalf of organ transplantation, including endorsements by the American Association of Kidney Patient, American Council of Life Insurers, American Kidney Fund, American Liver Foundation, American Society of Nephrology, American Society of Pediatric Nephrology, American Society of Transplantation, American Society of Transplant Surgeons, Dialysis Patient Citizens, National Kidney Foundation, Renal Physicians Association, and the Polycystic Kidney Disease Foundation.





#### **OTAP Mission Statement**

The mission of Organ Transplant Awareness Program is to promote organ donation and support transplant community members including transplant candidates, donor families, living organ donors, transplant recipients, and transplant families. We promote organ donation by participating in a variety of community events. Our support group meets once a month for those who need support or are seeking information about the transplant process.



