Caregiver Lifeline Program
Resources for Transplant Families

Online Support

Gift of Life Family House Caregiver Lifeline Program:
www.giftoflifefamilyhouse.org/resources/caregiverlifeline/
Has a wide variety of articles and resources to help patients and families understand and cope with the transplant process.

Gift of Life Donor Program: Donors1.org
Provides great information about regional and national resources to learn about transplant, support transplant families and patients, and suggest volunteering opportunities.

Transplant Living: Transplantliving.org
Overseen by the United Network for Organ Sharing (UNOS), is a great resource for patients and families new to transplant.

One-on-One Support

If you still have questions or concerns, 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.

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

Please call The Family House Social Worker at 267-546-9817 or email at CaregiverLifeline@GiftofLifeFamilyHouse.org.

Support and Volunteer Groups

There are many support and volunteer groups throughout the Gift of Life region (eastern half of PA, southern NJ and all of DE).
A listing of these groups can be found on our website: 
Giftoflifefamilyhouse.org/resources/caregiverlifeline/supportgroups/

You can also visit Transplantliving.org/community/support-groups/ for transplant groups or Resources.caregiver.com/ for caregiver support groups outside of the Gift of Life region.

You can also find support groups through Facebook. If you already have a Facebook account, go to the main page and search the type of group you are looking for. For instance, a heart transplant patient might search for “heart transplant support group.” (ex group: https://www.facebook.com/groups/320159724759759/)

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 or co-payments for doctor visits, hospitalizations and medications will I have?
  - Does my plan require prior authorization and how?
  - Does my plan have a lifetime maximum or "cap" for transplant services?

The Transplant Living website provides a good overview. See “Before the Transplant” and select “Financing the Transplant.” [http://transplantliving.org/](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/](https://www.helphopelive.org/) 
  Phone: 800-642-8399
  Helps families and patients use community-based fundraising to meet uncovered expenses related to transplantation – ex: mileage, lodging, copays, deductible.
NFT helps establish fundraising campaigns in patient communities.

- **Children’s Organ Transplantation Association**: [http://www.cota.org/](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/](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.

**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/](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/](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/](http://aircharitynetwork.org/)
  Toll Free: (877) 621-7177

**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.
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). www.aging.state.pa.us/
- Many drug manufacturer offer patient assistance programs for prescribed immunosuppressive medications, which your Hospital Transplant Social Worker can help you access.

### Living Donor Support

The **Gift of Life Donor Program** has information for living donors (www.Donors1.org) as do **Transplant Living** (Transplantliving.org/) and the **U.S. Department of Health and Human Services** (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 - www.livingdonorassistance.org/
- The Pennsylvania Department of Health (DOH) administers the **Organ Donor Incidental Expenses Family Benefit Plan**. Provides reimbursement for certain incidental expenses incurred by organ donors and/or family members. This grant must be applied for with The Family House Social Worker.

### Other Resources

- Family Caregiver Alliance, http://www.caregiver.org/
- Transplant Living, http://transplantliving.org/

For more information, call the Family House Social Worker at 267-546-9817 or email at CaregiverLifeline@GiftofLifeFamilyHouse.org
Gift of Life Regional Coalition and Support Groups
For meeting dates and times please call the contact person listed for each group or visit www.donors1.org

1. Berks Coalition on Organ & Tissue Donation
   Serving Berks and Schuylkill Counties.
   Meets at 7pm-8:30pm on the second Tuesday of the month (no meeting in June and July)
   Also has a Facebook page
   Dwendy Johnson
   Reading Hospital
   Sixth Avenue and Spruce Street
   West Reading, PA 19611
   Phone: 1-800-DONORS-1 ext. 1506

2. Capital Coalition for Organ and Tissue Donation
   Serving Cumberland, Dauphin, Juniata, Mifflin, Perry and Snyder counties.
   Meets at 7pm on the first Monday’s of each month (no meeting in June and July)
   Dwendy Johnson
   Satellite Gift of Life Hershey Office
   867 Fishburn Rd
   Hershey, PA
   Phone: 1-800-366-6771 x1506

3. Central Pennsylvania Coalition for Organ and Tissue Donation and Support Group
   Serving Lancaster and Lebanon Counties
   Meetings at 6:30pm -8pm on the second Wednesday of each month (no meeting in June or July)
   Also has a Facebook page
   Dwendy Johnson; Al Weibel
   Lancaster General Health Center
   2100 Harrisburg Pike
   Lancaster, PA 17603
   Phone: Dwendy: 1-800-366-6771 x1506; Al: (717) 672-0455

4. Central Susquehanna Valley Coalition on Organ Donation
   Serving Centre, Clinton, Columbia, Montour, Northumberland, Lycoming, Sullivan, Tioga and Union counties.
   Meetings and locations are TBD for more information call the number below.
   Dwendy Johnson
   Phone: 1-800-366-6771 x1506

5. Lehigh Valley Coalition on Organ and Tissue Donation
   Serving the Allentown, Bethlehem, and Easton areas
   Meets at 7 p.m. on the second Wednesday of the month (no meeting in July and August)
   Susan Koomar
   Northeast Pennsylvania Lions Eye Bank
   2346 Jacksonville Rd
   Bethlehem, PA 18017
   Phone: 267-421-7958 or 1-800-366-6771 x6173
6. **Liaisons for Life**  
*Serving Philadelphia County*: Liaisons for Life is Gift of Life Donor Program's core volunteer group

Tammy Buscher  
401 N. Third Street  
Philadelphia, PA 19125  
*Phone*: 1-800-366-6771 x 1137

7. **Northeast Pennsylvania Coalition on Organ and Tissue Donation**  
*Serving Carbon, Lackawanna, Luzerne, Monroe, Pike, Susquehanna, Wayne and Wyoming counties.*  
Meets at 6:30pm on the 3rd Thursday of the month (no meeting in July, August, December or March)

Susan Koomar  
The University of Scranton, Brennan Hall  
300 block of Madison Avenue  
Scranton, PA  
*Phone*: 267-421-7958 or 1-800-366-6771 x6173

*Serving Pocono’s area*  
Meets at 7pm on the 1st Thursday of each month

Pocono Medical Center  
Stroud Room  
East Brown Street  
East Stroudsburg, Pennsylvania, PA  
*Phone*: 570-223-2833

9. **South Central Pennsylvania Coalition on Organ and Tissue Donation & York Area Transplant Support**  
*Serving the York, Hanover and Gettysburg areas.*  
Meets at 7pm-8:30pm on the 4th Monday of each month (no meetings January, May, August)

Dwendy Johnson  
Apple Hill Surgical Center  
25 Monument Road Room #193  
York, PA  
*Phone*: 1-800-366-6771 x1506

10. **Southern New Jersey Coalition on Organ and Tissue Donation**  
*Serving the southern counties of New Jersey: Burlington, Camden, Gloucester, Salem, and Cumberland.*

Tammy Buscher  
401 N. Third Street  
Philadelphia, PA 19125  
*Phone*: 1-800-366-6771 x 1137

Meets at 10:00am – noon on the second Saturday of each month

Jim Gleason  
Gift of Life Donor Program offices  
401 N 3rd St, Phila, PA 19123  
Gleason jim@aol.com or call (609) 877-4493

12. **Cape Atlantic Support Group**  
*Serving Southern New Jersey Shore region*

Bill Carlsen  
Shore Medical Center  
One East New York Avenue  
Somers Point, NJ  
*Phone: 609-624-0853*

13. **Delaware Coalition for Organ and Tissue Donation**  
*Serving all of Delaware*

Northern DE - 1st Monday of every month – usually in Newark, DE  
Southern DE – 2nd Tuesday of every month (Milton or Dover, DE (varies)  
*Please reach out to Tammy below if interested for exact location*

Tammy Buscher  
401 N. Third Street  
Philadelphia, PA 19125  
*Phone: 1-800-366-6771 x 1137*