

Annual Report to the General Assembly

Pennsylvania Organ and Tissue Donation Awareness Program

2018-2019



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Introduction

In keeping with provisions of Act 102 of 1994 that established the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund (Trust Fund), Organ Donation Advisory Committee (ODAC) and Pennsylvania's Organ and Tissue Donation Awareness Program (OTDA), this annual report provides information for the period of July 1, 2018, to June 30, 2019. As required by Act 90 of 2018, this report provides information on expenditures of the Trust Fund and donor designation rates.

Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund

The Department of Health (DOH) oversees administration of the Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund, which consists of private, voluntary contributions. Promotion of the Trust Fund's vital work and accomplishments and diversification of revenue sources have become essential to the continued existence of a Pennsylvania organ and tissue donation program aimed at saving lives.

Figure 1: SFY 2018-19 Pennsylvania Budget for Trust Fund

Paginning Palance

GOVERNOR ROBERT P. CASEY MEMORIAL ORGAN AND TISSUE DONATION AWARENESS TRUST FUND July 1, 2018 - June 30, 2019

Beginning Balance	.\$881,424
Revenue	* 050.000
Driver's license applicants	
Vehicle registrations	
State income tax contributions	\$8,595
Private donations	\$685
Interest/investment income	\$23.046
Total Revenue	
	4: 00,0:=
Total Funds Available	\$1,585,236
Expenditures	
Department of Education	(\$190,000)
Department of Health (broken out by category below)	,
Statewide education and information campaign(\$363,549)	(ψ102,000)
, ,	
Voluntary benefit program reimbursements(\$10,809)	
Personnel/operating(\$27,637)	
Advisory committee (travel and meeting expenses)(\$998)	
Department of Transportation	
Total Expenditures	(\$592,993)
Ending Balance	<u>\$992,243</u>

Source: Pennyslvania Department of Health, 2019¹

¢004 404

The two major revenue sources to the Trust Fund are \$1 contributions from driver license and motor vehicle applications or renewals and state income tax refunds designated by taxpayers for the Trust Fund.

ODATF Annual Revenue FY2014 to FY2018 \$800,000,00 \$780,000,00 \$775,629.79 \$760,000,00 \$753,999.00 \$740,000.00 \$734.915.00 \$729,680.00 \$720,000.00 \$703.812.05 \$700,000.00 \$680,000,00 \$660,000.00 Revenue FY 2018 Revenue FY 2014 Revenue FY 2015 Revenue FY 2016 Revenue FY 2017

Figure 2: Governor Robert P. Casey Memorial Organ and Tissue Donation Awareness Trust Fund Annual Revenue Graph Charting State Fiscal Years (FY) 2014 through 2018

 $Source: \ https://www.revenue.pa.gov/GeneralTaxInformation/News\%20 and \%20 Statistics/Reports Stats/Revenue Receipts/Pages/default.asp \pounds 20 and \%20 Statistics/Reports Statis/Revenue Receipts/Pages/default.asp \pounds 20 and \%20 Statisfies Reports Statis/Revenue Receipts/Pages/default.asp \pounds 20 and \%20 Statisfies Reports Statisfies Reports$

Trust Fund expenditures include: (1) Pennsylvania Department of Education (PDE) contract for administering the OTDA Project, a statewide public awareness campaign, voluntary benefits program; (2) DOH administrative costs as the commonwealth agency that oversees the organ donation program; (3) ODAC meeting expenses: and (4) PennDOT expenses incurred for that agency's role in organ donor designation and providing a mechanism for citizens to make voluntary monetary contributions to the Trust Fund.

The voluntary benefits program provides for hotel reimbursement of lodging expenses associated with living donor procedures and grief counseling for family members of deceased donors. In 2018-19, benefits from the Trust Fund provided support for these services to 44 families.¹

Organ and Tissue Donation Awareness Project

Expenditures to the Pennsylvania Department of Education (PDE) are through contracts with the Lancaster-Lebanon Intermediate Unit 13 (IU13) to administer the **Organ and Tissue Donation Awareness Project**, which seeks to help secondary students consider critical issues that surround organ and tissue donation. Each teen can then make an informed decision about donor designation when obtaining their driver's license and discussing their wishes with family members. Accomplishments in 2018-2019 include:

- **Site visits:** Provide support and materials to schools for promotion of organ donation education. Events held included blood drives, health fairs, pledge days, National Donor Day events, school wide assemblies and visits to organ procurement organizations.
- Grant funding: Totaled over \$27,000 to the following 10 schools.
 First year recipients: Centennial School of Lehigh Valley, Central Mountain School District, Dubois Area School District, Hill House Passport Academy and Universal Aundenreid Charter School
 Second year recipients: Conemaugh Valley School District, Homer-Center School District and Windber Area School District
- Revised OTDA Toolkit (ADA adapted): Fulfilling the requirement in Act 90 of 2018, a
 revised teacher-friendly version of the 2014 OTDA toolkit was completed, including
 updated statistics, new lesson plans, reliable websites, links and real-life organ donation
 stories.

Third year recipients: Butler County Vo-tech and Southern Fulton School District

- Promotion opportunities: Coordinator attended four statewide conferences for teachers, administrators and nurses to promote the OTDA grant opportunity for Pa. schools.
- OTDA Kick-off meetings: The two partner Organ Procurement Organizations (OPOs)
 hosted annual kick-off meetings for newly awarded grantee schools in their regions. The
 events included guest speakers, collaborative opportunities and facility tours.
- Annual OTDA Conference: Held in May 2019, 70 attendees heard and discussed organ donation topics, met donor and recipient families, and engaged in collaboration with educators, nurses and administrators.
- **Seed grant opportunities:** Provided seed grants of up to \$500 if teachers missed the June deadline. The money is for one activity to introduce organ donation education and requires that educators write for the main grant at the end of the school year.³

Donate Life Pennsylvania

Donate Life Pennsylvania (DLPA) is the collaborative initiative between the Departments of Health and Transportation, the Center for Organ Recovery & Education (CORE) and Gift of Life Donor Program (GOL). 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 as organ donors on their driver's licenses and state identification cards. Trust Fund money is distributed to the OPOs according to the provisions of Act 102 of 1994. The OPOs use no funds directly; they subcontract with a marketing agency that uses Trust Fund contributions to design and execute public awareness campaigns under DLPA.

The year began with an in-depth immersion for the new agency, Tierney, into the DLPA business and processes. Items discussed were: the media outreach plan, the Public Relations Student Society of America (PRSSA) college outreach program timeline, updates and next steps on the creative briefing for the updated campaign, and immersion materials provided by the incumbent agency (Pavone).

Tierney began evolving the previous campaign of "Which Side Are You On" to the "Differences" creative. The "Differences" campaign highlights that, although we all have different interests, appetites and skills, we still have one thing in common – our ability to get on the right side of organ donation and make a difference for others by becoming a donor.

ABOUT DONATION WHY DONATE

SWEET

SALTY

OR

We're ALL DIFFERENT, BUT WE CAN MAKE A DIFFERENCE BY BEING AN ORGAN DONOR.

95% of people claim to support organ donation, but only 45% of Pennsylvanians have proven it by registering as donors. That number is way too low, considering over 8,000 lives in PA are on the line.

Figure 3: Donate Life PA Website

Source: Donate Life PA Website⁴

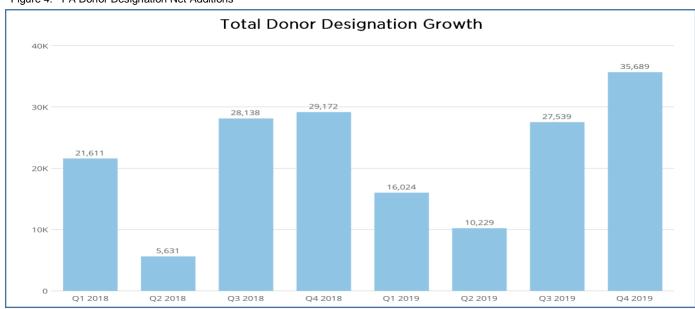
Additional areas of focus for Tierney in 2018-19 were as follows:

- Website updates and optimizations
- Foundation for strategic partnerships
- Public relations outreach
 - DMV Appreciation Week
 - Veteran's Day Pitch
 - o Black History Month
 - Tax Day
 - PRSSA Challenge
- Social media
- Paid media

The key performance indicator for Tierney's efforts is to increase statewide organ and tissue donor designations by 225,000 during the three-year contact. Following is the outline of the starting rate, current rate and goal for designations:

- Baseline (6/30/2018)
 - Designations as of 6/30/2018: 4,826,120
 - Designation percentage as of 6/30/2018: 48.5%
- Current (6/30/2019)
 - Designations as of 6/30/2019: 4,915,601
 - Designation percentage as of 6/30/2019: 49.2%
- Goal (6/30/2021)
 - Designation Goal for 6/30/2021: 5,051,120
 - Designation percentage goal: 50.0%⁵

Figure 4: PA Donor Designation Net Additions



Source: Tierney Annual Report⁵

Organ Procurement Organizations

When the National Organ Transplant Act (NOTA) was signed into law in 1984, it created the national Organ Procurement and Transplantation Network (OPTN) for matching donor organs to waiting recipients. The OPTN both standardized the process through which organs are donated and shared across the country and created the system of federally-designated Organ Procurement Organizations (OPOs) throughout the United States and its territories.

OPOs must be certified by the Centers for Medicare and Medicaid Services (CMS) and abide by CMS regulations. By federal law, all OPOs must be members of the OPTN, and all OPOs are members of the Association of Organ Procurement Organizations (AOPO).⁶

Pennsylvania is served by the Center for Organ Recovery & Education and Gift of Life Donor Program. OPOs have two major roles in their service area:

- Increasing the number of registered donors: OPOs reach out to individuals, families, communities and professionals through education and public awareness campaigns. The goal is to encourage people to legally register as a donor.
- 2. Coordinating the donation process: When donors become available, representatives from the OPO will evaluate the potential donors, check the deceased's state donor registry, discuss donation with family members, contact the OPTN computer system that matches donors and recipients, obtain a match list for that specific donor, and arrange for the recovery and transport of donated organs. These representatives also provide bereavement support for donor families and volunteer opportunities for interested individuals.

CORE is the non-profit, federally designated OPO serving the western half of Pennsylvania, West Virginia and Chemung County, New York. **Pennsylvania** population served: 4 million

Pennsylvania counties served:

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

Pennsylvania organ transplant centers served: Allegheny General Hospital, UPMC Children's Hospital of Pittsburgh, University of Pittsburgh Medical Center Hamot, 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 Pennsylvania⁷

GOL is the non-profit, federally designated OPO serving the eastern half of Pennsylvania, southern New Jersey and Delaware. **Pennsylvania population served:** 11.8 million

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 organ transplant centers served:

Albert Einstein Medical Center, Children's Hospital of Philadelphia, Geisinger Medical Center, The Hospital of the University of Pennsylvania, UPMC 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 SightLife⁸

Table 1: Pennsylvania Organ Procurement Organizations Donations, FY 2018-19

	CORE	GOL
ORGAN DONATION		
Total number of referrals	4,769	3,711
Total number of potential donors	250	876
Total number of donors recovered	166	494
Total number of organs recovered	708	2,242
Total number of organs transplanted	439	1,383
Total number of organs provided for research	116	396
TISSUE DONATION		
Total number of referrals	21,615	30,158
Total number of potential donors	8,700	4,411
Total number of donors recovered	722	1,037
Total number of tissue grafts produced	9,599	75,300
Total number of tissues provided for research	1,311	43
EYE DONATION		
Total number of referrals	21,615	30,158
Total number of potential donors	6,170	5,356
Total number of donors recovered	670	1,756
Total number of eye tissue procured	821	2,305
Total number of eye tissue transplanted	733	801
Total number of eye tissue provided for research	94	0

Source: CORE and GOL 20199

Organ Donor Designation on Driver's Licenses and State Identification Cards

In SFY 2018-19, a net of 89,481 organ donor designations were added to driver's licenses and state identification cards, raising Pennsylvania's statewide donor designation rate (DDR) to 49.2 percent. DLPA partners have set a goal of having a 50 percent DDR by June 30, 2021.¹⁰

Table 2: County Ranking by Percent of Driver Licenses and State Identifications Cards with Organ Donor Designation

COUNTY RANKING BY ORGAN DESIGNATION PERCENTAGE				
COUNTY RANKING	COUNTY	TOTAL DRIVERS	ORGAN DESIGNATION	PERCENTAGE
1	CENTRE	95,840	57,058	59.53%
2	CHESTER	397,749	235,134	59.12%
3	WARREN	30,413	17,534	57.65%
4	BUTLER	155,488	86,968	55.93%
5	CUMBERLAND	204,782	114,297	55.81%
6	YORK	359,230	198,945	55.38%
7	MONTGOMERY	672,893	366,849	54.52%
8	BRADFORD	47,062	25,540	54.27%
9	ADAMS	80,216	43,514	54.25%
10	SUSQUEHANNA	30,672	16,619	54.18%
11	MCKEAN	30,920	16,644	53.83%
12	ERIE	204,571	109,911	53.73%
13	LANCASTER	413,362	221,514	53.59%
14	WAYNE	43,686	23,214	53.14%
15	BUCKS	527,131	279,749	53.07%
16	ALLEGHENY	956,791	504,032	52.68%
17	MONTOUR	14,620	7,699	52.66%
18	UNION	29,105	15,325	52.65%
19	BLAIR	97,467	51,082	52.41%
20	ELK	25,488	13,316	52.24%
21	TIOGA	32,242	16,840	52.23%
22	CLINTON	26,330	13,747	52.21%
23	LYCOMING	88,737	46,063	51.91%
24	CAMERON	3,750	1,929	51.44%
25	WYOMING	22,642	11,582	51.15%
26	LACKAWANNA	164,408	83,851	51.00%
27	CLEARFIELD	59,606	30,340	50.90%
28	WASHINGTON	171,782	87,260	50.80%
29	FRANKLIN	116,960	59,167	50.59%
30	CAMBRIA	104,564	52,823	50.52%
31	HUNTINGDON	33,233	16,769	50.46%
32	BEAVER	131,942	66,534	50.43%
33	NORTHAMPTON	261,455	131,522	50.30%
34	LEBANON	112,904	56,570	50.10%
35	VENANGO	39,482	19,698	49.89%
36	PERRY	37,601	18,749	49.86%

COUNTY RANKING	COUNTY	TOTAL DRIVERS	ORGAN DESIGNATION	PERCENTAGE
37	MIFFLIN	32,585	16,222	49.78%
38	CRAWFORD	65,504	32,596	49.76%
39	FOREST	4,323	2,145	49.62%
40	COLUMBIA	48,757	24,178	49.59%
41	WESTMORELAND	280,875	138,640	49.36%
42	POTTER	13,044	6,438	49.36%
43	SULLIVAN	4,813	2,374	49.32%
44	MERCER	84,425	41,532	49.19%
45	LEHIGH	283,649	139,096	49.04%
46	SOMERSET	57,990	28,386	48.95%
47	LAWRENCE	71,125	34,596	48.64%
48	DAUPHIN	224,099	108,663	48.49%
49	PIKE	46,552	22,479	48.29%
50	JEFFERSON	34,795	16,712	48.03%
51	BERKS	327,727	156,539	47.77%
52	SCHUYLKILL	111,401	52,725	47.33%
53	DELAWARE	444,510	209,910	47.22%
54	CARBON	51,887	24,254	46.74%
55	SNYDER	29,191	13,633	46.70%
56	ARMSTRONG	56,318	26,086	46.32%
57	INDIANA	60,161	27,852	46.30%
58	BEDFORD	39,271	18,171	46.27%
59	CLARION	27,841	12,814	46.03%
60	NORTHUMBERLAND	70,421	32,337	45.92%
61	JUNIATA	17,743	8,146	45.91%
62	LUZERNE	252,398	112,318	44.50%
63	GREENE	27,104	12,025	44.37%
64	MONROE	138,072	59,982	43.44%
65	FULTON	11,783	5,017	42.58%
66	FAYETTE	110,579	46,384	41.95%
67	PHILADELPHIA	1,134,399	364,963	32.17%
ALL	TOTALS	9,988,466	4,915,601	49.21%

Source: Pennsylvania Department of Transportation, 2019¹⁰

Citations

¹ Pennsylvania Department of Health, 2019

² Pennsylvania Department of Revenue, 2019. <u>https://www.revenue.pa.gov/GeneralTaxInformation/News%20and%20Statistics/ReportsStats/Revenue Receipts/Pages/default.aspx</u>.

³ Pennsylvania Department of Education. Lancaster-Lebanon Intermediate Unit 13. Organ and Tissue Donation Awareness Program, 2019.

⁴ Donate Life PA Website, 2019. https://www.donatelifepa.org/.

⁵ Tierney Donate Life PA FY 19 Report. July 1, 2018 – June 30, 2019. Executive Summary, August 6, 2019.

⁶US Department of Health and Human Services, https://www.hhs.gov/, 2019. Health Resources & Services Administration (HRSA), US Government Information on Organ Donation and Transplantation, https://www.organdonor.gov/, 2019 and Association of Organ Procurement Organizations, 2019 https://www.aopo.org/.

⁷Center for Organ Recovery and Education, 2019. https://www.core.org/.

⁸ Gift of Life Donor Program, 2019. https://www.donors1.org/.

⁹ Center for Organ Recovery and Education and Gift of Life Donor Program State Fiscal Year 2018-19.

¹⁰ Pennsylvania Department of Transportation, 2019.