

Resources

For a kidney/pancreas transplant

This list of resources may be helpful to transplant patients, their families or support persons, and living donors.

The resources in this chapter are listed in alphabetical order. They include:

- Government agencies
- Community resources
- Printed resources
- Fundraising resources

If you want more resources, talk with someone on your transplant team. They will be happy to help you find more information on transplant topics.

Checking Online Health Information

When searching for health information online, please follow these guidelines:

- Find out who is providing the information. Make sure they are experts in their fields.
- Find out who owns the site. Consider if they might have a bias, such as a company that wants to sell a product.
- Look for sites with recent posts. Health information becomes outdated quickly.
- If you have questions about something you find online, ask your healthcare provider about it.



Follow the guidelines in this chapter when deciding what online information to trust.

Resource List

American Association of Kidney Patients

www.aakp.org

800.749.2257

3505 E. Frontage Rd., Suite 315, Tampa, FL 33607

Provides information, referral, and advocacy for people with chronic kidney disease.

American Kidney Fund

www.kidneyfund.org

800.638.8299

6110 Executive Blvd., Suite 1010, Rockville, MD 20852

Provides limited financial grants to needy transplant recipients and living kidney donors.

American Organ Transplant Association

www.aotaonline.org

832.930.2682

Provides transportation help to transplant patients.

Department of Social and Health Services (DSHS)

www.dshs.wa.gov

A state agency that runs programs such as Medicaid (medical coverage for the disabled and low-income), cash benefits for the disabled, and aid to low-income and single parents.

You can find information about your local DSHS office online:

- Go to *www.dshs.wa.gov*.
- Under “How Do I ... ?” click on “Find a local service office.”
- Under “How to Find an Economic Services Administration Office,” click on “Community Services Offices.”
- Enter your zip code and click on “Apply” for your local DSHS office address and phone number.

Financing Transplantation – What Every Patient Should Know By the United Network for Organ Sharing

A brochure from United Network for Organ Sharing (UNOS). See the UNOS listing on page 4 of this chapter.

Help Hope Live

www.helphopelive.org

A nonprofit group that helps transplant patients raise funds for unmet health and living expenses when having an organ transplant.

LifeOptions Rehabilitation Council

www.lifeoptions.org

A nonprofit agency that provides educational material for people who want to learn more about rehabilitation and returning to work, either while on dialysis or after a transplant.

Medicare

www.medicare.gov

800.MEDICARE

A federal agency that provides health insurance for senior citizens. It also runs the Medicare insurance program for End Stage Renal Disease.

National Family Caregivers Association

www.nfcacares.org

800.896.3650

10400 Connecticut Avenue, #500, Kensington, MD 20895-3944

Provides education, support, and advocacy for caregivers of people who have a chronic illness.

National Foundation for Transplants

www.transplants.org

800.489.3863

Helps patients raise funds to cover expenses of organ transplants.

National Kidney Foundation

www.kidney.org

800.622.9010

30 East 33rd Street, Suite 1100, New York, NY 10016

Provides educational materials on most aspects of kidney disease. Also provides information and advocacy for issues that are important to transplant recipients. Call the number for a list of materials, or visit the “Patients” section of their website.

National Living Donor Assistance Center

www.livingdonorassistance.org

Provides financial aid for costs of a living organ donation.

Organ Donor Information

www.organdonor.gov

Information about the need for both living and deceased organ donors.

Organ Procurement and Transplantation Network

<http://optn.transplant.hrsa.gov>

Up-to-date information on transplants in the U.S.

Renal Support Network

www.rsnhope.org

A nonprofit, patient-run organization that provides non-medical services to those affected by chronic kidney disease.

Social Security Administration

800.772.1213

www.ssa.gov

A federal agency that runs programs such as Social Security Disability, Supplemental Security Income (SSI), Social Security Retirement, and Medicare.

Team Transplant

Contact: Alysun Deckert, MSRD, CD, 206.598.6351, teamt@uw.edu

www.uwmcteamtransplant.com

A UWMC-affiliated running and walking group, open to all transplant recipients (any organ) and interested staff. Team Transplant promotes organ donation and is an informal support network. Special workshops are held on topics such as nutrition, stretching, and footwear. The group enters at least 1 half-marathon event each year, and other local events from time to time.

The Road Back to Life

www.theroadbacktolife.com

Offers mentoring, support, and advice to kidney patients.

Transplant Living

www.transplantliving.org

A service of the United Network for Organ Sharing organization.

Transplant Recipients International Organization

www.trioweb.org

Visit the website for contact numbers for your local chapter.

TransWeb

www.transweb.org

A web-based organization that provides information about transplants. This site can link you to an online chat list for transplant patients and those waiting for transplant.

United Network for Organ Sharing (UNOS)

www.unos.org

888.894.6361

A federally-chartered organization that sets policy and procedures for transplant organ distribution in the U.S. Their website has information on success rates for organ transplant listed by region and specific transplant centers. The site also has other information for transplant patients.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

Transplant Services:
206.598.3882