Pushing the Boundaries: The Crucial Need for OPO and Transplant Center Collaboration

Ashlei Lind, LICSW – LifeCenter Northwest
Rebecca Simon, LMSW – Cascade Life Alliance
An old man was walking on the beach one morning after a storm. In the distance, he could see someone moving like a dancer. As he came closer, he saw that it was a young woman picking up starfish and gently throwing them into the ocean. "Young lady, why are you throwing starfish into the ocean?"

"The sun is up, and the tide is going out, and if I do not throw them in, they will die," she said.

"But young lady, do you not realize that there are many miles of beach and thousands of starfish? You cannot possibly make a difference."

The young woman listened politely, then bent down, picked up another starfish and threw it into the sea. "It made a difference for that one."
Learning Objectives

1. Discuss the donation process: referral, the role of the Organ Procurement Organizations (OPO), timelines, and the role of Aftercare.

2. Identify the process for confidential donor family and recipient correspondence and discuss the benefits from a strong OPO/transplant center relationship.

3. Discuss the ways that organ donation and transplantation can challenge and support the grieving process, including survivor guilt for transplant recipients.
What is an OPO?

- Organ procurement organizations (OPOs) are the non-profit organizations responsible for the evaluation and procurement of deceased donor organs for transplant.
- All OPOs are regulated by multiple government agencies and adhere to medical and ethical standards.
- There are 56 federally designated OPOs in the United States, each responsible for organ procurement in a specific area. Find your OPO by visiting: [www.aopo.org/find-your-opo](http://www.aopo.org/find-your-opo)
- OPOs are structured to include the following services:
  - Donor Family Support
  - Clinical management of organ donors
  - Hospital education
  - Public education and advocacy
  - Tissue donation and research
The UAGA is a federal law, first declared in 1968. This Act created the power to donate organs, eyes, and tissue for transplant purposes throughout the United States. It was revised in 1987 and 2006 to reflect changes in the practice of organ donation, and the critical need to save more lives through donation. Because of the UAGA:

- An individual can document their decision to be a donor through the donor registry.
- Parents or guardians can make the decision to donate organs on behalf of their child.
- Families are unable to override their loved one’s organ donation registry status.
- If the registry status is unknown, a spouse or relative can make the decision to donate organs on behalf of their loved one.
- The trafficking of organs for profit is illegal.
UNOS is the private, non-profit organization that manages the nation’s organ transplant system under contract with the federal government.

UNOS helps place donated organs for transplantation 24 hours a day, 365 days a year.

UNOS is working to develop a more equitable system of allocating deceased donor organs. This approach is called continuous distribution.

The new framework allows for multiple factors to be considered all at once using an overall score that operates on a sliding scale. The new system ensures no single factor determines priority for donated organs.

OPOs across the country are sending organs well beyond their service areas, thus ensuring that life-saving organs are being used by those in need.
Donation Facts

Currently, there are 103,000 on the transplant waiting list

1% of deaths allow for organ donation

8 lives can be saved by 1 person through organ donation

Anyone, regardless of age or medical history, can register to be an organ donor

More than 42,800 organ transplants (deceased and living donors) performed in 2022, again setting an annual record

In 2022, the U.S. surpassed 1 million transplants, which is more than any other country in the world

There are an average of 117 organ transplants every day
In 2020, CMS issued a final rule that will require OPOs to increase the supply of lifesaving organs available for transplant across the U.S. The intention of this rule is to increase donation rates by updating the outcomes with transparent, reliable and objective outcome measures.

Change is occurring:

- Organs are traveling further than ever before
- Recovering hearts and lungs in DCD donors
- Donor candidate pool is expanding
- More organs are being placed per donor because of continuous distribution and aggressive placements

2022 and 2023 donors:

<table>
<thead>
<tr>
<th>Organization</th>
<th>2022:</th>
<th>Organs transplanted:</th>
<th>2023 YTD:</th>
<th>Organs transplanted YTD:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cascade Life Alliance</td>
<td>224</td>
<td>628</td>
<td>190</td>
<td>698</td>
</tr>
<tr>
<td>LifeCenter Northwest</td>
<td>310</td>
<td>866</td>
<td>312</td>
<td>966</td>
</tr>
</tbody>
</table>
Referral and Donation Process

- Diagnosis
- Referral
- Medical Evaluation
- Family Conversation
- Matching
- Surgical recovery
- Transplantation
- Family Aftercare
How are we connected?

- Organ Procurement Organization
- Donor / Donor Family
- Transplant Center
- Recipient
Aftercare

- Grief and bereavement support
- Recipient updates
- Correspondence
- Counseling / support groups
- Referrals to community resources
- Honoring ceremonies / events
- Memorial quilts
Following donation, all OPOs send the donor family an outcome letter with non-identifying information regarding recipient(s). Only non-identifying information is used to create this letter. This letter reinforces the power and importance of donation.

Information shared with donor families is not PHI or HIPPA protected. Information shared is generic to protect the recipient’s privacy.
Recipient Information

Clinical information that is utilized by OPO Quality Assurance and Process Improvement

- Transplant Surgeon
- Primary Disease
- Post-Operative Organ Function

Recipient social information

- Marital status
- Number of children / grandchildren
- Occupation
- Hobbies/interests
- Plans post-transplant
- Words of gratitude
A woman in her forties received your husband's heart. This grateful recipient is married and the mother of four children. With her renewed health, she looks forward to spending time doing the things she loves such as gardening, hiking and traveling. She is grateful for the opportunity to watch her children grow. The heart began to function immediately for this recipient, and she continues to do well post-transplant.
Do all donor families and recipients exchange letters?
• No, and that’s okay. Correspondence is a personal choice for both donor families and recipients.

Is there a waiting period to write?
• No. This was a rule that was in place well over two decades ago. There is no reason to put a timeline on when letters can be exchanged.

How does one say ‘thank you’ for a lifesaving gift?
• A simple ‘thank you’ can mean so much.

Does correspondence lead to direct contact?
• Not necessarily. Some donor families and recipient feel comfortable only exchanging letters, while others are ready to have direct contact and/or meet in-person.

How are letters between donor families and recipients exchanged?
• OPOs and transplant centers work together to facilitate letters going to the other party until there is a shared interest in having direct contact.
The Impact of Donation for the Donor Family

Loss narrative

Donation can change the loss narrative associated with death as space is created for meaning making or making sense of loss.

In honoring a person’s wishes to be a donor, it changes the ending of their story and creates a legacy that lives on in recipients and the families of those recipients.

Continuing bonds

Continuing bonds involve the ongoing connections through a dynamic, internal representation of the individual who has died.

Such bonds can enable an ongoing presence of that individual in the inner lives of the bereaved that may provide solace, comfort and support.

- Klass, Silverman and Nickman (1996)

Advocating

OPO staff act as advocates for donation and for those on the waiting list.

Following donation, donor families become advocates for donation within their families and communities.

There is pride in sharing the donor’s legacy, of which saving the lives of others is an important part.
The Impact of Donation for the Recipient

Survivor guilt

“Someone died in order for me to live.”

No one died because of you. This feeling is a natural response to knowing that your gift came because someone died.

Donor families separate the two situations. Their loved one died. Their loved one was a donor. You are living because of this gift.

“I don’t want to be a disappointment to them.”

What you are feeling is very common. Many recipients wonder if they are worthy of this gift. Donor families have few expectations of recipients. They want them to live their love and to be grateful for the second chance in whatever way possible.
Staying Connected

- Social worker / OPO annual or bi-annual connection meetings
- OPO Aftercare team available to provide support and information to recipients
- OPO Aftercare staff attending recipient support groups
- Transplant program picnics or annual gatherings
- OPO remembrance ceremonies
We are all in this together. Saving lives is our collective mission.
THANK YOU!

Ashlei Lind, LICNW
LifeCenter Northwest (Seattle, WA)
ashlei.lind@lcnw.org
(425) 201-6602

Rebecca Simon, LMSW
Cascade Life Alliance (Portland, OR)
simonr@ohsu.edu
(503) 494-5560