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

Ray Gabel, Chair
Laura Ellsworth, Vice-Chair
Richmond Virginia
June 28 – 29, 2011
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

OPTN
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

OPTN
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

OPTN

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 transplantation information, you can call the United Network for Organ Sharing (UNOS) toll-free patient services line at 1-800-879-6465.

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) website (www.optn.transplant.hrsa.gov), the UNOS website (www.unos.org), or the UNOS website for living donors and transplant recipients (www.transplanting.org).
- Learn more about 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 an independent, not-for-profit organization that provides all of the administrative services for the national OPTN under 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 materials for patients, the public, and professionals.
- Helping to make people aware of the need for donated organs and tissues.
- 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 results. UNOS is not your transplant center, and staff at UNOS will not be able to provide you with 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 1-800-879-6465.
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
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
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

OPTN
‘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

OPTN
PAC Roster Continued

- Thomas Falsey, Visiting Board Member
- Donna Banks, Visiting Board Member
- Bertram Kasiske, SRTR

- Holly Berilla, Ex-Officio
- Chinyere Amaefule, Ex-Officio

OPTN
Support Staff

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