

Pennsylvania Organ Donation Advisory Committee 2016 Annual Report



In keeping with provisions of Act 102 of 1994 that established the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund, Organ Donation Advisory Committee (ODAC) and Pennsylvania's Organ and Tissue Donation Awareness Program, this report provides information from the ODAC, the departments of Education, Health and Transportation, and Pennsylvania's two organ procurement organizations – the Center for Organ Recovery & Education (CORE) and Gift of Life Donor Program (GOL) – for the period July 1, 2015 to June 30, 2016.

Message from the Organ Donation Advisory Committee Chair

Dear Members of the General Assembly,

Pennsylvania is in the midst of a serious public health crisis that can be remedied by the General Assembly without the allocation of any public funds. There are some 8,000 people in the commonwealth awaiting organ transplants, but only 2,078 transplants were actually performed last year due to a lack of organ donations. Over 1,000 adults and children have been on the Pennsylvania organ transplant waitlist for five years or longer. Tragically, on average, over 400 adults and children in the commonwealth die every year due to a shortage of organ donors. Countless more recipients and their families struggle physically, emotionally and financially wondering if they or their loved one will make it off the organ donation waitlist in time.

In 1994, Pennsylvania set the standard for the United States by creating a set of best practices in the landmark Pa. Act 102. These best practices for organ and tissue donation were adopted nationally. Over the years, however, we have failed to keep up and now find ourselves at the bottom of the pack. In January 2017, the Department of Health and Human Services reported that, while organ donation has increased by 20 percent nationally over the last five years, the number in Pennsylvania has remained basically flat, increasing by less than 1 percent during this period. The ratio of adults to adult donors in Pennsylvania places us in the bottom quarter of the nation. In addition, 47 states have adopted the latest national best practices created by the Uniform Law Commission in 2006, with Pennsylvania being one of the three outliers.

To be clear, our goal is not to shame, let alone to force, anyone to become an organ and tissue donor. This is a gift of life that must be made only after people are fully educated about, and comfortable with, their decision. Providing the facts so citizens can make an informed choice is our mission — one that has been hampered by information that is incomplete, incorrect and, at times, wholly untrue. By way of example, one group recently claimed that patients receive organs medically unsuitable for use, that minorities are ineligible to receive donated organs from white donors, and that organ donation education programs will teach children that organ donation could be an alternative to sentencing prisoners to death. All of these claims are baseless, but they must be rebutted to prevent a worsening of this crisis. Again, I wish to emphasize the aim of our committee is to provide factual information so everyone can make an informed choice either way.

The strides we have made in education have been solely funded by voluntary donations to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund, 97 percent of which came from checking the \$1 donation box on applications for driver's licenses, state ID cards and vehicle registrations.

As of Jan. 1, 2017, Pennsylvanians can elect to renew their vehicle registrations for two years, but the donation check box remains at \$1. Thus, organ donation awareness education is facing a drastic loss in revenue from contributions, an unintentional consequence of an otherwise very sensible change to the

registration process. Should PennDot follow other states to extend the licensure time for driver's license renewal, the decline in donations will worsen.

All of these facts reveal a bitter, but undeniable truth: most other states are meeting the needs of critically ill adults and children better than us. The commonwealth can, and must, do better at educating its citizens about the option to donate organs and tissue and bringing its policies in line with best national practices.

Two simple actions by the Legislature could greatly impact this public health crisis, and, in the process, ensure Governor Robert P. Casey's immeasurable legacy of organ and tissue donation awareness. First, the Legislature should update the best practices utilized in the commonwealth by adopting the improved national guidelines set forth in 2006.

Second, to prevent a drastic decline in the budget for organ and tissue donor awareness education, the contribution amount on PennDot applications needs to be increased to prevent unintended funding declines from longer registration periods.

Allow me to close by thanking everyone who has made an educated choice about whether or not to be a donor, as well as all those who work to support those in need of organ and tissue transplants — especially the friends and family of those on our donation waitlist. I am also grateful to Governor Tom Wolf for his support, as well as to the other volunteers who serve with me on the Governor's Organ Donation Advisory Committee.

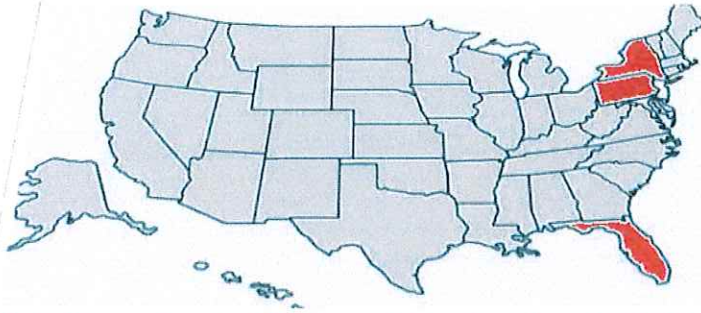
Respectfully submitted,

A handwritten signature in black ink that reads "Lisa R. Battat, M.D." The signature is written in a cursive style with a clear, legible font.

Lisa R. Battat, M.D.

Chairperson

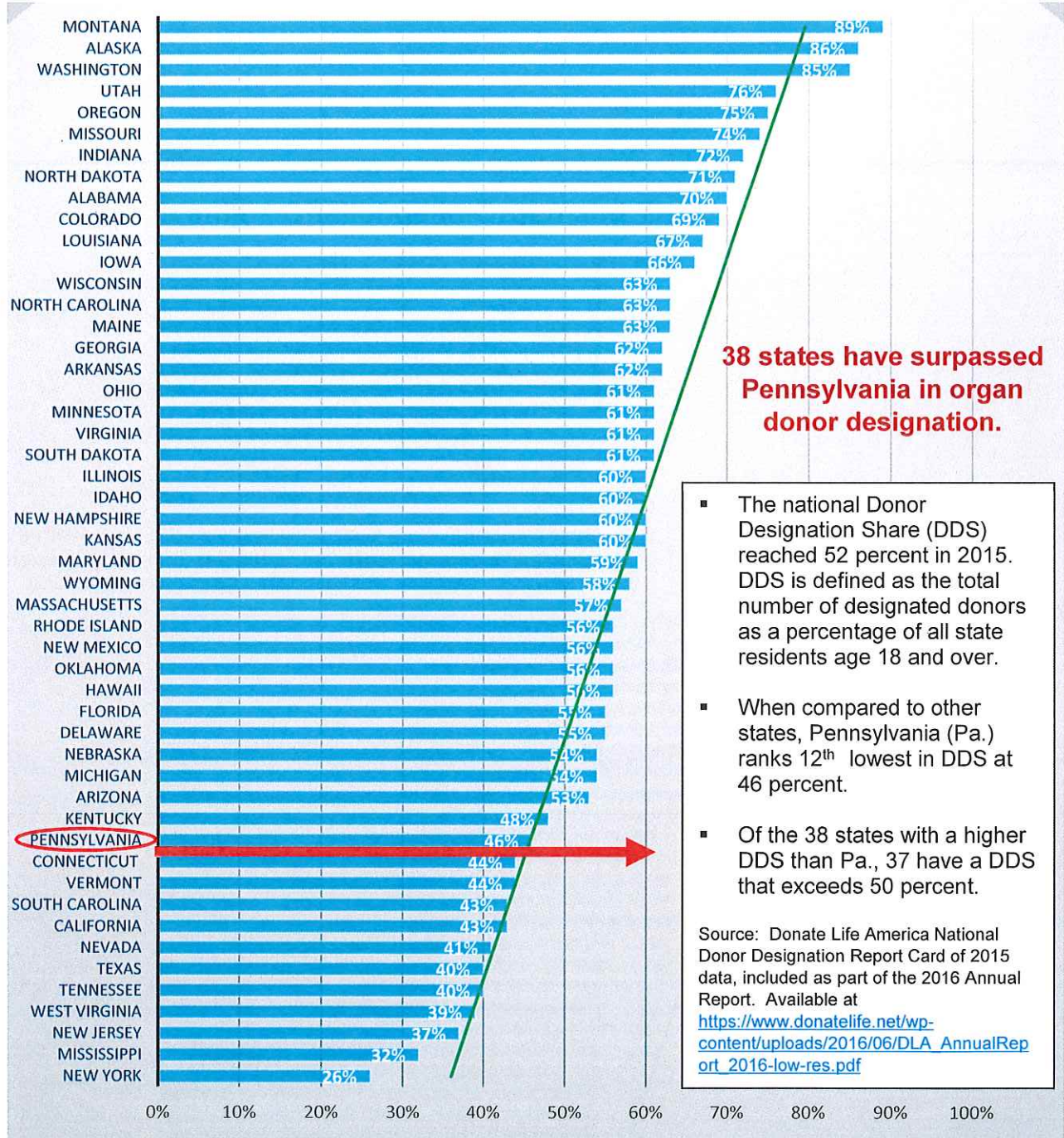
What's Pennsylvania's Challenge in Organ and Tissue Donation?



The Uniform Law Commission (ULC) was established in 1892 to provide "states with non-partisan, well-conceived and well-drafted legislation that brings clarity and stability to critical areas of state statutory law." In 2006, the ULC revised the Uniform Anatomical Gift Act (UAGA) to better align with changes in federal law and advancements in organ and tissue donation. In the past 10 years, 47 states have enacted all or some of its best practice provisions. Pennsylvania remains one of only three states failing to pass provisions from the 2006 UAGA.

Only Pennsylvania, Florida and New York have failed to enact provisions aligned with the 2006 Uniform Anatomical Gift Act.

Source: [http://www.uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20\(2006\)](http://www.uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20(2006))



38 states have surpassed Pennsylvania in organ donor designation.

- The national Donor Designation Share (DDS) reached 52 percent in 2015. DDS is defined as the total number of designated donors as a percentage of all state residents age 18 and over.
- When compared to other states, Pennsylvania (Pa.) ranks 12th lowest in DDS at 46 percent.
- Of the 38 states with a higher DDS than Pa., 37 have a DDS that exceeds 50 percent.

Source: Donate Life America National Donor Designation Report Card of 2015 data, included as part of the 2016 Annual Report. Available at https://www.donatelife.net/wp-content/uploads/2016/06/DLA_AnnualReport_2016-low-res.pdf

In August 2015, Pennsylvania’s Organ Donation Advisory Committee (ODAC) started a new strategic planning process to evaluate progress made since the release of the 2010 Pennsylvania Organ and Tissue Donation Action Plan. Unfortunately, although the commonwealth was a pioneer and leader in 1994 with the enactment of Act 102 and its two organ procurement organizations (OPOs) continue to be among the highest performing OPOs in the nation, Pennsylvania has not kept pace with other states in 1) updating legislation to reflect best knowledge and practice and 2) increasing organ and tissue donor designation rates.

So, while this report highlights activities and progress during state fiscal year (SFY) 2015-16 or the “how” and “what” of what we do, ODAC recognizes that the “why” of what we do – to save and heal lives – must be valued, voiced and embraced by every Pennsylvanian. Only then will Pennsylvania be recognized for creating a culture in which organ, tissue and eye donation is actively promoted and the accepted norm.

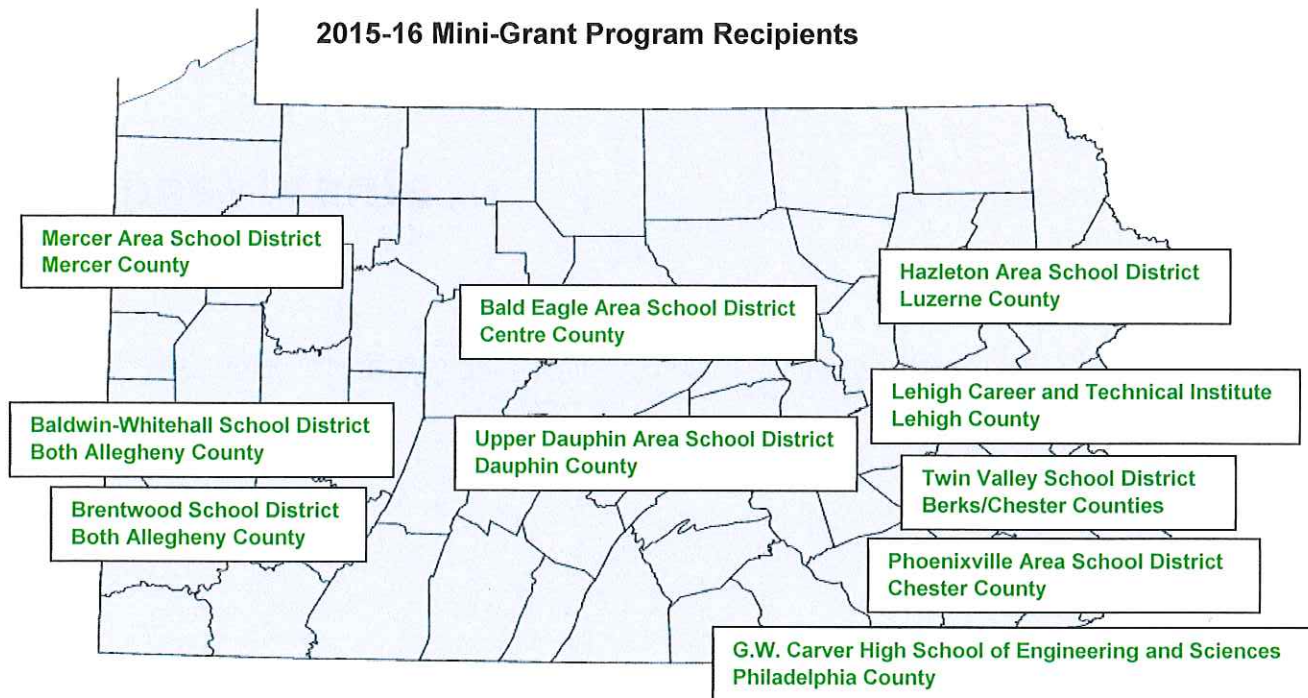


The Pennsylvania Department of Education’s Organ and Tissue Donation Awareness (OTDA) Project assists secondary students in pre-thinking critical issues that surround organ and tissue donation. Each teen can then make an informed decision and communicate his or her wishes to family members. The 2015-16 program year marked the second year

of a three-year contract with the Lancaster-Lebanon Intermediate Unit 13 (IU13) to administer the OTDA education project. The IU13 previously developed the OTDA curriculum framework and classroom toolkit for use in secondary schools, which is available at <http://www.iu13.org/educators/instruction/improvement/state-initiatives/otda>. The curriculum framework is multidisciplinary in nature and can be used in any academic discipline. In 2015-16, several strategies continued to ensure the broadest implementation of the OTDA curriculum framework:

- Fifteen secondary schools from across the commonwealth proposed projects through the competitive **mini-grant program**, the most ever submitted. Ten projects were funded with a total of \$27,000.
- Integration of organ and tissue donation topics occurred across classes in biology, health, safety and first aid, health occupations, English, Spanish, world language, law and ethics, statistics, visual media and web design, and industrial arts.
- In total, the mini-grant program raised awareness of the importance of organ and tissue donation for more than 9,570 students and school district faculty, staff, parents and the community.

2015-16 Mini-Grant Program Recipients



- “Everyday Heroes: Some Heroes Are There When You Need Them; Others Are Always There,” was the **OTDA Spring Institute** theme for educators, school nurses and administrators; it successfully engaged fifty registered attendees in diverse sessions on addiction and transplantation, healthy lifestyles, donation in the multicultural community, and clinical considerations in donation and transplantation. Thirty-nine attendees completed the final

evaluation with thirty-six (92 percent) rating the institute as “Excellent” and the remaining three giving no response.

- More than 250 students participated in three **student camps** – two held at the Center for Organ Recovery & Education’s (CORE) headquarters in Pittsburgh and one camp at the IU13 in Lancaster. Students at CORE participated in a cadaver presentation from Adventures in Medicine and Science (AIMS), along with a presentation on living donation kidney transplant surgery. At IU13, students learned about living donation via a videotaped kidney transplant surgery through the Center of Science and Industry at Ohio State University and interacted with a transplant coordinator, liver transplant surgeon and living kidney donor. Importantly, the camps used critical organ and tissue donation content and medical advances in transplantation to expand students’ knowledge in science, technology and math.



Department of Health Compliance Report: As part of licensure and complaint surveys, the Department of Health’s Bureau of Facility Licensure and Certification, Division of Acute and Ambulatory Care, assesses Pennsylvania acute care hospitals’ compliance with provisions of the Uniform Anatomical Gift Act. During SFY 2015-16, 11 licensure surveys were completed. No hospital facility was cited for failure to comply with the federal requirements related to organ procurement. In 2014, hospitals could use accreditation for licensure, which decreases the number of surveys the department will do annually.

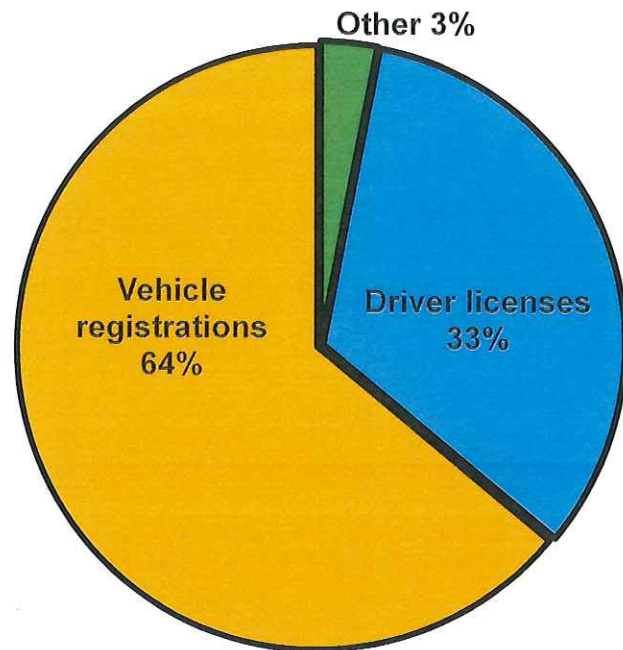
Voluntary Benefits Program for Vital Organ Donors: In 2015-16, more than 80 people received support from the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund (Trust Fund) for hotel reimbursement of lodging expenses associated with living donor procedures and grief counseling for family members of deceased donors.

**GOVERNOR ROBERT P. CASEY MEMORIAL ORGAN AND TISSUE
DONATION AWARENESS TRUST FUND
July 1, 2015 - June 30, 2016**

Beginning Balance	\$1,570,465
 Revenue – Pennsylvanians may contribute 1) \$1 at the time of application or renewal of a driver’s license and \$1 at the time of vehicle registration 2) by designating all or some of their state income tax refund to the Trust Fund and 3) through direct check donations to the Trust Fund in care of the Department of Health:	
Driver's License Applicants	\$262,889
Vehicle Registrations.....	\$512,741
State Income Tax Contributions	\$12,664
Private Donations.....	\$5,247
Interest/Investment Income.....	\$5,226
Total Revenue	\$798,767
 Total Funds Available	 \$2,369,232
 Expenditures	
Department of Education.....	(\$194,785)
Department of Health (broken out by category below).....	(\$769,556)
- Statewide Education and Information Campaign.....	(\$648,857)
- Voluntary Benefit Program Reimbursements.....	(\$16,056)
- Personnel/Operating.....	(\$102,344)
- Advisory Committee (travel and meeting expenses).....	(\$2,299)
Department of Transportation.....	\$0
Total Expenditures	(\$964,341)
 Ending Balance	 \$1,404,891

Source: Pa. Department of Health

The Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund Revenue Sources SFY 2015-16



Ninety-seven percent of revenue for the Trust Fund was generated through \$1 contributions added voluntarily by individuals when registering their motor vehicle and/or obtaining/renewing their driver's license or state identification card through PennDOT (based on 2015-16 revenue and receipts obtained at

http://www.revenue.pa.gov/dorreports/Documents/2015-16/2016_06_bfmmonthlyreport.pdf).

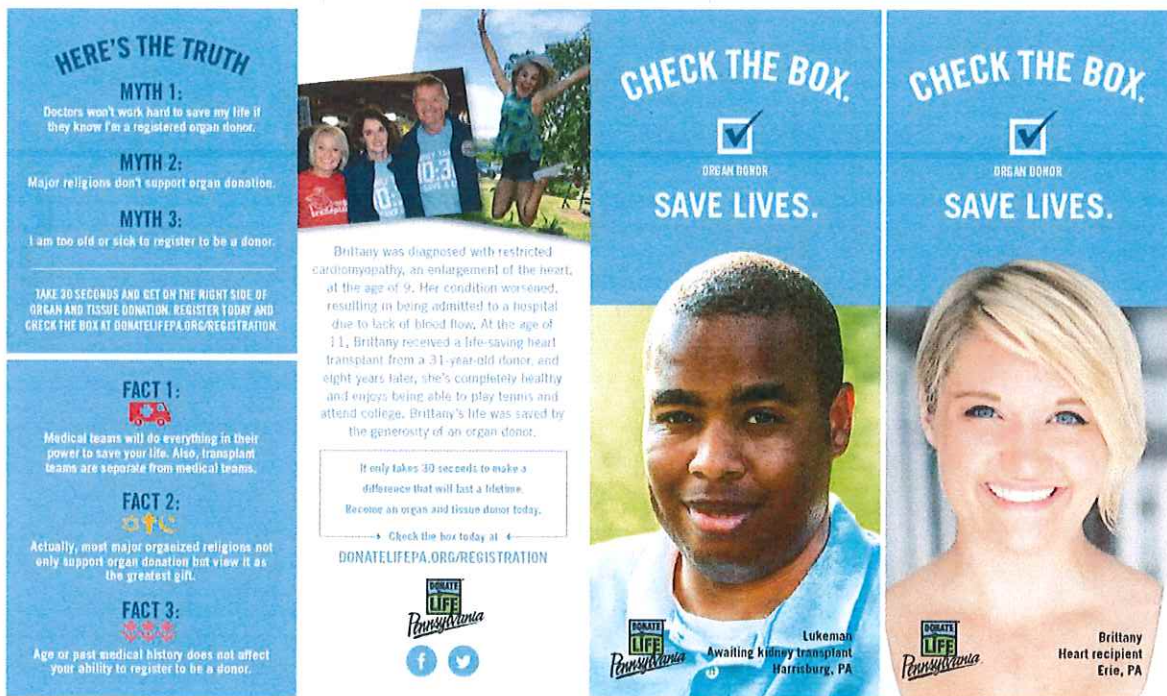
The sustainability of the Trust Fund faces significant challenges:

- ⇒ Motor vehicle customers may now elect to pay a two-year vehicle registration fee for a two-year registration period for certain types of motor vehicles, yet they are only given the opportunity to contribute \$1 and not \$2 to the Trust Fund at that time. As the percentage of vehicle registrants who opt for the two-year registration grows, it is anticipated Trust Fund revenue will be reduced from this source. In addition, the "Local Use Fund" established by Act 89 of 2013 enabled counties to pass an ordinance that adds a \$5 fee to each vehicle registered with an address in that county. The additional \$5 county fee is collected by PennDOT at the time of vehicle registration, and the funds are used by the county for transportation purposes (Pa. Department of Transportation Fact Sheet at <http://www.dot.state.pa.us/public/dvspubsforms/BMV/BMV%20Fact%20Sheets/fs-feeLocal.pdf>). Residents of counties adding the fee may begin to reconsider their voluntary contributions.
- ⇒ Twenty-five states have driver license renewal periods of six years or more for the general population (Insurance Institute for Highway Safety at <http://www.iihs.org/iihs/topics/laws/olderdrivers>). While it is uncertain as to whether Pennsylvania might lengthen the driver's license renewal period from the current four-year cycle to a longer renewal period, Trust Fund contributions unavoidably would be reduced if such a change was enacted.
- ⇒ The Legislative and Budget Finance Committee's (LBFC) June 2007 Performance Evaluation Report of the Organ and Tissue Donor Awareness Program included a recommendation to give Pennsylvanians the option to contribute more than \$1 when obtaining or renewing their driver's license and/or motor vehicle registration. To achieve this, there has been a provision included in proposed Donate Life Pennsylvania (Donate Life PA) legislation for the last four years to authorize PennDOT to revise driver license and vehicle registration processes to give Pennsylvanians the option to contribute \$3 to the Trust Fund. Since the Donate Life PA legislation has failed to pass, this measure has not taken effect.



Donate Life PA is a collaborative initiative between the Pennsylvania departments of Health, Education and Transportation and Pennsylvania's two organ procurement organizations, the Center for Organ Recovery and Education (CORE) and Gift of Life Donor Program (GOL). It is funded solely through voluntary contributions made by Pennsylvania citizens to the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund. The Trust Fund contributions are used to educate Pennsylvanians, build awareness about the importance of organ and tissue donation, and increase the number of people who sign up to become organ donors on their driver's license or state identification cards. A goal of adding 180,000 new organ donor designations was set for the three-year period of July 1, 2015 through June 30, 2018. In SFY 2015-16:

- Brochures, mailer inserts, computer toppers and posters were redesigned for distribution by the Department of Transportation at nearly 100 photo centers and driver license centers and through driver license photo card mailings. Information from a new Donate Life America brochure that was researched for its effectiveness was adapted for the Donate Life PA materials. The brochures were translated into Spanish and used two different cover panels to better represent diverse populations.



- To promote **National Donate Life Month** in April, the departments of Health and Transportation, with support from CORE and GOL, hosted a press conference in the Keystone Building Atrium in Harrisburg on April 5, 2016, to highlight Governor Tom Wolf's proclamation on the significance of the month and draw attention to the more than 8,000 men, women and children in Pennsylvania waiting for an organ transplant. Harrisburg and Scranton television stations, and the Erie Times-News and Gant Daily reported on the event.
- The Hospital and Healthsystem Association of Pennsylvania (HAP) partnered with CORE, GOL and the Department of Health for the fourth consecutive year to engage hospitals and health systems in education and awareness events and donation process improvement initiatives for the **2016 Donate Life Hospital Challenge**. Nearly 100 hospitals and health systems across the commonwealth participated in the competitive challenge, capturing their activities on a scorecard to achieve bronze, silver, gold and platinum level point totals. The hospital challenge has progressively increased participation and it has been so successful that, starting in 2015, the Pennsylvania Association of Community Health Centers (PACHC) partnered with Donate Life PA to adapt the challenge for community health centers. To facilitate participation and ease of access, a **Community Health Center Challenge** landing page was created on the Donate Life PA website where health centers could register, download the scorecard, and access materials and resources.
- On-the-ground public outreach initiatives included **Transit Campaigns in Philadelphia and Pittsburgh** that used public relation materials, press conferences, Donate Life PA messaging on transit trains and at stations, and eight events

in which trained canvassers interacted with transit riders to answer questions and reinforce messages on the importance of organ and tissue donation. Canvassers engaged with over 1,900 passersby and distributed nearly 2,200 informational cards that clarified facts about organ donation and provided the donor registration website.

Pennsylvania Organ Procurement Organizations (OPOs)

July 1, 2015 through June 30, 2016

CENTER FOR ORGAN RECOVERY & EDUCATION (CORE)

CORE is the non-profit, federally designated OPO serving the western half of Pennsylvania, West Virginia and Chemung County, New York.

Pennsylvania Counties Served:

Allegheny, Armstrong, Beaver, Bedford, Blair, Bradford, Butler, Cambria, Cameron, Clarion, Clearfield, Crawford, Elk, Eric, Fayette, Forest, Franklin, Fulton, Greene, Huntingdon, Indiana, Jefferson, Lawrence, McKean, Mercer, Potter, Somerset, Venango, Warren, Washington and Westmoreland

Pennsylvania Population Served: 4.2 million

Pennsylvania Organ Transplant Centers Served:

Allegheny General Hospital, Children’s Hospital of Pittsburgh UPMC, University of Pittsburgh Medical Center Presbyterian and Veterans Administration Pittsburgh Healthcare System

Pennsylvania Tissue Procurement Providers Within CORE’s Service Area:

Center for Organ Recovery & Education (CORE)

Pennsylvania Eye Procurement Providers Within CORE’s Service Area:

Center for Organ Recovery & Education (CORE) and Lions Eye Bank of Northwestern Pennsylvania

ORGAN DONATION

Total number of referrals.....	4,724
Total number of potential donors.....	253
Total number of donors recovered.....	160
Total number of organs recovered.....	651
Total number of organs transplanted.....	472
Total number of organs provided for research.....	132

TISSUE DONATION

Total number of referrals.....	21,218
Total number of potential donors.....	9,928
Total number of donors recovered.....	787
Total number of tissue grafts produced.....	11,883

EYE DONATION

Total number of referrals.....	21,218
Total number of potential donors.....	7,667
Total number of donors recovered.....	735
Total number of eye tissue procured.....	1,127
Total number of eye tissue transplanted.....	798
Total number of eye tissue provided for research.....	12

GIFT OF LIFE DONOR PROGRAM (GOL)

GOL is the non-profit, federally designated OPO serving the eastern half of Pennsylvania, southern New Jersey and Delaware.

Pennsylvania Counties Served:

Adams, Berks, Bucks, Carbon, Centre, Chester, Clinton, Columbia, Cumberland, Dauphin, Delaware, Juniata, Lackawanna, Lancaster, Lebanon, Lehigh, Luzerne, Lycoming, Mifflin, Monroe, Montgomery, Montour, Northampton, Northumberland, Perry, Philadelphia, Pike, Schuylkill, Snyder, Sullivan, Susquehanna, Tioga, Union, Wayne, Wyoming and York

Pennsylvania Population Served: 7.8 million

Pennsylvania Organ Transplant Centers Served:

Albert Einstein Medical Center, Hahnemann University Hospital, Children’s Hospital of Philadelphia, Geisinger Medical Center, The Hospital of the University of Pennsylvania, Harrisburg Hospital, St. Christopher’s Hospital for Children, Temple University Hospital, Penn State Milton S. Hershey Medical Center, The Lankenau Hospital, Lehigh Valley Hospital, Crozer Chester Medical Center and Thomas Jefferson University Hospital

Pennsylvania Tissue Procurement Providers Within GOL’s Service Area:

Gift of Life Donor Program, Community Tissue Services, CryoLife, Inc., LifeNet Transplant Services, Musculoskeletal Transplant Foundation and National Disease Research Interchange

Pennsylvania Eye Procurement Providers Within GOL’s Service Area:

Gift of Life Donor Program, Lions Eye Bank of Delaware Valley and SightLife

ORGAN DONATION

Total number of referrals.....	4,641
Total number of potential donors.....	625
Total number of donors recovered.....	501
Total number of organs recovered.....	1,702
Total number of organs transplanted.....	1,309
Total number of organs provided for research.....	509

TISSUE DONATION

Total number of referrals.....	37,187
Total number of potential donors.....	4,491
Total number of donors recovered.....	1,265
Total number of tissue grafts produced.....	37,950

EYE DONATION

Total number of referrals.....	37,187
Total number of potential donors.....	6,509
Total number of donors recovered.....	2,204
Total number of eye tissue procured.....	4,393
Total number of eye tissue transplanted.....	4,350
Total number of eye tissue provided for research.....	67

For SFY 2015-16, a total of 86,220 new organ donor designations were added to driver's licenses and state identification cards. Although this was nearly double the number of donor designations added the previous year, Pennsylvania's statewide donor designation rate (DDR) has only moved incrementally in the last eight years from 44.36 to 46.97 percent. DDR is the rate at which individuals join or remain in the state donor registry as a percentage of all driver's licenses and identification cards issued within a specific period.

County Ranking by Percent of Driver Licenses and State Identification Cards with Organ Donor Designation

Source: Pa. Department of Transportation, July 2016

Rank	County	Total Licenses and ID Cards	# with Organ Donor Designation	%	Rank	County	Total Licenses and ID Cards	# with Organ Donor Designation	%
1	Centre	95,782	54,568	56.97%	35	Perry	37,535	17,804	47.43%
2	Chester	391,897	222,139	56.68%	36	Cambria	108,432	51,248	47.26%
3	Warren	31,322	17,192	54.89%	37	Venango	40,847	19,287	47.22%
4	Cumberland	201,501	108,570	53.88%	38	Mifflin	32,777	15,475	47.21%
5	York	355,880	190,105	53.42%	39	Pike	46,261	21,754	47.02%
6	Montgomery	664,620	349,099	52.53%	40	Beaver	134,830	63,254	46.91%
7	Butler	153,769	80,669	52.46%	41	Forest	4,302	2,018	46.91%
8	Adams	79,871	41,278	51.68%	42	Washington	172,226	80,329	46.64%
9	Wayne	44,267	22,824	51.56%	43	Sullivan	4,897	2,280	46.56%
10	Susquehanna	31,623	16,281	51.48%	44	Mercer	87,597	40,647	46.40%
11	McKean	31,850	16,396	51.48%	45	Columbia	49,771	23,006	46.22%
12	Erie	210,517	107,965	51.29%	46	Westmoreland	285,772	131,619	46.06%
13	Bradford	48,057	24,642	51.28%	47	Delaware	442,741	202,811	45.81%
14	Lancaster	408,280	209,144	51.23%	48	Potter	13,394	6,120	45.69%
15	Bucks	524,285	268,328	51.18%	49	Somerset	59,524	27,120	45.56%
16	Cameron	4,028	2,060	51.14%	50	Lawrence	73,257	33,144	45.24%
17	Montour	14,795	7,426	50.19%	51	Berks	323,295	145,978	45.15%
18	Elk	26,171	13,074	49.96%	52	Jefferson	35,656	16,008	44.90%
19	Union	29,386	14,632	49.79%	53	Schuylkill	113,047	50,261	44.46%
20	Blair	98,638	49,001	49.68%	54	Snyder	29,454	13,080	44.41%
21	Lackawanna	165,510	81,864	49.46%	55	Carbon	51,867	22,951	44.25%
22	Lycoming	89,633	44,259	49.38%	56	Indiana	61,647	26,850	43.55%
23	Allegheny	968,990	478,312	49.36%	57	Northumberland	71,243	30,853	43.31%
24	Clinton	26,705	13,120	49.13%	58	Bedford	40,061	17,348	43.30%
25	Tioga	33,028	16,006	48.46%	59	Juniata	17,649	7,630	43.23%
26	Wyoming	23,424	11,351	48.46%	60	Armstrong	58,021	25,079	43.22%
27	Franklin	116,561	56,257	48.26%	61	Clarion	28,478	12,252	43.02%
28	Clearfield	60,689	29,264	48.22%	62	Monroe	136,075	58,074	42.68%
29	Dauphin	218,636	105,268	48.15%	63	Luzerne	251,880	107,045	42.50%
30	Lebanon	110,507	52,911	47.88%	64	Greene	27,964	11,355	40.61%
31	Northampton	258,325	123,669	47.87%	65	Fulton	11,920	4,726	39.65%
32	Lehigh	274,716	131,383	47.83%	66	Fayette	113,409	44,076	38.86%
33	Crawford	67,338	32,160	47.76%	67	Philadelphia	1,113,972	346,277	31.08%
34	Huntingdon	33,682	16,029	47.59%		TOTAL	9,974,084	4,685,005	46.97%