The Independent Living Donor Advocate

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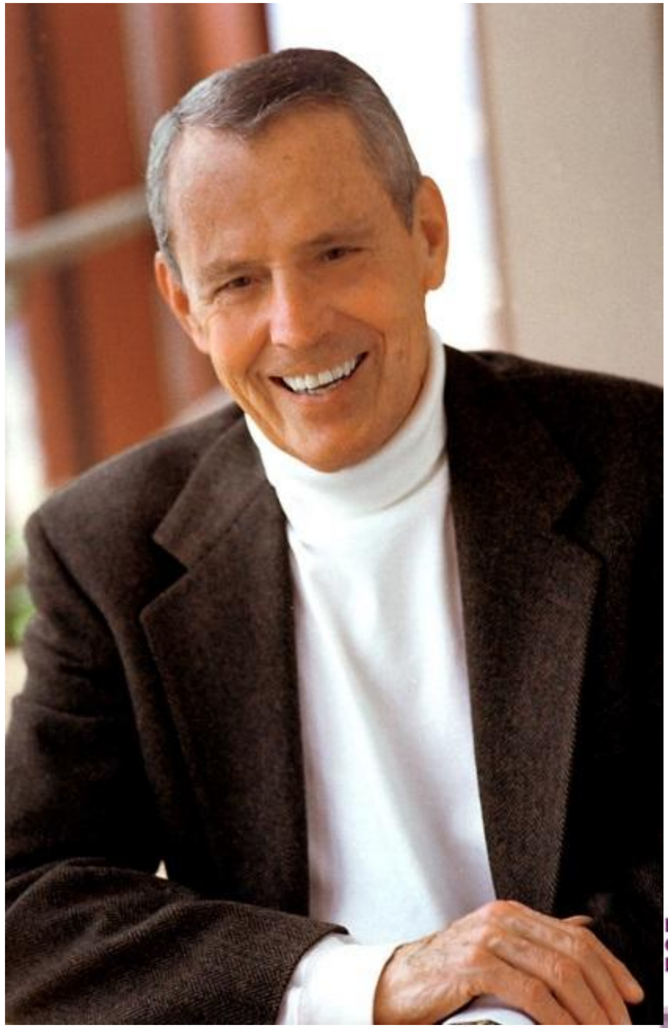

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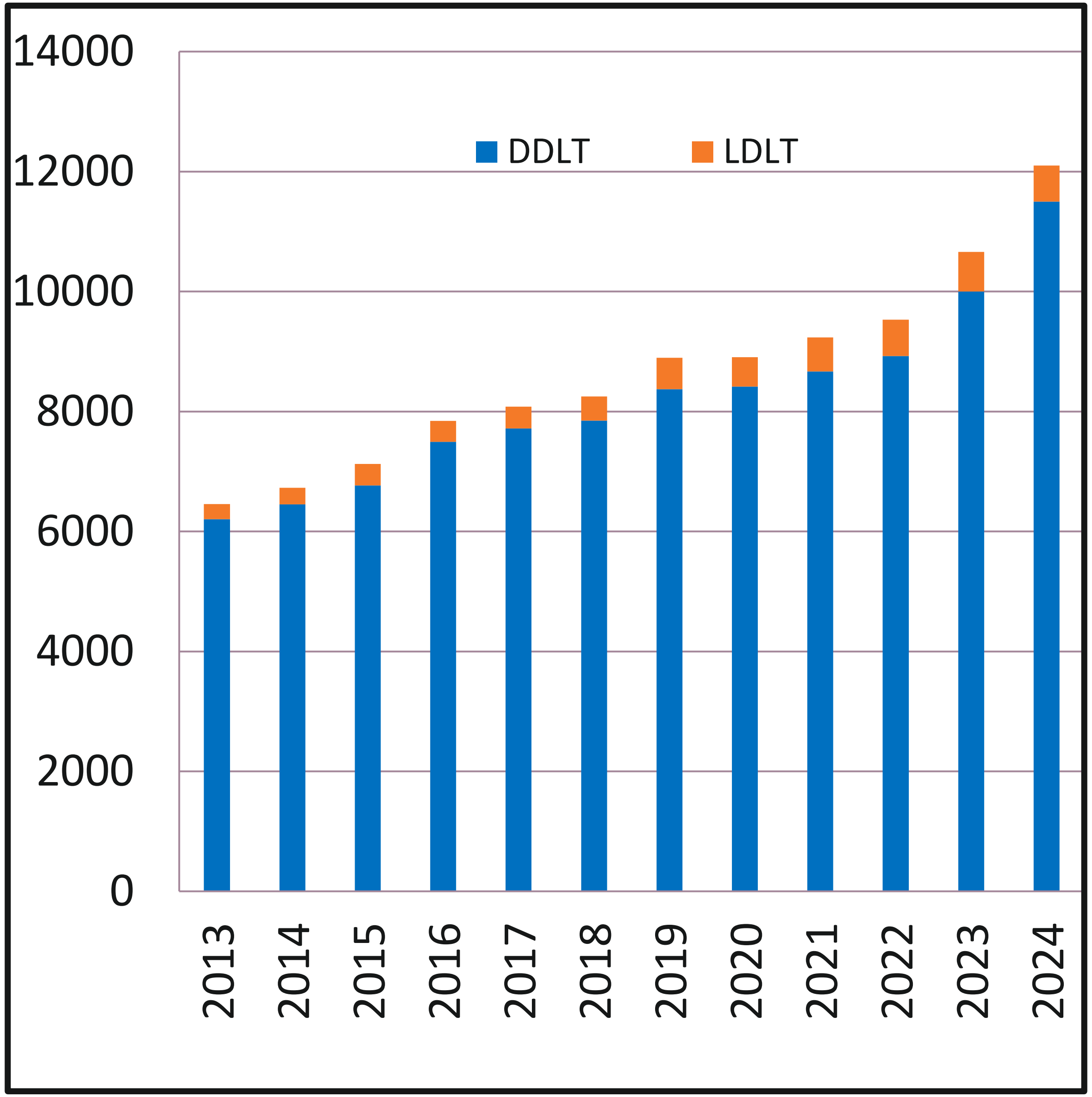
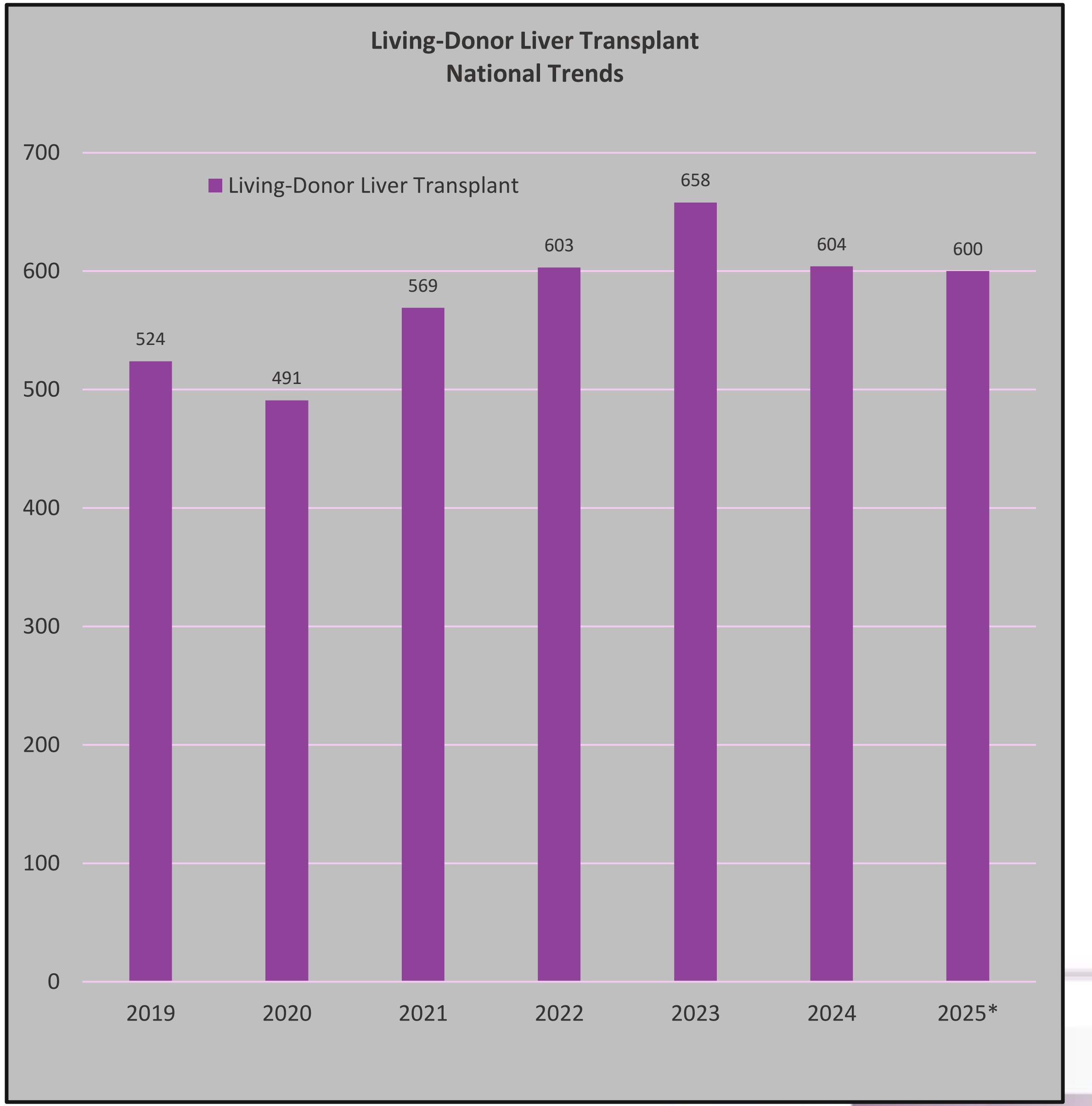
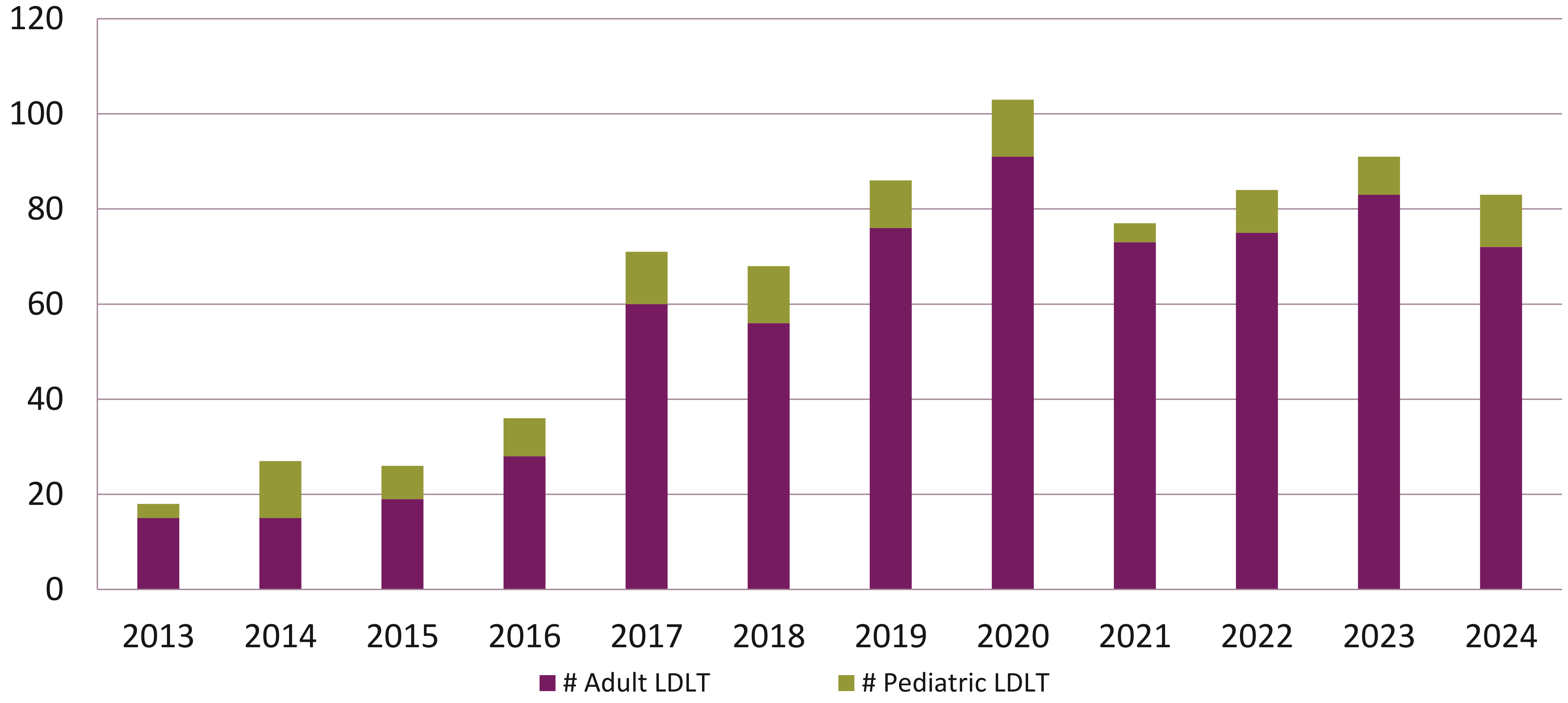
LIFE
CHANGING
MEDICINE

NUMBER OF LDLT BY YEAR in the USA





NUMBER OF LDLT AT UPMC BY YEAR



- **In 2023, 60% of our adult transplants were with a living donor**

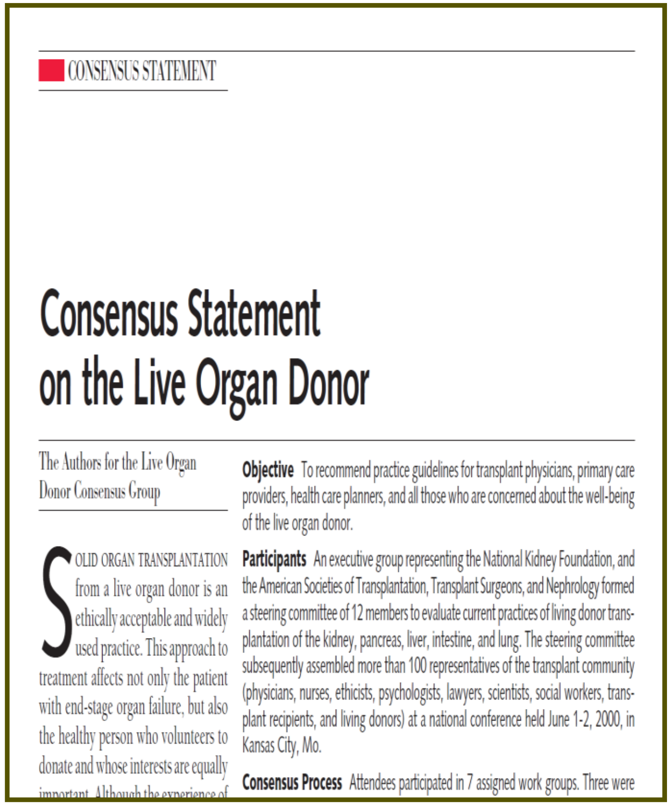
UPMC LIFE CHANGING MEDICINE

Living Donor Consensus Statement (2000)

- Consensus meeting and statement with the goal to promote the welfare of living donors (JAMA, 2000)

- A key recommendation was that transplant centers, performing living donor surgeries, were recommended to have an ILDA "**whose only focus is the best interest of the donor**"

- **The ILDA should have "veto" power over the final approval.**



CONSENSUS STATEMENT

Consensus Statement on the Live Organ Donor

The Authors for the Live Organ Donor Consensus Group

Objective To recommend practice guidelines for transplant physicians, primary care providers, health care planners, and all those who are concerned about the well-being of the live organ donor.

Participants An executive group representing the National Kidney Foundation, and the American Societies of Transplantation, Transplant Surgeons, and Nephrology formed a steering committee of 12 members to evaluate current practices of living donor transplantation of the kidney, pancreas, liver, intestine, and lung. The steering committee subsequently assembled more than 100 representatives of the transplant community (physicians, nurses, ethicists, psychologists, lawyers, scientists, social workers, transplant recipients, and living donors) at a national conference held June 1-2, 2000, in Kansas City, Mo.

Consensus Process Attendees participated in 7 assigned work groups. Three were

SOLID ORGAN TRANSPLANTATION from a live organ donor is an ethically acceptable and widely used practice. This approach to treatment affects not only the patient with end-stage organ failure, but also the healthy person who volunteers to donate and whose interests are equally

DHHS and UNOS (2007)

Roles and Responsibilities of ILDA:

- To ensure the protection of current and prospective living donors (DHHS).
- To be knowledgeable about living organ donation, transplantation, medical ethics, and the informed consent process (DHHS and UNOS).
- To not be involved in transplantation activities on a routine basis and independent in the decision to transplant the potential recipient.
- To represent and advise the donor, protect and promote the interests of the donor, respect the donor’s decision, and ensure that the donor’s decision is informed and free of coercion (DHHS).
- To assist the potential living donor in understanding the consent and evaluation process, surgical procedures, and the benefit and need for post-surgical follow-up (UNOS).

National Survey of Living Donor Advocates

American Journal *of* Transplantation

AST | AMERICAN SOCIETY OF TRANSPLANTATION ASTS

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A National Survey of Independent Living Donor Advocates: The Need for Practice Guidelines

n=120

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Abbreviations: ILDA, independent living donor advocate.

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Introduction

The inadequate supply of organs in the United States and other countries continues to drive living donor transplantation (1). In 2000, representatives of the transplant community convened for a meeting on living donation in an effort to provide guidelines to promote the welfare of living donors (2). The consensus statement that resulted from

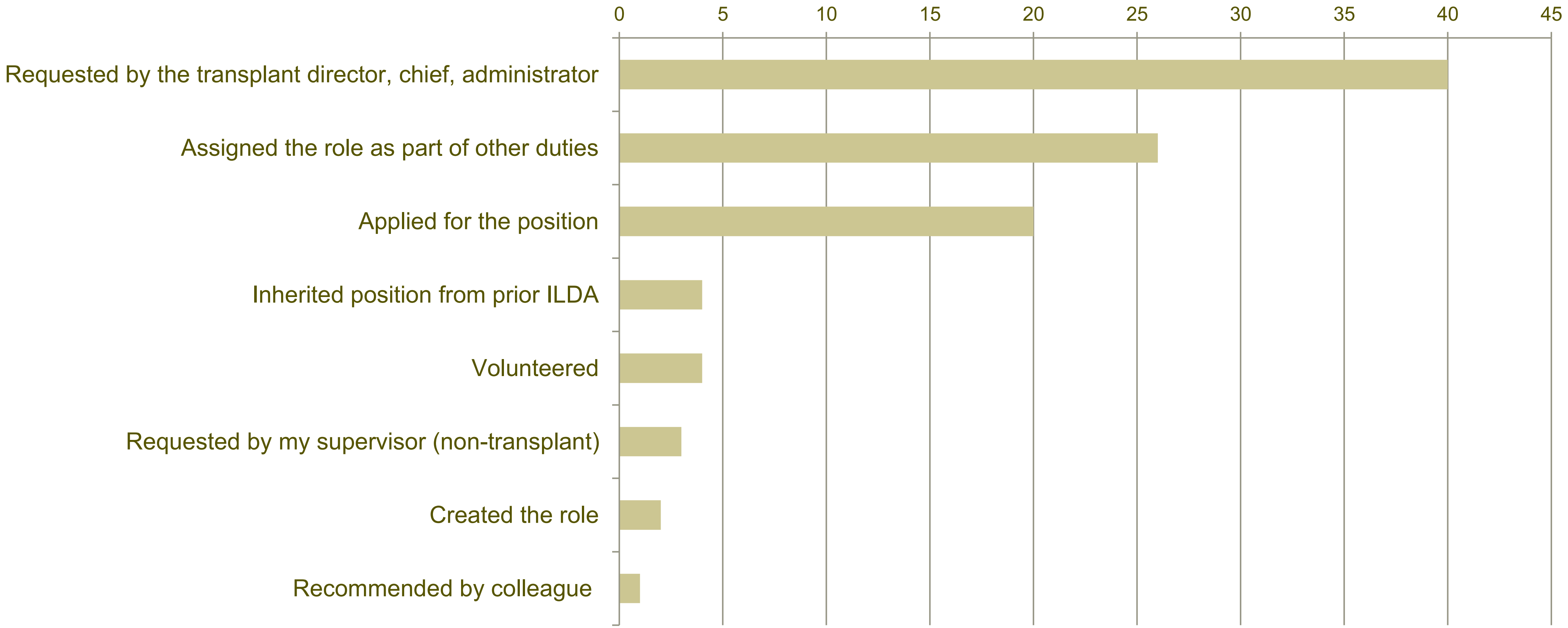
Demographics and Training

Table 1: Sociodemographic Characteristics	
Gender (n, %)	
Male	21 (17.5)
Female	99 (82.5)
Age	
Mean (SD)	49.17 (9.96)
Range	25-74

Table 2: Educational and Training of ILDAs	
Education Level (n, %)	
High School or less	1 (0.8)
Associate’s Degree	6 (5.0)
Bachelor’s Degree	33 (27.5)
Master’s Degree	66 (55.0)
Doctorate	9 (7.5)
MD/DO	4 (3.3)
Professional Training/Discipline (n, %)	
Nursing	38 (35.8)
Social Work	35 (33.0)
Clergy	14 (13.2)
Psychology	4 (3.8)
Other	15 (14.2)

How were you selected?

Figure 2: Selection of ILDAs



Living Donor Advocacy

Table 3: Clinical Practice of ILDAs	
Type of Evaluations Conducted (n,%)	
LDA Evaluation Only	49 (47.6)
LDA and Other Evaluation	55 (53.4)
Position Paid or Volunteer (n, %)	
Paid and hired by transplant center	35 (41.2)
Volunteer	5 (5.9)
Paid but part of other responsibilities	40 (47.1)
Bill for ILDA Evaluations (n, %)	
Yes	12 (14.5)
No	71 (85.5)
ILDA Attends Candidate Selection Meetings (n, %)	
Live Donors Presented	36 (53.7)
Live Donors and Candidates Presented	26 (38.8)
I do not attend	5 (7.5)
Only attend occasionally	6 (9.0)

Table 3 (continued): Clinical Practice of ILDAs	
Timing of Contact (n, %)	
Screening	38 (45.2)
Evaluation	67 (79.8)
Post-evaluation/prior to surgery	49 (58.3)
Post-surgery	47 (56.0)
Length of follow up post surgery (n, %)	
< 6 months	40 (50.0)
6 months - 1 year	13 (16.3)
1 year – 18 months	3 (3.8)
18 months – 2 years	10 (12.5)

Figure 1: Definition of "Independent" Living Donor Advocate

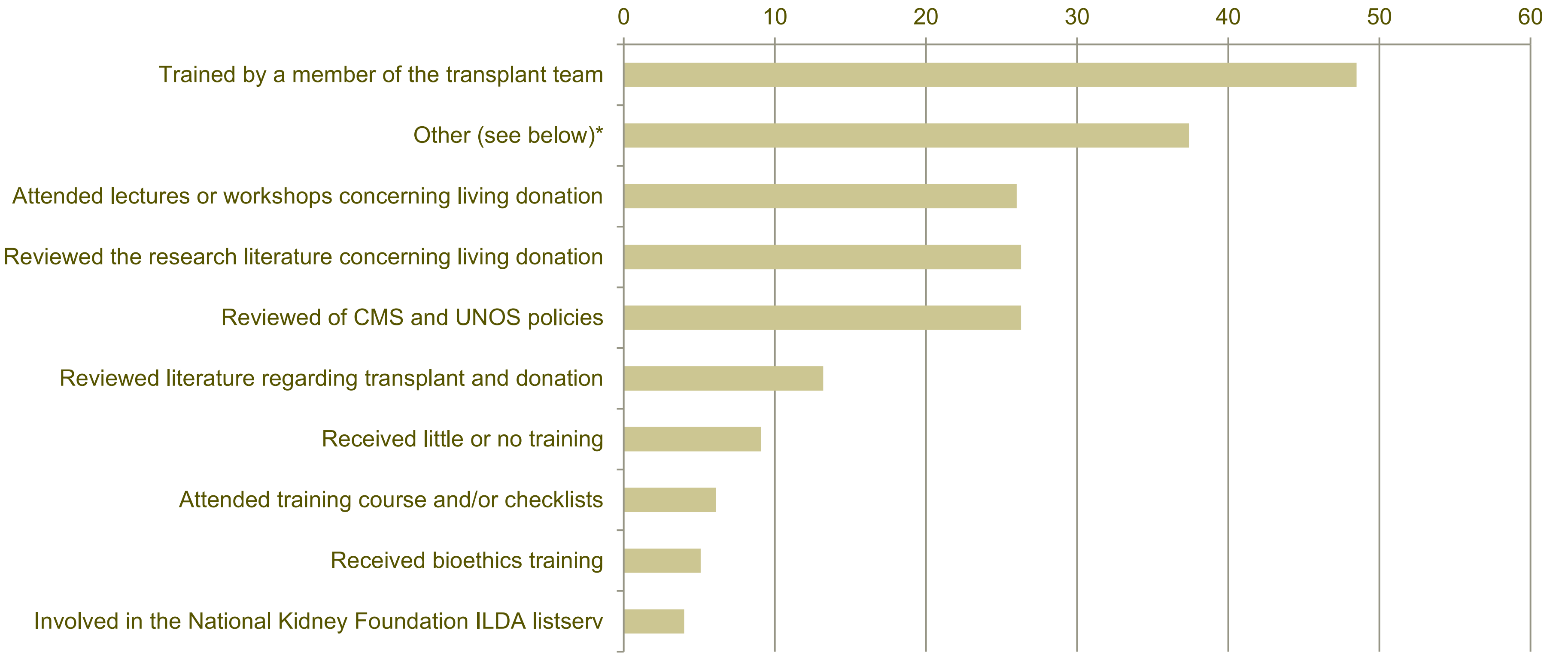
“Advocate” or “Protect” the Donor

“How would you proceed if you felt that the donor having surgery would be detrimental to their physical or psychological well being but …”

- this had been explained to the donor in detail and the donor understood the potential consequences;
- the donor has been approved to proceed with surgery by the medical and psychosocial team members; and
- the donor wants to proceed with surgery despite the potential risks

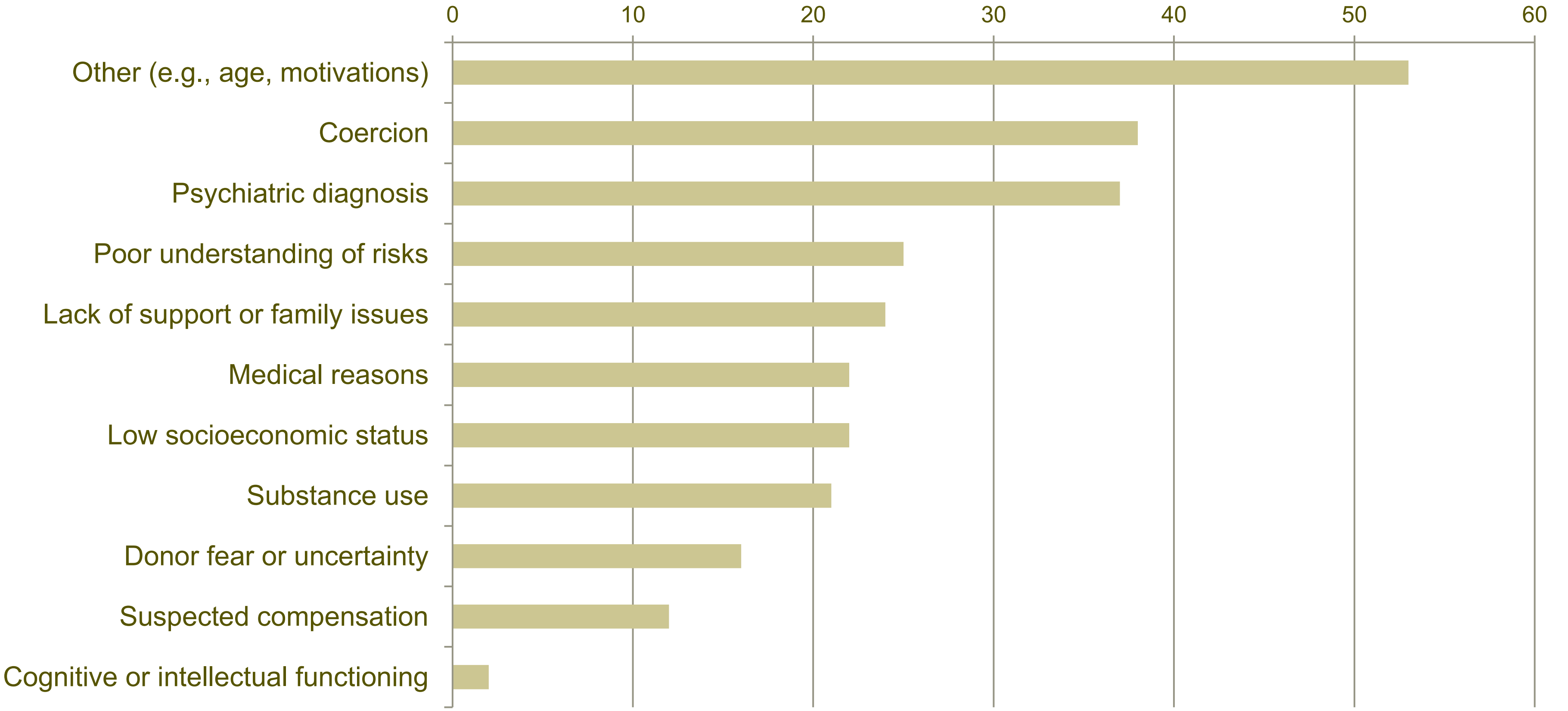
Not Approve the Surgery (“protect”):	50.7%
Approve the Surgery (“advocate”):	20.3%
Not aware ILDAs involved in the selection process:	10.0%

Training of the ILDAs



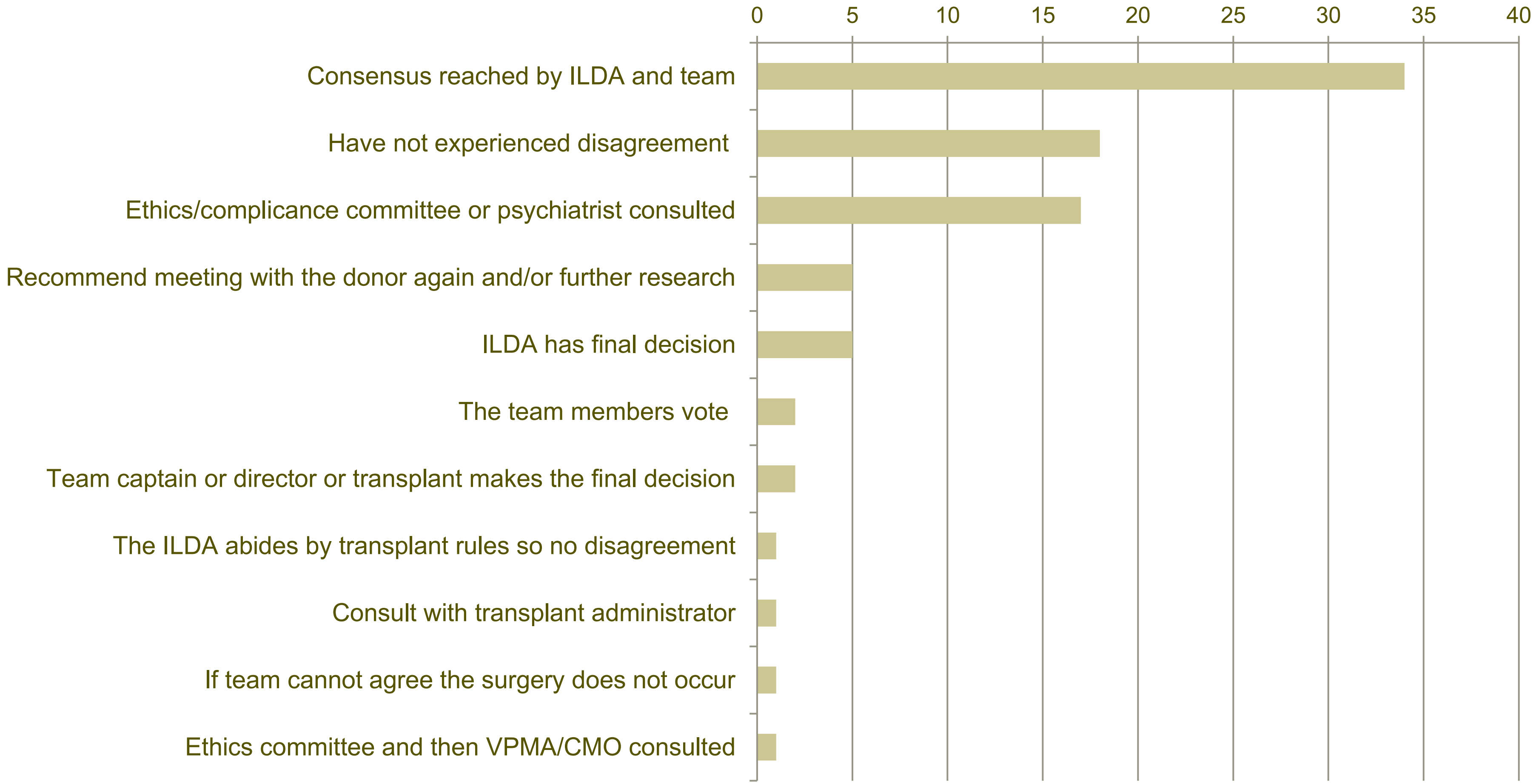
*Other=serve on ethics or selection committee, own research and writing, consult with other health care professionals, learned from patients and families

Figure 4: Reasons ILDAs Declined Donors



*Other= age, motivations for donation, unstable life, no transportation/insurance, adherence to medical treatments

How ILDA and Transplant Team Disagreements were Resolved



Assess for financial coercion

Table 4: "Acceptable" instances of *valuable consideration* reported **by the ILDAs**	
Receiving financial assistance from the transplant candidate (or family) for…..	
….the flight to be evaluated for donation or for the surgery	7.1
….unemployment benefits lost while recovering from surgery	47.1
….wages lost while recovering from surgery	64.7
….time off for the surgery/recovery with pay from the employer who is the candidate.	35.3
….a vacation with the candidate's family	2.9
….expenses for lodging/food while being evaluated for donation or surgery	85.3
....mortgage/rent, car payment, and utilities while recovering from surgery	41.2
….$5000 for expenses related to the donation	25.3
….the donor's discretion	2.9

Guidelines for ILDA

Characteristics of the ILDA:

- Somewhat separate form the rest of the transplant team
- Not involved with recipients
- Background can be variable- but should receive training
- Integral part of transplant evaluation team- present at selection

Guidelines for ILDA

Evaluation parameters:

- Relationship with the Recipient
- Motivations for donation
- Financial assistance vs. renumeration from candidate or family
- Willingness to donate, pressure or coercion
- Understanding of medical, psychosocial and financial risks

Guidelines for ILDA

Evaluation parameters:

- Understanding of how the donor’s personal medical history affects their ability/risks to donate
- Brief psychosocial history and health behaviors
- Potential to be declined and ability to decline
- Post-operative follow up
- NOTA law

Guidelines for ILDA

Presentation of donors:

- Present during the selection meeting
- Input regarding candidacy of donor
- Disagreement over clearance for donation- discussion at selection and resolution or reevaluate.
- Ultimately have veto power

Guidelines for ILDA

Follow up of donors:

- Post-Evaluation Follow up
- Post-Surgery or Decline Follow-up
- Long term follow up of donors
    - Complications or bereavement

Summary

- Great variability in regard to the ILDA selection process, training, definition of the role, and practices
- The ILDAs' role is critical and integral in the multidisciplinary evaluation and selection of appropriate living donors