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

Laura Ellsworth, Chair
Kristie Lemmon, Vice Chair
Richmond Virginia
June, 2013
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

- 23 Members:
  - Surgeons/Physicians – 2
  - OPO Staff – 2
  - TX Administrators – 1
  - TX Coordinators – 2
  - Candidates/Donors/Recipients – 14
  - TX Psychiatry/Social Worker – 1
  - Minority – 2
  - Female - 14
PAC Project Highlights

- Teen Adherence Project (TAP)
- Wait Time Transfer
- Non-Renal Solid Organ Transplant Priority
- Patient Notification
- Social Media
Teen Adherence Project (TAP)

- Review and identify teen adherence and transition educational resources and practices

- Partner with the Pediatric Transplantation Committee

- Develop professional education resources on teen adherence and transition based on effective practices
Wait Time Transfer

- Collaboration with the Operations and Safety Committee
  - Policy 3.2.1.9 Wait Time Transfer
  - Bylaw Appendix K Mass Wait Time Transfer

- Establish consensus on definitions

- Clarify policy and areas of responsibility

- Clarify definitions and processes for transfer of waiting time
Non-Renal Solid Organ Transplant Priority

- 1.3% of current kidney-only candidates are recipients of previous non-renal solid organ transplants

- Candidates are:
  - More highly sensitized
  - Longer wait times
  - Greater potential for death on the waiting list

- Loss of functioning non-renal graft

- Committee requested that the Kidney Transplantation Committee review impact of newly proposed KAS on this population
2010 vs. 2012 – Patient Notification Post-Education Survey Results

**2010**
- Red – Non-compliance: 31%
- Blue - Compliance: 69%

**2012**
- Red – Non-compliance: 16.2%
- Blue - Compliance: 83.8%

Red – Non-compliance
Blue - Compliance
Social Media and Transplantation

- Increasing usage among candidates
- Positive impact
- Risks

Committee Goal
- Develop means of encouraging responsible use of Social Media
- Provide resources for transplant programs to use in educating patients
Questions?

- Laura Ellsworth
  Chair, Patient Affairs Committee
  Laura.Ellsworth@ppvotesnorthwest.org

- Freda Wilkins
  Liaison, Patient Affairs Committee
  Freda.Wilkins@unos.org

*Special thanks to Anna Kucherayavaya, Bill Lawrence, and the entire Committee!*