

OPTN/UNOS Patient Affairs Committee Report to the Board of Directors

Ray Gabel, Chair

Laura Ellsworth, Vice-Chair

Richmond Virginia

June 28 – 29, 2011

OPTN



PAC Charge

- Advises the Board and other Committees on Patient Perspectives on Policy and initiatives
- Works independently or in collaboration with other committees in the development of policy initiatives of import to patients; emphasizing transplant access, outcomes and patient safety
- Helps to develop educational resources for transplant candidates, donors and families

Current Roster

- 21 Members:
 - Surgeons/Physicians – 2
 - OPO Staff – 2
 - TX Administrators – 2
 - TX Coordinator – 2
 - Candidates/Donors/Recipients – 9
 - TX Psychiatry/Social Worker – 1
 - Minority – 2
 - Female - 12

Geographic Distribution



Focus 2010-2011

- PAC has had an ongoing interest in Patient Notification – specifically Waitlist Notification
- Discovered Patient Notification was the number one issue for which centers were cited on survey
- Investigated means for addressing this issue

Three-Pronged Approach


- Proper Positioning and Plain Language rewrite of UNOS Bylaws Appendix B.11.F
- Plain Language Rewrite of the Patient Information Letter
- Transplant Community Education regarding requirements of UNOS Bylaws Appendix B.11.F

Bylaw Rewrite

- Investigated potential for Plain Language Rewrite of the Bylaw and re-positioning from Bylaw to Policy
- Determined that the Bylaw Rewrite Project would affect both of these changes

Patient Information Letter

- Plain Language Rewrite
- Committee developed language
- Healthcare Icons Added





UNOS DONATE LIFE
UNITED NETWORK FOR ORGAN SHARING

Since 1981 — sharing organs, sharing data, sharing life.


700 North 10th Street, Richmond, VA 23228
703-304-2183, Richmond, VA 23228
toll-free: 1-888-894-6361
www.unos.org

OPTN/UNOS: Your Resource for Organ Transplant Information

 If you have a question regarding your own medical care, you always should call your transplant center first. However, for general organ transplant-related information, you can call the United Network for Organ Sharing (UNOS) toll-free patient services line at 1-888-894-6361.


 Anyone, including potential transplant candidates, recipients, family members/friends, living donors, and/or donor family members can call this number to:

- talk about organ donation, living donation, how transplant and donation work, the donation process, transplant policies, and transplant/donor information;
- get a free patient information kit with helpful booklets, waiting list and transplant information, and a list of all transplant centers;
- ask questions about the Organ Procurement and Transplantation Network (OPTN) web site (www.optn.transplant.hrsa.gov); the UNOS Web site (www.unos.org); or the UNOS web site for living donors and transplant recipients (www.transplantliving.org);
- learn how UNOS and the OPTN can help you;
- talk about any concerns that you may have with a transplant center and how they perform

 UNOS is a not-for-profit organization that provides all of the administrative services for the national OPIN under federal contract to the Health Resources and Services Administration (HRSA), an agency under the U.S. Department of Health and Human Services (HHS).

UNOS and OPTN responsibilities include:

- writing educational material for patients, the public and professionals;
- helping to make people aware of the need for donated organs and tissue;
- writing organ transplant policy with help from doctors, nurses, transplant patients/candidates, donor families, living donors, and the public;
- coordinating the organ matching and placement process;
- collecting information about every organ transplant and donation that occurs in the United States.

 Remember, you should contact your transplant center directly if you have questions or concerns about your own medical care including medical records, work-up progress and test reports. UNOS is not your transplant center, and staff at UNOS will not be able to transfer you to your transplant center, so keep your transplant center's phone number handy. But, while you research your transplant needs and learn as much as you can about transplantation and donation, we welcome your call to our toll-free patient services line at 1-888-894-6361.

UNOS PIL Final Rev 10-27-2010.1

Patient Information Letter

- Now Active on the OPTN website under Professional Resources
- Spanish Version is on the web
- Working on versions in Chinese, French and Tagalog

Community Education

- The Committee authored a series of three articles for the UPDATE on patient notification and the benefits of the Patient Information letter
- These included personal narratives from a kidney candidate, a lung recipient and two living donors.
- The Living Donor Article will also appear in an upcoming issue of AAKP's RENALIFE

An Introduction to Patient Notification

- The Committee sponsored a webinar on Patient Notification with DEQ
- Retrospective on Patient Notification within the OPTN
- Detailed Overview of current notification requirements
- Best Practice Guidelines

Waitlist Notification Quick Reference Guide

- A one page overview of the Patient Notification Requirements
- Contains sample language
- Includes links to the evaluation plan for further guidance
- Available on the OPTN website

OPTN The Organ Procurement and Transplantation Network **UNOS** **DONATE LIFE**
UNITED NETWORK FOR ORGAN SHARING

Waitlist Notification Quick Reference Guide

The Waitlist Notification Quick Reference Guide provides a concise overview of the OPTN patient waiting list notification requirements, effective March 2011. This Guide is not a comprehensive guide to all OPTN notification requirements. It is simply a summary of the requirements for notifying patients about their placement on or removal from the waiting list. This Quick Reference Guide will help you comply with the requirements defined in the OPTN/UNOS Bylaws Section II, Transplant Hospitals and B.11.F Appendix B, Attachment I, XIII-Transplant Programs Patient Notification, Section 13. <http://www.unos.org/about/index.php?topic=bylaws>

Wait List Notification Requirements

Transplant Hospitals are expected to notify patients in writing within 10 business days of when:

- The candidate evaluation has been completed but the candidate will not be placed on the waiting list.
- The candidate is placed on the waiting list. *Note: The Date of Listing should be included in the body of the letter.*
- The candidate is removed from the waiting list for reasons other than transplant or death. *Note: This requirement is waived if the candidate dies within the 10-day requirement.*

Each Notification must include the following items:

1. A written statement from the Transplant Hospital explaining, in detail, the reason the notification is being sent. It must be in one sentence that refers to the attached OPTN/UNOS Patient Information Letter. Sample language may be found online at <http://open.transplant.hrsa.gov/resources/professionalResources.asp>

Waitlist Notification Compliance Tips

- Be sure to include *both* the Patient Notification Letter from the Transplant Hospital and the OPTN/UNOS Patient Information Letter.
- Be sure that the date on the Hospital Patient Notification Letter is within 10 business days as required in the Bylaws. *Note: 10 days is an OPTN/UNOS Bylaw requirement and may differ from any similar CMS Requirements.*
- If the removal date is included in the body of the letter, make sure that it is accurate. *Note: The removal date is not required.*
- Be sure that the Patient Notification Letter states that the candidate has been either added or removed from the waiting list.
- The UNOS Patient Services Phone Line number (888-894-6361) should *not* be included in the Patient Notification Letter.
- Include a statement that refers to the OPTN/UNOS Patient Information Letter which is included with the Transplant Hospital Patient Notification Letter.
- Keep documentation of all Patient Notification correspondence for future compliance monitoring.

<http://unos.pearstreammedia.com/stores/streaming/seminar-iaunon.php?eyo831/DWVIGdH7er5UnU8dPq1Mu4ex2e7e672er4h3D>
GLN Date 3/9/2011
Version: 1.0

Ongoing Webinar Follow-up

- Introduced patientnotify@unos.org
- This provides a single portal for centers to ask Patient Notification Questions
- Monitored by the Liaison to PAC
- Requests are sent out to the appropriate resource for response
- To Date has received over 75 contacts

Monitors

- Immediate Monitor:
 - Webinar Evaluations
 - Requests to patientnotify@unos.org
- Short Term Monitor:
 - Overall change in Patient Notification Citations
- Long Term Monitor
 - Kept list of participating centers
 - DEQ will provide summary report of Patient Notification Outcomes from scheduled site surveys over the next survey cycle

‘What Every Patient Needs to Know’

- Privately funded patient education resource
- Distributed through the Patient Store for centers and through the Patient Information Line for individual patients
- Approximately 60,000 distributed annually

‘What Every Patient Needs to Know’

- Historically written by UNOS staff
- New version written by the Committee
- More personalized tone
- Written by patients, for patients
- Incorporated issues which patients said they needed to know

2010-2011 PAC Members

- Ray Gabel – Chair
- Laura Ellsworth – Vice-Chair
- Keith Diaz
- James Gleason
- Kathleen Giery
- Joseph Sharp
- Le Ann Stamos
- Kristie Lemmon
- Alison Walsh
- Merle Zuel
- Shari Kurzrok Schnall
- Laura Stillion
- Karen Starr
- Doni Bell
- Kathe LeBeau
- Sidney Locks
- Kim McMahon
- Thomas Starr
- Isabel Stenzel Byrnes
- Heidi Yeh MD
- David Zaas MD

PAC Roster Continued

- Thomas Falsey,
Visiting Board
Member
- Donna Banks,
Visiting Board
Member
- Bertram Kasiske,
SRTR
- Holly Berilla,
Ex-Officio
- Chinyere Amaefule,
Ex-Officio

Support Staff

- William Lawrence, Dir. UNOS
- Anna Kucherayavaya, Biostatistician
 - Stacey Burson, Business Analyst
 - Freda Wilkins, Liaison

QUESTIONS?

OPTN

