

Patient Education and Advocacy

American Diabetes Association www.diabetes.org • 800-DIABETES (342-2383)

American Organ Transplant Association www.aotaonline.org
P. O. Box 418 Stilwell, KS 66085 • 832-930-2682

American Society of Transplantation www.myast.org/
National Office 1120 Route 73 Suite 200 Mt. Laurel, NJ 08054 • 856-439-9986

American Society of Transplant Surgeons www.astso.org
2461 South Clark St., Suite 640 Arlington, VA 22202 • 703-414-7870

Association for Multicultural Affairs in Transplantation www.amat1.org
10825 Midlothian Turnpike, Suite 201R Richmond, VA 23235 • 844-654-2628

Association of Organ Procurement Organizations www.aopo.org
8500 Leesburg Pike, Suite 300 Vienna, Virginia, 22182 • 703-556-4242

Caregiver Action Network(CAN) <https://www.caregiveraction.org/>
A family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age.

Caring Bridge www.caringbridge.org
A website that serves as a personal health journal, updating friends and family and rallying support during any type of health journey.

Family Caregiver Alliance <https://www.caregiver.org/>
FCA is a longtime advocate for caregivers in the areas of policy, health and social system development, research, and public awareness, on the state, national and international levels.

International Society for Heart and Lung Transplantation (ISHLT) www.isHLT.org
ISHLT@isHLT.org 14673 Midway Road, Suite 200 Addison, Texas 75001 • 972-490-9495

Resources for Lung Transplant Recipients and Caregivers



International Transplant Nurses Society www.itns.org
8735 W. Higgins Road, Suite 300 Chicago, IL 60631 • 847-375-6340

Joint Commission on the Accreditation of Healthcare Organizations
www.jointcommission.org • 630-792-5800
1 Renaissance Blvd. Oak Brook Terrace, IL 60181

Lotsa Helping Hands: Create a community to help those in need.
<https://lotsahelpinghands.com/>

Lung Transplant Foundation: Improves the lives of Lung Transplant patients and their families. <https://lungtransplantfoundation.org/>

National Minority Organ and Tissue Transplant Education Program (MOTTEP)
www.natlmottep.org • 202-865-4888
2041 Georgia Avenue, NW Room 4B21 Washington, DC 20060

National Organization for Rare Disorders(NORD) rarediseases.org
A patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them.

North American Transplant Coordinators Organization (NATCO) www.natco1.org
12820 Rose Grove Dr. Oak Hill, VA 20171 • 703-483-9820

Patient Advocate Foundation www.patientadvocate.org
Provides patient services, eliminating obstacles in access to quality healthcare.

Scientific Registry of Transplant Recipients(SRTR) www.srtr.com
Supports the transplant community with statistical analysis to improve patient outcomes.

Second Wind Lung Transplant Association, Inc. www.2ndwind.org
2781 Chateau Circle Columbus, Oh 43221 • 614-488-1149

The Gift of Life Family House <https://www.giftoflifefamilyhouse.org/>
Provides temporary, affordable lodging and supportive services to those who travel to Philadelphia, Pennsylvania for transplant-related care.

Resources for Lung Transplant Recipients and Caregivers



TRIO(Transplant Recipients International Organization) <https://www.trioweb.org/>

An independent, not-for-profit, international organization committed to improving the quality of life of transplant candidates, recipients, their families and the families of organ and tissue donors.

Transplant Recipients International Organization, Incorporated (TRIO)

www.trioweb.org info@trioweb.org • 800-874-6386
7055 Heritage Hunt Drive, #307 Gainesville VA 20155

United Network of Organ Sharing(UNOS) www.unos.org

The United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system under contract with the federal government. Coordinates organ placement in the United States. Patient education and support.

U.S. Department of Health & Human Services <https://www.organdonor.gov/>

Financial Resources

Air Charity Network www.aircharitynetwork.org • 877-621-7177

Transports ambulatory patients up to a distance of 500 to 700 miles using private pilots and their aircraft. Can transport people for transplant and follow-up appointments. Medical and financial need must be documented. Service is free of charge.

Air Care Alliance www.aircarealliance.org • 888-260-9707

2060 State Highway 595 Lindrith, New Mexico 87029
Provides the only central listing of all known groups whose members perform free public benefit flights for patient transport and other missions of public service.

Angel Flight www.angelflight.com • 918-749-8992

12345 E. Skelly Drive Tulsa, OK 74128
Provides free air transportation on private aircraft for those in need who have healthcare problems, and for healthcare agencies, organ procurement organizations, blood banks and tissue banks. No fees of any kind. Volunteers serving the public since 1983.

Resources for Lung Transplant Recipients and Caregivers



Boomer Esiason Foundation/LTX grant program <https://www.esiason.org/>

COTA (Children's Organ Transplant Association) www.cota.org cota@cota.org

2501 West COTA Drive Bloomington, IN 47403 • 800-366-2682

Helps children and young adults who need a life-saving transplant (organ, bone marrow and cord blood) by providing fundraising assistance and family support. COTA does not charge for its services and does not take a percentage of funds raised.

Georgia Transplant Foundation (GTF) www.gatransplant.org • 770-457-3796

2201 Macy Drive Roswell, GA 30076

Provides both financial and educational assistance during a time that is often overwhelming for those undergoing or waiting for a transplant throughout the entire state of Georgia.

GiveForward www.GiveForward.com

Empowers families to create individual fundraising pages for their loved ones facing a medical crisis.

Health Insurance Marketplace www.healthcare.gov • 800-318-2596

Stay up to date on health insurance regulation and policy information and learn more about health insurance options under the Affordable Care Act.

HelpHOPELive (formerly NTAF) www.helphopelive.org • info@helphopelive.org

800-642-8399

Help Hope Live's mission is to support community-based fundraising for people with unmet medical and related expenses due to cell and organ transplants or catastrophic injuries and illnesses.

Medicare Hotline www.medicare.gov • 1-800-633-4227

7500 Security Blvd Baltimore, MD 21244-1850 800-MEDICARE

National Foundation for Transplants: <https://transplants.org/>

Resources for Lung Transplant Recipients and Caregivers



National Living Donor Assistance Center (NLDAC) www.livingdonorassistance.org

2461 S. Clark Street, Suite 640 Arlington, VA 22202 703-414-1600

This program provides financial assistance to those who want to donate an organ. Priority is given to individuals not otherwise able to afford the travel and subsistence expenses associated with living organ donation.

National Organization of Social Security Claimants' Representatives

www.nosscr.org • 201-567-4228

560 Sylvan Ave, Suite 2200 Englewood Cliffs, NJ 07632 The National Organization of Social Security Claimants' Representatives (NOSSCR) is a specialized bar association for attorneys and advocates who represent Social Security Disability Insurance and Supplemental Security Income claimants throughout the adjudicative process.

National Foundation for Transplants www.transplants.org info@transplants.org

5350 Poplar Avenue, Suite 430 Memphis, TN 3811 • 800-489-3863

NFT offers hope and help to transplant patients and their families by providing fundraising expertise, advocacy, promoting organ and tissue donation and supporting innovative solutions for lifesaving treatment.

Patient Airlift Services: Air ambulance www.palservices.org

Second Wind Lung Transplant Association <https://www.2ndwind.org/>

Improve the quality of life for lung transplant recipients, lung surgery candidates, people with related pulmonary concern and their families, by providing support, advocacy, education, information and guidance.

Scholarship Programs

TRIO Scholarship Program <http://www.trioweb.org/resources/trio-scholarships.html>

Each year, the Transplant Recipient's International Organization Scholarship Program gives thousands of dollars in academic grants to transplant candidates, recipients, donors or their family members. These scholarships are generously funded by several TRIO chapters, individuals and interested organizations. Each recipient receives \$1,000 toward their education at colleges and universities throughout the United States.

The Jessica Beth Schwartz Scholarship

<http://www.donors1.org/patient/resources/jessiesday/>

Awards \$2,500 scholarships yearly to transplant recipients under the age of 25 who are a senior in high school or enrolled in a 2 or 4 year college, university, or trade/technical school, offered to students residing in the Gift of Life Donor Program (OPO) service area (Eastern half of Pennsylvania, Southern New Jersey or Delaware).

The David Nelson Jr Memorial Fund Scholarship

<http://www.donors1.org/donor/nelsonmemorialfund/>

This \$1,000 scholarship is offered to a donor family's children living in the Gift of Life Donor Program region (Southern NJ, Delaware, and southeastern Pennsylvania) and is available for private/parochial high school in addition to college, university or trade school.

The Marcena Lozano Memorial Scholarship Fund

<http://marcenasmiracles.com/scholarship.html>

In memory of their daughter, Marcena, the Lozanos offer several \$1,000-\$3,000 undergraduate scholarships with preference to candidates in western New York state but awarded to students all across the country.

Legacy of Life Scholarship

<http://www.beadonor.org/community-outreach/scholarship-information>

The Washington Regional Transplant Center (WRTC) awards \$14,000 in scholarship to high school seniors in their jurisdiction of Virginia (Arlington, Fairfax, Loudoun, Prince William, Stafford, and Fauquier counties and cities of Alexandria, Falls Church, Fairfax, Manassas, and Manassas Park); Maryland (Montgomery, Prince George's, and Charles counties). Endowed by the Leslie Ebert Memorial Fund.

The Betty Montoya Gift of Life Scholarship • <http://otapnm.com/scholarship>

This award honors former APS teacher and kidney transplant recipient Betty Montoya with two \$1,000 scholarships and two \$500 scholarships to graduating seniors from a New Mexico high school.

Resources for Lung Transplant Recipients and Caregivers



Georgia Transplant Foundation

<https://www.gatransplant.org/-support-programs/academic-scholarships>

The Georgia Transplant Foundation awards seven scholarships to residents of Georgia attending college.

Michael Corea Scholarship <https://www.triocleveland.org/>

This scholarship, offered by TRIO Greater Cleveland Chapter, is awarded to a deserving transplant candidate, recipient or living donor who is a resident of Ohio.