



*America*

**NATIONAL DONOR DESIGNATION  
REPORT CARD**

— APRIL 2010 —



Peter, heart recipient

*Challenged to  
Save Lives*

## **NATIONAL GOALS**

**100 MILLION DESIGNATED DONORS**

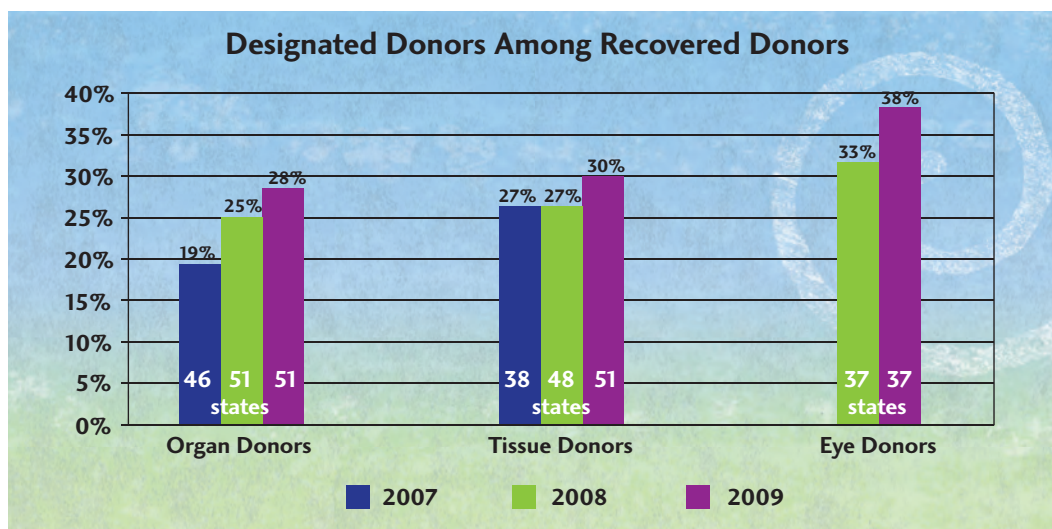
**50% DONOR DESIGNATION RATE**

## DONOR DESIGNATION IN BRIEF

Donate Life America launched the Donor Designation Collaborative (DDC) in 2006 to focus on sharing best practices and creating high-functioning state donor registries to dramatically increase the number of designated donors in the United States. Progress is tracked quarterly by state-based teams and released annually in this National Donor Designation Report Card.

As a result of the DDC and the efforts of the donation and transplant community nationwide, we have registered 86.3 million donors — an increase of 24.4 percent since 2007. This concerted effort has helped facilitate more than 82,000 organ transplants, approximately 120,000 cornea transplants, and millions of tissue transplants in the past three years. In 2009, 28 percent of organ donations, 30 percent of tissue donations and 38 percent of eye donations were authorized through state donor registries.

### Impact on Donation, 2007–2009



By any measure, the Donor Designation Collaborative has been a success. We have achieved a strong collaboration between state teams, helped develop effective state donor registries in a majority of states, increased designated donors by tens of millions, and saved and improved countless lives. Above all, we have moved from the Donor Designation Collaborative as a finite program to the realization of a new and ongoing way of conducting business. What started as a strategy to bring change has become a movement to ensure that as many lives as possible are saved and improved each day through the miracle of donation and transplantation.

## HOW DONATION HAPPENS AND WHY THE NEED IS SO GREAT

The generosity of the American people is seen in the more than 86 million registered organ, eye and tissue donors who are motivated to save or improve the lives of others as deceased or even living donors. With so many designated donors, why is there still a shortage of donated organs? Why are there more than 106,000 men, women and children, 18 of whom die waiting every day, still in need of lifesaving organ transplants and thousands more in need of tissue and corneal transplants?

Quite simply, the conditions under which a person can qualify to donate organs, eyes and tissue are complex. Although everyone should consider him or herself a potential donor, not everyone is able to donate at the time of death. For a donor designation to be realized, a potential donor must be free of certain communicable diseases and must meet various medically-related and behavioral-risk criteria.

### Organ Donation

- In order for a person to become an organ donor, blood and oxygen must flow through the organs until the time of recovery to ensure viability. This requires that a person die under circumstances that have resulted in an irreparable neurological injury, usually from massive trauma to the brain such as aneurysm, stroke or automobile accident. Only after all efforts to save the patient's life have been exhausted, tests are performed to confirm the absence of brain or brain stem activity, and brain death has been declared, is donation a possibility. The state donor registry is searched to determine if the patient has personally authorized donation. If the potential donor is not found on the registry, his or her legally authorized representative (usually a spouse, relative or close friend) is offered the opportunity to authorize the donation. Once the donation decision is established, the family is asked to provide a medical and social history. Donation professionals determine which organs can be transplanted and to which patients on the national transplant waiting list the organs are to be allocated.
- According to the United Network for Organ Sharing (UNOS), "A person who may benefit from an organ transplant is referred by his or her doctor to a transplant center, which evaluates the patient. The transplant center runs a number of tests and considers the patient's mental and physical health, as well as his or her social support system. If the center accepts this person as a transplant candidate, it will add his or her medical profile to the national patient waiting list for organ transplant. The candidate is not placed on a ranked list at that time. Rather, his or her information is kept in a constantly updated, confidential, computerized database. When a deceased organ donor is identified, a transplant coordinator from an organ procurement organization accesses the UNOS computer. Each patient in the database is matched by the computer against the donor characteristics. The computer then generates a list of candidates for each available organ in ranked order according to the Organ Procurement and Transplantation Network (OPTN) organ allocation policies." Waiting time for transplantation varies widely depending on factors such as the organ needed, blood type and the degree of the patient's

medical urgency. Some candidates are transplanted less than a day after listing; others may wait years for a transplant. Median wait times include three to eight months for a heart, eight to 15 months for a liver, 15 months to two years for a lung, and three to five years for a kidney (United Network for Organ Sharing, 2010).

## Tissue Donation

- In case of tissue donation, for which most deceased persons can be potential donors, the local tissue recovery organization receives a referral from a hospital, medical examiner or funeral home notifying them that an individual has died. An initial determination of donor eligibility is made based on basic criteria and available information (i.e., age, cause of death, immediate evidence of infection, etc.). If it is determined that the deceased individual is a candidate for donation, the state donor registry is searched and one or more persons who know the potential donor (i.e. historians) are contacted for a medical and social history. If the potential donor is not found on the registry, his or her legally authorized representative (usually a spouse, relative or close friend) is offered the opportunity to authorize the donation. Tissue donation must be initiated within 24 hours of death. Unlike organs, tissue can be processed and stored for an extended period of time for use in burn cases, ligament repair, bone replacement, etc. (American Association of Tissue Banks, 2010).

## Cornea Donation

- In case of cornea donation, for which most deceased individuals are potential donors, an eye bank receives a call from a hospital, an organ procurement organization or another federally designated third party that an individual has died and has met preliminary criteria for donation. Cornea donation usually happens within 12 hours of death. The state donor registry is searched and if the potential donor is not found on the registry, the donor's legally authorized representative (usually a spouse, relative or close friend) is given the opportunity to authorize the donation. In addition, they are asked for the donor's medical and social history, which provides the eye bank with information to help determine donor eligibility. The donor profile is screened for physical signs of infectious disease or behavior that may have put them at risk, such as intravenous drug use. Corneas are evaluated for cell count and clarity of the tissue. That information, together with the donor's age, is used to determine which patient will receive the cornea for transplant. Whenever possible, eye banks try to place the cornea with a patient that is close in age to the donor to help ensure that the cornea will last throughout the patient's lifetime. Corneas are transplantable for up to 14 days after recovery (Eye Bank Association of America, 2010).

Understanding the circumstances and processes involved in organ, eye and tissue donation makes it clear that the greater the pool of registered donors, the greater the chances of saving the more than 106,000 people who await organ transplants and helping the thousands more in need of corneal and tissue transplants.

# CURRENT NATIONAL STATUS

## (2009 YEAR END DATA)

The DDC’s goals are to achieve 100 million actionable donor designations (ADD) and a 50 percent donor designation rate at Departments of Motor Vehicles (DMVs), which as an enrollment channel accounts for 97 percent or more of donor registrations in most states.

- At the end of 2009, 86.3 million people were enrolled in state donor registries, representing 37.1 percent of all U.S. residents age 18 and over and an 8.2 percent increase from one year ago.
- In the 26 states and the District of Columbia that were able to track donor designation rates in Q4 2009, 35.8 percent of DMV driver’s license and ID card applicants signed up as donors.

The essential role of state donor registries is demonstrated by their effect on organ, tissue and eye recovery.

- At least 2,254 organ donors in the United States, or 28.4 percent of the total (vs. 25.2 percent in 2008), had joined their state donor registry before their death.
- A reported 9,183 tissue donors in the United States, or 29.6 percent of the total (vs. 27.2 percent in 2008), had joined their state registry before their death.
- A reported 15,882 eye donors in the United States, or approximately 37.6 percent of the total in the 37 reporting states, had joined their state registry before their death. This compares to 12,168 designated eye donors, or 32.8 percent of the total, in 2008.

## STATE COMPARISONS

### 1. Actionable Donor Designation (ADD) Population 18+ Share for 2009

ADD Population 18+ Share is the total number of designated donors as a percentage of all state residents age 18 and over. (Some donor registries allow minors to enroll, so these states will reflect higher percentages than actual.) The DDC also tracks designated donors as a percentage of licensed drivers, but because non-drivers account for a substantial percentage of designated donors, this is not deemed an accurate measure.

State	Actionable Donor Designations	State Population Age 18+**	ADD Population Age 18+ Share
Alaska	378,446	514,927	73%
Alabama	1,664,728	3,579,844	47%
Arkansas	1,180,000*	2,179,482	54%
Arizona	1,661,400	4,863,759	34%
California	5,955,716	27,525,982	22%
Colorado	2,250,000*	3,796,985	59%
Connecticut	1,001,608	2,710,303	37%
District of Columbia	165,141	485,621	34%
Delaware	302,393	678,129	45%
Florida	5,173,409	14,480,196	36%

State	Actionable Donor Designations	State Population Age 18+**	ADD Population Age 18+ Share
Georgia	3,487,019	7,245,419	48%
Hawaii	366,350	1,004,817	36%
Iowa	990,732	2,294,701	43%
Idaho	633,833	1,126,611	56%
Illinois	5,065,524	9,733,032	52%
Indiana	3,190,000*	4,833,748	66%
Kansas	555,670	2,113,796	26%
Kentucky	771,465	3,299,790	23%
Louisiana	1,788,853	3,368,690	53%
Massachusetts	2,119,696	5,160,585	41%
Maryland	2,007,299	4,347,543	46%
Maine	467,008	1,047,125	45%
Michigan	1,731,387	7,619,835	23%
Minnesota	2,280,661	4,005,417	57%
Missouri	2,647,146	4,556,242	58%
Mississippi	378,033	2,184,254	17%
Montana	545,159	755,161	72%
North Carolina	3,945,660	7,102,917	56%
North Dakota	317,355	502,873	63%
Nebraska	633,605	1,344,978	47%
New Hampshire	101,125	1,035,504	10%
New Jersey	2,023,618	6,661,891	30%
New Mexico	933,546	1,499,433	62%
Nevada	791,047	1,962,052	40%
New York	1,948,487	15,117,370	13%
Ohio	4,874,080	8,828,304	55%
Oklahoma	1,695,509	2,768,201	61%
Oregon	2,078,954	2,952,846	70%
Pennsylvania	4,271,416	9,829,635	43%
Rhode Island	323,706	826,384	39%
South Carolina	315,309	3,480,510	9%
South Dakota	334,336	612,767	55%
Tennessee	1,318,789	4,803,002	27%
Texas	440,000*	17,886,333	2%
Utah	1,206,472	1,915,748	63%
Virginia	3,387,371	6,035,408	56%
Vermont	NA	495,485	NA
Washington	3,456,433	5,094,603	68%
Wisconsin	2,362,868	4,344,524	54%
West Virginia	473,000*	1,433,328	33%
Wyoming	335,000*	412,245	81%
<b>TOTAL</b>	<b>86,326,362</b>	<b>232,458,335</b>	<b>37.1%</b>

\*Estimated

\*\*Source: US Census Bureau estimate as of 12/31/09

## 2. Designation Rate – 2009

Designation rate is the number of individuals who joined the state donor registry expressed as a percentage of all driver's licenses and ID cards issued within a specific period of time. Due to limited access to this data, only the following 25 states and the District of Columbia were able to report this measure for the year.

State	Actionable Donor Designations in 2009	DLs & IDs Issued by State DMV	Designation Rate
Colorado	542,670	842,038	64.4%
Iowa	561,234	894,021	62.8%
Montana	109,558	175,532	62.4%
Washington	923,506	1,627,659	56.7%
Wyoming	78,815	142,169	55.4%
Ohio	878,951	1,610,406	54.6%
North Carolina	1,151,197	2,230,344	51.6%
Utah	332,238	648,185	51.3%
Louisiana	643,106	1,256,349	51.2%
South Carolina	306,693	622,183	49.3%
Pennsylvania	1,208,806	2,681,666	45.1%
Maryland	785,910	1,776,104	44.2%
Nebraska	208,921	484,110	43.2%
Hawaii	64,139	154,801	41.4%
Oregon	157,315	420,428	37.4%
Connecticut	321,030	878,108	36.6%
Missouri	608,037	1,676,425	36.3%
Illinois	788,888	2,215,522	35.6%
District of Columbia	34,545	101,816	33.9%
Virginia	147,980	446,605	33.1%
Tennessee	550,568	1,819,682	30.3%
Kentucky	262,799	1,013,234	25.9%
California	2,142,068	8,392,139	25.5%
Arizona	264,401	1,536,300	17.2%
Michigan	254,269	1,995,704	12.7%
New York	427,562	3,835,971	11.1%

Source: Reported by DDC state teams

States appearing in green have met the DDC goal of a designation rate of 50 percent.

### 3. Registry Design

The following 36 states and the District of Columbia meet effective donor registry design criteria as determined by the DDC Faculty:

Alabama	Idaho*	Missouri*	South Carolina
Alaska	Illinois	Montana	Tennessee
Arizona	Indiana	New Hampshire*	Utah
California	Iowa*	New Mexico*	Virginia
Connecticut*	Kentucky	North Dakota*	Washington
Colorado	Maine*	Ohio	West Virginia*
Delaware*	Maryland	Oklahoma	Wyoming
District of Columbia	Massachusetts	Rhode Island*	
Florida*	Minnesota	Oregon	
Georgia*	Mississippi*	Pennsylvania	

\*Effective Registry status achieved in 2009

#### Effective Registry Design Criteria

1. Donor designation is considered legally binding consent
2. Includes consent for tissue donation
3. Individuals can enroll through a dedicated Web site
4. DMV enrolls donors via driver's license and ID card applications and renewals
5. No follow-up step required for DMV or online enrollment
6. DMV exports donor records to registry database
7. Organ, eye and tissue recovery agencies can effectively access donor designations

### 4. Growth Phase

As state donor registries mature, one of the DDC's challenges will be to increase donor designations. Once a state donor registry completes its first driver's license/ID card renewal cycle, new designated donors come from only three sources – first-time drivers, new residents, and current residents who previously elected not to enroll. This maturity factor will affect designation rate and require focused strategies to maximize growth opportunities. The following 32 states have donor registries that have entered a mature growth phase:

Alabama	Indiana	Nevada	Pennsylvania
Alaska	Kansas	New Jersey	Rhode Island
Arkansas	Louisiana	New Mexico	South Dakota
Connecticut	Maine	New York	Tennessee
Colorado	Maryland	North Carolina	Utah
Delaware	Massachusetts	North Dakota	Washington
Georgia	Minnesota	Ohio	West Virginia
Hawaii	Nebraska	Oklahoma	Wyoming

## FACILITATING DONATION...AGAINST THE ODDS

*Every day, donation and transplant professionals work tirelessly to save and improve lives. We educate the public about their power to save lives and the steps required to sign up as a donor. We are obligated to honor the documented wishes of all registered donors and to offer the opportunity to authorize donation to the donor's legally authorized representative (usually a spouse relative or close friend) if he or she is left to make the donation decision on their loved one's behalf. Underlying our every effort is our commitment to help save and improve the lives of those in need.*

*Below are the stories of two donors and their families who, in times of unimaginable tragedy, were able to save lives. For one family, the situation was compounded by a natural disaster. The other family struggled with the husband's initial resistance to the idea of donation. Through it all, donation and transplant professionals stood by them, and the families found peace through the lifesaving gifts of their loved ones.*

### The Heart that Conquered a Storm

After Hurricane Katrina, the people of Louisiana thought things could not get worse. Then, Hurricane Rita approached them from the west. In the mayhem, a local family scrambled to evacuate. While Roger Leger was at work, his wife Christie and their son Devan were able to get a ride from a friend. Sadly, what was intended to be a trip to safety, resulted in the untimely death of 3-year-old Devan – and a gift of life to others.

After their friend's car was hit by a truck, Devan was rushed to Lafayette General Medical Center where Christie and Roger were devastated by news that their little boy would not survive. But in the face of tragedy, Roger immediately thought of organ donation and of other parents who would face the loss of a child without the donation of a lifesaving organ.



Devan, organ donor

The conditions were extreme. The hospital was working on generators, and many staff members were facing personal challenges due to the storm. Land lines were down and cell phones were not working. Somehow the hospital was able to reach the Louisiana Organ Procurement Agency, and a first responder came to the hospital to explain the donation process to the family. Still more obstacles arose, as the hospital had limited power and was not able to fax documents, book operating room time or even get a team in to recover the organs.

At the family's insistence, arrangements were made to transfer little Devan to Baton Rouge, which had fared better in the storm. Unfortunately, the ambulance sent to transport Devan did not have the pediatric ventilator necessary to keep Devan's organs viable. Amidst the chaos, a recovery coordinator was reached. Despite his own personal hurdles due to the storm he volunteered to ride in the ambulance with Devan for the 50-mile trip to Baton Rouge, and using a hand-bagging device to simulate breathing and the flow of oxygen.

Meanwhile in North Carolina, Sarah and Charles McBride were saying goodbye to their 5-year-old son, Peter, born with hyperplastic left heart syndrome. Peter had undergone numerous surgeries, and his ailing heart could take no more. Only a transplant could save him. In their most dire moment, they received a call to say that a heart – Devan’s heart – was available for Peter.

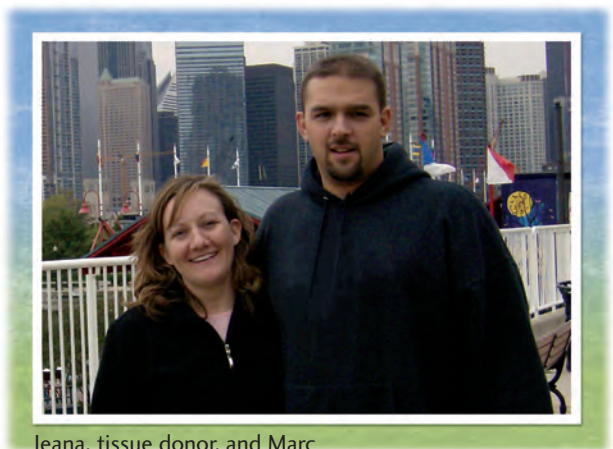
Devan’s heart saved Peter’s life. Today, Peter (pictured on the front cover of this report card) is a healthy, active third grader and Boy Scout who enjoys jumping on the trampoline, riding roller coasters, swimming and playing his Wii. Even at such a young age, he is ever grateful for the generosity of the Leger family and all of those who rose above their own personal tragedies and turmoil to ensure the lifesaving wishes of two families were made possible in the form of Devan’s heart now beating inside of him.

## From Skepticism to Advocacy

Marc and Jeana’s love story was like something out of a movie. They met over the telephone and what started as Jeana’s irate complaint to a vendor, developed into a lasting love and a wonderful life. Jeana had spunk and always lived life to the fullest. She had told her husband that, when she died, she wanted to donate her organs and tissue. Although he respected her decision to become a registered donor, Marc did not wish the same for himself. He found donation morally wrong and a grievous lack of respect for what God had created. Jeana believed differently. Having studied nursing for a time, Jeana understood the wonders of donation and transplantation. When her time on earth came to an end, she wanted to make a difference in someone’s life.

One evening last June, Marc needed to return his company car to work and pick up his motorcycle. A motorcycle lover, Jeana jumped at the chance to accompany him for the evening ride back home. Unfortunately, the ride came to a terrible end when a deer ran onto the road, causing them to wreck. Jeana was airlifted to the hospital in critical condition, while Marc was sent by ambulance to a different hospital. Throughout the night, Marc asked for Jeana, and the next day he was transported to his wife’s hospital so they could be together. Jeana never regained consciousness, and Marc was devastated.

During those moments of despair, Jeana’s dad asked Marc about donation, remembering that after an accident, Jeana’s brother had received a tissue transplant that restored him to his normal life. Although Marc wanted to honor Jeana’s wishes, his extreme grief and personal opposition to donation blurred his thinking. Eventually, despite his discomfort, Marc cooperated with the hospital and donation professionals to ensure that Jeana’s wishes were honored. Through the process, something changed in him. He began to see that donation was an act of compassion and not frowned upon by God. As a result, Jeana was able to donate tissue, restoring health and mobility to many. Marc is now a registered donor and advocates for donation. His pastor, his wife’s family, donation and transplant professionals, and above all, his wife, helped him understand the wonderful gift donation provides – not only to transplant recipients, but to the donor’s family.



Jeana, tissue donor, and Marc

## THE CHALLENGE TO SAVE LIVES CONTINUES

Despite the complexities involved in organ, eye and tissue donation and transplantation, tremendous strides have been made. In the early days only siblings (specifically twins) could donate. Today, deceased and living donation among strangers is the norm. The age criterion has been extended, with donors as old as 92 on record. Donation after cardiac death, as opposed to brain death, is now possible in some cases, expanding the number of organs that can be donated. Still, with the miraculous success of transplantation, the need for donors continues to increase. In order to meet this need, it is essential that millions of people step forward to register as donors, and that the thousands of people who are asked to make the decision for their loved ones say 'yes' to donation.

To determine the public's attitudes toward donation and related actions, thus better understanding how to increase donation, Donate Life America, in partnership with Astellas Pharma US, Inc., commissioned an online survey of 5,100 adults in the United States. Fielded by Survey Sampling International in January 2010, and compared to the February 2009 survey, findings revealed both positive signs and continuing barriers among the public.

### Signs of Hope

- A majority of U.S. adults now wish to be organ or tissue donors –56 percent versus 50 percent in 2009.
- Among adults who have registered to be organ or tissue donors, 19 percent were previously reluctant or hesitant to do so.
- Three-fourths (75 percent) of those surveyed want their donation wishes fulfilled regardless of family desires, up from 2009.
- The percentage of adults who believe the organ and tissue allocation system is fair has increased in the past year – 37 percent versus 32 percent in 2009.

## Challenges Ahead

- 52 percent of people incorrectly believe that doctors may not try as hard to save their lives if they know they wish to be organ or tissue donors.
- 19 percent of people are not sure they would be acceptable donors.
- Approximately half of adults (48 percent) believe a black market exists in the U.S. for organs and tissue, up from 44 percent in 2009.
- While only 16 percent believe a regular funeral is not possible following donation, this percentage is up from 13 percent in 2009 and 11 percent in 2004.
- 61 percent mistakenly believe it may be possible for a brain dead person to recover from his or her injuries.
- Despite the strong desire for first person consent, many barriers, including lack of urgency, exist regarding registration.
  - 27 percent “just haven’t done it” or “gotten to it.”
- Confusion on how to register and whether one is indeed registered are more common than expected.
  - Among adults who wish to donate all or some of their organs or tissue but have not registered to do so, just over half (53 percent) say they do not know how to register, while another 25 percent are neutral.

With this knowledge in hand, our resolve grows ever stronger, and our work continues. Increasingly, Americans are enrolling in state donor registries, bringing new life and new hope that deaths on the waiting list will cease, and that there will be an organ, eye or tissue available for everyone in need.

## APPENDIX A\*

### Revised Uniform Anatomical Gift Act, 2010 Introductions and Enactments:

**Connecticut:** Introduced as SB 250 in 2010 - Joint Public Health

**Nebraska:** Introduced as LB 1036 in 2010 - Judiciary

**New Hampshire:** Introduced as HB 1430 in 2010 - Passed House

**New York:** Introduced as AB6966/SB4488 in 2009-10 - Assembly Health

**Vermont:** Introduced as SB 205 in 2010 - Senate Health

### The following states have enacted the Revised Uniform Anatomical Gift Act:

Alabama	Indiana	New Jersey	Tennessee
Alaska	Iowa	New Mexico	Texas
Arizona	Kansas	North Dakota	Utah
Arkansas	Maine	North Carolina	Virginia
California	Michigan	Ohio	Washington
Colorado	Minnesota	Oklahoma	West Virginia
District of Columbia	Mississippi	Oregon	Wisconsin
Georgia	Missouri	Rhode Island	Wyoming
Hawaii	Montana	South Carolina	
Idaho	Nevada	South Dakota	

\*Source: <http://www.anatomicalgiftact.org>

## APPENDIX B

### Terms

**Actionable Donor Designation (ADD):** *An individual's commitment to donate recorded in a searchable donor registry.*

**Actionable Donor Designation (ADD) Population 18+ Share:** *ADD Population 18+ Share is the total number of designated donors as a percentage of all state residents age 18 and over. (Some donor registries allow minors to enroll, so these states will reflect higher percentages than actual.)*

**Actionable Donor Designation (ADD) Share:** *The total number of designated donors as a percentage of all licensed drivers.*

**Designation Rate:** *The number of individuals who join the state donor registry expressed as a percentage of all driver's licenses and ID cards issued within a specific period of time.*

**Donor Designation:** *A documented, legally binding commitment by an individual to make an anatomical gift that can be revoked only by that individual.*

**Donor Registry:** *A searchable database of individuals who have designated themselves as donors.*

**Effective Registry:** *A donor registry with best-practice characteristics that support the donor designation and maximizes opportunities to enroll and streamline donor searches.*

## ABOUT DONATE LIFE AMERICA

*Donate Life America is a not-for-profit alliance of national organizations and state teams, serving as a national voice and inspiring all people to save and enhance lives through organ, eye and tissue donation.*

*Based in Richmond, Virginia, Donate Life America was founded by the donation and transplant community in 1992 to educate the public about organ, eye and tissue donation and avoid duplication of effort.*

**For more information, visit [www.donatelife.net](http://www.donatelife.net).**



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