Resources
For a kidney/pancreas transplant

How to Check Online Health Information
Most of the resources in this chapter include an Internet address. When searching for medical information on the Internet or visiting websites, please keep these guidelines in mind:

- It should be clear who is providing the medical data. Their qualifications should be included.
- Find out who owns the site and consider possible biases, such as a company that wants to sell a product.
- Look for sites with recent postings. Health information does get outdated.
- If you have questions about something you find online, ask your health care provider about it.

About this Chapter
The resources in this chapter are listed alphabetically. They include:

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

If you want more information than you can find from these sources, ask someone on your transplant team for help. They will be glad to see if they can find more information on any transplant topic.
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.a-o-t-a.org  
800-373-1646  
Provides fundraising assistance to transplant patients.

**Coping with an Organ Transplant**  
By Elizabeth Parr, PhD, and Janet Mize, RN  
This book was written by an organ transplant recipient and a transplant nurse. You are most likely to find this book through an Internet site such as www.amazon.com or www.barnesandnoble.com, or through the publisher at www.penguin.com.

**Department of Social and Health Services (DSHS)**  
www.dshs.wa.gov  
This state agency runs programs such as Medicaid (medical coverage for the disabled and low-income), cash benefits for the disabled, and assistance to low-income and single parents.  
You can also find information about your local DSHS office online. From the home page, click on “Find a local service office” then enter your zip code under “Find an office.”

**Financing Transplantation – What Every Patient Should Know**  
By the United Network for Organ Sharing  
A brochure available from United Network for Organ Sharing (UNOS). See the UNOS listing on page 18-4 of this chapter.
**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  
This federal agency provides health insurance for senior citizens. It also administers 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  
Assists patients in fundraising 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 almost all 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 Transplant Assistant Fund**  
www.ntafund.org  
Assists patients in fundraising to cover expenses of organ transplants.

**Organ Donor Information**  
www.organdonor.gov  
Information about the need for both living and deceased organ donors.
Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC clinic staff are also available to help.

Transplant Services:
206-598-8881

Social Security Administration
800-772-1213
www.ssa.gov

This federal agency 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

This UWMC-affiliated running and walking group is for all transplant recipients (any organ) and interested staff. Team Transplant promotes organ donation and serves as 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.

Transplant Recipients International Organization
206-364-0813
Local contact: Irwin Etter

TransWeb
www.transweb.org

An Internet-based organization that provides information about transplants. This site can link you to an Internet discussion list for transplant patients and those waiting for transplant.

United Network for Organ Sharing (UNOS)
ww.unos.org
888-894-6361

UNOS is a federally chartered organization that sets policy and procedures for transplant organ distribution in the United States. The website contains detailed information on success rates for organ transplant listed by region and specific transplant centers. The site also has a lot of information for transplant patients.