Can We Find Your Perfect Match?

The Logistics of the Living Donor Paired Exchange Program

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How you want to be treated.

Overview

- LDPE principles and guidelines
- Match run logistics
- Types of exchange proposals
- Donor and Recipient work-ups
- Proposal logistics
- Surgery planning
- Post-Donation / Post-Transplant

LDPE Principles and Guidelines

- National Program when direct donation is not possible
- Managed by Canadian Blood Services
- Recipient needs an approved LDPE donor
- Linked so no donation without a Recipient transplant
- Usually Canadian donors
- Non-Directed Anonymous Donation (NDAD) possible
- If NDAD then the final donation is to the wait list in Donor's home province
- LDPE Consent is required to enter health information

LDPE Privacy Guidelines



PRIVACY GUIDELINES

Living Donor Paired Exchange Registry

Answers for Kidney Donors and Recipients

WHY SHOULD PRIVACY MATTER TO ME?

WHAT ARE THE RISKS OF SHARING MY STORY?

WHAT IF I WISH TO REMAIN ANONYMOUS?

WHEN SHOULD I SHARE MY STORY?

WHAT IF I WANT TO SHARE MY STORY WITH THE MEDIA?

WHAT SHOULD I CONSIDER WHEN SPEAKING WITH THE MEDIA?



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Key Privacy Principles

The right to remain anonymous (Canadian law)

- May share their personal story but not that of others
- Keep information general not specific
 Omit date, location of surgery, specifics about the chain
- Wait 4 weeks post-surgery before speaking with media
- Should speak with the Transplant team first
 Counselled about pros and cons of publicity
- For staff: Provide information on a need to know basis

LDPE Match Run Logistics

- New match run every 3 to 4 months
- Pairs must be ready 1 month prior to a match
 - Need time for immunology screening
 - Recipients need a PRA update
 - Donor testing is updated annually
- No guarantees of a match
- Possibility of matching is dependent on:
 - Pair's own profile
 - Other pairs registered in the cycle

Types of Exchanges



LDPE Match Run

- The more complex the chain is, the greater the risk for collapse
 - Proposals with multiple participants / transplant centres
 - > Highly sensitized Recipients
 - Recipients with multiple co-morbidities
- Proposals typically take 2-4 months to finalize all arrangements – longer if complications
- Recipients transplanted in their home centre
- Donors frequently matched with an OOP Recipient

LDPE Donor Work-up

- Donor unable to donate directly
 - ABO incompatible or cross match positive
- No other suitable direct donation donors are available
- LDPE Program information given
- The donor chooses to continue work up
- Same work up as all living donors
- Donor approved

LDPE const obtained

- Confidentiality and Privacy guidelines reviewed
- LDPE consents obtained
- OOP travel wishes discussed

Challenges for the LDPE Donor

- Donor may choose not to travel but the match options will be decreased
- Donor OOP challenges:
 - Requires more flexibility
 - > Matched centre may require additional donor testing
 - Donor re-imbursement programs vary
 - No companion funding at present
 - Meeting new team just before surgery
 - Recovery time in other provinces varies

LDPE Recipient Work-up

- Standard Recipient work-up and approval
- LDPE Donor has been approved
 - · No other suitable direct donation donors are available
- LDPE Program information given
 - Confidentiality and Privacy guidelines reviewed
- LDPE consents obtained

 If for pre-emptive transplant: Pair is not entered until the Recipient's function is suitable to proceed with a proposal

Proposal Logistics

- Transplant nephrologist reviews the initial proposal
 - Accepts or declines
- All candidates contacted and agree to proceed
 - Donor travel discussed (if needed)
 - Recipients on the Wait List agree to be "On Hold"
- Interim cross-matches arranged at the Recipient's centre
- If cross-matches are negative:
 - > Donor charts are shipped for review by the Recipient's team
- Status report is emailed to participants not matched
 If an initial proposal collapses match still possible before next run

LDPE Proposal Accepted

Each centre accepts the proposal when:

Recipient:

- Cross-match is negative
- > Donor is appropriate for the chosen Recipient
- > No further donor testing required
- > Donor is accepted by the proposed surgical team

Donor: Is confirmed as willing to travel

Managing Patient Expectations of a Proposed Match Transplant



All pairs must pass:

- Preliminary chart review
- Cross-match
- •Full medical chart review

Logistics Issues to Solve:

- How to get kidneys to recipients
- OR dates at multiple centres
- Expense reimbursement

Collapsed Chain

Possible Reasons for Collapse:

- Medical or other issue of a donor or recipient
- A donor or recipient unable or unwilling to proceed at any time up to time of surgery
- Positive cross-match even 2 weeks prior to transplant date
- Last minute travel issues
- Medical decision to stop a transplant or chain





Collapsed Chains

- CBS does an interim analysis to see
 Can part of chain be salvaged
 Can a new chain be created with cycle participants
- A new proposal may involve pairs not previously matched
- If no re-match is possible the participants wait for the next match run

Surgery Planning

- Choosing an OR date:
 - Challenge: to find a common date with multiple centres, provinces and participants
 - > All surgeries as close to the same time as possible
- If OOP Donor:
 - Transplant Nurse coordinates final OR work-up, teaching etc. with donor previously not known to their program
 - Social workers help to coordinate OOP donor travel, accommodation, and reimbursement funding
 - Donor is not fully approved until they meet the transplanting surgeon

Admission Logistics / Challenges

Strategies to maintain confidentiality if multiple donors and recipients at the same hospital:

- Staggered pre-admission appointments
- May pre-admit one pair to the inpatient ward
- Participants coached to maintain anonymity and not to answer invasive questions
- Asked to minimize visitors while in hospital

Post-Transplant / Donation

Recipients:

- Seen as usual in post-transplant clinic
- Thank-you letters to the matched donor can be arranged with the transplant team

Donors:

- > Short term follow-up with surgeon in the surgical centre
- Long-term follow-up with the home province

Requests to meet after 1 year only if both Donor and Recipient independently ask for a meeting

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Questions ???

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