

Dear Patient,

Because you are interested in organ transplantation, we want you to be aware of important resources and services provided by the national transplant network. We also encourage you to learn more about transplant data and policies and to take part in the policy development process.

United Network for Organ Sharing (UNOS) is a not-for-profit organization that administers the national Organ Procurement and Transplantation Network (OPTN). This is made possible through a contract with the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The OPTN and UNOS help the transplant community and patients like you by:

- coordinating the organ matching and placement process;
- collecting data about every transplant that occurs in the United States;
- developing organ transplant policy with input from medical staff, transplant patients, donor families, and living donors;
- creating educational material for professionals, patients, and the public; and increasing public awareness of the need for donated organs and tissues.

#### **UNOS Patient Services**

An important service is the UNOS toll-free Patient Services line: 1-888-894-6361 (Please do not call this UNOS number to reach your transplant center). Transplant patients, family members/friends, living donors, donor family members, and the public can call this number to:

- discuss general information about organ donation, living donation, the transplant process,
- transplant policies, and transplant data;
  - receive a free patient information kit with helpful booklets, waiting list and transplant data,
- and a list of all transplant centers;
  - ask questions about information on the UNOS Web site for transplant patients and living donors: <https://www.transplantliving.org> ; and
- discuss concerns you may have with a transplant center related to a possible policy violation. (Call your center directly to discuss questions or concerns about

your personal medical care.)

### **Data Access**

Understanding transplant data can help you make informed decisions about your transplant care. The Federal government makes sure that important data about all transplant programs in the U.S. are available to the public. You can access transplant survival rate data at: <https://srr.org> (choose "Program-Specific Reports and OPO Reports"). You can contact the SRTR at 877-970-SRTR (7787). You can view the size of waiting lists and the number of transplants completed at each transplant center at: <https://optn.transplant.hrsa.gov> (choose "Data," then "View Data Reports").

### **Transplant Policies**

Patients have a role in the transplant policy-making process. When OPTN/UNOS Committees develop policy proposals, you can provide your opinion through the public comment process. To comment on a proposal, visit the OPTN Web site at <https://optn.transplant.hrsa.gov/governance/public-comment> (choose "Governance," then "Public Comment").

At this Web site, you can sign up to be notified every time proposals are ready for public comment. If you do not have internet access, UNOS will mail the public comment information to you. Please send your request to: OPTN/UNOS Public Comment Coordinator; United Network for Organ Sharing; 700 N. 4th Street; Richmond, VA 23218.

UNOS is happy to provide you with helpful information as you address your transplant needs. If you have questions about the role of UNOS and the OPTN, the transplant system, transplant data, or transplant policies, please contact the UNOS Patient Services line at: 1-888-894-6361.