



Center for Organ Recovery & Education

Pennsylvania House of Representatives
Republican Policy Committee Hearing
Testimony of Susan Stuart

April 2015

Good afternoon Chairman Benninghoff and members of the House Republican Policy Committee. My name is Susan Stuart, and I am President and CEO of the Pittsburgh-based Center for Organ Recovery & Education, or CORE.

Thank you for the opportunity to testify this afternoon. I am here to explain the role of Organ Procurement Organizations (OPOs), the current healthcare crisis related to donation and transplantation, and why the two OPOs in the Commonwealth of Pennsylvania – CORE and Gift of Life Donor Program in Philadelphia – work to save and enhance lives every day.

Regulatory Framework

The United States organ donation and transplantation system is primarily regulated by the federal government. Congress' enactment of the National Organ Transplantation Act of 1984 provided for establishment of the Organ Procurement Transplantation Network (OPTN) to oversee donation and transplantation throughout the United States. All OPOs are nonprofit, federally designated and regulated organizations responsible for coordinating the organ donation and transplantation process, and educating the public about organ donation.

The federal Centers for Medicare and Medicaid Services (CMS) has certified 58 OPOs to serve designated donor areas across the country. The two OPOs that serve Pennsylvania are CORE, which serves the western half of Pennsylvania, and Gift of Life Donor Program (GDLP), which serves the eastern half. Together, we work with approximately 175 acute care hospitals and 18 transplant hospitals with the common mission to save lives through organ donation and enhance lives through tissue and cornea donation.

OPOs serve as the vital link between the donor, donor family and transplant recipients. We are responsible for collaborating with acute care hospitals on the identification and medical suitability of potential donors, and the communication with families regarding their opportunity to say "yes" to donation. Following the authorization process, the OPOs follow national allocation policies to place organs with the transplant centers and coordinate the organ procurement process, which involves the storage and transportation of organs for transplantation.

Federal regulations require that all OPOs be recertified by CMS every four years. This process also involves continuous reporting of data on every patient death and the assessment of donor potential, as well as on-site audits. In addition to CMS oversight, OPOs are also required to be members of OPTN and most (including CORE and Gift of Life Donor Program) are accredited by the Association of Organ Procurement Organizations (AOPO). CORE and Gift of Life Donor Program also coordinate tissue and cornea donation and, as a result, are regulated by the Federal Food and Drug Administration (FDA) and accredited by the American Association of Tissue Banks (AATB) and the Eye Bank Association of America (EBAA).

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Compliance is assessed with regard to comprehensive standards relating to hospital relationships and referrals of deceased patients; donor screening and suitability determinations; donor family communications, including communications regarding donation authorization and ensuring sensitivity and discretion; donation rates and outcomes; staff training and quality monitoring; retrieval, processing and preservation; confidentiality and information security; governance and management; fiscal stability; and donor management and clinical support.

The Heart of the OPOs

Our OPOs are comprised of committed staff members and volunteers who bring integrity and expertise to help us fulfill our mission of promoting donation, education and research to save and improve lives through organ, tissue and cornea transplantation.

All of the dedicated individuals who work on behalf of the OPOs have a unique opportunity to see the result of their hard work in the faces of those we help. They are a constant reminder of our life-saving mission.

- We would not exist without the trust and support of the community we serve. We rely on public oversight and in return offer transparency as we fulfill our mission. As nonprofit organizations, we are fiscally responsible and maintain high performance standards.
- We honor our donors and donor families. They are the heart of our organizations and the foundation of our mission. Without them, transplantation would not be possible. We are respectful of the gift of life and give tribute to its power through community outreach and education.
- We uphold stringent clinical standards to ensure the quality of donated organs and tissue. We are compliant in all aspects of organ, tissue and cornea procurement.
- We operate in a fast-paced, detail-oriented manner. Our staffs are available 24 hours a day, seven days a week, to respond to the needs of our donor, their families, our hospitals partners and the communities we serve.
- We recognize that education is critical to uphold public trust and for the public we serve to make informed donation decisions. Education of the community about organ, tissue and cornea donation, the need for donors, the donation process and debriefing misconceptions are essential components of our daily activity.
- We have respect for both the dying process and saving of another's life. We provide hope when a life is lost, all the while maintaining the dignity of our donors.

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- Most importantly, we value the legacy of life that our donors have left and the second chance at life that transplant recipients have been given.

The Health Care Crisis

The shortage of organs available for transplantation is nothing less than a public health crisis – across the United States and here in Pennsylvania. Nationally, there are 123,303 individuals awaiting a second chance at life. Every 10 minutes another patient is added to the national waiting list, and 21 Americans die each day waiting for a life-saving organ transplant. As of April 2015, there are 8,509 people waiting for a transplant in Pennsylvania, and we lost 435 patients last year because organs were not available.

The precious gift of an organ donation is only possible in 2 percent of all hospital deaths, and so it is essential that, when possible, every effort is made to offer the donor family the option of donation. The only way for Pennsylvania to save more lives of those awaiting transplants is to improve on its existing processes for coordinating the donation in hospitals and educating the public about donation.

Organ Donation Saves Lives

Although you have heard many compelling statistics that illustrate the disparity between the number of organs available and the number of transplant candidates, it is vital that you know why we are so passionate about our mission. Behind every statistic is a human story, and nothing is more compelling than meeting the people who drive our work each and every day.

People like SaMaya Martin, of Oakland, Pennsylvania, who was born with a dead bowel and relied on stomach feedings and intravenous fusion for nourishment as a baby. After more than two years on the transplant waiting list – moving to Pittsburgh to await the call that an organ was available – she received that call, and is now a healthy, energetic child. Organ donation saved her life.

Also, 15 year old Victoria Birch of Butler Pennsylvania was the recipient of a liver transplant at the young age of 5 months. She is now a healthy and beautiful young lady. They are both stories of triumph.

However, others like Marty Brown, a 22-year-old from Corry, Pennsylvania, has been diagnosed with hypertrophic cardiomyopathy at birth and has lived his entire life thus far under the stress of heart disease. In 2013, Marty went into full congestive heart failure and now requires a Left Ventricular Assist Device (LVAD) to pump the left side of his heart to keep him alive.

In addition, Moses Hart, a 52-year-old from Pittsburgh, Pennsylvania, is also in need of a heart transplant. Moses has been waiting for over three years for the call that will save his life.

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Hope comes in many forms, but for Marty and Moses, transplantation is their only chance at life.

We also help people like Jan and Jim Eddy from Cherry Tree, Pennsylvania, whose son, Michael James Eddy, was a registered donor when, at the age of 16, he died in a motor vehicle accident. Today, Michael's parents say the fact that Michael was able to help others through organ donation has been a great comfort to them and their family.

These are real-life stories of donor families, transplant recipients and candidates, and they are the reason for what we do every day.

In closing, I would like to share how organ donation and transplantation embodies the circle of life from the East Coast to the West Coast.