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 Health information becomes outdated quickly.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, teamtx@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