

The power to heal lives.



ORGAN AND TISSUE DONATION

Developing a Robust Aftercare Program

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Donor Services Center Director

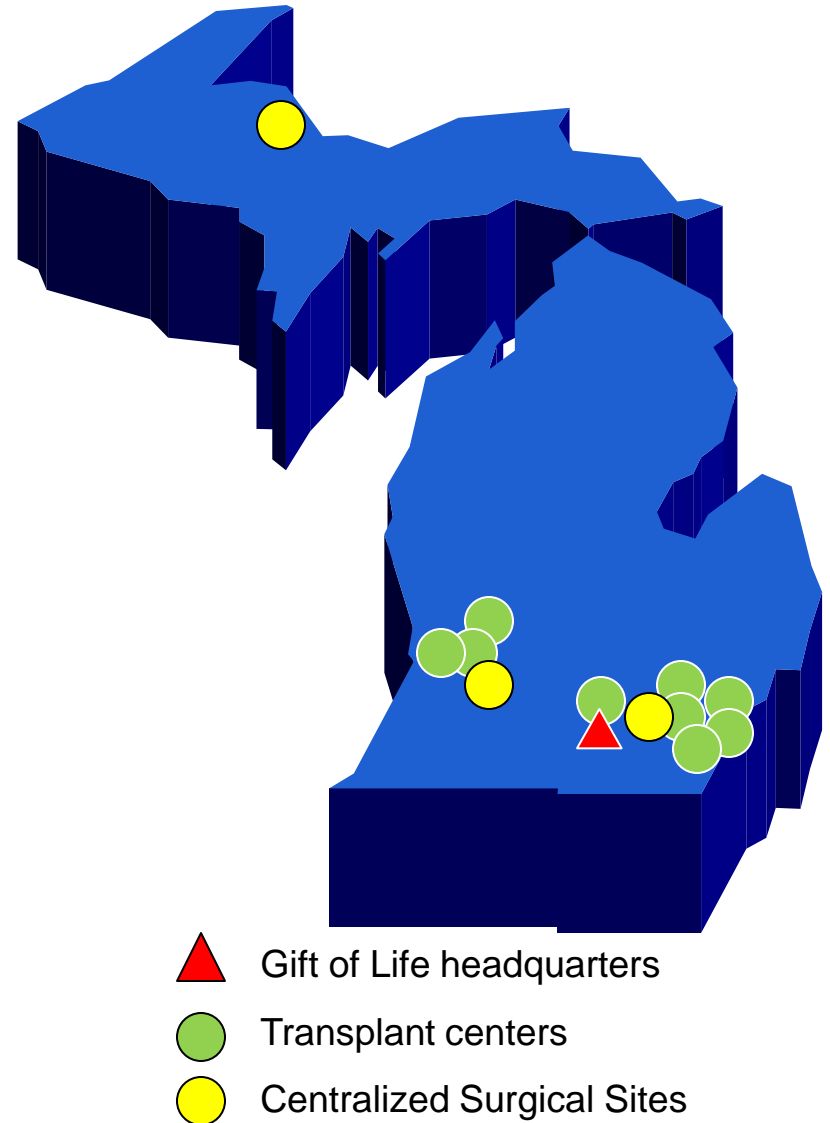
AMAT
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Gift of Life Michigan is one of 58 federally designated organ and tissue recovery organizations that act as the intermediary between donors, hospitals and transplant centers.



Donation Service Area

- Service area: Entire state
- Covers 155 critical-care hospitals, 9 Tx centers, 83 medical examiner offices
- 200 FT, PT, and per diem employees
- Centralized surgery centers
- Population: approx 9.5M
- 2014: 254 organ donors, 978 tissue donors



Donor Family Services Provided

- Letter following donation from CEO. Includes medallion, pins and informational donation brochure that also offers bereavement guidance
- One-year anniversary card
- Donor Family Gathering at least once a year, depending on location and amount of anticipated donors
- Other items offered depending on circumstances – pediatric donors, families with special needs.
- Donor Family Advisory Committee

Donor Family Services-Staffing

- One FT Donor Family Services Coordinator
- Five employees who assist as part of their responsibilities
- Director who oversees multiple departments
- Soon to change – one dedicated Family Services Manager and position to move as part of the Family Services Department

Note: services provided in coordination with Eversight Michigan, local eye bank.

Gift of Life Michigan Policy:

Donor family refers to the person(s) who authorized an organ and/or tissue donation. In first person authorization cases, this refers to the person(s) who participated in the DRAI. Other family members may be included at the discretion of the donor family.

For the purposes of this policy, a donor is any person at or near death for whom authorization is recorded, regardless of subsequent organ or tissue recovery or transplant.

- Donor families
- Organ recipients
- Tissue recipients
- Families of deceased organ recipients
- Families of deceased tissue recipients

- Transplant center
- Tissue processor
- The recovery organization



Gift of Life Michigan's Mission

To maximize organ and tissue donation for transplantation through innovative programs and exceptional service.

Key customers (service)

Donor Families

Transplant Centers

Donor Family-Recipient Correspondence

- Organ recipients and donor families
- Tissue recipients and donor families (since 2009)



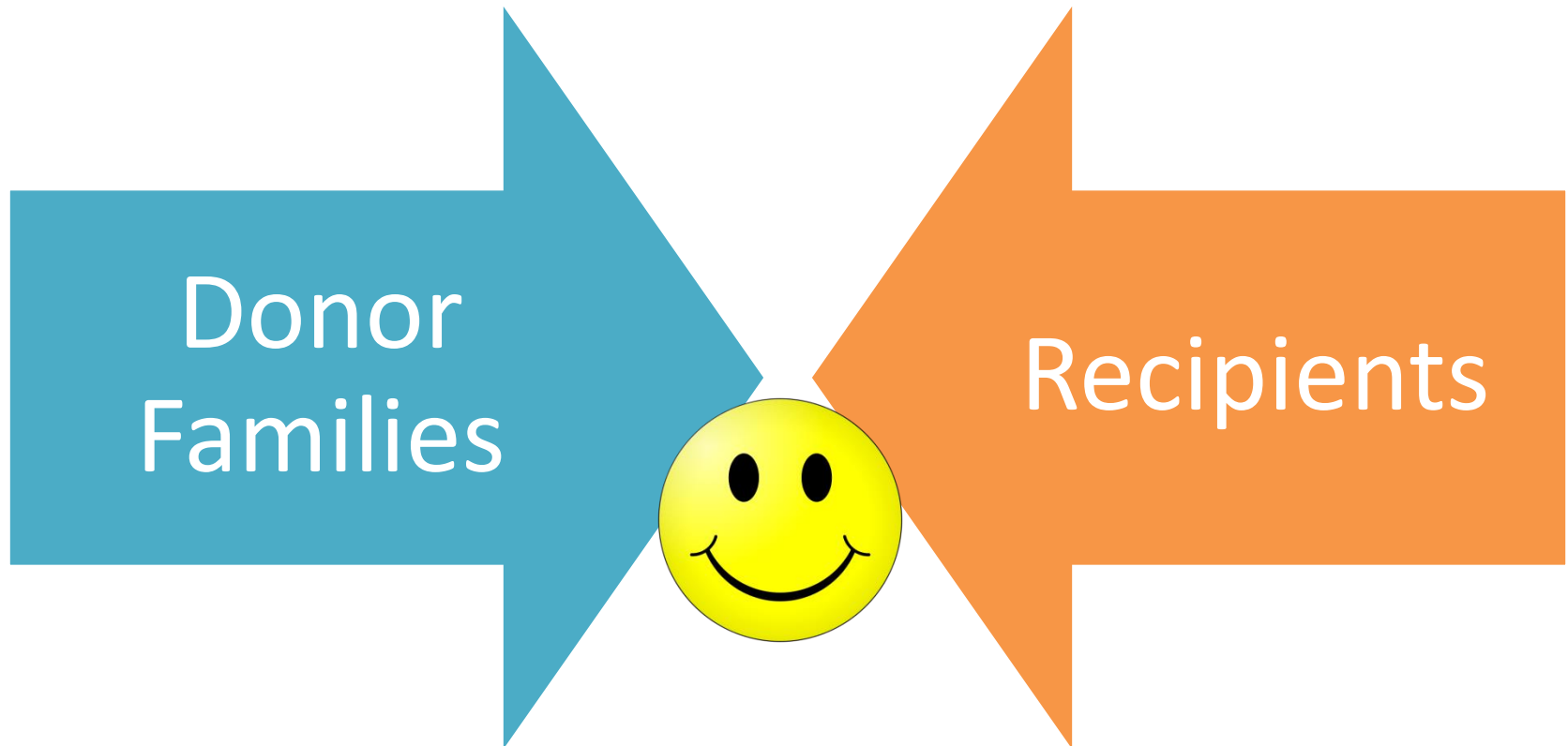
Volume

Over 600 organ-related correspondence/year processed

Over 500 tissue-related correspondence/year processed

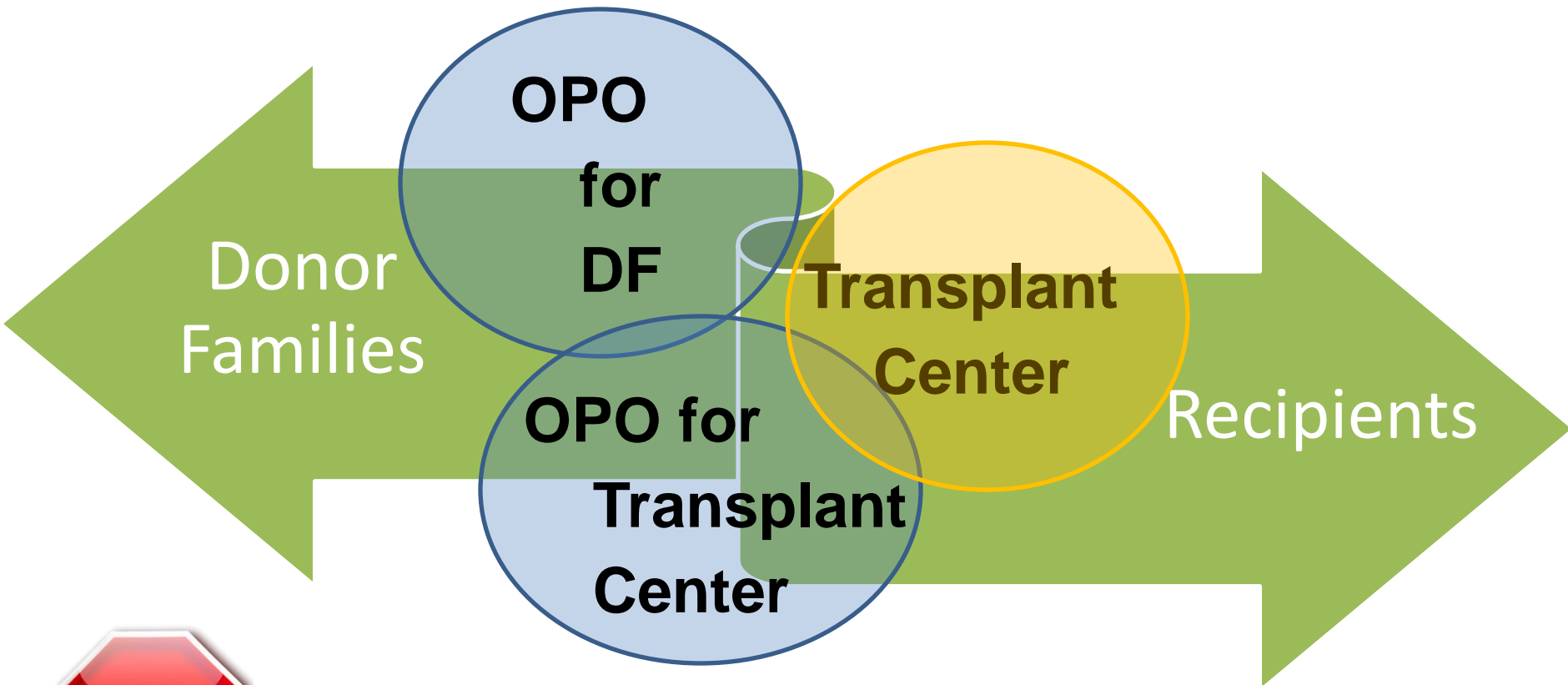
About 20 families/year opt-out of communications

Correspondence



Assumption: Both the DF and the recipient have opted-in

Correspondence (reality)



Any of the circles can stop/hold the correspondence

OPO: Goals

Protect the donor family

Follow OPO policy/SOPs

Provide as much information to the donor family as possible

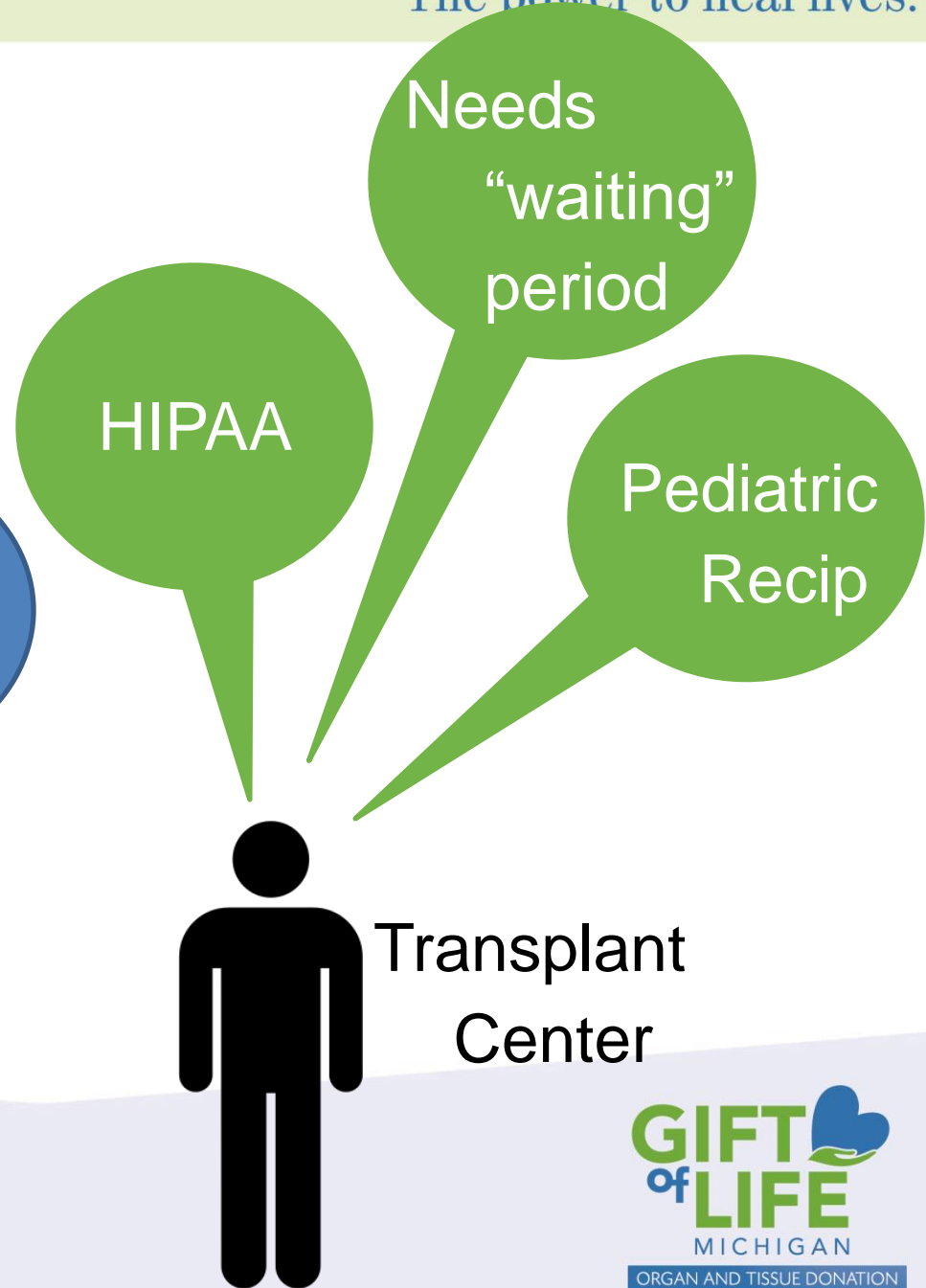
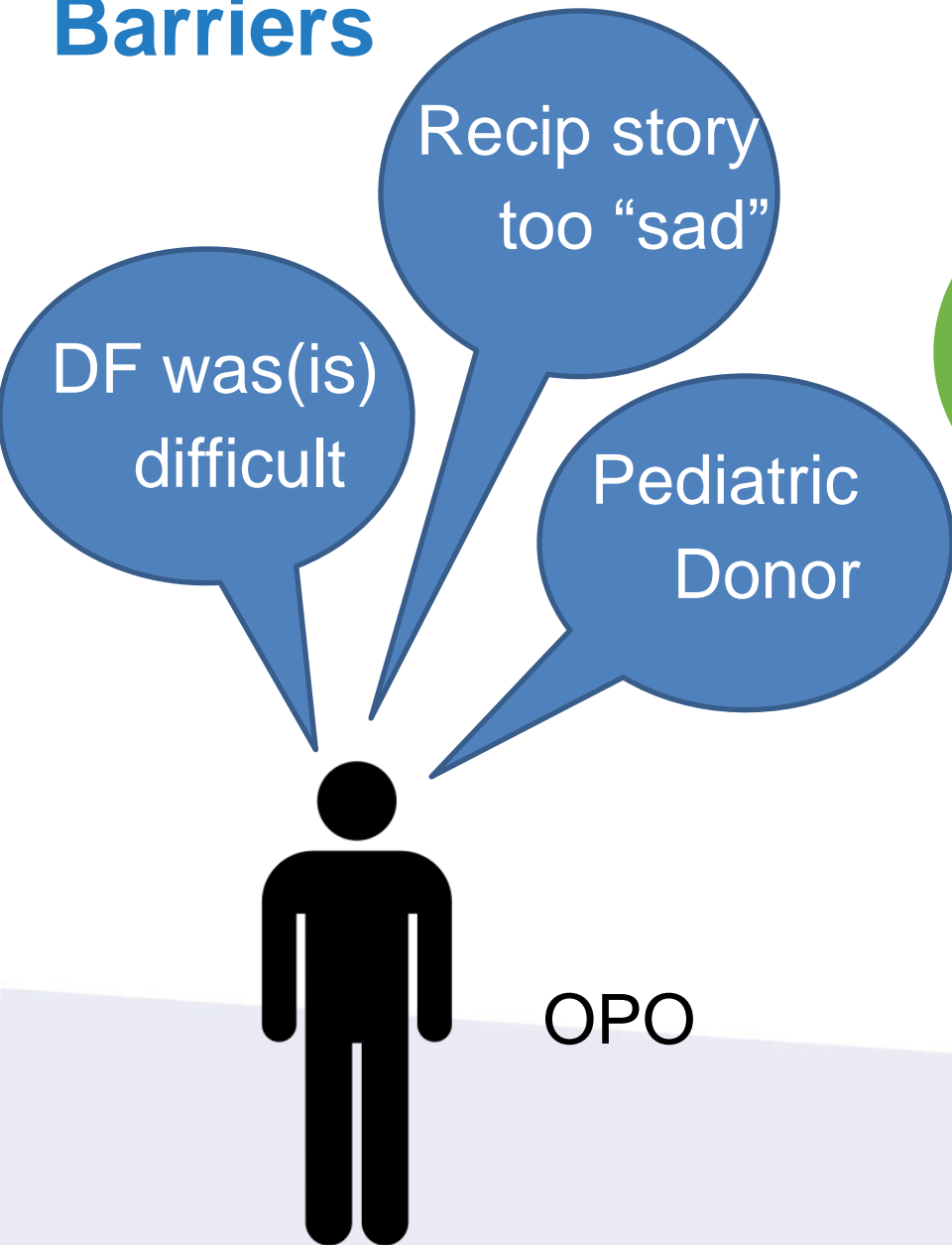
Transplant Center: Goals

Protect the recipient

Follow Center policy/SOPs

Provide as much information to the recipient as possible

Barriers



A community conflict

- Gift of Life Michigan
- Local Transplant Center

Asked to a meeting with:

- Transplant social workers
- Risk management (hospital)
- Transplant administration



Concerns

Gift of Life Michigan

- Center was holding back letters (not passing them to recipient families)
- OPO was receiving calls from families asking if letters received by recipients
- Inconsistent distribution of letters by organ/peds vs adult
- Out-of-state OPO requests were inconsistent with Gift of Life policy

Concerns

Transplant Center

- Transplant social workers concerned with content of letters/emotional effect on recipients
- Transplant admin concerned with the extent of information OPOs were asking regarding their recipients
- Risk management concerned with HIPAA

Basis of conversation

HRSA guidance document
Guidance for Donor and Recipient Information
Sharing; February 2012.

[http://optn.transplant.hrsa.gov/ContentDocuments/
Guidance_Information-Sharing_HIPAA_2012.pdf](http://optn.transplant.hrsa.gov/ContentDocuments/Guidance_Information-Sharing_HIPAA_2012.pdf)

A collaborative guideline document created with OPO
and transplant center input

Easy-Peasy Items

Common ground – both communities believed in donor family-recipient contact and communication.

1. Center agreed to no waiting period
2. Center established one employee as the contact for correspondence
3. OPO agreed to serve as conduit for all out-of-state OPO communications.

Center agreed to release recipient status according to the guidelines:

Recipient information routinely shared with the donor family should be limited to:

- age
- general health status (general condition, not specific medical information),
- gender
- sex

OPO is exempt from HIPAA with regards to the communications between the OPO and the center.

This is communication between living persons regarding health and medical information, both of the deceased and the living.

HIPAA is very specific regarding the release of information.

Even if an organization is HIPAA-exempt, it should behave in a manner consistent with HIPAA policy.

Risk management for the hospital wanted to shut down all correspondence.

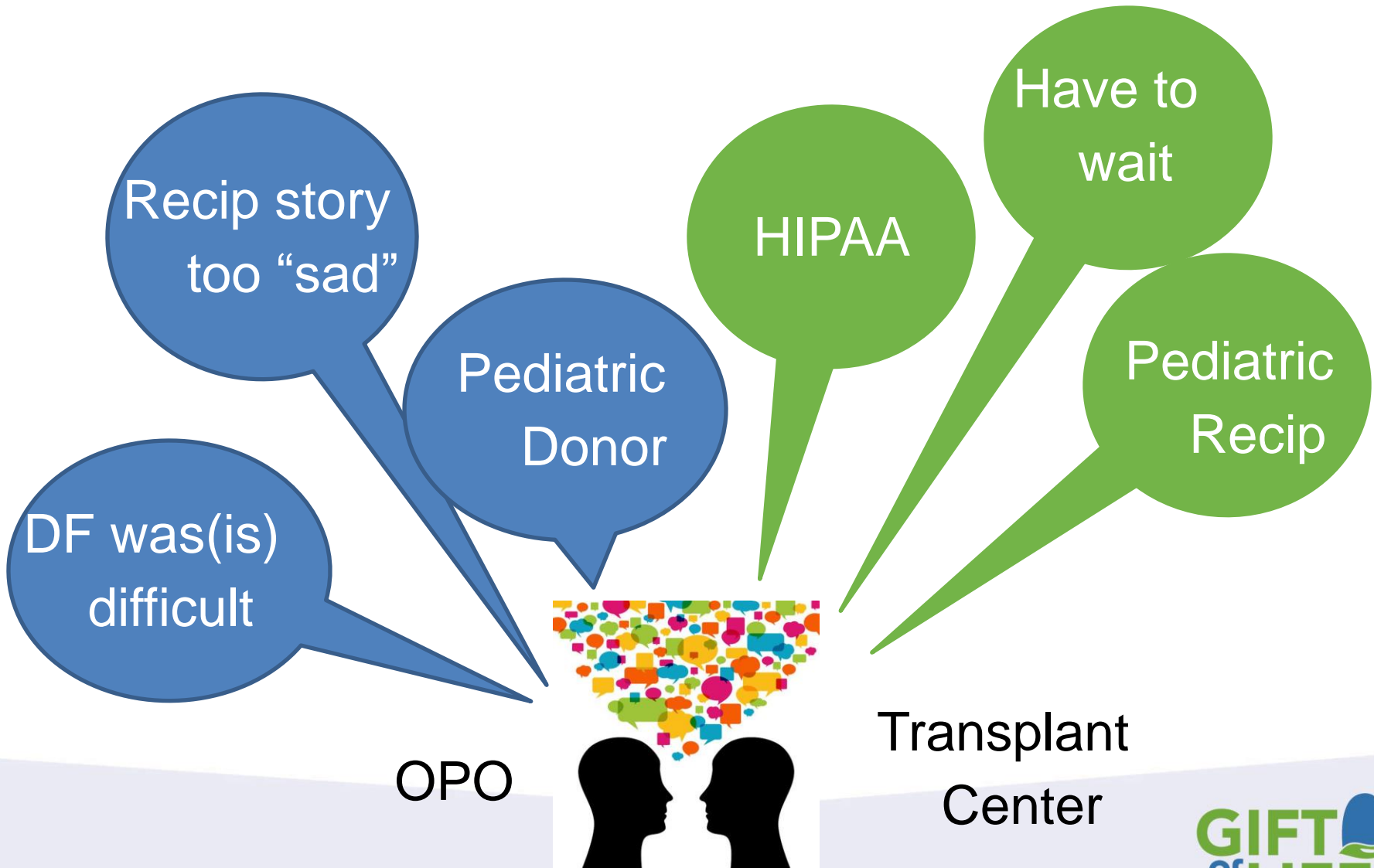
OPO reviewed internal policies and SOPs with regards to privacy and security of health information.

In the end, legal relented and agreed to the release of information with a tightened release document for their patients.

HIPAA is a major concern for hospitals.

- Sweeping changes of HIPAA were enacted in 2013.
- New rule allows family members or others who were involved in the care of the decedent to access the decedent's personal health information. These rules are accessible at: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/decedents.html>.
- Applies up to 50 years following the decedent's death.

- Agreed to continue to collaborate on issues with families and recipients, especially pediatric recipients.
- Agreed to continue the conversation with regards to social media and pictures.
- Transplant center has correspondence policy
- OPO recognizes the limitations on releasing recipient information



- We have a common goal.
- We are professionals.
- We recognize the human condition and celebrate the gift to the extent both the donor family and the recipient allow.



Thank you!

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