

Understanding the Financial Challenges Facing **Pediatric Organ Transplant Families**

Organ and tissue transplants are lifesaving, but they bring significant financial burdens that many families are unprepared for.

Rick Lofgren's journey with The Children's Organ Transplant Association (COTA) began 26 years ago and was inspired by a personal connection — a cousin who passed away after an unsuccessful bone marrow transplant. This loss motivated him to help other families facing similar struggles. When he first joined COTA, the organization helped around 30 families annually. Today, that number has grown exponentially to nearly 250 new families each year, with more than 4,500 families helped since COTA was founded in 1986. Despite this growth, Lofgren says he would be happy if COTA were no longer necessary, although the need remains substantial.

One of the most pressing challenges for transplant families is the non-medical costs associated with transplantation. Even with good insurance coverage, families face hefty expenses related to transportation, lodging, and basic living needs — especially if they must travel far for appointments and the transplant itself. High deductibles and co-pays also add to the financial strain. As Lofgren points out, many families meet their annual out-of-pocket maximums early in the year, and these costs reset every January, making long-term financial planning daunting.

The new normal

The cost of transplant care varies depending on the type of organ. Kidney transplants, which make up about 85% of all transplants, are more accessible due to the higher number of hospitals performing these surgeries. Rarer transplants, such as pancreas or lung transplants, are more costly due to their complexity, as well as the limited number of hospitals performing these surgeries. This often requires families to travel across states.

Long-term care presents another financial hurdle. All transplant recipients

face a lifetime of transplant-related costs; however, pediatric cases far outpace those of adult recipients. For instance, families of children facing a transplant must plan for decades of ongoing expenses, such as medications, lab visits, and hospitalizations for additional health issues that may arise.

Beyond the immediate medical costs, there is a broader impact on transplant families' lives. Many parents must leave their jobs to care for their children, leading to a sharp reduction in household income. While remote work has helped ease this burden for some, the reality remains that caring for a child in the hospital is a full-time job.

Easing the process

Looking ahead, Lofgren believes policy changes could help ease the burden on transplant families. Proposals like tax incentives for organ donors, paid time off for transplant-related care, and increased financial support for living donors are among the solutions he envisions. He hopes these measures will become standard — much like the military's recent policy offering 12 weeks of paid leave to new fathers.

Ultimately, while transplants are vital, the financial and emotional toll on families is immense. The work being done by organizations like COTA is essential in helping transplant families manage these challenges, ensuring they can focus on their child's health rather than mounting bills.

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