

# SNEPT: PATIENT VOICE

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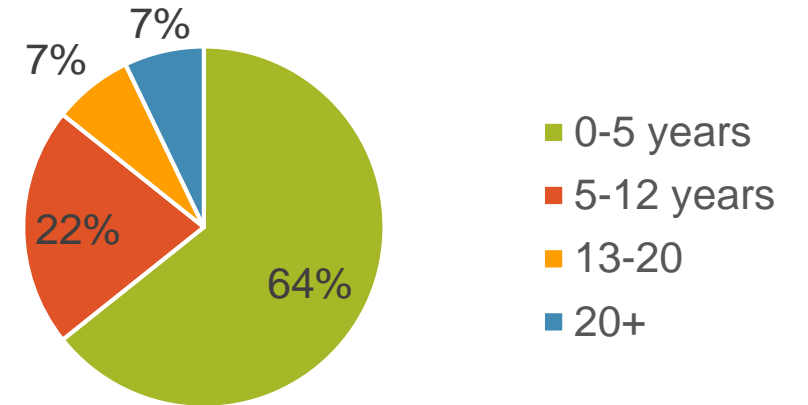
Results of Pre-Meeting Survey

# Who We Are

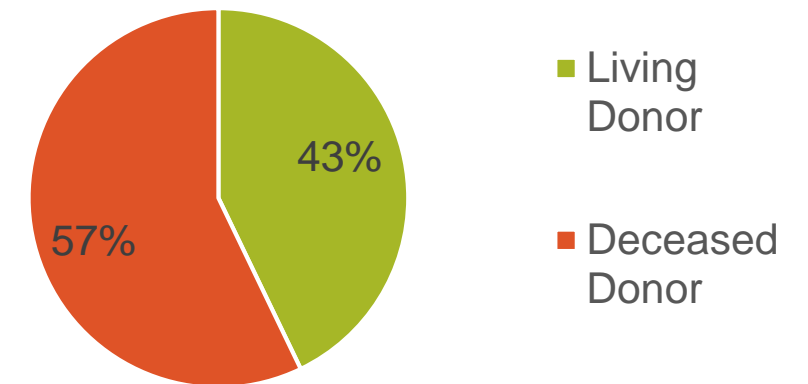


Transplant Centers Represented

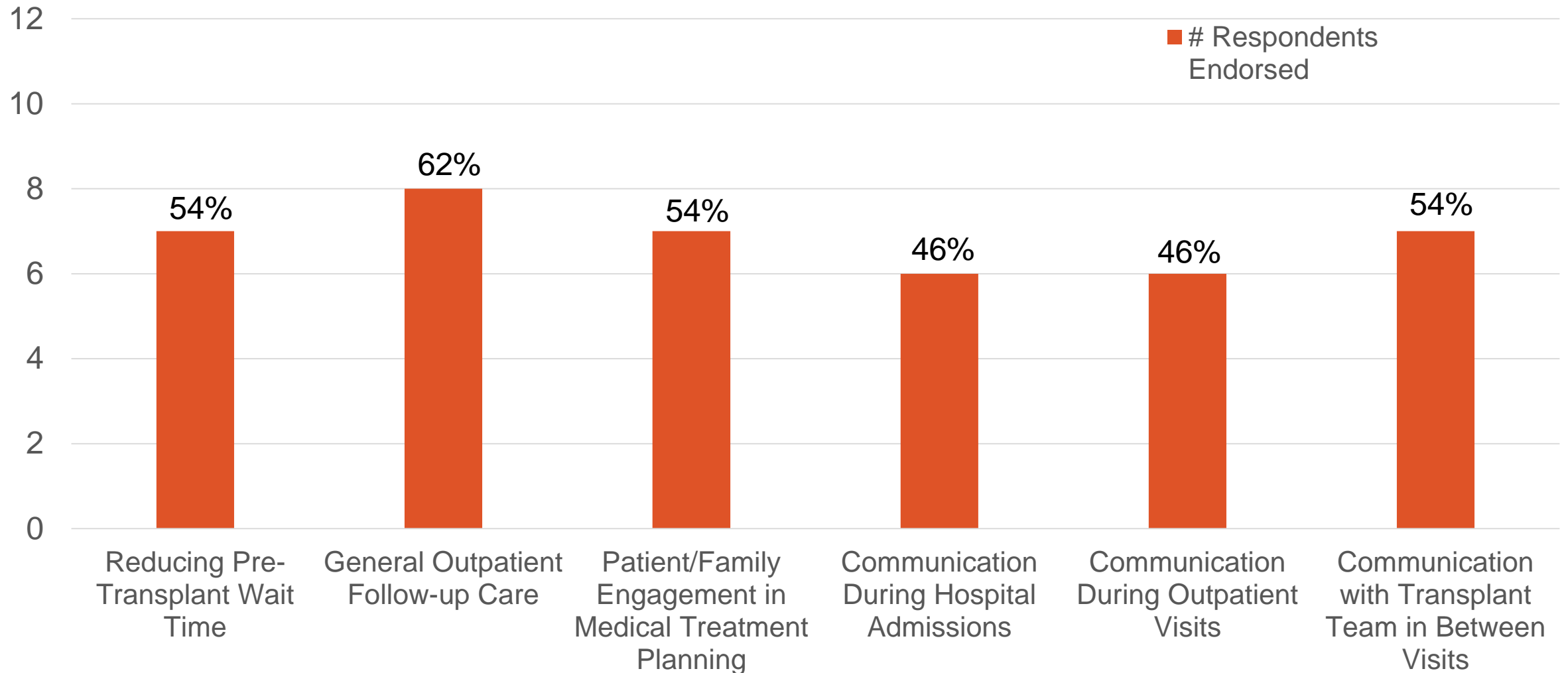
## Age at Transplantation



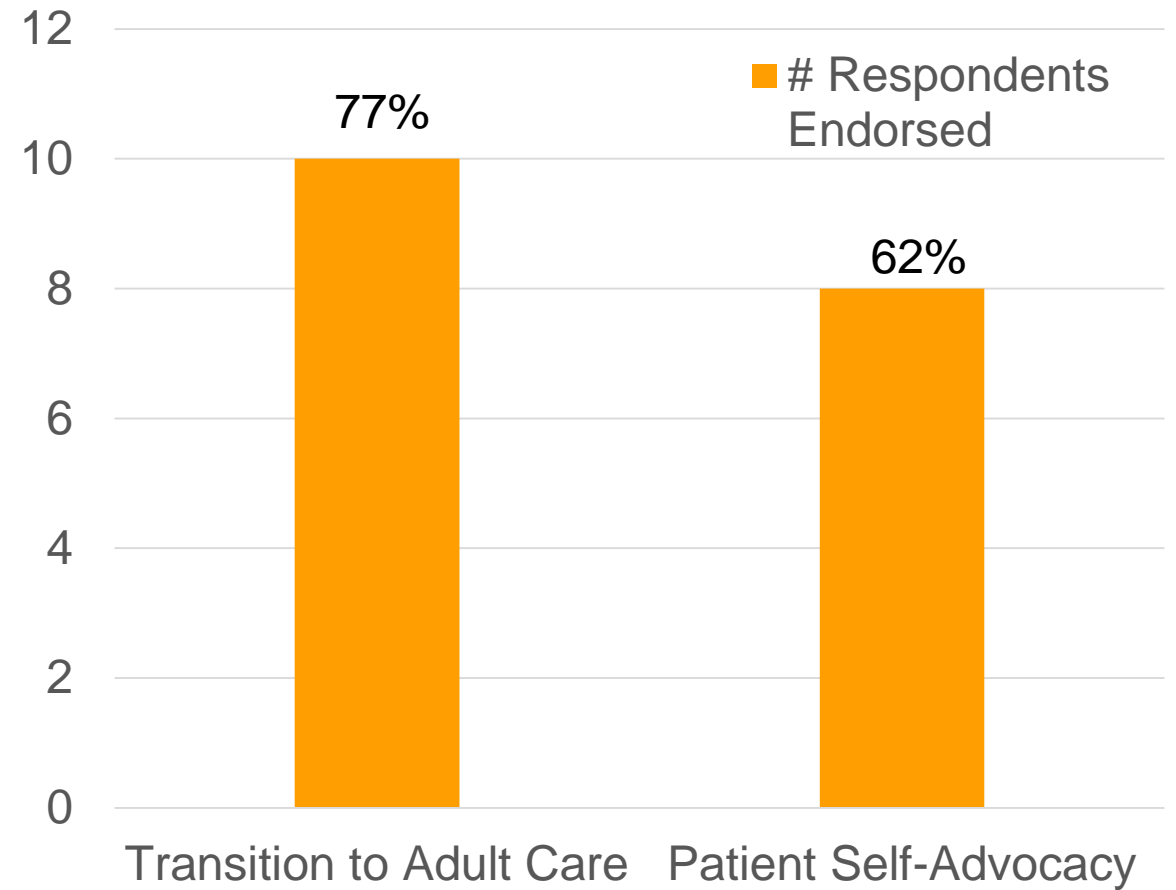
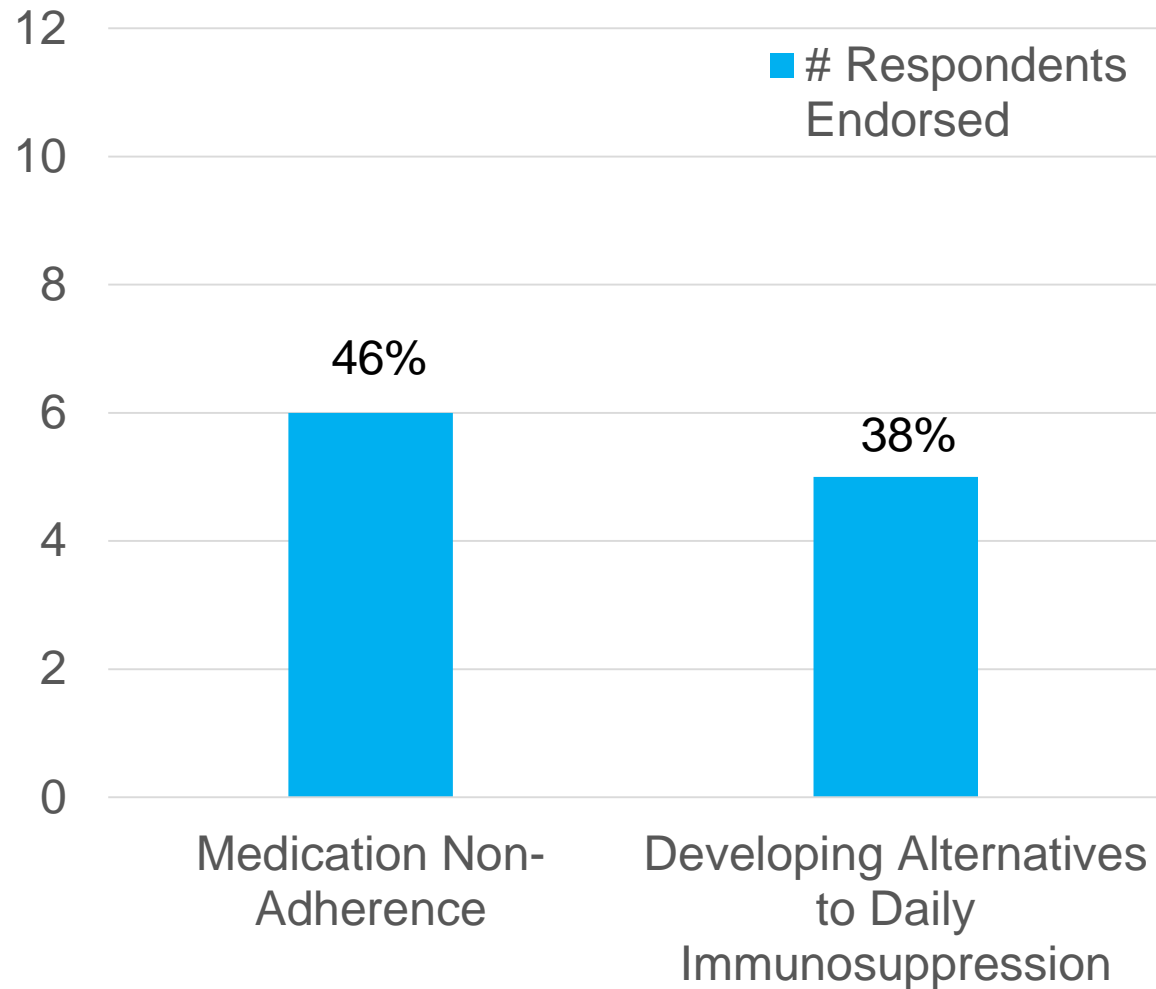
## Donor



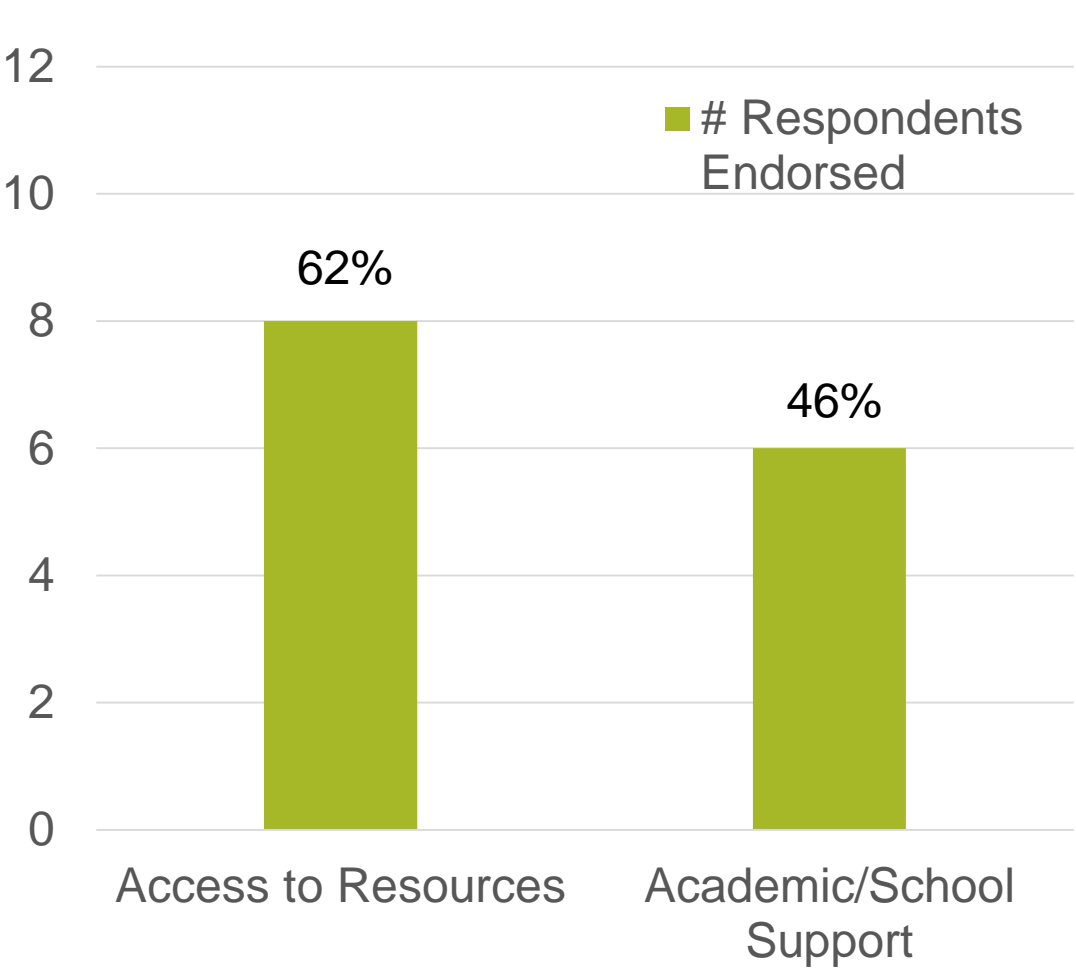
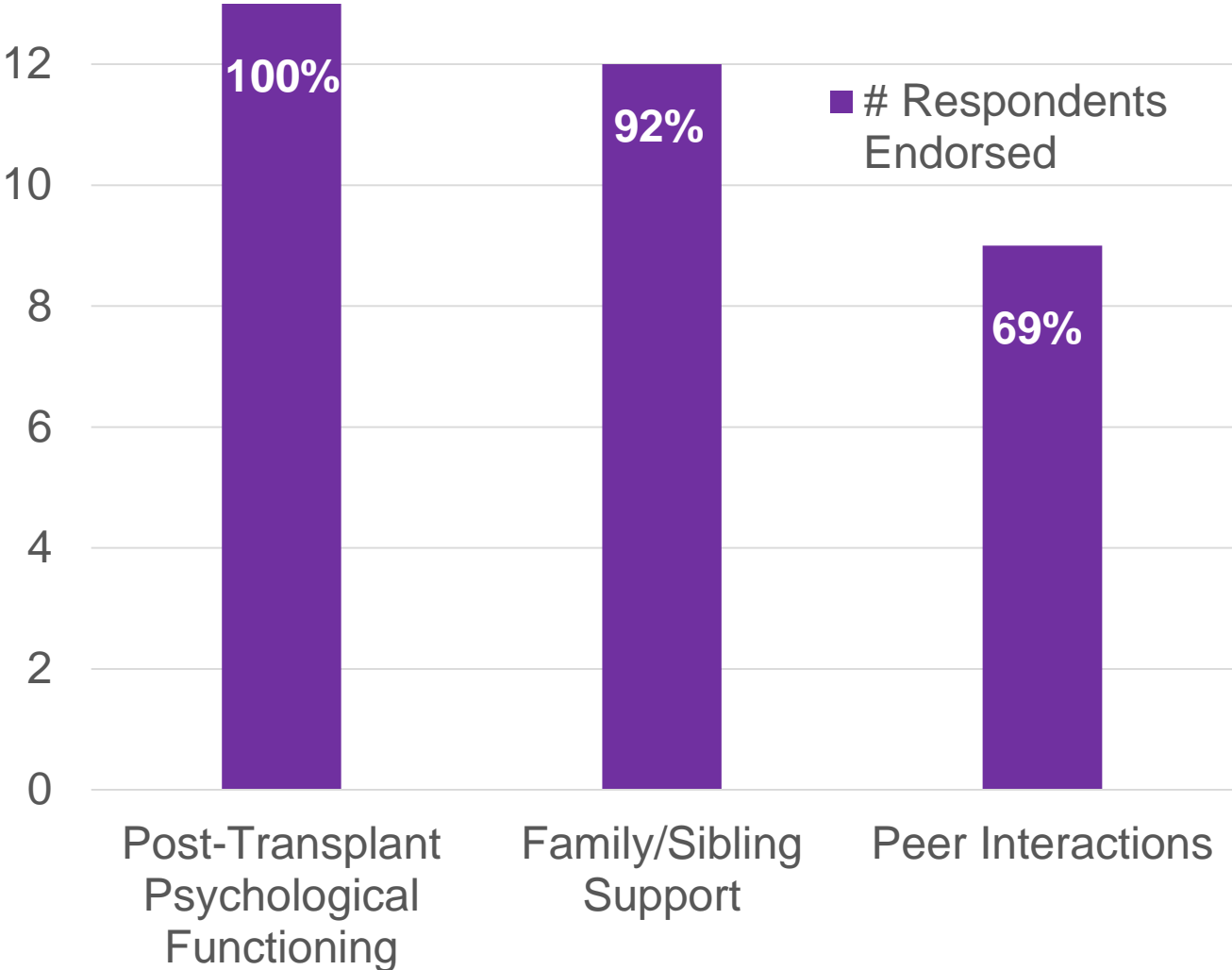
# Results: SNEPT Targets – General Care



# Results: SNEPT Targets – Medication and Adult Care



# Results: SNEPT Targets – Psychological and Social Care



# Guide for Workgroup

- Introduce yourselves
- Identify a group member willing to present ideas to larger group tomorrow
- Create outline for presentation
  - Identified problem or challenge: What is the challenge that needs to be addressed?
  - Specific issues
  - Proposed solutions
    - How could a learning network guide solutions?
    - How could they be implemented at your individual center?
    - How can patients and families be involved in the process?

# Pre-Transplant Themes

## Identified Needs

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- *Desire to be connected with other families who have been through process*
- **Overwhelming nature of information presented during a period of high stress and life-or-death circumstances for child**
- Helping families to know how to seek living donors
- Help families ask the difficult questions
- Helping families through ups and downs of waiting, particularly for those families who wait long periods of time

## Proposed Solutions

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- Hiring a mentorship coordinator who could meet families face-to-face and pair families together
- Put evaluation resources in online format

# Peri-Transplant Themes

## Identified Needs

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- **Increased emotional support for parents, particularly in cases where one parent is living donor**
- Increased communication about status of child; and when applicable, the living donor parent
- Improving communication between medical providers to deliver a consistent message to families
- **Resource support for families to stay close to the hospital/at bedside**
- Involving parents in daily medical decision-making

## Proposed Solutions

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- Psychologist/counseling visits during the early post-transplant period
- Network/website/social media
- Create an online resource for families containing transplant information, make it searchable and keep it up to date
- Communicate consistent information



# Short-Term Post-Transplant Themes (0-3yrs)

## Identified Needs

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- **Emotional support for family**
- **Being heard by doctors post-transplant**

## Proposed Solutions

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- Short-term post therapy network
- Social work care after discharge
- Support groups
- Binder containing information about parent care
- Centralized bank of resources to serve as a “one stop shop” for all things families may need

# Long-Term Post-Transplant Themes (3+ yrs)

## Identified Needs

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- **Emotional support for family**
- **Emotional support for patients**
- Guidance for parents on staying ahead of emotional needs that may arise (e.g., body image issues, peer difficulties)
- Address effects of long-term stress on families
- Helping patients feel as though they are still “important” despite being far out from transplant and no longer needing close follow up
- **Support to help teens manage their post-transplant care independently/transition to adult care**
- Helping parents learn to advocate when they disagree with a care decision and ensuring their voices are heard

## Proposed Solutions

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- Website with centralized resources that addresses issues teens may experience, as well as parents/caregivers and siblings
- Training modules for patients and/or parents who want to become peer mentors
  - “Need a mentor, be a mentor”™