



Donate Life America is a 501(c)3 not-for-profit alliance of national organizations and state teams across the United States dedicated to saving and healing lives through increased organ, eye and tissue donation. Donate Life America, with the help of its corporate partners, is committed to spreading the word about the importance of being a registered donor so that others may live. Our vision is a nation that embraces organ, eye and tissue donation as a fundamental human responsibility. Donate Life America manages and promotes the national brand for donation, Donate Life<sup>SM</sup>, and assists Donate Life State Teams and national partners in facilitating high-performing donor registries; developing and executing effective multi-media donor education programs; and motivating the American public to register now as organ, eye and tissue donors.

[DonateLife.net](http://DonateLife.net) | [DoneVida.org](http://DoneVida.org) | [facebook.com/DonateLife](https://facebook.com/DonateLife)



2013

Registered Donor



## NATIONAL DONOR DESIGNATION REPORT CARD

*The Challenge to Register More  
Organ, Eye and Tissue Donors*

# Our Mission for Life

To drive individuals, organizations and communities to increase the number of designated organ, eye and tissue donors who save and heal lives.

## Introduction

### BACKGROUND

Donate Life America (DLA) is invested in initiatives to increase donor designation nationwide. The Donor Designation Collaborative, launched in 2006, has evolved into our standard of practice for advancing donation, thus helping to save the lives of the tens of thousands of men, women and children awaiting organ transplants and heal the hundreds of thousands more in need of corneal and tissue transplants.

At the core of the collaborative effort are the gathering, evaluation and comparison of state registry data. This analysis allows us to enhance the quality of systems that enable recovery agencies to follow a donor's decision to make an anatomical gift.

Annually, data from the donor registries of all 50 states, the District of Columbia and Puerto Rico is reported through this National Donor Designation Report Card.

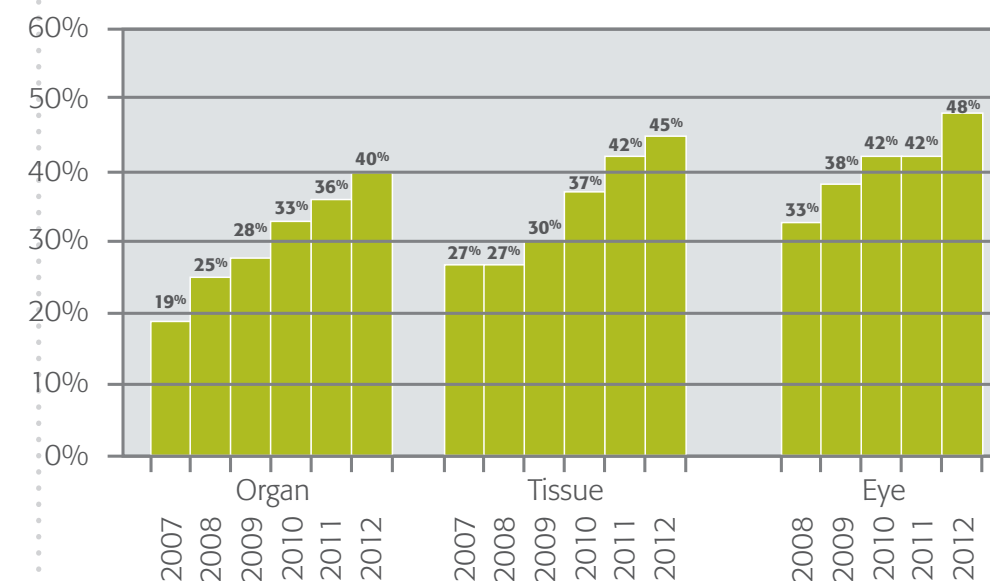
### PROGRESS TO DATE

In 2012, as part of an effort to drastically increase the number of registered donors, DLA launched the "20 Million in 2012" campaign. The aggressive goal of adding 20 million people to the 100 million already registered served as a bold statement about both the dire need for more donors and our commitment to saving and healing lives. The campaign created excitement and successfully engaged more people to register and to participate in countless activities to promote organ, eye and tissue donation across the United States.

As a result of the building momentum and the focus on donor designation by the donation and transplant community nationwide, 109 million individuals have registered as donors, 7.5 million of those registered in 2012. Also in 2012, 41 percent of recovered organ donors, 46 percent of recovered tissue donors and 50 percent of recovered eye donors were authorized through state donor registries. These growing percentages help facilitate the process of recovery agencies following a donor's decision to make an anatomical gift.

### National Impact on Donation, 2007-2012

Designated Donors Among Recovered Donors



2007 recovered eye donors not available

“Measuring our progress and growth over time as well as measuring the success of individual states and individual campaigns to identify best practices is key to our long-term success in achieving DLA’s mission. This 2013 data report is the latest, best data...data we can use to look backward and to celebrate progress, and data we can use to look forward as we strive for broad implementation of best practices and higher levels of success.”

— Jeff Orlowski

## Bone Graft Restores Active Lifestyle

Diagnosed with Ewing’s Sarcoma at age 12, Kristen Main was devastated to learn that to stop the cancer from spreading, her arm would need to either be amputated or debilitated by radiation. Fortunately, a bone transplant provided another option.

Thanks to the gift of a tissue donor, the bone graft surgery was a success and Kristen returned to playing softball and water polo. Kristen was overjoyed to be back to her active lifestyle. Eventually, she went on to college at Grand Valley State University, where she majored in criminal justice. After graduating in 2009, she attended the police academy in Grand Rapids, MI, and is now a Police Sergeant.



Kristen, bone graft recipient, standing by her patrol car with her niece and nephews

“Donation is a gift that keeps on giving,” says Kristen. “I know this sounds cliché, but it truly changes someone’s life.”

# National Status

## 2012 YEAR-END DATA

Every year, Donate Life America tracks progress to determine the increase in donor designation state by state. Data is compiled and analyzed to establish four important measures: Total Donor Designation, Donor Designation Share, Donor Designation Rate, and Effective Registry Design. This information is critical to identifying states that excel at donor designation so that successful programs can be replicated by other states.

## DONOR DESIGNATION

A Donor Designation is a documented, legally authorized commitment by an individual to make an anatomical gift that cannot be revoked by anyone other than the registered donor.

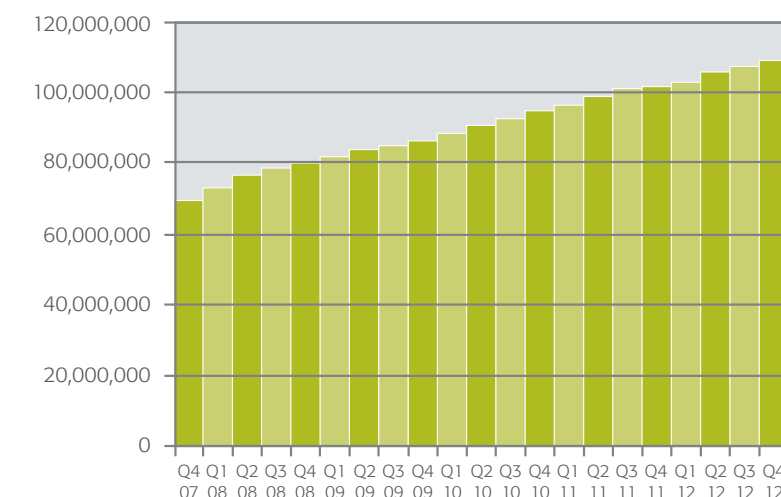
## DONOR DESIGNATION SHARE

The Donor Designation Share is the total number of designated donors, as a percentage of all state residents age 18 and older. The goal is for every state to reach a minimum 50 percent Donor Designation Share.

Some donor registries allow minors to enroll, so these states will reflect higher percentages. The date of registry inception may also affect the number of people accounted for in each registry and could cause some states to have a smaller number of registered donors than expected. Registries that have existed for many years have had a longer period of time to enlist donors compared to more recently launched registries.

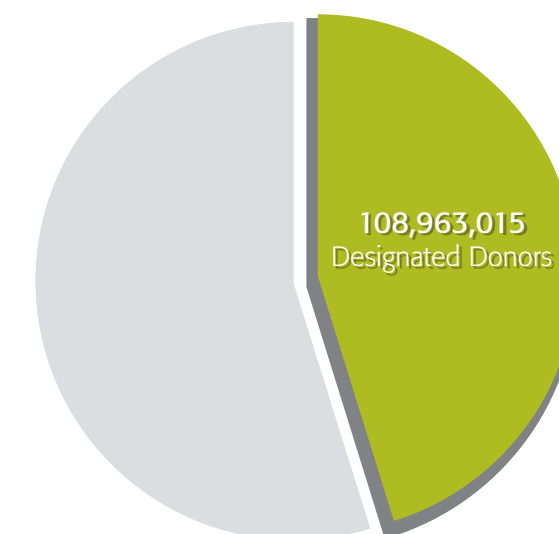
## Donor Designation in the United States

108,963,015 as of 12/31/12



## Donor Designation Share in the United States

50 states and DC



US Population Age 18+: 240,185,952

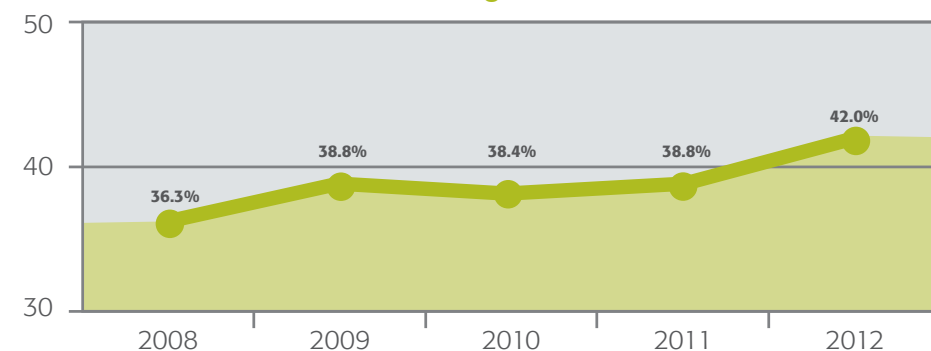


# Donor Designation Rate

The Donor Designation Rate is the rate at which individuals join the state donor registry as a percentage of all driver's licenses and ID cards issued within a specific period of time. Another goal is that each state achieves a minimum 50 percent Donor Designation Rate. For example, if 1,000 people apply for their driver's license or state ID today and at least 500 register as new donors or chose to remain donors during this process, that is a 50 percent Donor Designation Rate.

Some states are unable to report the data necessary to calculate Donor Designation Rate. Fortunately, every year since 2006, additional states have been able to overcome that barrier by changing elements of their registry reporting system. Some states still struggle to meet the 50 percent minimum and until they do so, we must continue sharing information and best practices so that the national goal can be achieved.

National Donor Designation Rate 2008-2012



Alfonso, liver recipient

## A Young Advocate for Donation

As a child, Alfonso Garcia wanted to follow in his brother's footsteps as an amateur boxer and military man.

But, in January 2010, Alfonso quickly fell into a spiral of declining health and became very ill. "I learned that I had Wilson's disease," reveals Alfonso, "an inherited disorder in which there is too much copper in the body's tissue. The excess copper damages the liver and nervous system. Doctors told me that I had just days to live without a transplant." Alfonso's future was uncertain, until a registered donor named George saved his life and the lives of two others.

Alfonso's new liver has given him renewed focus on what's important in life.

Soon after he was well again, Alfonso and his parents joined the California Transplant Donor Network as Donate Life Ambassadors to help spread the word about donation. Alfonso has appeared before California legislators, urging them to include donation education in the high school curriculum.

"Transplant recipients, such as Alfonso Garcia, show legislators that organ donation isn't just a numbers game," says Charlene Zettel, Executive Director of Donate Life California. "Alfonso Garcia's story reminds California's legislators of the human element in organ donation and brings tears to their eyes."

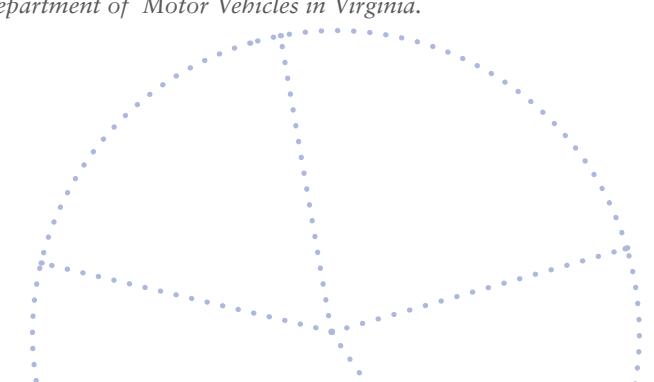
*"I was on the edge of dying, and through a miracle, I am alive today. It's because of a donor and his gift. I think about George every day."*

# Effective Registry Criteria

The Donor Designation Collaborative determined that the design of a registry plays a key role in its effectiveness. Over the years, several factors have been identified as critical, and each year more state registries have been able to make changes to meet these criteria. They include:

1. **No follow-up step required** for Department of Motor Vehicles or online enrollment, allowing a registration to take effect without unnecessary delay.
2. **Active legislation that authorizes recovery agencies to honor a donor's decision** to make an anatomical gift with no further requirement for family authorization for organ, eye and tissue donation. Legislation makes a donor's decision the priority and prevents delays due to confusion or indecision that could result in the organs and tissue no longer being viable or preventing the donation from taking place.
3. **24/7 access** to the system by organ, eye and tissue recovery agencies to search donor designations. A system that limits the times a registry can be searched also limits the number of donors. Making a registry searchable 24/7 ensures that designated donors are identified immediately and allows donation professionals to follow the donor's documented decision.
4. **Department of Motor Vehicles enrolls donors via driver's license and ID card applications and renewals by all available channels**, including field office, online and mail, maximizing opportunities to designate a donation decision.
5. **Individuals can enroll online through a dedicated website**, providing potential donors the ability to register their decision at any time. Whether it is time to renew their license or not, a person can register their decision through this dedicated website.
6. **Individuals can enroll by completing a paper form or registry brochure form**. Multiple registration channels allow those without a license or ID card or access to the Internet to register. It also allows people to designate a donation decision at health fairs, conferences and community events.
7. **Department of Motor Vehicles donor records are searchable within one week of enrollment**. It is essential that registrations can be acted upon whenever a person becomes a candidate for donation.

*Note: The names of licensing offices vary by state. i.e. The Department of Public Safety in Texas, the Bureau of Motor Vehicles in Indiana and the Department of Motor Vehicles in Virginia.*



# 2012 State Comparisons

If the 50 percent minimum Donor Designation Share or Donor Designation Rate has been met or exceeded or effective registry design criteria has been met, these numbers are highlighted in green. When minimum criteria in all areas are met, the entire state row is highlighted. Note again that some states are unable to report Donor Designation Rate. These states will have some blank cells.

State	Donor Designations	State Population 18+	Donor Designation Share	Donor Designations at DMV	DLs & IDs Issued by State DMVs	Donor Designation Rate	Registry Inception & Effective
Alabama	2,270,377	3,697,617	61%				1997
Alaska	437,884	544,349	80%	86,479	107,760	80.3%	2004
Arizona	2,064,556	4,932,361	42%				2003
Arkansas	1,287,091	2,238,250	58%				1997
California	9,764,155	28,801,211	34%	1,528,540	5,544,233	27.6%	2005
Colorado	2,650,000	3,956,224	67%	918,762	1,380,886	66.5%	2001
Connecticut	1,128,441	2,757,082	41%	401,554	964,626	41.6%	2005
Delaware	368,562	766,884	48%	368,562	766,884	48.1%	1998
Dist.of Columbia	234,433	522,843	45%	42,217	108,831	38.8%	2006
Florida	6,926,821	15,315,088	45%	1,642,776	3,787,916	43.4%	1995
Georgia	4,370,837	7,429,820	59%				1996
Hawaii	591,162	1,089,302	54%	84,245	201,738	41.8%	1991
Idaho	714,442	1,169,075	61%	373,568	660,234	56.6%	2003
Illinois	5,225,958	9,811,190	53%				1992
Indiana	3,428,530	4,945,857	69%	1,396,599	2,520,863	55.4%	2001
Iowa	1,780,000	2,351,233	76%	431,542	683,672	63.1%	2002
Kansas	927,387	2,161,601	43%	265,894	577,700	46.0%	2002
Kentucky	1,267,716	3,362,177	38%	362,698	1,038,029	34.9%	2006
Louisiana	2,115,832	3,484,090	61%	766,212	1,290,906	59.4%	1997
Maine	590,116	1,063,274	55%				2007
Maryland	2,371,183	4,540,763	52%	591,024	1,285,799	46.0%	1991
Massachusetts	2,648,200	5,244,729	50%	448,468	1,101,523	40.7%	2006
Michigan	2,975,830	7,616,490	39%	852,806	1,960,892	43.5%	1994
Minnesota	2,537,024	4,102,991	62%	1,006,427	1,679,075	59.9%	2003
Mississippi	530,099	2,239,593	24%				2008
Missouri	3,081,317	4,618,513	67%	747,083	1,739,436	42.9%	1996
Montana	639,652	783,161	82%	132,598	200,674	66.1%	2004

State	Donor Designations	State Population 18+	Donor Designation Share	Donor Designations at DMV	DLs & IDs Issued by State DMVs	Donor Designation Rate	Registry Inception & Effective
Nebraska	685,321	1,392,120	49%	251,182	558,804	44.9%	2003
Nevada	834,802	2,095,348	40%	357,793	864,077	41.4%	2001
New Hampshire	424,799	1,045,878	41%	104,723	198,950	52.6%	2009
New Jersey	2,359,529	7,252,127	33%	718,334	2,097,081	34.3%	1998
New Mexico	969,000	1,571,096	62%	319,455	575,885	55.5%	1980's
New York	3,096,996	15,307,107	20%	540,183	4,261,914	12.7%	2000
North Carolina	4,312,768	7,465,545	58%	856,855	1,650,404	51.9%	2007
North Dakota	357,334	545,020	66%				2003
Ohio	5,248,500	8,880,551	59%	1,794,030	3,123,671	57.4%	2002
Oklahoma	1,846,555	2,877,457	64%				2004
Oregon	2,234,427	3,038,729	74%	327,864	578,653	56.7%	2007
Pennsylvania	4,468,470	9,787,464	46%	4,468,470	9,787,646	45.7%	1994
Puerto Rico							2011
Rhode Island	418,260	833,818	50%				2005
South Carolina	1,057,931	3,643,633	29%	212,559	980,256	21.7%	2009
South Dakota	343,359	629,185	55%				2003
Tennessee	1,803,640	4,962,227	36%	652,578	1,859,026	35.1%	2008
Texas	3,163,639	19,073,564	17%	928,760	4,854,712	19.1%	2006
Utah	1,360,213	1,967,315	69%	405,293	710,115	57.1%	2002
Vermont	22,937	502,060	5%				2009
Virginia	3,585,845	6,329,130	57%				2003
Washington	4,117,914	5,312,045	78%	1,004,755	1,686,587	59.6%	2004
West Virginia	513,000	1,471,372	35%				1991
Wisconsin	2,545,171	4,408,841	58%	679,072	1,142,230	59.5%	2010
Wyoming	265,000	440,922	60%	92,806	156,997	59.1%	2003
Total	108,963,015	240,378,322	45.3%	26,162,766	62,688,685	42%	

## Crucial Next Steps

As more state registries reach “maturity” (defined as an effective registry that has gone through a complete driver’s license and ID card renewal cycle), it is necessary for the donation community to focus particular efforts on those segments of the population that have proven most difficult to register.

According to research by DLA and others, barriers that prevent U.S. adults from deciding to become registered donors include:

- lack of urgency
- lack of understanding or knowledge of the registration process
- fear that in an emergency doctors will not try as hard to save the lives of registered donors.

With this in mind, while continuing to reach out to everyone, DLA is also placing special emphasis on multicultural communities with long-held misconceptions; those over 50, who may erroneously think they are too old to be donors; and the young adult demographic, 18-24 year olds, who register at a less than average rate. For this year’s Report Card, we focus our examples on 18-24 year olds.

Quantitative research conducted by Donate Life America in 2010 revealed that 76 percent of all adults 18 years and older who wish to donate at least some of their organs and tissue believe they are registered to be organ or tissue donors. That number drops to 66 percent among the 18 to 24 demographic. Of those 18-24 year olds not registered,

14 percent said they had “just not considered it” and 18 percent stated that they “do not have the time to do it” or “haven’t gotten around to it;” and 13 percent were confused as to how they should register.

Other research of this age group, conducted by the British Columbia Institute of Technology for the Collegiate American Marketing Association revealed:

- 25 percent said they had not registered as donors because they “had not heard about it.”
- 30 percent said they “have not gotten around to it.”
- A majority of respondents also intended to register “soon” or “one day.”

At DLA’s annual meeting in 2011, marketing expert Rebecca Ryan described how young adults are aching to be a part of something larger than themselves. Whether due to a personal sense of responsibility or a desire to become more well-rounded citizens, young adults want to be taken seriously as future funders, volunteers and leaders for the issues they care about.

Donate Life America and its constituency are committed to reaching out to this group with a compelling message of hope and urgency and to provide clear instructions on the registration process. We must not only instill a sense of immediacy of the need for more registered donors, but also tap into their drive and passion and engage them as advocates who will influence their peers to make the decision to register as organ, eye and tissue donors.

## Successful Programs Reaching 18-24 Year Olds

Many initiatives have been developed to reach out to this generation of not-yet registered donors. The following are two successful outreach programs.

### New Guinness World Record Set for Most Organ Donor Registrations in a Day

Gift of Hope Organ & Tissue Donor Network, in partnership with the University of Illinois Urbana-Champaign, set a new Guinness World Record for registering the most people as organ donors in a single, 8-hour day. Gift of Hope nearly tripled the previous record by registering 2,262 organ donors on August 26 at the University’s 2012 Quad Day event.

“We are very proud of setting this new Guinness World Record, but we are even more proud of the fact that, by setting this record, we will ultimately make more life-saving organs and healing tissue available to those in need,” said Kevin Cmont, President/CEO of Gift of Hope. “We are extremely grateful to the University of Illinois community for its generous support of our lifesaving mission.”

University of Illinois Vice President and Chancellor Phyllis M. Wise applauded the University community for its strong support. “We challenged students, faculty and alumni to help break the Guinness World Record and save lives by registering as organ donors during Quad Day, and they successfully met that challenge,” she said.

Donor challenge events can be done through registered student organizations or during Welcome Week fairs where students learn more about campus and community resources. Events like these provide the perfect opportunity to engage with students and discuss organ, eye and tissue donation.



Students who registered as part of Quad Day

*“Through the collective action and selfless decisions of more than 2,000 people, we have shown the world that the University of Illinois is committed to transforming lives, not only inside the classroom, but outside the classroom, as well.”*



# California High School Program Spreads

One approach used to reach young adults has been to educate teenagers before it is time for them to apply for their first learners driving permit, where they will have the opportunity to designate themselves as organ, eye and tissue donors. *Note: This serves as an indication of intent until the registrants eighteenth birthday at which point it becomes a legal authorization.* Various educational programs are in place across the United States that include special curriculums, videos and literature to be used by teachers in either science, health or driver’s education programs. If students do not make a decision when they are 15-16 and are first exposed to the opportunity to register through the DMV, it becomes more difficult to reach them between then and the next time they are renewing their license in four to twelve years, depending on the state.

In 2010, Donate Life California worked with GOAL Productions to create a new video aimed at educating and inspiring teens to join the state’s donor registry. Titled “Your Decision to Donate”, the video includes interviews with three teenagers personally touched by donation and transplantation



– a liver transplant recipient, a kidney transplant recipient and a donor sister. Complementing these powerful stories is an interview with a transplant surgeon and information about joining the donor registry when applying for a driver’s license.

The video was created so that it could be easily modified for other states, enabling eleven additional states thus far to use it. Details on donor registry changes in the target age groups is not consistently available from all states, but here is a sampling of changes seen in two Donation Service Areas that used the video between 2010 and 2012.

Donor Registry, before and after “Your Decision to Donate” video				
	California Transplant Donor Network ages 13-24		Gift of Life Michigan under age 20	
	Raw #	% Change	Raw #	% Change
Year prior to implementation	213,123	-	44,972	-
Year after implementation	302,528	42%	113,234	52%
2 years after implementation	387,506	28%		
3 years after implementation	476,361	23%		

Please note that other changes in public education and outreach may also be a factor in donor registration increases.

# Moving Forward

Engaging the younger generation by registering more organ, eye and tissue donors will not only result in a significant addition to the number of registered donors, but will also create passionate and dedicated advocates who will educate and inspire others to register.

While efforts to increase donor designation have been a success, as long as those who so desperately need a lifesaving or healing transplant remain in need, we must continue to develop tactics and programs to reach and inspire more people to join their state donor registry.

Kristen and Alfonso are examples of the advocates we hope to create. Their personal experiences with donation make them great examples of the dire need for people of this demographic to register as donors. They can relay the message of the life-changing power of donation and the channels that can be used to register in a way that translates easily to their peers. It is our mission to ensure that everyone registers because people of all ages, people like 20 year-old Becky, die every day waiting for a transplant that never comes.

## Patient Waiting Becomes Donor

Becky was introduced to the need for organ, eye and tissue donors when a fellow tennis player at her school received a heart transplant. Her teammate’s experience inspired her to join the Michigan Organ Donor Registry when she received her driver’s license. What she did not know when she joined the registry was that one day she too would need a lifesaving transplant.

Becky was an active, happy child with a passion for equestrian riding and arts and crafts. In her early teens, she began experiencing health issues, but her illness went undiagnosed for years. At 17, doctors discovered that Becky had severe pulmonary hypertension and she was immediately put on medication. At 19, she was added to the national organ transplant waiting list for a lung transplant.

Once at Wayne State University (WSU), Becky began sharing her story and educating her friends and other college students about the importance of donation. Sadly, Becky’s transplant did not come in time and she died shortly after her 20th birthday. “Although she did not receive the second chance at life she was waiting for,” expresses her mom, “Becky did give that gift to others as a cornea and tissue donor.”

Becky’s death also inspired WSU students, family and friends to rally together and tell her story. In two events held in Becky’s honor, they motivated more than 2,000 new donors to register.



Becky, died awaiting a lung transplant and became a cornea and tissue donor.

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## Our Vision

A nation that embraces organ, eye and tissue donation as a fundamental human responsibility.