



Canadian National
TRANSPLANT
Research Program

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FAST FACTS: PUBLIC SOLICITATIONS for Solid Organs and Hematopoietic Stem Cells from Living Donors

INTRODUCTION

People needing some solid organ transplants (e.g. a kidney, liver, lung) or a hematopoietic stem cell transplant (HSC) from bone marrow or cord blood have the option of receiving an organ or HSC from a living donor (LD). A LD could be a patient's family member, a friend or someone from the general public. To find a LD, there needs to be:

1. awareness of the need of an organ or HSC
2. knowledge that living donation is an option

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WHAT IS A PUBLIC SOLICITATION FOR AN ORGAN OR HSC?

When a patient does not have a family member or friend who is a potential, willing donor, s/he may choose to make an appeal to the general public to find a willing donor (called a Public Solicitation). Vehicles for solicitation include newsletters and "donor drives", billboards, news stories, appeals through community groups (e.g. churches), dedicated kidney matching websites and HSC donor registries. Social media platforms, such as Facebook and Twitter, have become increasingly popular as a method for public solicitation of organs or HSC donors, as social media can reach a broader audience quickly. Some patient stories are publicized by journalists in the media.

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FAST FACTS: PUBLIC SOLICITATIONS

HOW DOES PUBLIC SOLICITATION WORK?

SOLID ORGANS: In certain public solicitation campaigns using donor matching websites or social media, the people responding to a public solicitation for an organ may contact the solicitor directly and therefore the recipient knows the identity of the donor. In other campaigns, such as newspaper appeals, potential donors are often asked to contact the LD program at the local transplant hospital. In this situation, the recipient and donor usually do not meet and the donor is considered an anonymous directed LD. The recipient does not know the identity of the LD and the LD is given no further information about the potential recipient. Potential donors are screened by the hospital and only suitable candidates are accepted to donate.

HEMATOPOIETIC STEM CELLS: Immune matching has always been a critical criterion for a safe and successful HSC transplant. The best HSC donor is a perfectly matched sibling. Recent scientific advances have allowed only half matched, or haplo-identical, family donors to be used widely and safely. Consequently, it is possible that nearly everyone needing a donor now has one and this has deeply influenced the landscape of HSC. If patients do not have family members, have a difficult-to-match immune system or cannot find a donor match in the HSC registries, the patient may need to resort to public solicitation to find a HSC donor.

Public solicitation in HSC donation often solicits ethnic groups, who are under-represented in HSC registries, to register with the bone marrow registry. Whilst a public appeal may feature a person in need of HSC transplantation, a blood test or cheek swab is done only on those who agree to be entered on a voluntary registry to consider donation to any needy recipient who is a match. In Canada, this is done via the One Match registry run by Canadian Blood Services (CBS), which links with other worldwide registries. The registries are searched to find a match. The donors are anonymous to the recipient. Public solicitations for umbilical cord blood collection are run by CBS at selected delivery hospitals.

LAW AND REGULATION

No law in Canada addresses public solicitations for organs directly. Laws and regulations on donation of solid organs from living donors, sometimes called “inter vivos” donations and Health Canada Standards apply to regulate this process³. Legislation typically requires that a living organ donor be above a specified age, be competent to give their own consent to the donation and that no money or goods of valuable consideration be exchanged for the organ⁴. Hematopoietic stem cells from younger donors have a much better chance of being suitably matched with better survival outcomes in the recipient,^{5*} however registries typically list age limits as guidelines to support a fully informed consent process.



FAST FACTS: PUBLIC SOLICITATIONS

ETHICAL ISSUES IN PUBLIC SOLICITATIONS

JUSTICE/EQUITY

Traditional living donation is inequitable by virtue of being partial and directed⁶. Those who are offered living donation by a family member or friend benefit as the transplant avoids the risk of death on a waiting list. For those who do not have a LD, public solicitation is an opportunity to find one; it provides public awareness of the need for organs, enables donation and helps others by reducing the waiting list for a transplant from a deceased donor by at least one⁷. Also, solicitations have led to an increase in registration to be a deceased donor⁸.

Public solicitations are inequitable as they privilege those who are personally appealing⁹, computer literate, and have access to resources such as fame, money and power. Some people's stories have more emotional appeal than others. A request for a small child may have a greater impact than that of an adult. People who are well known to the public may elicit more donors due to their wealth, fame or public profile¹⁰. It seems unfair that emotional appeal and social status rather than medical need should influence who gets a life extending organ or HSC transplant. Further, social media appeals are more accessible to people with computers and smartphones, who speak English and are computer literate, thereby increasing their chances of finding a LD⁶.

INFORMED CONSENT

Solid Organ: When someone responds to a public solicitation they are offering to donate to an identified person (the solicitor), although the identity of the LD often remains unknown to the recipient. The legal standard for informed consent requires a process aiming to inform the LD adequately of the likely risks, benefits and consequences of the donation. This information includes how transplant listing works and that some other people waiting for this form of transplant may be medically worse off than the solicitor of the donation. The transplant centre does not want to discourage a LD from giving to a particular recipient, but is required to provide full disclosure to the donor. Living donors who give to family members or friends are not customarily informed of the needs of others: their wish for directed donation is respected.

Hematopoietic Stem Cells: HSC donors who respond to a public solicitation are accepted to a registry only if they agree to consider donation to any potential matched patient. The cost of testing and very low likelihood of matching make directed donation to the solicitor impractical. The donor's identity is not revealed to the recipient.



FAST FACTS: PUBLIC SOLICITATIONS

RISK AND EXPLOITATION IN PUBLIC SOLICITATIONS

There is often discomfort with public solicitations of solid organs for several reasons, including:

- the lack of relationship between donor and recipient,
- transplant programs' limited experience in how to respond to a public solicitation
- the potential for exploitation of the recipient who could be approached for payment by an unscrupulous donor¹¹
- a concern that the parties may not be fully apprised of the non-medical risks of a donation from a public solicitation, such as a LD who wants an on-going relationship with the recipient.

The study of the psychology and motivations of anonymous LDs has contributed to the selection of suitable LDs who do not know their recipients, and are able to cope with the psychological impacts of being an anonymous organ donor.

MINORS

Public solicitations by parents desperate to save their child's life are often successful in finding potential organ donors¹². By publicizing the child's story and photograph, the enormous benefit of saving a child's life may carry the lesser cost of not maintaining the child's privacy. Use of social media means that a child's digital footprint will follow them for the rest of their lives. Most children are too young to consent to the solicitation. In future years, they may have discomfort around their public profile and the method used to find a donor. This may also have implications for finding employment and insurance.

ADDITIONAL ISSUES

ONE-SIDED ANONYMITY: There is an imbalance of information and power when the LD offers to give to a person who is identified by their public solicitation while remaining anonymous to the recipient. Recipients need to be comfortable with this situation. Some vulnerability occurs as the recipient could be approached by someone claiming to be the LD asking for some advantage, but the recipient does not know if this is true or not. The advent of social media reduces the ability of a transplant centre to guarantee LDs that anonymity will be upheld.

CONTACT POST TRANSPLANT: In the world of solid organs from anonymous donors, practice varies worldwide with positive and negative outcomes of contact¹³. In the HSC world, contact between the donor and recipient occurs via an anonymous card or letter through the agency for the first year or so, after which contact may be arranged if both parties consent (rules vary by registry). It is generally recommended that prior to the donation, the parties be informed of and accept the transplant centre's policy on contact post-transplant.

HOSPITAL RESOURCES: A public solicitation for organs can lead to a large number of people calling a transplant hospital offering to donate. Hospitals need to have staff available to screen calls, provide accurate information and send out information packages to those suitable to proceed to evaluation. This creates a surge in demand for trained personnel and accompanying resources for which the hospital may not be equipped.

MISINFORMATION: While media stories inform the public of a need for organs, readers may not understand how the organ allocation system works, leading to misunderstandings such as why a recipient receives an organ from a LD before someone who may have waited longer for an organ from a deceased donor.

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PROS & CONS

OF PUBLIC SOLICITATIONS FOR ORGANS & HSC:

PRO

- Enables recipients to find a LD
- Elicits LDs for other patients
- Reduces the waiting list
- Promotes public awareness of the need for organs and HSC

CON

- Some recipient characteristics or solicitations may be more appealing than others
- May not help the sickest patient
- Potential for exploitation of the recipient or LD in organ donation
- May encourage organ sales