



Caregiver *Lifeline* Program Resources for Transplant Families

This document is a good starting point for identifying potential transplant-related resources for patients, their caregivers and families. We've included a variety of information about transplant, transplant fundraising resources, grant assistance providers, travel assistance, prescription coverage, and living donor support.

Where to Start

The **Gift of Life Family House** website has a wide variety of educational, support group, transplant, governmental, stress, fitness and nutrition, and caregiver resources under "Resources" and under "*Caregiver Lifeline Program*." The Gift of Life Family House offers the **Caregiver Lifeline Program** as a resource *for all transplant caregivers*, whether or not you stay at The Family House. We're happy to help both before and after transplant. Many of these resources will be helpful to patients and other family members as well.

<http://www.giftoflifefamilyhouse.org/>

Phone: 267-546-9800

Toll Free: 855-632-6459

The **Gift of Life Donor Program** provides great information about regional and national resources to learn about transplant, support transplant families and patients, and suggest volunteering opportunities. <http://www.donors1.org/>

The **Transplant Living** website, which is run by the United Network for Organ Sharing (UNOS), is a great resource for patients and families new to transplant. <http://transplantliving.org/>

Support Services at The Family House

The Family House Social Worker is available to help answer questions, provide support, and identify resources as you and your loved ones go through the transplant process. The Social Worker can answer questions about:

- Travel, lodging, and medications
- Household bills
- Employment
- Handling the wait before and after the transplant
- Navigating the hospital system and working with your transplant team

For more information, please call The Family House Social Worker at 267-546-9817, visit our website, or email at CaregiverLifeline@GiftofLifeFamilyHouse.org.

Insurance

If you have any questions about your specific plan, please contact The Family House Social Worker.

- **Medicare:** Federal program with universal coverage. Covers 80% of transplant costs. You may need an insurance supplement.
- **State Medicaid:** May cover lodging and travel. Coverage varies, state to state.
- **Private Health Insurance:** Coverage varies, but be sure to ask for your insurance's Transplant Case Manager.

Questions to ask your private health insurer:

- Is my transplant center in-network with my insurance company?
- If my transplant center is out-of network, do I have an out-of-network benefit for transplant?
- What deductibles will apply?
- What are my co-payments for doctor visits, hospitalizations and medications?
- Does my plan require prior authorization?
- Who needs to get prior authorization?
- Does my plan have a lifetime maximum or "cap" for transplant services?
- Do any pre-existing-condition requirements exist?

The Transplant Living website provides a good overview. See "Before the Transplant" and select "Financing the Transplant." <http://transplantliving.org/>

Transplant Fundraising

The costs of transplant vary, and patients typically use several sources to help pay for their medical and non-medical costs before and after transplantation. Fundraising is easier than you think. These organizations provide help and tools for getting started.

- **Help Hope Live:** <https://www.helphopelive.org/>
Phone: 800-642-8399
Helps families and patients use community-based fundraising to meet uncovered medical expenses related to transplantation.
- **National Foundation for Transplants:** <http://www.transplants.org/>
Phone: 901-684-1697
Toll Free: 800-489-3863
NFT helps establish fundraising campaigns in patient communities.
- **Children's Organ Transplantation Association:** <http://www.cota.org/>
Phone: 800-366-2682
Helps children and young adults who need a life-saving transplant by providing fundraising assistance and family support.
- **Sink or Swim Philadelphia:** <http://sinkorswimphiladelphia.org/>

Phone: 267-940-7462

Helps people who are staying in the Philadelphia area who are uninsured and underinsured with necessary medical expenses via Facebook and web donations.

- **Your community resources:** Your church, school, community center, or a club can host fundraisers. All you have to do is ask.

Grants

There are a great number of grant resources, but they are organ-, disease- or state-specific. The Family House Social Worker is very knowledgeable about available options, so please consult with him or her first. Please note that many grants must be completed with a social worker. We suggest you start your online search with “grants for transplant patients” and add specifics.

Selected Grants:

- **The American Kidney Fund** offers a Safety Net Grant (for Dialysis ESRD patients) that helps dialysis patients who are in need of assistance with treatment-related expenses that insurance does not cover. Look under Patient Programs.
<http://www.kidneyfund.org/>
- **The American Liver Foundation** has resources listings based on area and disease.
<http://www.liverfoundation.org/>
- **Queen of Hearts Foundation** seeks to provide financial assistance to individuals and families dealing with the stress, uncertainty and financial burden associated with the battle against cancer and illness in NJ and PA.
<http://niqueenofhearts.org/>

Please Note: There are many other available grants, please see The Family House Social Worker for help.

Travel Support

Please note that none of these services provide emergency flights. All flights must be coordinated ahead of time.

- **Patient Airlift Services (PALS)** arranges volunteer medical flights and free air transportation for needy individuals throughout the greater Northeast region, from Virginia to Maine, Ohio to Massachusetts.
<http://www.palservices.org/>
Phone: 631-694-7257
- **Air Care Alliance/Angel Flights** has a directory of more than sixty groups with volunteer pilots who will fly patients for care or provide other flights or aviation services to help those in need or serve our communities.
<http://www.aircarealliance.org/>
Toll Free: 888-260-9707

- **Air Charity Network** is a charitable organization that provides access for people in need who are seeking free air transportation to specialized health care facilities or distant destinations due to family, community, or national crisis.
<http://aircharitynetwork.org/>
Toll Free: (877) 621-7177
- **Transplant Recipients International Organization Inc. (TRIO) United Airlines Travel Program** provides donated frequent flyer miles to donors or recipients who can substantiate financial need.
<http://www.trioweb.org/images/files/resources/communications/UALINFO-NoAppREV072011.pdf>
Phone: 1-800-TRIO-386

Prescription Coverage Assistance

If you have any issues covering your medications or concerns about future coverage, *immediately contact your Transplant Coordinator at the hospital.*

- If you have copays, some grants might help you cover these costs. Please reach out to The Family House Social Worker to see if there are resources for support.
- **Medicare Extra Help** program for prescription costs. This program is available to persons receiving Medicare, with limited resources and income, and residing in one of the 50 States or the District of Columbia.
<http://www.ssa.gov/prescriptionhelp/>
- **The PA Department of Aging** can link you to many different resources, including the Pennsylvania Pharmaceutical Assistance Program for the Elderly (PACE).
<http://www.aging.state.pa.us/>
- Many drug manufacturer offer patient assistance programs for prescribed immunosuppressive medications, which your Transplant Social Worker can help you access:
 - Abbott (Gengraf)
 - Astellas (Prograf)
 - Burroughs Wellcome (Imuran and Zorvarax)
 - Novartis (Cyclosporine and Neoral)
 - Roche (Cellcept)

Living Donors

Most living donors either donate a kidney or a liver segment. The **Gift of Life Donor Program** has good information for living donors (<http://www.donors1.org/>) as do **Transplant Living** (<http://www.transplantliving.org/>) and the **U.S. Department of Health and Human Services** (<http://organdonor.gov>).

- **National Living Donor Assistance Fund** provides financial assistance (travel & subsistence) to those who want to donate an organ. This grant must be applied for with a Transplant Social Worker. <http://www.livingdonorassistance.org/>
- The Pennsylvania Department of Health (DOH) administers the **Organ Donor Incidental Expenses Family Benefit Plan** (ODIEFBP). Provides reimbursement for certain incidental expenses incurred by organ donors and/or family members, as well as ESRD patients. This grant must be applied for with The Family House Social Worker. Under “Health Services and Resources/Organ Donation Awareness” <http://www.epht.pa.gov/>

Other Resources

- **Gift of Life Donor Program**, <http://www.donors1.org/>
- **Family Caregiver Alliance**, <http://www.caregiver.org/>
- **The United Network for Organ Sharing**, <http://www.unos.org/>
- **Transplant Living**, <http://transplantliving.org/>

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