



Live Donation: Financial Toolkit

SECTION • 5

Fundraising for Living Donor Expenses – Q & A

Q: *What do I do if I don't have enough funds to cover my expenses, or lost wages due to donation? (This may be paying routine monthly household bills, in addition to donor-related costs.)*

A: Once you've figured out how much you need during your recovery to meet your monthly routine cost-of-living expenses and current financial obligations (see *Kidney Donation Cost-Estimation Worksheet*), you'll be able to determine whether seeking additional financial resources is necessary for your personal situation. If you're employed and have adequate vacation, sick leave, or short-term disability benefits then you may not have to do much more, should that income meet your needs. If you find that you don't have resources to meet your monthly obligations then you may need to consider additional sources.

It's important to recognize whether or not you can afford to donate. This may sound strange, since you're really trying to help another, but depending on the type of relationship you have with your recipient, this could be a huge factor as you weigh the financial impact donation may have on your current situation. Only you can decide this for yourself (with your family). If donation may impair your household financial situation, then you may have to choose not to donate. Financial stressors can sometimes negatively impact a donor's experience and should be factored into your decision.

The transplant community recognizes the financial impact donors may have and has attempted to create financial assistance programs for living donors to reduce any financial burden. (Please see *Nonprofit Sources of Financial Assistance for Living Donors* section.) You may, or may not, be eligible for available donor grants and should discuss your options with your donor social worker and/or Independent Donor Advocate.

Some individuals explore alternative ways to cover expenses when off for donation. Although seeking funds may seem awkward, fundraising for living donors so they can donate may occur, or be necessary. The National Organ Transplant

Act (NOTA) prohibits the sale of an organ by a donor for profit; making it illegal to gain financially by any compensation beyond a donor's expenses, or routine bills. That said, receiving financial assistance to defray costs associated with donation is permitted since the Organ Donation and Recovery Improvement Act of 2004 allows for reimbursement of travel and subsistence as long as those funds are raised to the extent that they cover bills related to travel or lost wages for donation. Donors may not financially profit (gain) from these funds so that their situation remains "cost-neutral," i.e. not making money from the donation.

The recipient, family members, friends, or general public may be aware of your need for financial assistance and may offer to assist you. You should discuss with your donor social worker how to handle such circumstances. In addition, each hospital may have varying policies specific to organ donation fundraising. In general, we suggest that you hold off on fundraising until you know that you have been medically cleared as a donor (otherwise, the funds may be raised for no reason.)

Q: *What if the recipient offers financial assistance?*

A: Accepting assistance to make donation 'cost neutral,' meaning no financial gain is made by you for donating, is acceptable. Importantly, most recipients are not in any position to help, nor should it be expected (since expecting it would rule out a donor.) However, a recipient (or family) may want to assist the donor in donor-related expenses. Recipients or their family members may have fundraisers on their own behalf, or for donor expenses which are sometimes included in that effort. Completing the *Kidney Donor Cost -Estimation Worksheet* will allow donors to readily know any amount for which he or she requires assistance, and a donor would be able to inform the recipient of that amount, if asked. Examples of common donor costs where funds may be directed are: hotel, gasoline, food, household bills, etc. Be clear about the 'top amount' that you'd be able to accept and still be within the NOTA guidelines.



Q: Should I consider doing my own fundraiser?

A: Even with excellent health insurance and supportive employers, transplant candidates, recipients and donors can have significant expenses. Personal fundraising may raise questions or ethical concerns at first glance, yet it may be the only way in which an individual can donate. Again, no profit can be made, as reinforced by the NOTA law. Calculations of the amount needed to cover costs associated with donation should be determined, so that monies or gift cards can be targeted to those specific items—and so you can set an appropriate ‘ceiling amount’ for moneys raised. It sounds like a lovely problem, to raise too much money, but it can be a legal hassle, ethically murky for the transplant hospital, and a confusing process for you of needing to give funds back to donors—so the ‘ceiling amount’ is helpful to define at the outset. Fundraising should be discussed with your donor social worker if this is a consideration.

Sometimes, donors feel more comfortable if a family member or friend can oversee any fundraising efforts, to reduce the appearance of any possible conflict.

There are many ways in which fundraising can be done, depending on the donor’s personal situation. Charities, local churches, work, social groups/circles, or other organizations may be well-known in the community to help specific causes. Others may utilize more popular methods like, ‘crowd-sourcing’ and other media-driven efforts. Facebook, Caring Bridge, or other fundraising venues are sometimes utilized. No matter what, however, it is important to document what your expected expenses will be, and state clearly the plan for what to do if a fundraiser raises more money than you need. The easiest thing to do is set a ‘ceiling’ for funds to raise.

There are organizations (see below) that help people do fundraising to help with transplant (or donation)-related expenses. These groups are nonprofit and donations to the organization in the name of a specific recipient are tax deductible. For people who receive Medicaid assistance, funds raised through these groups do not affect eligibility.

Help Hope Live

- <https://helphopelive.org/faq>
- Funds raised can be used for approved donor expenses, as well as the recipient’s expenses.

National Foundation for Transplants

- www.transplants.org
- Funds raised can be used for approved donor expenses, as well as the recipient’s expenses.
- NFT is launching a new program that will allow living donors to create their own fundraising campaign.

Children's Organ Transplant Association

- www.cota.org/cota-families/cota-advantages/
- Specializes in providing assistance to pairs in which the recipient is a child, but this isn't a requirement.

Potential benefits of fundraising through these types of nonprofit organizations:

- The funds raised are not considered taxable.
- Contributors to the fundraiser can get a tax deduction.
- The fundraising process is transparent (contributors can be assured the money raised will be used for living donor expenses).
- A mechanism is already in place for use of excess funds.

Potential pitfalls of fundraising through nonprofit organizations:

- The effort must be connected to the intended recipient’s fundraising profile. In other words, it’s not a helpful option for a non-directed donor, or for someone whose recipient doesn’t want to participate in the fundraising effort.
- The social media component of these organization may not be as dynamic as some other methods (i.e. “crowd-sourcing” efforts), so therefore the fundraising effort may not be as effective.

Q: What if excess funds are raised?

A: Individuals should be very specific in the goal of how much is needed, since a process for where any excess funds raised may be directed must usually be pre-determined, i.e. a secondary charity where excess monies might be donated.

It’s highly recommended that you discuss any financial needs with your donor social worker when considering fundraising efforts.