

Mark Dybis: Living Liver Donor

And

Dave Galbenski: Living Liver Transplant Recipient



<https://www.youtube.com/watch?v=LcNEQuLiKCw>

Mark Dybis & Dave Galbenski In Person Testimony

Senate Bill 384
In-Person Testimony: Dave Galbenski & Mark Dybis
House Health Policy Committee
Thursday, September 28, 2023

I. Greeting

Chair Rogers and members of the House Health Policy Committee, Mark and I are grateful for the opportunity to present testimony in support of Senate Bill 384 to create protections for living organ donors against any increase in premiums or denial of coverage related to life insurance, disability insurance and long-term care insurance.

We have prepared written testimony for the Committee and we look forward to sharing our personal experience with living liver transplant.

II. My Story

It was a beautiful fall September evening in 2019 when my wife, Lynn, and I arrived at my brother-in-law Mark's house. I was getting sicker and sicker as my rare auto-immune disease continued its attack on my liver. I was anxiously waiting on the transplant list for the availability of a liver from a deceased donor.

We entered the living room and were joined by Mark's wife and Lynn's sister, Karen. Mark had us both sit down and after catching up a bit said: "Dave, I have some great news, I am going to be your living donor. How does late November, early December look to get this done?" You can only imagine the feeling of relief that overwhelmed me, the tears of joy that we shed and the bear hugs given. And, of course, I let Mark know that those dates would definitely work in my calendar!

In late November at Henry Ford Health, Mark donated a portion of his liver to me and saved my life. He is my angel on earth, my hero and is the only reason that I am able to be here today to give this testimony.

III. Background for SB 384

As this Committee may be aware from prior organ donation bills introduced this legislative session, over 2200 Michiganders are on the transplant list waiting for either a kidney or a liver resulting in an acute need to increase the number of organs available from deceased donors while furthering living organ donation.

The American Kidney Fund publishes an annual report that grades all 50 states on 7 key criteria that protect living donors. Michigan currently does not have any laws that address these 7 key criteria and rates an “F”, the worst possible score, on the A through F grading scale.

Protecting living donors from increased premiums or denial of coverage for life insurance, disability insurance and long-term care insurance is 1 of the 7 key factors in the annual report. 30 states already have legislation in place that provides this protection to their citizens.

By enacting SB 384 into law, Michigan will take the first step to improving its grade while eliminating an obstacle to those deciding to become a living organ donor.

The written testimony that has been submitted provides current transplant wait list numbers, detailed information on the annual report, legislation passed in other states in 2023 and grade ratings of peer states.

IV. Mark’s Story

Submitted as written testimony via a separate document.

V. Conclusion

Mark: I picture a day when living donors don't encounter financial burdens or insurance obstacles in order to save a life.

Dave: I picture a day when Michigan is rated as one of the top states for living organ donation.

Dave & Mark (Together): We picture a day when there are enough living donors so that no one has to die while waiting for an organ.

Dave: We strongly urge the members of the House Health Policy Committee to support SB 384 and save lives by providing these insurance protections to living donors.

Current Transplant Waiting List in Michigan

State data

[Home](#) » [Data](#) » [View data reports](#) » [State data](#) » Overall by Organ

Page 1 of 1

Overall by Organ

Current U.S. Waiting List

For State = Michigan

Based on OPTN data as of June 7, 2023



Change Report (Optional) :

Count

Candidates

[Create a New Report](#)

State

Michigan

Go

count flip export print
[portrait](#) [landscape](#)

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Intestine
Candidates	2,409	2,030	214	30	33	124	56	2

Data subject to change based on future data submission or correction. This report shows OPTN data for Overall by Organ through June 7, 2023. OPTN Data is updated on a monthly basis. Totals may be less than the sums due to patients included in multiple categories.

Need more detailed data? [Build an Advanced Report](#)

Register to be a donor

Sitemap

Related Sites

Legal Resources

Contact

**Number of Kidney Transplants in Michigan By Donor Type
(Deceased Donor & Living Donor)**

Donors Recovered in the U.S. by Donor Type

Donors Recovered : January 1, 1988 - April 30, 2023

For Count = Kidney, State = Michigan

Based on OPTN data as of June 7, 2023

Percent of Living Kidney Donors in Michigan

1/1/1988 - 4/30/2023:

44%

2023 YTD:

23%

Change Report (Optional) :

Organ

State

Kidney



Michigan



Go

Add Field to Report :



Go

	To Date	2023	2022	2021	2020	2019	2018	2017	2016	2015	2014	2013	2012	2011	2010	2009	2008	2007
All Donor Types	15,642	221	610	577	540	530	567	498	504	468	423	499	471	449	479	515	528	515
Deceased Donor	8,753	170	471	431	388	345	336	311	297	277	243	287	254	259	275	281	300	281
Living Donor	6,889	51	139	146	152	185	231	187	207	191	180	212	217	190	204	234	228	234

Data subject to change based on future data submission or correction. This report shows OPTN data for Donors Recovered in the U.S. by Donor Type th

**Number of Liver Transplants in Michigan By Donor Type
(Deceased Donor & Living Donor)**

Donors Recovered in the U.S. by Donor Type

Donors Recovered : January 1, 1988 - April 30, 2023

For Count = Liver, State = Michigan

Based on OPTN data as of June 7, 2023

Percent of Living Donors in Michigan

1/1/1988 - 4/30/2023:

3.6%

2023 YTD:

7.6%

Change Report (Optional) :

Organ

State

Liver



Michigan



Go

Add Field to Report :



Go

	To Date	2023	2022	2021	2020	2019	2018	2017	2016	2015	2014	2013	2012	2011	2010	2009	2008
All Donor Types	7,018	105	267	281	284	285	277	269	232	221	207	217	208	206	219	233	226
Deceased Donor	6,763	97	257	270	275	265	264	256	224	214	198	209	197	195	205	226	226
Living Donor	255	8	10	11	9	20	13	13	8	7	9	8	11	11	14	7	7

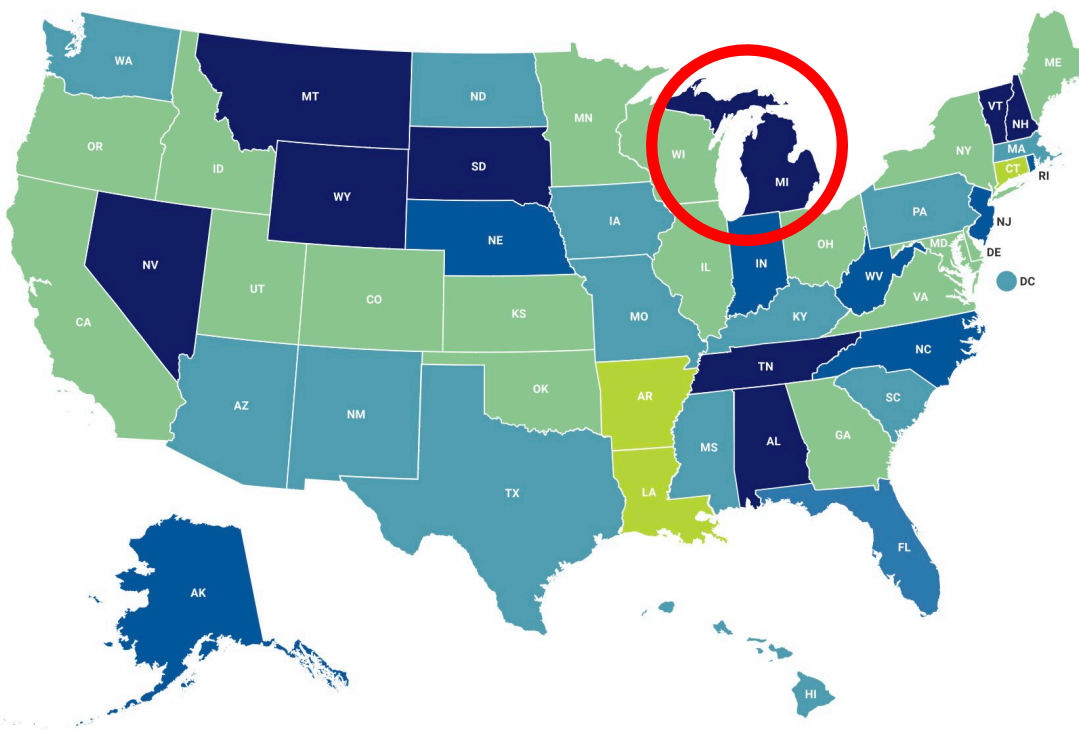
Data subject to change based on future data submission or correction. This report shows OPTN data for Donors Recovered in the U.S. by Donor

State Ratings of Living Donor Protections in State Law

Grading Scale: A to F

In 2023, Michigan Scores an F

Together, we can give living organ donors the protections they need, no matter where they live.



GRADES:

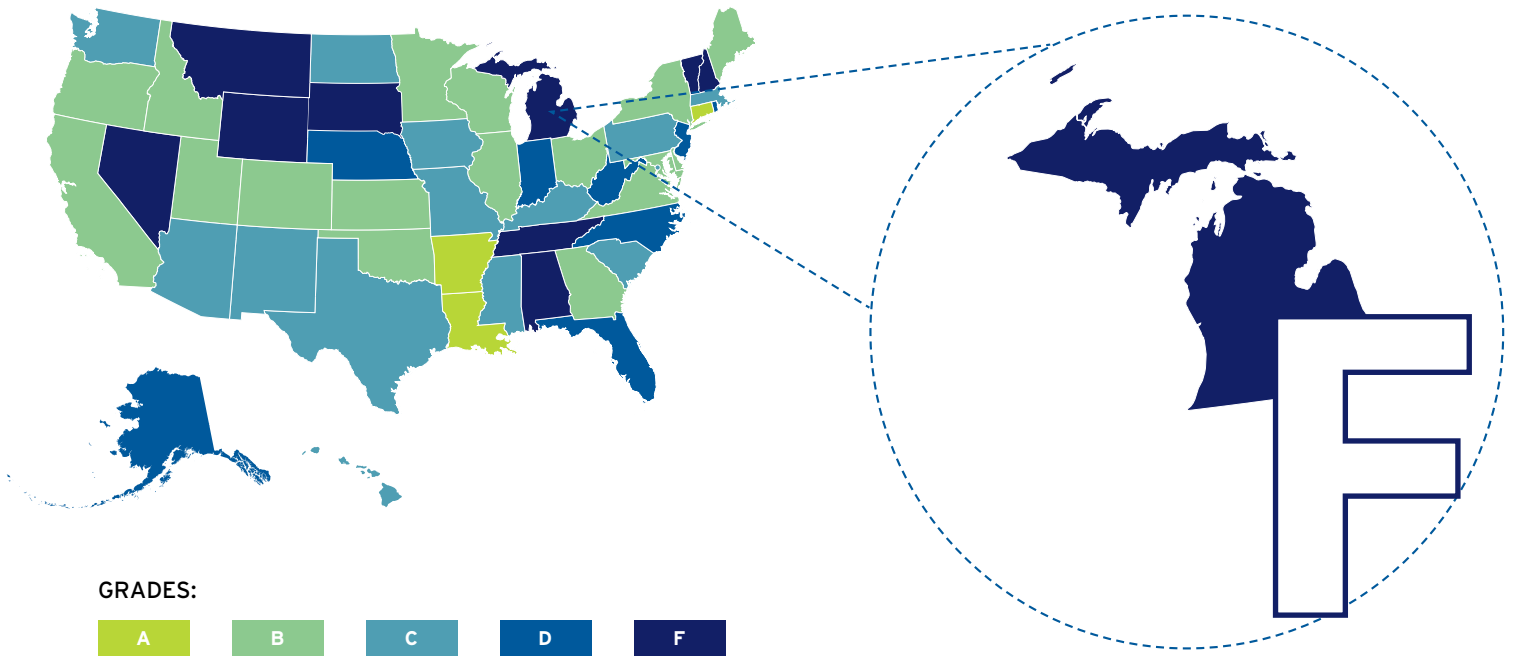


[Learn how we graded the states](#)



STATE of the STATES: 2023 Living Donor Protection Report Card

MICHIGAN



Out of **SEVEN** possible types of living donor protection legislation, Michigan currently has **ZERO** laws in place.



- Job-protected leave from private employers
- Job-protected leave from public employers
- Tax credits for employers who provide paid leave
- Paid leave via Family and Medical Leave Act (FMLA) law
- Direct reimbursements, tax credits or tax deductions for donor expenses
- More than 60 days of leave via FMLA laws
- Protection from life, disability or long-term care insurance discrimination

For a complete breakdown of the American Kidney Fund's Living Donor Protection Report Card results and methodology, visit KidneyFund.org/livingdonors or scan the QR code.



STATE of the STATES: 2023 Living Donor Protection Report Card

MICHIGAN

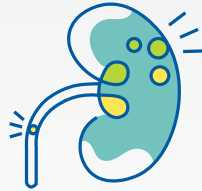
Who is impacted?



23,931 Michiganians have kidney failure. Without treatment – dialysis or a transplant – kidney failure is fatal.

7,909 have transplants
16,022 depend on dialysis to stay alive

SOURCE: 2022 USRDS Annual Data Report



3,955 new cases of kidney failure were diagnosed in Michigan in 2020 (most recent data available).

124 were able to get a transplant
3,831 went on dialysis

SOURCE: 2022 USRDS Annual Data Report



583 kidney transplants were performed in Michigan in 2022.

136 living donor transplants
447 deceased donor transplants

SOURCE: Organ Procurement and Transplantation Network

Legislation is needed to protect living organ donors

Donating a kidney is one of the most altruistic actions a person can take, and being a living donor is much easier when you have guaranteed paid leave from work and protection from insurance discrimination. AKF has been spearheading efforts at the state and federal levels to get such legislation enacted. Until federal legislation passes that would give baseline protections to donors nationwide, states should enact living donor protection laws, including: anti-insurance discrimination for life, disability and long-term care insurance; job-protected leave from private employers; job-protected leave from public employers; tax credits for employers who provide paid leave; direct reimbursements, tax credits or tax deductions for donor expenses; paid leave via Family and Medical Leave Act (FMLA) laws; and extended FMLA leave (more than 60 days).



Text **KIDNEY** to **52886** or visit KidneyFund.org/act to get involved in legislative efforts in your state.

STATE OF THE STATES: 2023 AKF Living Donor Protection Report Card

How states are graded

The American Kidney Fund (AKF) Living Donor Protection Report Card identifies seven categories of publicly reported legislation enacted by states to protect living organ donors from discrimination and encourage living organ donation. States receive one point for each type of legislation that has been enacted and receive their grade based on their total points.

The AKF Living Donor Protection Report Card assigns a grade of an “A,” “B,” “C,” “D” or “F” on the following scale:

- A: 5+
- B: 3-4
- C: 2 *
- D: 1
- F: 0

* (this would be the baseline grade for all states if a federal Living Donor Protection Act were passed)

**Summary Description of 7 Key Protections
For Living Donors**

Protection from life, disability or long-term care insurance discrimination

Michigan SB 384

This type of legislation typically prevents life, disability and long-term care insurance companies from discriminating against living organ donors by charging higher premiums or refusing to insure them altogether.

Why it's important

Only people in excellent health (<https://weileracademy.com/>) can become living donors. Research has shown that people who donate a kidney live as long as similarly healthy people (<https://weileracademy.com/>) who have both kidneys. The prospect of being denied insurance or charged higher premiums in the future may deter someone from becoming a living organ donor.

Job-protected leave from private employers

This type of legislation guarantees a period of job-protected leave, which varies by state, and ensures that employees of private employers can take time off for living organ donation without losing their jobs.

Why it's important

Living organ donors typically need from 2 to 12 weeks for surgery and recovery. Job-protected leave ensures that a living donor can take the time needed to recover adequately from surgery.

Job-protected leave from public employers

This type of legislation guarantees that a living organ donor who works for state or local governments will not be penalized for taking time off from work for surgery and recovery.

Why it's important

Public employees make up about 15% of the U.S. workforce overall, and in some states it's as high as 25%. Federal employees enjoy job-protected leave for living organ donation, but not all states offer that benefit to their employees. Job-protected leave ensures that a living organ donor can recover adequately from surgery.

Tax credits for private employers who provide paid leave

This type of legislation reimburses, via a tax credit, some or all of the salary of employees of private companies who become living donors if their company provides paid job-protected leave.

Why it's important

Not every worker is able to afford to take unpaid leave to become a living organ donor. Legislation that incentivizes private employers to provide paid leave can make it possible for more employees to consider becoming living organ donors.

Direct reimbursements, tax credits or tax deductions for donor expenses

This type of legislation allows a living organ donor to recoup some or all of the expenses they incur by either direct reimbursement, tax deduction or a tax credit. Tax credits provide a more generous benefit than tax deductions, but neither are as inclusive as direct reimbursements. Direct reimbursements of allowable expenses would benefit every living donor, regardless of tax return filing status.

Why it's important

The transplant recipient's health insurance typically pays all the medical costs of the surgery for the living donor, but does not necessarily reimburse out-of-pocket expenses such as travel, lodging and prescription medications that may be needed during recovery. Direct reimbursement, tax deductions or tax credits can help to eliminate or lessen this potential financial obstacle for living donors.

Paid leave via Family and Medical Leave Act (FMLA) laws

This type of legislation recognizes living organ donation as a serious health condition that qualifies an employee for FMLA paid leave.

Why it's important

Many working Americans cannot afford to take any time off work without pay. Providing paid leave for living organ donation under a state's FMLA laws eliminates the primary financial hurdle—loss of income—that might keep someone from considering becoming a living organ donor.

Enhanced FMLA leave beyond 60 days

This type of legislation goes above and beyond most FMLA laws by extending the eligibility period beyond 60 days (12 work weeks), which is the limit of many FMLA laws.

Why it's important

Though most living organ donors recover and return to work in less than 12 weeks, medical complications may extend the recovery period. Generous FMLA laws that extend the leave period beyond 60 work days provide living donors with peace of mind in the event their recovery takes longer than is typical.

Text **KIDNEY** to **52886** or visit **KidneyFund.org/act** (<https://www.kidneyfund.org/act>) to get involved in legislative efforts in your state. Visit **KidneyFund.org/ldpa** (<https://www.kidneyfund.org/ldpa>) to ask your members of Congress to support the federal Living Donor Protection Act

Take action
(<https://www.kidneyfund.org/act>)

**Summary of the Number of States That Have Enacted
Legislation For Each of the 7 Living Donor Protections**

The Report Card measures seven types of legislation:

Number of states

Protection from life, disability or long-term care insurance
discrimination

Michigan SB 384

31

Job-protected leave from private employers

12

Job-protected leave from public employers

37

Tax credits for employers who provide paid leave

5

Direct reimbursements, tax credits or tax deductions for
donor expenses

21

Paid leave via Family and Medical Leave Act (FMLA) laws

2

More than 60 days of leave via FMLA laws

2

Grade Ratings of Geographic Peer States:

Illinois: B

Ohio: B

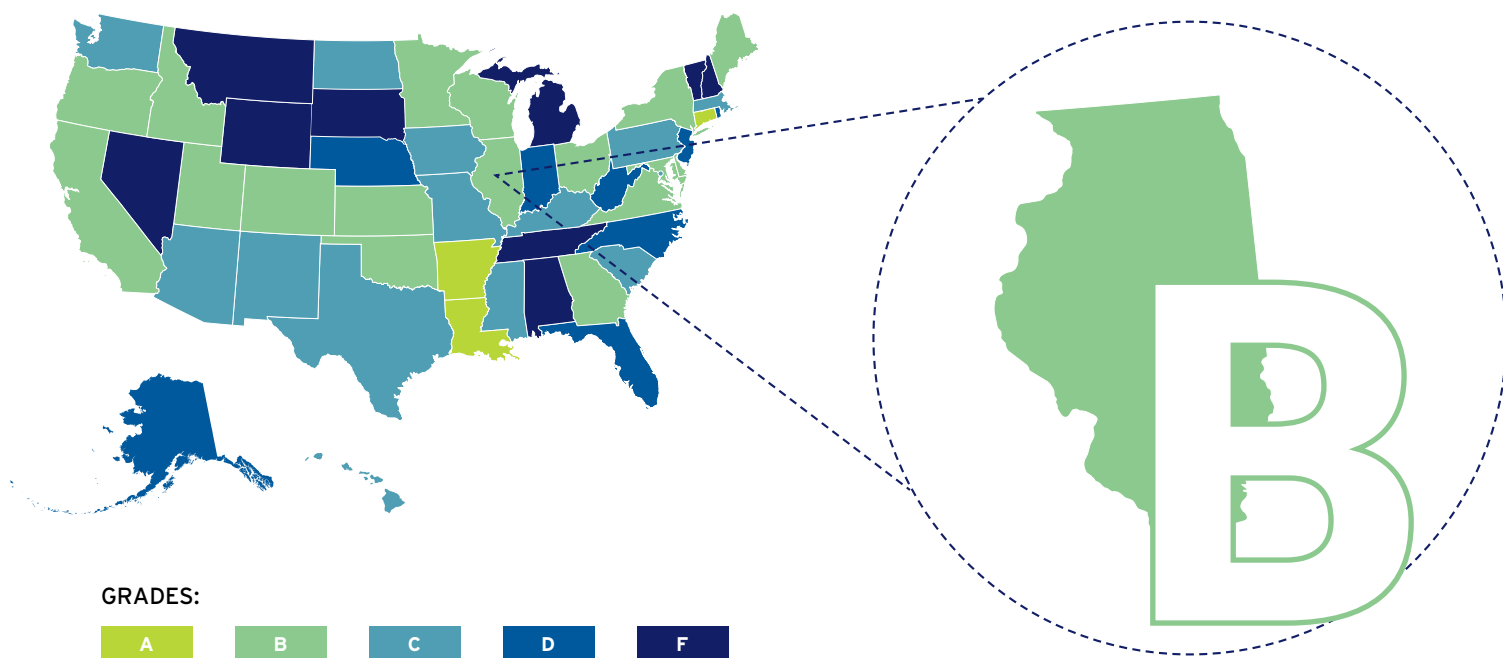
Minnesota: B

Wisconsin: B

Indiana: D

STATE of the STATES: 2023 Living Donor Protection Report Card

ILLINOIS



Out of **SEVEN** possible types of living donor protection legislation, Illinois currently has **THREE** laws in place.



- Job-protected leave from private employers
- Job-protected leave from public employers
- Tax credits for employers who provide paid leave
- Paid leave via Family and Medical Leave Act (FMLA) law
- Direct reimbursements, tax credits or tax deductions for donor expenses
- More than 60 days of leave via FMLA laws
- Protection from life, disability or long-term care insurance discrimination

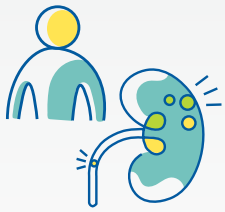
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STATE of the STATES: 2023 Living Donor Protection Report Card

ILLINOIS

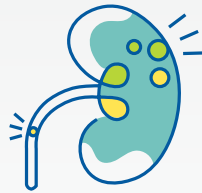
Who is impacted?



34,927 Illinoisans have kidney failure. Without treatment – dialysis or a transplant – kidney failure is fatal.

11,520 have transplants
23,407 depend on dialysis to stay alive

SOURCE: 2022 USRDS Annual Data Report



5,343 new cases of kidney failure were diagnosed in Illinois in 2020 (most recent data available).

134 were able to get a transplant
5,209 went on dialysis

SOURCE: 2022 USRDS Annual Data Report



1,342 kidney transplants were performed in Illinois in 2022.

267 living donor transplants
1,075 deceased donor transplants

SOURCE: Organ Procurement and Transplantation Network

Legislation is needed to protect living organ donors

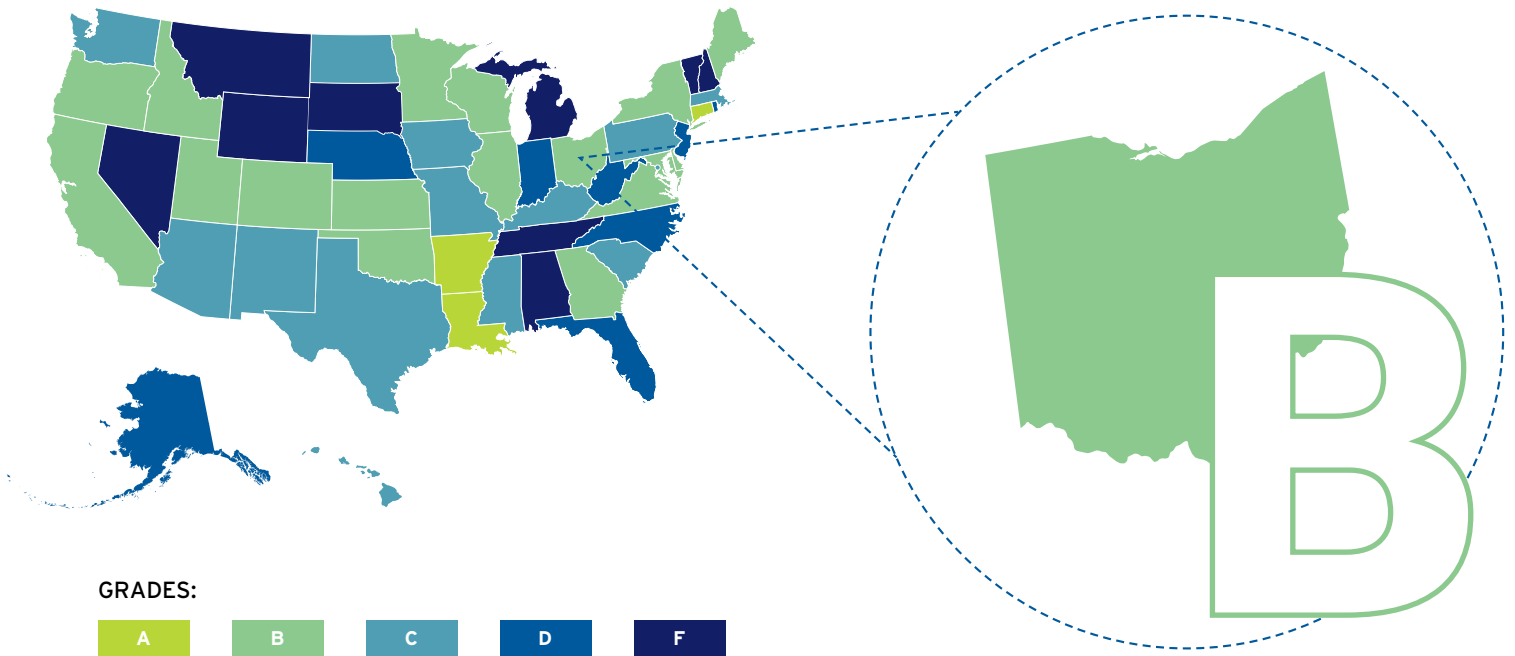
Donating a kidney is one of the most altruistic actions a person can take, and being a living donor is much easier when you have guaranteed paid leave from work and protection from insurance discrimination. AKF has been spearheading efforts at the state and federal levels to get such legislation enacted. Until federal legislation passes that would give baseline protections to donors nationwide, states should enact living donor protection laws, including: anti-insurance discrimination for life, disability and long-term care insurance; job-protected leave from private employers; job-protected leave from public employers; tax credits for employers who provide paid leave; direct reimbursements, tax credits or tax deductions for donor expenses; paid leave via Family and Medical Leave Act (FMLA) laws; and extended FMLA leave (more than 60 days).



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STATE of the STATES: 2023 Living Donor Protection Report Card

OHIO



Out of **SEVEN** possible types of living donor protection legislation, Ohio currently has **THREE** laws in place.



- Job-protected leave from private employers
- Job-protected leave from public employers
- Tax credits for employers who provide paid leave
- Paid leave via Family and Medical Leave Act (FMLA) law
- Direct reimbursements, tax credits or tax deductions for donor expenses
- More than 60 days of leave via FMLA laws
- Protection from life, disability or long-term care insurance discrimination

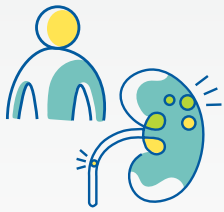
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STATE of the STATES: 2023 Living Donor Protection Report Card

OHIO

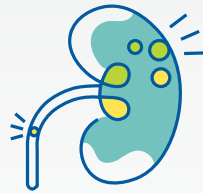
Who is impacted?



27,501 Ohioans have kidney failure. Without treatment – dialysis or a transplant – kidney failure is fatal.

8,764 have transplants
18,737 depend on dialysis to stay alive

SOURCE: 2022 USRDS Annual Data Report



5,098 new cases of kidney failure were diagnosed in Ohio in 2020 (most recent data available).

177 were able to get a transplant
4,921 went on dialysis

SOURCE: 2022 USRDS Annual Data Report



1,239 kidney transplants were performed in Ohio in 2022.

226 living donor transplants
1,013 deceased donor transplants

SOURCE: Organ Procurement and Transplantation Network

Legislation is needed to protect living organ donors

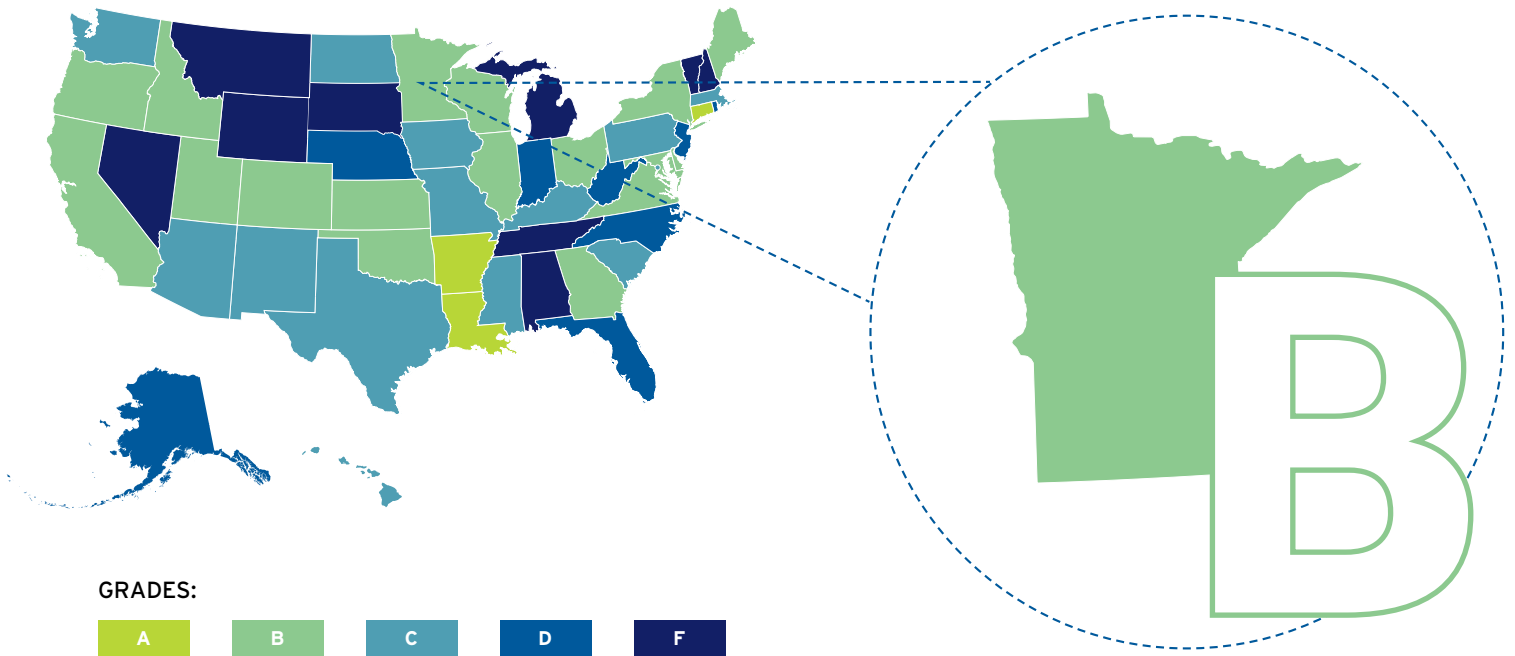
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Text **KIDNEY** to **52886** or visit KidneyFund.org/act to get involved in legislative efforts in your state.

STATE of the STATES: 2023 Living Donor Protection Report Card

MINNESOTA



Out of **SEVEN** possible types of living donor protection legislation, Minnesota currently has **FOUR** laws in place.



- Job-protected leave from private employers
- Job-protected leave from public employers
- Tax credits for employers who provide paid leave
- Paid leave via Family and Medical Leave Act (FMLA) law
- Direct reimbursements, tax credits or tax deductions for donor expenses
- More than 60 days of leave via FMLA laws
- Protection from life, disability or long-term care insurance discrimination

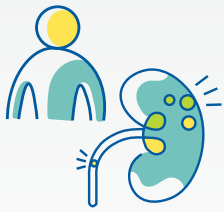
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STATE of the STATES: 2023 Living Donor Protection Report Card

MINNESOTA

Who is impacted?

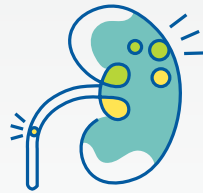


10,509 Minnesotans have kidney failure. Without treatment – dialysis or a transplant – kidney failure is fatal.

4,886
have
transplants

5,623
depend on dialysis
to stay alive

SOURCE: 2022 USRDS Annual Data Report



1,496 new cases of kidney failure were diagnosed in Minnesota in 2020 (most recent data available).

81
were able to get a
transplant

1,415
went on dialysis

SOURCE: 2022 USRDS Annual Data Report



629 kidney transplants were performed in Minnesota in 2022.

260
living donor
transplants

369
deceased donor
transplants

SOURCE: Organ Procurement and Transplantation Network

Legislation is needed to protect living organ donors

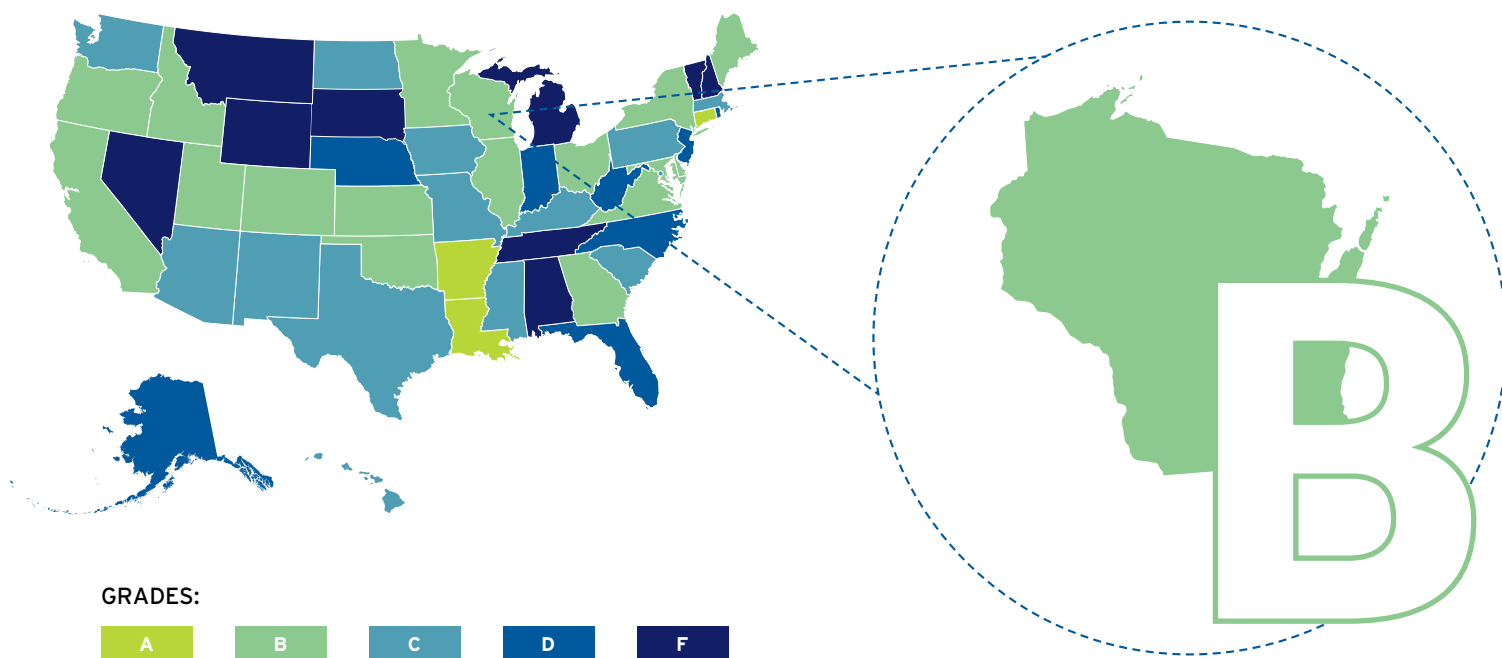
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STATE of the STATES: 2023 Living Donor Protection Report Card

WISCONSIN



Out of **SEVEN** possible types of living donor protection legislation, Wisconsin currently has **THREE** laws in place.



- Job-protected leave from private employers
- Job-protected leave from public employers
- Tax credits for employers who provide paid leave
- Paid leave via Family and Medical Leave Act (FMLA) law
- Direct reimbursements, tax credits or tax deductions for donor expenses
- More than 60 days of leave via FMLA laws
- Protection from life, disability or long-term care insurance discrimination

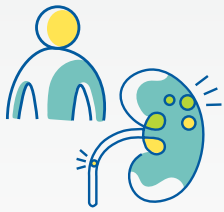
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STATE of the STATES: 2023 Living Donor Protection Report Card

WISCONSIN

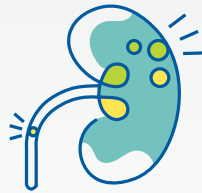
Who is impacted?



12,158 Wisconsinites have kidney failure. Without treatment – dialysis or a transplant – kidney failure is fatal.

4,850 have transplants
7,308 depend on dialysis to stay alive

SOURCE: 2022 USRDS Annual Data Report



1,920 new cases of kidney failure were diagnosed in Wisconsin in 2020 (most recent data available).

72 were able to get a transplant
1,848 went on dialysis

SOURCE: 2022 USRDS Annual Data Report



391 kidney transplants were performed in Wisconsin in 2022.

96 living donor transplants
295 deceased donor transplants

SOURCE: Organ Procurement and Transplantation Network

Legislation is needed to protect living organ donors

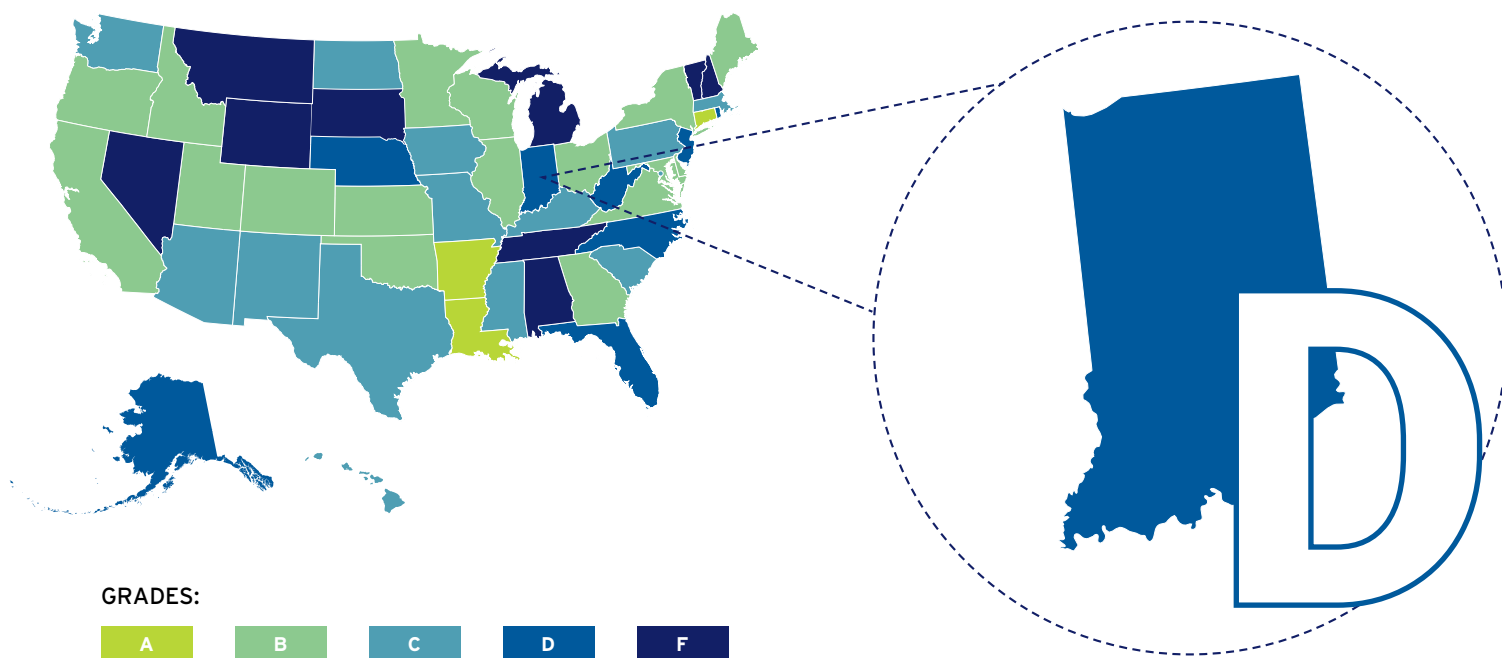
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Text **KIDNEY** to **52886** or visit KidneyFund.org/act to get involved in legislative efforts in your state.

STATE of the STATES: 2023 Living Donor Protection Report Card

INDIANA



Out of **SEVEN** possible types of living donor protection legislation, Indiana currently has **ONE** law in place.



- Job-protected leave from private employers
- Job-protected leave from public employers
- Tax credits for employers who provide paid leave
- Paid leave via Family and Medical Leave Act (FMLA) law
- Direct reimbursements, tax credits or tax deductions for donor expenses
- More than 60 days of leave via FMLA laws
- Protection from life, disability or long-term care insurance discrimination

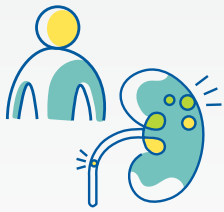
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STATE of the STATES: 2023 Living Donor Protection Report Card

INDIANA

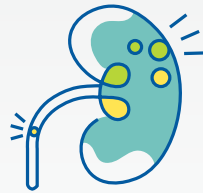
Who is impacted?



14,682 Hoosiers have kidney failure. Without treatment – dialysis or a transplant – kidney failure is fatal.

4,670 have transplants
10,012 depend on dialysis to stay alive

SOURCE: 2022 USRDS Annual Data Report



2,465 new cases of kidney failure were diagnosed in Indiana in 2020 (most recent data available).

76 were able to get a transplant
2,389 went on dialysis

SOURCE: 2022 USRDS Annual Data Report



317 kidney transplants were performed in Indiana in 2022.

54 living donor transplants
263 deceased donor transplants

SOURCE: Organ Procurement and Transplantation Network

Legislation is needed to protect living organ donors

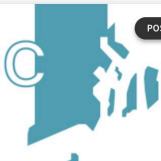
Donating a kidney is one of the most altruistic actions a person can take, and being a living donor is much easier when you have guaranteed paid leave from work and protection from insurance discrimination. AKF has been spearheading efforts at the state and federal levels to get such legislation enacted. Until federal legislation passes that would give baseline protections to donors nationwide, states should enact living donor protection laws, including: anti-insurance discrimination for life, disability and long-term care insurance; job-protected leave from private employers; job-protected leave from public employers; tax credits for employers who provide paid leave; direct reimbursements, tax credits or tax deductions for donor expenses; paid leave via Family and Medical Leave Act (FMLA) laws; and extended FMLA leave (more than 60 days).



Text **KIDNEY** to **52886** or visit KidneyFund.org/act to get involved in legislative efforts in your state.

**In 2023, Nevada, Wyoming & Rhode Island Have Enacted
Insurance Protections For Living Donors Similar to SB
384**

Recent updates



POSITIVE UPDATE

Rhode Island is now a C state after enacting an anti-insurance discrimination law that prohibits life, disability and long-term care insurers from discriminating against living organ donors.

JUNE 23, 2023



POSITIVE UPDATE

Nevada is now a D state after enacting an anti-insurance discrimination law that prohibits life, disability and long-term care insurers from discriminating against living organ donors.

MAY 15, 2023



POSITIVE UPDATE

Wyoming is now a D state after enacting an anti-insurance discrimination law that prohibits life, disability and long-term care insurers from discriminating against living organ donors.

FEBRUARY 27, 2023



POSITIVE UPDATE



POSITIVE UPDATE



POSITIVE UPDATE



**Percentage of Donor Age Population To Become Living
Donors That Clears Transplant Wait List**



Population by age range (Table B01001) [View table](#)

Column	Michigan				United States			
0-9	11.3%	±0.1%	1,131,553	±10,506.8	11.7%	±0%	38,672,058	±73,096.7
10-19	12.8%	±0.1%	1,288,086	±11,682.4	13.2%	±0%	43,645,580	±83,716
20-29	13.1%	±0.1%	1,316,885	±12,386.4	13.1%	±0%	43,483,096	±84,740.9
30-39	12.6%	±0.1%	1,264,306	±9,888.8	13.7%	±0%	45,350,083	±75,738.2
40-49	11.8%	±0.1%	1,181,072	±9,373.1	12.4%	±0%	41,144,488	±71,588
50-59	13.2%	±0.1%	1,321,930	±9,088.7	12.7%	±0%	42,032,544	±62,242.5
60-69	13.3%	±0.1%	1,335,832	±13,703	12.1%	±0%	40,025,667	±89,747.2
70-79	8.2%	±0.1%	825,071	±9,287.3	7.6%	±0%	25,299,187	±58,986.1
80+	3.8%	±0.1%	386,076	±7,586.9	3.7%	±0%	12,241,042	±48,452

Hide data

Michigan Donor Age Population: 5,084,193
Michigan Kidney/Liver Waitlist: 2244

% of Donors Needed To Clear Waitlist: .04%