



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/>

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.helpholive.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.
- **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.

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

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

- **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/>
- **The American Transplant Association**, <http://www.americantransplant.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

8. Northeast Pennsylvania Transplant Support Group (<http://www.nepatsg.org/>)

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

11. TRIO Philadelphia chapter (Transplant Recipients International Organization – <https://triophiladelphia.wordpress.com/>)

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
GleasonJim@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