

Children's Organ Transplant Association®

Giving Hope ... Making Miracles

FREQUENTLY ASKED QUESTIONS

Do Children's Organ Transplant Association (COTA) parents typically have insurance?

Yes, COTA parents typically have individual (private, Medicaid or Medicare) and family coverage (private only), and most COTA transplant-needy kids and young adults have been insured since birth.

If COTA families have insurance, why do they need help?

No insurance plan covers all transplant-related expenses, which are significant. Transplant costs vary tremendously based on a number of factors, but generally transplants can cost anywhere between \$250,000 and \$800,000. These costs do not include family needs including lodging, food and transportation during the transplant stay. Additionally, post-transplant medications and medical care costs often add up to more than \$10,000 annually.

Most insurance providers require a family to pay an annual deductible that can exceed \$10,000 and require a co-payment for each visit to the doctor, clinic or for individual medical tests. No plan pays all transplant-related expenses and even a 'solid' insurance plan may only cover 80% of the 'normal and customary' expenses incurred within a pre-determined network or at a specific hospital.

Even with insurance coverage, very few transplant families have the resources to meet these tremendous financial demands. When faced with the burden of a child's potentially fatal diagnosis, most families need help.

Why do families choose to raise funds through an organization like COTA?

When most parents first hear of a medical diagnosis where a transplant is the only chance at survival, the medical team typically tells them they are going to need a strong and supportive social network of family and friends to help them not only emotionally, but also financially. Several transplant fundraising organizations exist, and COTA encourages transplant families to research all of the options before making their decision regarding which one to partner with for assistance. Fundraising for transplant-related expenses eliminates a significant stress for families and allows them to focus on their patient's medical and emotional needs.

While contributors' natural instinct is to provide financial support directly to the transplant family, there are several reasons it is recommended that a qualified not-for-profit, such as COTA, is utilized for fundraising:

- *Money received directly from friends and family could be considered taxable income to a transplant family, whereas the support received from COTA is not.*
- *Money received directly from friends and family could jeopardize government-based aid (Medicare, Medicaid and others) for a transplant family, whereas the support received from COTA does not.*
- *Gifts made to COTA are tax-deductible to the fullest extent of the law. Contributions made directly to a transplant family are not tax-deductible to the contributor.*
- *Contributors who give to COTA can do so with the reassurance that all monies given to transplant families are used solely for transplant-related expenses, such as annual co-payments, deductibles and medications.*

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The Internal Revenue Service (IRS) does not allow tax-deductible gifts to be made to individuals. Therefore, COTA works with community volunteers and ensures that 100% of the funds raised by a COTA community campaign in honor of a child or young adult will be used for transplant-related expenses. Once a family chooses to work with COTA, that family is eligible to submit reimbursement requests to COTA throughout their patient's lifetime.

Does COTA take a percentage of what is raised in honor of a child or young adult?

No, COTA does not charge for its services or take a percentage of funds raised. 100% of funds raised in honor of patients are used for transplant-related expenses. Each COTA family (at no cost to the family) is provided a website for fundraising and communications through their community campaign volunteer team.

How does COTA invest the funds it collects?

COTA's Board of Directors has approved an investment policy statement, which the Board believes is a conservative approach to minimize risk, preserve investment capital and meet the transplant-related expenses of patients as well as day-to-day operational needs of COTA.

How do COTA families access the funds contributed?

COTA has established internal procedures to ensure funds granted to families are used for appropriate transplant-related expenses. Each family must follow COTA guidelines, which includes providing appropriate documentation for all transplant-related expense requests. COTA reviews the documentation, and distributes funds to patient families or service providers.

Is COTA considered a reputable charity?

Most definitely; Guidestar, considered by those in philanthropy to be the gold standard for evaluating charitable organizations, has given COTA an "Exchange Seal" that is comparable to the Good Housekeeping Seal of Approval and demonstrates COTA's 'commitment to transparency.' Also, COTA is an Accredited Charity with the Better Business Bureau and its Wise Giving Alliance.

In June 2013, COTA received Charity Navigator's 4-star rating for the third year in a row. The 4-star rating (Charity Navigator's highest) is given to not-for-profit organizations that practice exceptional fiscal responsibility and governance in fulfilling their mission. According to Charity Navigator CEO Ken Berger, *"Only 10% of the charities we rate have received at least three consecutive 4-star evaluations indicating that the Children's Organ Transplant Association outperforms most other charities in America. This 'exceptional' designation from Charity Navigator differentiates COTA from its peers, and demonstrates to the public that COTA is worthy of their trust."*

What if COTA is not around in 10 years?

COTA was founded in 1986 and COTA's Board of Directors and supporters are committed to ensuring its sustainability long into the future. In the unlikely event that COTA would cease business operations, COTA's corporate and legal structure ensures that remaining funds would be disbursed for qualified transplant-related services to the patients on its roster.

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