



Successful strategies to increase organ donation: the Gift of Life Donor Program Philadelphia model

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Abstract

Organ donation connects the ending of one life with the renewal of another. Acute care hospitals care for the organ donor and transplant organizations complete life-saving surgeries. Between them is a vital component: a less-known medical team dedicated to ensuring that organ donation and transplantation are possible. Organ procurement organizations (OPOs) support grieving families during a painful time of loss, providing a rare and precious opportunity in donation. The OPO is simultaneously poised to ensure that organs successfully begin their journey to renewing life and restoring hope for recipients and their loved ones. Every OPO faces a myriad of challenges in meeting its responsibilities. A recognized leader in the field, Gift of Life Donor Program (GLDP) in Philadelphia, Pennsylvania has been committed to meeting these challenges for nearly fifty years. The successes of this OPO reflect the legacies of organ donors, recipients, and their cherished loved ones.

Keywords Organ donation · Organ procurement organization · Organ transplantation · Organ donors · Transplant recipients

Introduction

Solid organ transplantation has remained a viable option to address end-stage organ failure for over 50 years [1]. Despite progress, healthcare professionals worldwide share a common challenge: how to increase the number of organ donations [2] to meet the increasing need. Achieving life-saving organ transplantation requires exceptional synchrony between three stakeholders: acute-care hospitals, where potential organ donors receive medical treatment, organ procurement agencies (OPOs) that evaluate and facilitate allocation of organs for transplant, and ultimately, transplant centers, completing life-saving organ transplant surgeries. Of the three, an OPO is the pivotal cogwheel connecting donors to recipients.

Developing solutions to the shortage of donors begins with a review of statistical information. A 2019 survey of public attitudes revealed 90% of Americans are supportive of organ donation [3]. As of January 2021, there were over 108,000 people awaiting transplantation in the USA (Fig. 1: USA wait list). Over 90,000 of these individuals

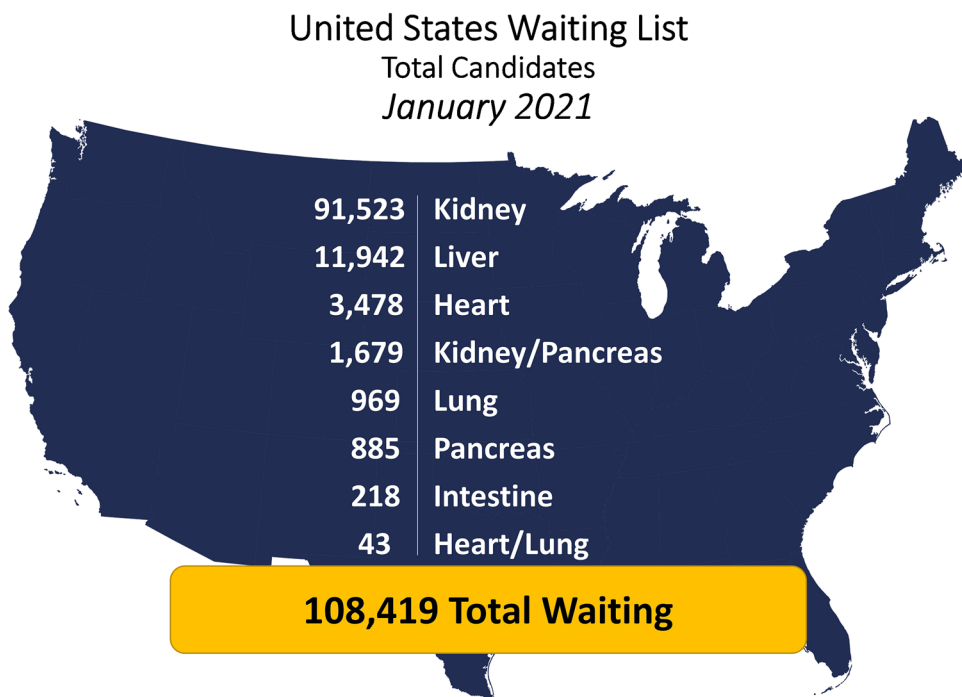
need kidney transplantation. Specific to thoracic organs, nearly 3500 are awaiting heart transplant and over 950 need lung transplantation [4]. Since 1995, organ donation in the USA has increased 134%. Sadly, the number of individuals awaiting transplant continues to outpace donations (Fig. 2: USA national trends in deceased organ donation). Mournfully, 17 people die each day waiting for transplant [5]. Given the relative rarity of organ donors, determining barriers to donation is an ongoing process with many challenges [6] when considering the potential for donation (Fig. 3: USA estimated annual potential).

Individuals may donate many types of anatomical gifts through organ and tissue donation in the USA. Organs that may be donated include the heart, lungs, liver, kidneys, pancreas, small intestine, and vascularized composites allografts (VCA), which includes upper limbs, face, and abdominal wall. Donated tissues may include corneas and whole eye, bones, heart valves, saphenous veins, skin, ligaments, and tendon. Organ donation is possible following brain death or cardio-respiratory death. Life-enhancing tissue donations are a possibility for many families experiencing the loss of a loved one. Never forgotten are the individuals behind the numbers; donors families seeking a comforting aspect to a tragic loss and recipients hoping for a new, healthier beginning. An OPO should advocate for both groups.

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Fig. 1 USA wait list



Source: OPTN data

National structure

In the 1970s, medical advancements in life-saving treatments led to new considerations of brain function following severe injuries and illness [7]. Medical professionals were faced with understanding concepts regarding the loss

of brain function and brain death. No longer would death be singularly determined by cessation of respiration and heartbeat. On February 10, 1981, the Uniform Determination of Death Act (UDDA) established medical criteria for pronouncing death by cardio-respiratory and neurologic criteria. This legislation was the catalyst to further the

Fig. 2 USA national trends in deceased organ donation

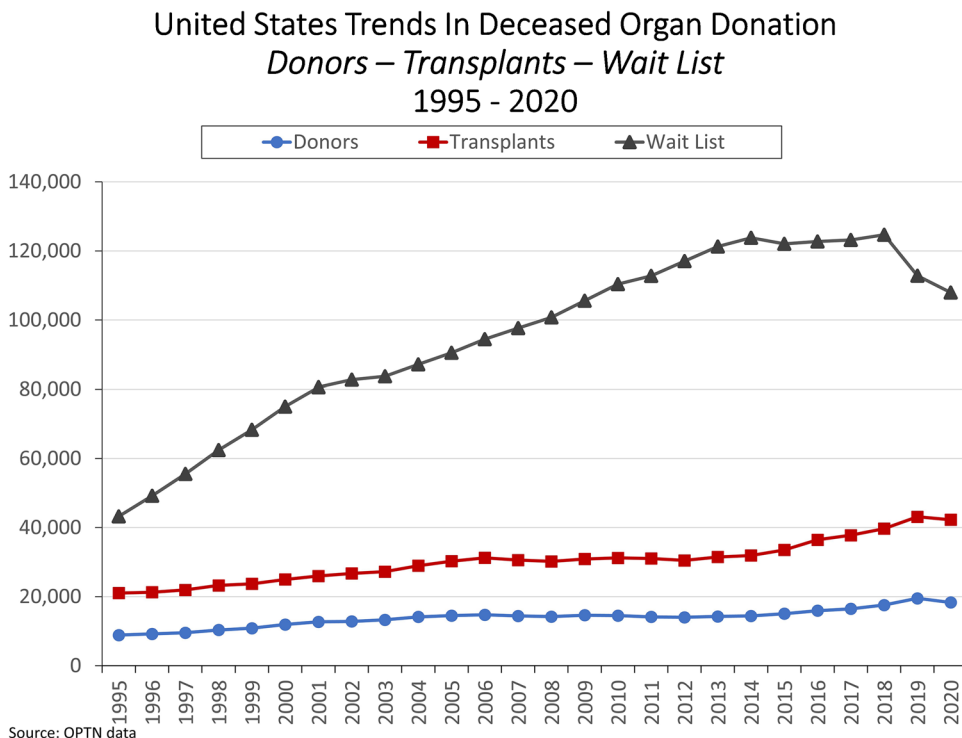
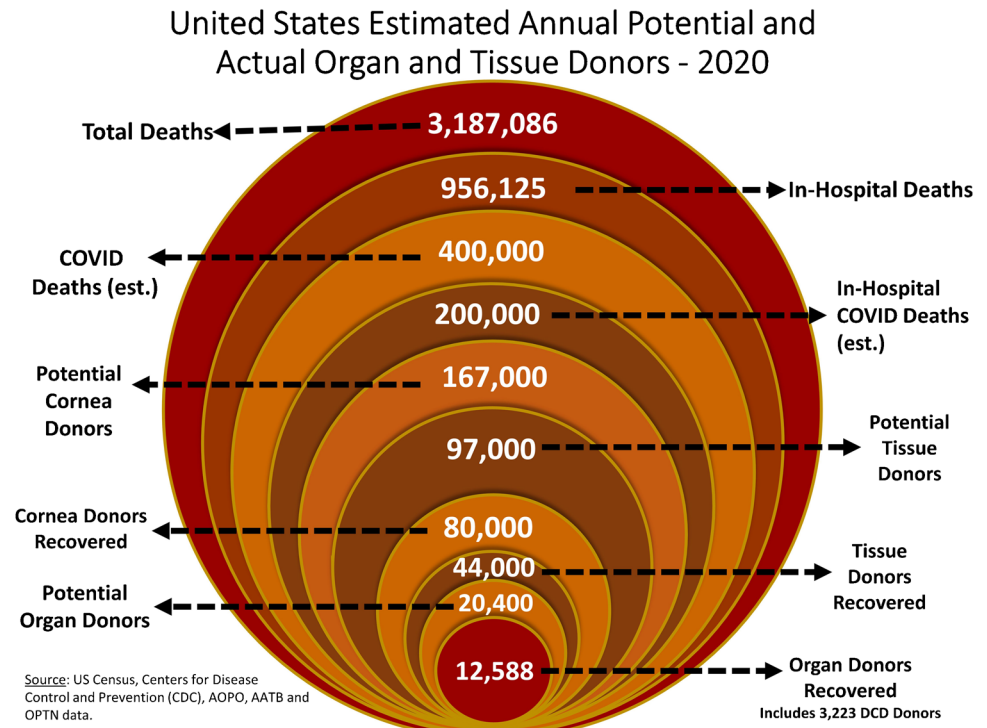


Fig. 3 USA estimated annual potential



development of organ transplantation [8]. Grieving families began to learn how their loved one could establish a legacy through the gift of life-saving organ donations. Patients faced with end-stage organ failure had new opportunities for life-saving organ transplantation.

The National Organ Transplant Act (NOTA) of 1984, authored by then-Congressman Al Gore, established the national Organ Procurement and Transplant Network (OPTN) [9]. The primary responsibility of OPTN is to approve transplant centers. The OPTN connects OPOs, transplant programs and tissue typing laboratories. OPTN's goals are to increase the number of and access to transplants, improve survival rates following transplant and ensure organ transplantation operates safely and effectively. An OPO is federally designated to carry out its mission by the US Centers for Medicare and Medicaid (CMS). All US transplant centers, and organ procurement organizations must be members of the OPTN.

UNOS

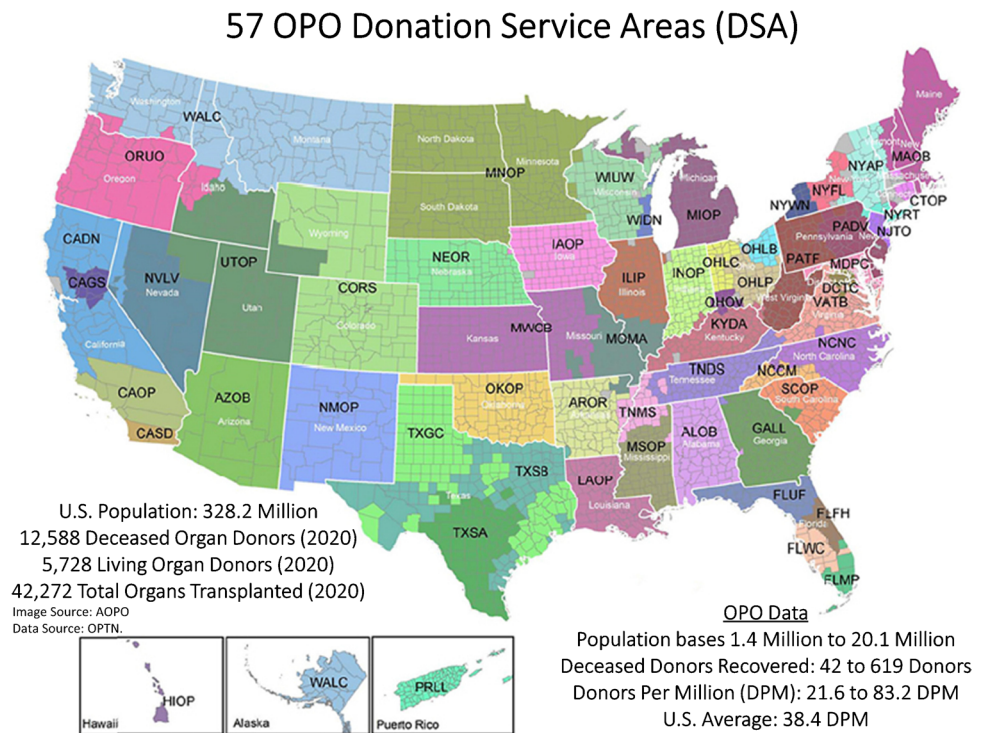
Contracted by the Department of Health and Human Services, Health Resources and Services Administration (HRSA), the United Network for Organ Sharing (UNOS) is responsible for managing the US organ transplant system. Eleven geographical regions organize the nation-wide response for organ transplantation with 57 OPOs distributed among these regions (Fig. 4: United Network for Organ

Sharing Donor Service Area Map). Regional groupings provide effective mechanisms for dialogue regarding shared challenges and trends unique to the geographical area, such as population, health care system structures, and cultural identities [4].

Since 1986, UNOS has provided oversight of the national database of clinical transplant information and operation of a computerized system in constant operation, 24 h a day, 365 days per year are primary responsibilities. UNOS manages the wait list, establishes wait list criteria and develops allocation policies for all deceased donor organs. UNet, the web-based hub connecting donors to recipients, is comprised of multiple electronic applications supporting the US donation and transplantation network. For example, organ matching is accomplished through the DonorNet system. TransNet, another tool in the UNet system, provides secure electronic labeling of organs and tissues. Further, UNOS establishes criteria for transplant centers and maintains data on all donors and transplants, living and deceased. Audits of OPOs and transplant centers are performed to ensure policies are being followed [4].

The NOTA also provides a platform for statistical and analytical scrutiny of organ transplantation. The Scientific Registry of Transplant Recipients (SRTR) provides healthcare professionals and laypersons alike access to the transplant related information. Both the UNOS and SRTR websites are easily operated. The public may access UNOS via <https://unos.org/> to learn how organs are matched for transplant and read about current research topics and trends.

Fig. 4 United Network For Organ Sharing Donor Service Area Map



Allocation policies are also posted, including a public comment opportunity for proposed policy changes. The SRTR <https://www.srtr.org/> provides transplant program data, useful for potential recipients when deciding upon a provider for their transplant. For example, a potential lung transplant patient can visit the SRTR website to review locations of lung transplant programs nearest to them. They can also review data including the number of transplants a transplant program has completed and recipient survival rates [10].

Legislative and policy development

In addition to establishing the OPTN, the NOTA established an organ transplantation task force. This group’s 1986 report was a mandated, comprehensive “examination of medical, legal, ethical, economic and social issues” [11] and put in writing a basic tenet regarding organ donation; that it is a supreme act of kindness to be regarded as a national treasure [11]. With the need identified, the next step was to gain an idea of what the potential for organ donation was. In 1990, a state-wide Pennsylvania (PA) Donor Study estimated a donor rate of 38–55 potential organ donors per million population per year [12]. PA Act 102 of 1994 provided residents of the Commonwealth of PA the most comprehensive legislation surrounding organ and tissue donation in the country. This early document served as a framework defining the varied and complex processes for organ donation. Individuals were given the ability to pre-determine wishes

regarding anatomical gifts. It established a process for hospitals to identify and refer a potential organ donor to their local OPO. With a noted increase in PA donations of 43% as compared to 6% nationally over a three-year period [13], this early legislation became a model for similar measures in other states [11].

A significant outcome of PA Act 102 was establishing a routine referral practice in hospitals, whereby all patient deaths and imminent brain deaths must be referred to the OPO. With the advent of brain death determination in acute care hospitals, standard messaging was provided by Gift of Life Donor Program (GLDP), encouraging hospital staff to initiate “Early referral of all non-recoverable, neurologically injured, ventilator dependent patients” [14]. This message resonates so well it has remained a guideline for potential organ donor referrals. GLDP provides trigger cards to guide hospital staff in making timely referrals to the OPO. This laminated tool fits into a clinician’s pocket providing details including appropriate clinical criteria for referral to the OPO and the GLDP contact phone number. The legislation also set forth the OPO’s responsibility to determine a patient’s medical suitability for donation of organs and tissues. The OPO is committed to immediate on-site evaluation of a potential donor, important for establishing the OPO’s credibility with hospital staff [14]. These factors are essential measures preserving the option of organ donation for grieving families.

Broad medical suitability criteria for donation eliminate perceived barriers for early referrals and linkage of the

OPO. To ensure optimal family donation conversations, PA Act 102 further required the donation consent requests be restricted to OPO staff or “designated requestors” who were individuals specifically trained in speaking with families regarding organ and tissue donation. OPO staff collaborate with hospital personnel to periodically review medical records for all inpatient deaths to ensure all possible referrals were reported to the OPO. Fines may be imposed for issues of non-compliance [11].

In August 1998, CMS supplemented the Conditions for Participation policy for hospitals, bringing advancement in the organ donation process to the entire USA. Modeled after PA Act 102 of 1994, it incorporated the requirement for routine referral of potential organ donors as a condition for receiving Medicare funding [15]. Hospitals were also required to have and implement written agreements with at least one OPO, one tissue bank, and one eye bank, thus ensuring each potential donor’s family is informed of their donation options. Mirroring PA Act 102, it requires the individual making the donation request be an OPO representative or a trained designated requestor. Discretion and sensitivity are encouraged with respect to the circumstances, views, and beliefs of families of potential donors. Finally, hospital staff are to work collaboratively with the OPO, tissue bank and eye bank in educating hospital staff on donation issues, reviewing death records and medically maintaining potential donors [16].

In summary, the US organ donation and transplantation process is exceptionally regulated and monitored. Agencies providing oversight include the US Department of Health and Human Services (DHHS), the Joint Commission on Accreditation of Healthcare Organizations (JC), United Network for Organ Sharing (UNOS), Centers for Medicare and Medicaid Services (CMS) and finally each state’s Department of Health (DOH). Acute care hospitals, OPOs and transplant centers are responsible for addressing standards set forth by these organizations. These three groups have unique perspectives on reducing the ever-widening gap between donations and transplantation. Legislation, policy changes and actionable initiatives among the group over the past forty years reflect organ donation and transplantation refinement in the USA.

Challenges

Legislation and formal directives regarding organ donation were an impetus for changing the landscape of patients awaiting organ transplantation; however, legislation alone cannot resolve all barriers to fully realized organ donations. One of the most significant problems faced by an OPO is gaining family permission for organ donation [1, 17]. Individuals may avoid discussing topics pertaining to death and

dying; this “communication apprehension” [18] then results in family members faced with life-changing decisions at a moment of emotional crisis.

Effective communication for such a high-stakes conversation demands careful planning and preparation. Education of OPO staff responsible for family conversations resulted in improved skills and higher rates of consent [19]. In 2001, GLDP recognized that maintaining increased donation rates would necessitate a comprehensive review of coordinator training. Focus on family donation conversations was paramount with coordinators receiving extensive education on family grief reactions, brain death, non-verbal communication, and conversation skills. Through formal didactic and role-playing exercises, coordinators are rigorously prepared for effective family conversations. Results of a 10-year review, shared at the 2011 Organ Donation Congress, demonstrated GLDP observed a 29% increase in authorization rate and a 32% increase in organ donors after developing and implementing a systematic and comprehensive staff training program.

Public knowledge regarding donation can be fraught with misunderstandings. National surveys regarding public attitudes about organ donation topics have been conducted periodically. Results from the 2019 survey indicated overall general support of organ donation remains above 90% [3]. Compared to surveys done in 2005 and 2012, consistently strong beliefs in the benefits of organ donation remain; however, only half of the respondents had ever discussed decisions regarding organ donation with their family members [3]. Of concern was the finding that if a family member’s decision regarding donation were known, 88% would choose donation and alarmingly, just 69% would elect to save lives if wishes were unknown [3].

Donor registries are in place within each state, so that individuals may pre-designate themselves to be organ donors upon their death. “Donor designation” is considered a definitive choice made by an individual and should be supported at the time of death. The State of PA, like many others, considers “organ donor” designation on a driver’s license or state issued identification a legal document [20]. Donation registries are available via national sites and each state’s department of motor vehicles. Educational materials and interpersonal communications have shown to be effective in boosting rates of donor registrations [21].

Cultural belief systems and perceptions about age and medical suitability also pose challenges for donation. Recognizing the US breadth of cultural diversity, OPOs must assess their demographic and educate staff on relevant topics. For example, American Indian cultural experts shared how typical messaging regarding organ donation would not resonate with their belief systems [22]. They cautioned against the comparison of American Indian donation rates to white Americans and suggested emphasizing the

significance of ongoing spiritual life after death and how status from giving is far more valued over possessions [22]. Religious implications regarding organ donation must also be considered. The support of a religious leader, such as an Imam, may hold sway over decision-making [23]. Intrinsic mistrust of health care and lack of knowledge about organ donation point to the need for ongoing education and relationship-building in culturally diverse communities [24].

Sixty percent of those awaiting organ transplant in the USA are people of color [4]. Focused efforts to educate minority communities have had a profound impact on donation rates [25]. Ongoing themes of mistrust, lack of knowledge and religious connections to decision-making point the way for further donation awareness efforts [26]. Healthcare providers can take steps to create trust. Five actions for every health care professional to undertake are noted: (1) explore and understand the mistrust; (2) take steps to repair mistrust; (3) be “culturally humble”; (4) bring empathy to the conversations, and (5) commit to awareness of implicit bias and truly understand where mistrust comes from while educating oneself to decrease them [27].

GLDP overview

With humble beginnings in spring 1974, the Delaware Valley Transplant Program was established by the Greater Delaware Valley Society of Transplant Surgeons. Now known as GLDP, the workforce has grown from one individual to 265 dedicated personnel. The service area has seen population growth from 10.1 to 11.3 million, and currently has 128 acute care hospitals, with 15 transplant centers containing 40 programs for heart, lung, liver, kidney, and pancreas transplantation. GLDP is an OPO located in the eastern USA serving the needs of donor families and transplant recipients in eastern Pennsylvania, southern New Jersey, and Delaware for nearly fifty years. Proud to be one of the oldest OPOs in the US, GLDP is a leader in the field, within the Nation, and internationally (Fig. 5: All deceased organ donors). Executive leadership is provided by the OPO President/Chief Executive Officer (CEO), with input from Medical Advisory and Policy Boards. Clinical and Administrative Divisions, each led by a Vice President, provide oversight of the multifaceted OPO operations. The GLDP Mission encompasses goals not just within the local area, but also recognizes a greater responsibility on national and international levels. First, the organization strives to improve the quality of life by maximizing the availability of donor organs and tissues for transplantation while upholding the highest medical, legal, ethical, and fiscal standards. In addition, there is focus on working in partnership with the region's hospitals and health care professionals to ensure that the family of each potential donor is offered the option of donation in a

sensitive and caring manner. Offering educational programs and materials to positively predispose all members of the community to organ and tissue donation so that donation is viewed as a fundamental human responsibility is an additional aspect of the mission. GLDP seeks to function as a community resource through support of donor families as well as transplant recipients and their loved ones. Ultimately, GLDP endeavors to serve as a leader in the advancement of organ and tissue donation and transplantation.

Despite the challenges of 2020, the GLDP team drew on their dedication, partnership, compassion, and resilience to inspire their community to continue a 13-year trend as the most generous region for organ donation in the USA (Fig. 6: Gift of Life Donor Program organ donor experience). In 2020, GLDP coordinated life-saving gifts from 619 organ donors, resulting in 1621 organ transplants. Life-enhancing tissues were received from 2295 donors, including 1385 musculoskeletal donors (the most ever in Gift of Life's history) and 1726 cornea donors.

The ideal donation process

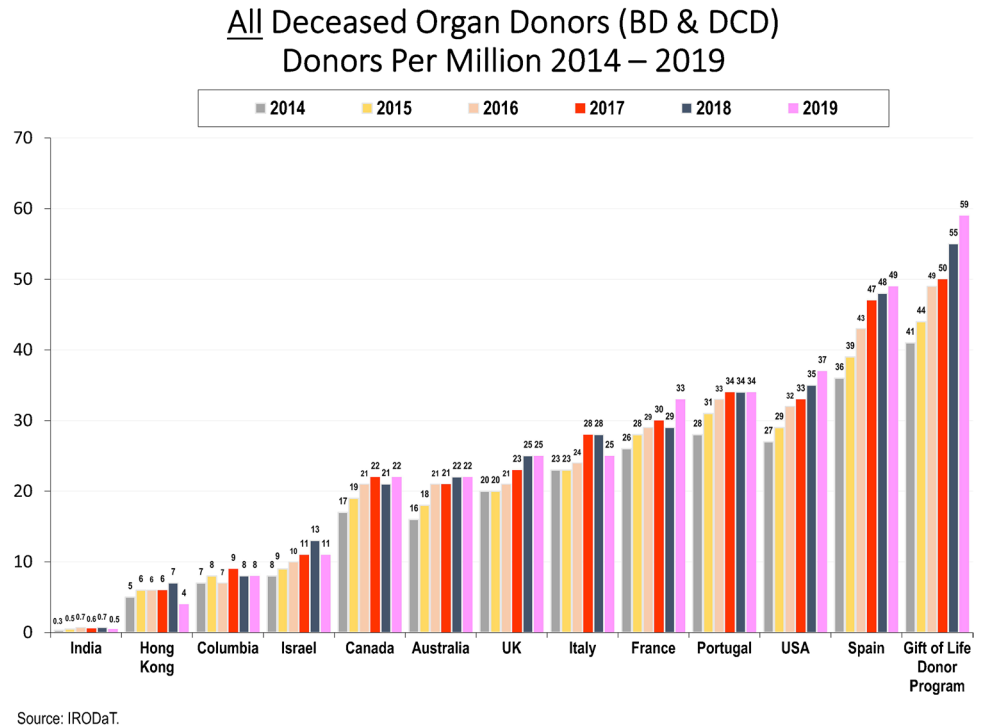
GLDP has developed an ideal process for organ donation (Fig. 7: Pillars of an ideal donation process). Drawing on nearly fifty years of experience, lessons taken from interactions with donor families, healthcare professionals, transplant recipients and members of the community have assisted in the development of this practice. Efforts making transplantation a reality require the commitment of a team. Medical expertise of GLDP clinical staff, combined with contributions of non-clinical professionals drive GLDP to achieve as many organ donations as possible. GLDP staff collaborate and brainstorm to overcome challenges. Notable components of the GLDP team include Community Relations (CR), the Hospital Services Department (HS), Transplant Coordinators (TC) and Family Support Services (FSS).

Community relations

GLDPs CR department works with schools, businesses, houses of worship and various segments of the community to encourage individuals to register as an organ and tissue donor. The CR team includes experts in grief counseling, volunteer engagement, special events and communications. Community outreach includes public events, presentations, special observances, and news, radio, and social media platforms. Countless volunteers support the goal of raising awareness regarding organ donation and are invaluable resources.

Recognizing donor designation significantly increases the likelihood of organ donation occurring [28],

Fig. 5 All deceased organ donors



GLDP promotes all forms of donor registration. Efforts are focused on promoting the value of donor designation, as many donor families share feelings of relief and empowerment when following through on a loved one’s wishes. Sharing donation decisions with loved ones is also encouraged. There are multiple ways for people to register as

organ donors. Perhaps most common, individuals register through their state of residence when they obtain or renew a driver’s license. In addition, they may also sign up to be an organ donor electronically through state online registries, helpful for those who need an identification (ID) card but may not be drivers. National organ donor registries

Fig. 6 Gift of Life Donor Program organ donor experience

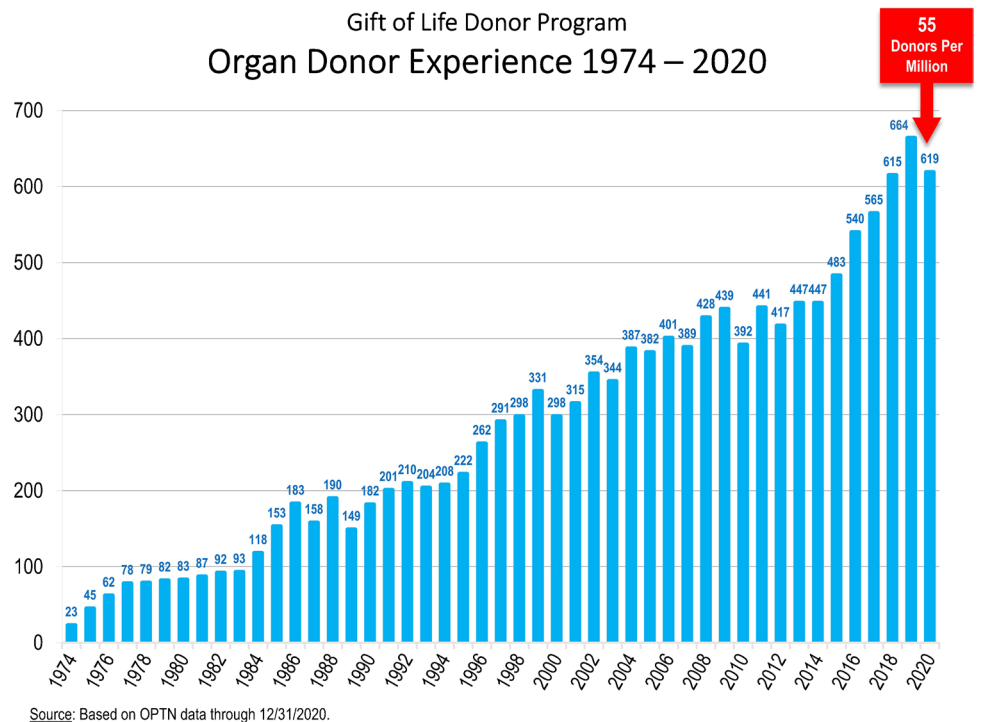






Fig. 7 Pillars of an ideal donation process

Public 	Public Education
	Multicultural Outreach
	Student Education & Awareness
	DMV/State Awareness Campaigns
	Social Media
Hospital 	Case Follow Up/Debriefing
	Routine Education
	Resident/Physician Education
	CEO & Leadership Meetings
	Conferences & Symposiums
Clinical /OPO Staff 	Declaration of Death & Referral
	Potential Donor Evaluation
	Family Approach & Authorization
	Clinical Management
	Matching & Allocation
	Surgical Recovery
	Transplantation
Family Support 	Donor Recognition Package
	Counseling & Referrals to Resources
	Correspondence Between Recipients & Donor Families
	Support Groups

provide additional avenues. One is provided by HRSA at www.organdonor.gov, which connects to applicable state registries. Another opportunity is provided by Donate Life America (DLA) www.donatelife.net/register/. In 2020, 55% of US organ donors were “donor designated” (Fig. 8: US donor designation trends).

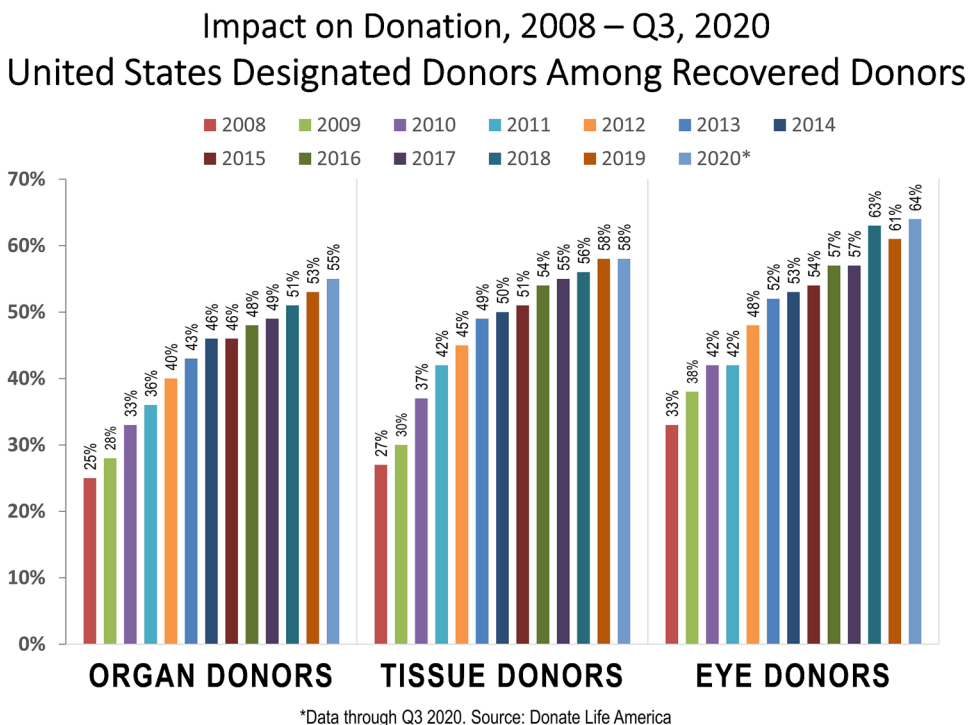
Volunteer ambassadors, including organ transplant recipients, donor families, living donors and supporters also educate the community about organ and tissue donation and transplantation. These dedicated individuals speak to community groups, participate in media interviews, support special events organized by GLDP and share messages via social media. Reaching out into communities and educating the public is crucial as misconceptions about being too old or sick to donate are pervasive [29].

Inspiring stories of donation and transplantation are shared through media, including newspapers, radio, television stations, and social media. GLDP produces two publications. An electronic newsletter is sent by email to 20,000 subscribers every month. A print newsletter published three times per year is mailed to 120,000 supporters. GLDP has a strong presence on social media using all major platforms including Facebook, Twitter, Instagram, and others. The GLDP Facebook page has more than 60,000 followers.

Educating students at the high school and college levels is essential. Among key factors that should be addressed are connecting young people personally to donation and correcting misinformation about organ donation [30]. This is accomplished by speaking with classes and student groups, providing community service opportunities, and sponsoring special programs that encourage students to share information about donation through their school community. The influence of social media and student organizations is notable in this population.

National observances also spotlight organ donation. GLDP participates in several of these events in partnership DLA. Coordinating outreach on a national scale since 1992, DLA strives to increase donations of organs and tissues for transplant hoping the act of donation is viewed as a “fundamental human responsibility” [31]. Celebrated in April each year, National Donate Life Month features an entire month of activities to help encourage Americans to register as organ, eye, and tissue donors and to honor those that have saved lives through the gift of donation. The month features National Blue & Green Day when the public is encouraged to wear blue and green (DLA’s colors) and to engage in sharing the Donate Life message and promoting the importance of registering and an organ, eye, and tissue donor. One of the most significant public

Fig. 8 US donor designation trends



events of the year for GLDP is the annual Donor Dash, also held in April. Since 1996, a quarter of a million people have attended the Donor Dash and its life-saving message has reached millions through media and community participation. The Donor Dash has been a tradition for 25 years and is the organization’s largest fundraiser. All proceeds from the Dash benefit the Transplant Foundation, the charitable foundation that supports programs and activities for donor and recipient families.

National Minority Donor Awareness Month is held annually in August. Special efforts are made to bring heightened awareness to donation and transplantation in multicultural communities — focusing primarily on African American/Black, Hispanic/Latinx, Asian Pacific Islander and American Indian/Alaskan Native communities. In addition, National Donor Sabbath is observed annually in November. GLDP connects with houses of worship to educate congregations how all major religions in the US support donation, considering it an ultimate act of compassion and generosity [32]. National Donor Sabbath provides an opportunity to encourage people of faith to register as a donor, since they often turn to their religious leaders for guidance when dealing with life and death issues.

Donor hospital collaboration

The HS Department is responsible for creating strategic plans that establish a foundation for optimal donation outcomes through advocacy and education of health care professionals. Data review of donor potential for

hospitals, hospital networks, and regions helps to determine development of hospital portfolios assigned to each Hospital Services Coordinator (HSC). Hospital Development (HD) utilizes a strategic approach to optimize donation processes in each hospital portfolio. Strategic planning is data driven and best supported when hospital leadership relays this vision throughout the hospital team, from executive staff to those working at the bedside. This approach reinforces best-demonstrated practices, reduces variability in practice, and improves donation outcomes. These plans include staff education, case followup, donor council development and planning, and relationship building. The review of data helps the OPO HSC identify areas for improvement, revealing variations in practice surrounding key donation process metrics.

Best Demonstrated Practices (BDPs), developed by The Partnership for Organ Donation, encourage four key elements: timely referral of a potential organ donor, OPO evaluation of donation potential, an appropriately timed and planned family approach, and a collaborative family request by the healthcare team (HCT) and OPO staff. Referrals are considered timely when made at the first indication of a non-recoverable neurologic injury or illness, prior to formal brain death exams, and before the family makes any decisions to limit or decelerate life sustaining therapies. A “planned approach” to the family discussion about donation occurs when the OPO representative initiates that conversation in consultation with the HCT, rather than if the attending physician or another member of the HCT initiates it independently. When a

“timely referral” and “planned approach” occur together, optimal donation outcomes are observed; OPO data have shown that when these two metrics are in place conversion rates are higher [33].

HSCs develop relationships with hospital partners in their portfolio allowing them to quickly follow up on cases and reach out to leadership for assistance when needed. Hospital leadership frequently meets with the HSC, who continuously updates leadership regarding donation outcomes. The HSC shares BDPs with hospital leadership and guides development of their customized strategic plan to implement educational offerings and create or expand case follow-up with the healthcare team. These plans are regularly reviewed for efficacy and modified as needed. Trends are identified, and individual cases are dissected to determine learning points and areas for improvement, as well as for opportunities to recognize highly performing staff.

One factor noted as a barrier to optimal donation outcomes is staff comfort with OPO processes [34]. Education is the cornerstone to improving staff comfort and understanding of donation measures and supports team understanding of the donation process [35]. Information is delivered in various ways, including grand rounds and formal in-servicing, critical care courses, professional symposia, and informally through unit rounding. HSCs provide instruction for nurses in new hire hospital orientation, various other initial trainings such as trauma nurse courses, and nurse internship and residency programs. Messages are reinforced regularly in interactions with hospital staff via unit-based rounding and re-education daily or near-daily. GLDP data has shown that frequent OPO interactions with hospital staff improve referral processes and increase the likelihood of staff making a referral for a potential organ donor.

One unique out-of-hospital forum developed by GLDP is the Donation Champion Learning Session (DCLS). This educational event is held monthly at locations throughout the OPO region. The program includes presentations on OPO Best Practices, Brain Death Diagnosis, Medical Management of the Organ Donor, Donation After Circulatory Death, and Family Communication. Session attendees include nurses, respiratory therapists, pastoral care, social workers, and other staff who interact with the OPO staff or donor families. A review of organ referrals from the hospitals attended by these programs has shown an increase in GLDP referrals of 113% [36]. An 88% decrease in missed referrals was also noted (Fig. 9: Referral trends).

GLDP has developed an e-learning module geared to hospital partners. This online educational component is designed for all clinical staff and reinforces the in-person education by HSCs. Focus is on organ and tissue referrals, family supports, and family donation conversations. A review of data at one hospital system that utilized the online training found increases in both referral

metrics and overall donation outcomes [37]. This program continues to be employed by many hospitals within the GLDP donor service area.

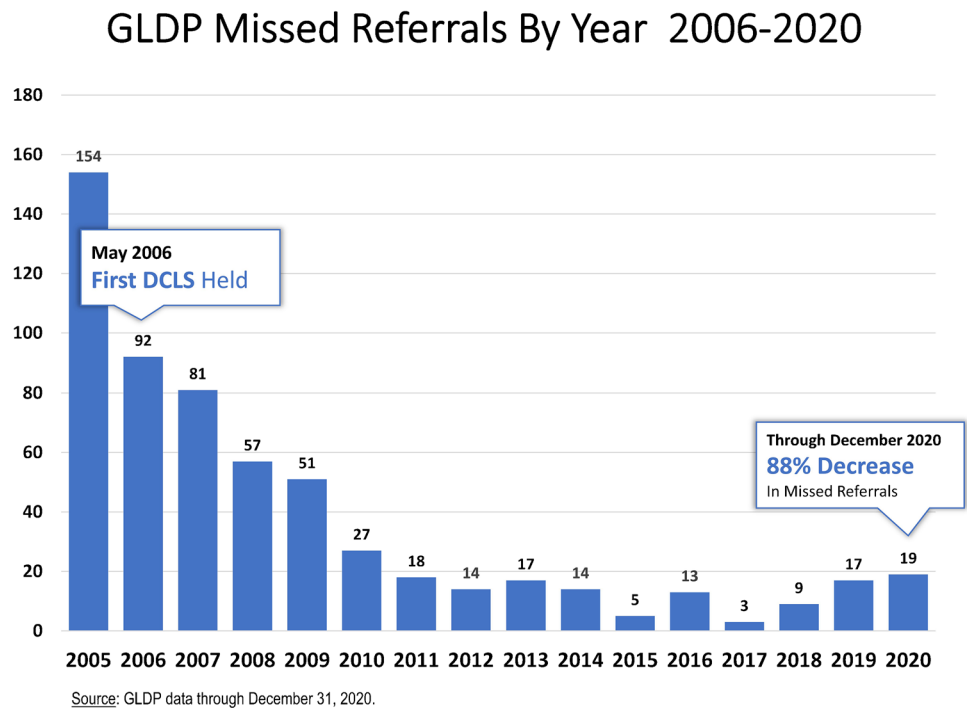
Training for resident physicians in critical care areas is also targeted for direct education. A survey of medical professionals found one barrier to family conversations was limited communication skills of physicians [38]. Research has shown that families who do not receive an adequate explanation regarding their loved one's diagnosis of brain death are more likely to decline donation [39]. “Explaining Brain Death Training,” developed in partnership with Dr. Amy Goldberg, Surgeon-in-Chief at Temple University Hospital, is a program in which residents receive didactic education regarding best practices and brain death followed by participation in role-play scenarios where they speak with a “family member” and explain their loved one's injury. This training has been shown to improve resident understanding of brain death and their comfort (Fig. 10: Explaining brain death resident survey) in discussing end of life topics with their patients' families [40].

Transplant coordinator

Of the multiple positions established by GLDP, none carries a greater responsibility to see the organ donation process through than the TC. While many OPOs in the USA have variations in the TC role, GLDP has maintained the TC role as a position that can address nearly any aspect of an organ donation, from hospital referral to organ recovery. TCs have established experience as nurses, paramedics, and respiratory therapists, bringing a unique skill set to the multi-faceted role as a TC. Recognizing that family authorization for donation is a considerable challenge, a keen focus has always been on the TCs ability to effectively conduct a family donation conversation (FDC). TC staff complete biannual workshops addressing identified challenges in FDCs, including simulated role-play conversations with immediate feedback. The development of a robust staff training program supports an organizational goal of sustaining increases in organ donors' numbers.

The TC works closely with hospital staff to develop collaborative plans for family care. Every effort is made to provide the family with an optimal donation conversation setting. Clear dialogue regarding prognosis and brain death, effective family support and care, and the development of trusting relationships between healthcare providers and the potential donor's next-of-kin are critical [41]. Hospital policy for neurologic determination of death typically incorporates guidelines from the American Academy of Neurology [42]. While policy guides the physician in pronouncement of death, clearly conveying that information to the donor

Fig. 9 Referral trends



family can make every difference in their acceptance of their loved one’s death and, eventually, their authorization for organ donation. TCs have no role in the pronouncement of death, instead focusing on family acceptance and understanding poor prognosis or death prior to an FDC. Significant research has concentrated upon what comprises the best

possible scenario for a pivotal conversation regarding organ donation. One of the most significant factors has consistently revolved around family understanding and acceptance of death [43]. Physician completion of apnea testing as part of brain death determination is an observable test that many families say is the moment when they truly understood that

Fig. 10 Explaining brain death resident survey

GLDP Explaining Brain Death Training Resident Responses in Pre- and Post-Training Assessment

Question	Response (n=1,432)	All Residents	
		Pre- (%)	Post- (%)
Is brain death synonymous with death?	Yes	56	99*
When a patient is declared brain dead, what is the time of death on their death certificate?	Time of brain death	37	98*
In general families understand brain death.	Disagree	56	71*
I feel comfortable in discussing brain death with families.	Agree	26	87*
I am confident in my ability to speak with families about brain death.	Agree	33	93*

* p<0.05 between pre- and post-training responses. Pre=pre-training; Post=post-training.

Source: GLDP Resident Training data through December 31, 2020.

their loved one had died. As such, this component of brain death testing could significantly impact authorization rates for donation [44].

Advocates for donors and recipients, GLDP staff work within a framework of “Dual Advocacy.” This is also the name of GLDP’s trademarked Family Donation Conversation (FDC) process taught nationally and internationally through the Gift of Life Institute, the arm of GLDP providing donation education to professionals worldwide. The goal of an FDC conversation is that a family decision be fully informed, proactive, and enduring. TCs ensure the donor family receives accurate donation information, that the family is in the best possible state of mind to hear about this rare opportunity and that their decision is the same one the family would make at any point in the future.

Physiologic changes following brain death are complex [45] and partnership of the health care team and OPO TC are essential to being good stewards of the donor’s gifts. Donor management protocols, including hormone replacement therapy [46], are instituted and adjusted by the TC as clinical diagnostic data is received. Exhaustive efforts are made to offer organs to transplant centers, despite less than perfect condition. One GLDP donor was found to have a 50% Left Anterior Descending (LAD) coronary lesion, and, despite this, the heart was successfully transplanted in a recipient who was gravely ill. Donors with other challenging factors, such as advanced age and co-morbidities are thoroughly evaluated. Under-utilization of less-than-ideal organs is a real concern that must be avoided [47]. Indeed, an organ need not be perfect to save a life.

The GLDP clinical team extends beyond the donor hospital, as the TC communicates with team members working in Philadelphia headquarters. The TC is responsible for allocation of the heart, lungs, liver, and intestine. Organ allocation schema had traditionally reflected concentric circles radiating from the donor hospital, identifying, and offering to local, regional, and national recipients closest to the donor. UNOS policies have been changing with allocation becoming based upon broader sharing to critically ill patients in consideration of clinical criteria, such as Lung Allocation Score (LAS) and Model for End-Stage Liver Disease (MELD)/Pediatric End-Stage Liver Disease (PELD) scores. In-house coordinators (IHCs) manage allocation of kidneys and pancreata with a mindset to treat every kidney and pancreas as if it were a heart. These staff also communicate with research programs, increasing opportunities for donated organs unsuitable for transplant to further advance the science of medicine and transplantation.

Culminating in supervision of operative recovery, the TC has several final responsibilities. Reviewing donor information with each surgeon includes scope of consent provided by the donor family, and brain death documentation, specifically highlighting the steps taken

by the healthcare team in the determination of death. Providing connection of the hospital and recovery team to the donor and their families is indispensable [48], and the TC pauses clinical activity with a solemn Moment of Honor, providing a powerful moment of reflection. Hospitals have also developed unique ways to recognize organ donors, with ceremonies such as Honor Walks, Donate Life flag raisings and overhead announcements like those used to recognize a birth. Prior to departing the donor hospital, the TC once more connects with the donor family, providing support and appreciation.

Family support services

The FSS is a team of licensed social workers who specialize in supporting the families of organ and tissue donors as they learn to cope with the death of their loved one. The FSS group provides several critical services to families. Primary is to provide grief counseling in person or via phone, as well as referring families to counseling or support groups closer to their homes, if necessary.

A common question among donor families pertains to how they may learn about recipients of their loved one’s gifts [49]. The FSS team coordinates anonymous correspondence between donor families and transplant recipients, as well as facilitating meetings when both parties request it. The team also provides donor families with updates on recipients’ progress in recovery. TCs meeting with donor families offer donor memorial displays for use at funeral or memorial services. Each kit includes Donate Life wristbands, a certificate honoring the donor and other materials regarding organ donation. Hundreds of loved ones attend funeral and memorial services; connecting with others who are grieving, reminiscing the loved one who died and celebrating their life. These materials provide an additional opportunity to share organ donation with the public, particularly at a time when individuals may reflect upon their own choices regarding organ and tissue donation. Since 2011, GLDP has provided donor families with 20,108 recognition displays.

Life & Legacy Celebrations are unique occasions held annually honoring donors and their families. Coordinated by the FSS team, donor families receive support from each other, and inspirational stories from donor families and recipients are shared. GLDP staff participate in this event, ensuring a connection to the heart of the GLDP mission. The poignant support for gifts given that can never be repaid becomes emotional for all parties.

Social media platforms have shown to be helpful in connecting donor families with a community of support. The FSS team moderates a private Facebook group for

donor families and provides workshops and presentations to address specific aspects of grief, for example, coping with grief during the holiday season. The FSS team offers their grief expertise to the community through articles, presentations, and media interviews.

Gift of Life Institute — international training center

A vital part of GLDPs mission is to “serve as a leader in the advancement of organ and tissue donation and transplantation.” With this core principle in mind, GLDP and the Transplant Foundation founded Gift of Life Institute (Institute) in 2004 and opened the door to a newly structured, formal education and training center that invited OPO and healthcare professionals to learn and share expertise on a global scale. The Institute is the pre-eminent resource for proven clinical and educational programs serving the organ and tissue donation community. Its vision is to increase organ and tissue donation rates worldwide through its center of expertise for evidence-based training, education, and research for donation professionals.

Since the Institute’s establishment, highly skilled, experienced faculty have worked with every OPO in the USA to provide training and consulting services, including comprehensive, multi-modal training in all aspects of organ and tissue family communication and authorization practices; hospital development strategies for creating and sustaining strong hospital partnerships; executive consulting services, and a variety of leadership, clinical and OPO-related training programs. Customized Institute trainings include problem-based learning and skills practice sessions utilizing reality-based family, hospital, and clinical scenarios. The Institute takes pride in its commitment to provide a learning environment where professionals can develop, strengthen, and practice new skills and formulate solutions to existing practical challenges.

In addition to its innovative virtual classroom trainings, OnDemand programs, and eLearning series, the Institute has partnered with Enhanced Learn, LLC to offer WebEncounter, a unique online learning platform which integrates practice and assessment in an enriched learning environment. The WebEncounter engages a live, skilled coach who takes on the role of a grieving family member or a physician in a one-on-one conversation. During the conversation, both the coach and the application record the learner’s responses. Learners receive both real-time and recorded feedback from the coach with specific, actionable recommendations for improvement. This same record of learning and assessment may also be shared with the learner’s manager.

As part of its dedication to enriching global learning, the Institute has significant experience sharing best practices of GLDP through training, lectures, a Mini Fellowship program, and by regularly hosting OPO and healthcare colleagues from around the world. Its consulting services take a deep dive into the needs of an OPO, an entire region or country.

Conclusion

Within these accomplishments, the GLDP team remains focused on efforts to eliminate the wait for life-saving organ transplants. Expanding donor criteria, closer evaluation of donation after circulatory determination of death opportunities, and advancements in organ preservation are just some innovations in development to increase the numbers of organs available for transplant. Sharing experiences so that colleagues around the world can find solutions to their challenges is an honor and extension of the legacies of donors and recipients GLDP cares for. Reminding each of us to continue seeking answers and solutions, Thomas Starzl, regarded as the “father of modern transplantation,” wrote, “All knowledge can be traced to its roots and ultimately to a seed,” [50]. Donor mom, Tara Storch shared her emotions after learning her daughter Taylor’s organs would go on to save several lives, “I didn’t know how to feel, yet somehow that news planted a seed of hope” [51]. With each of our hands on the shovel, may we unearth more seeds and knowledge, applying ourselves to elimination of the organ transplantation waiting list.

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