

# 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

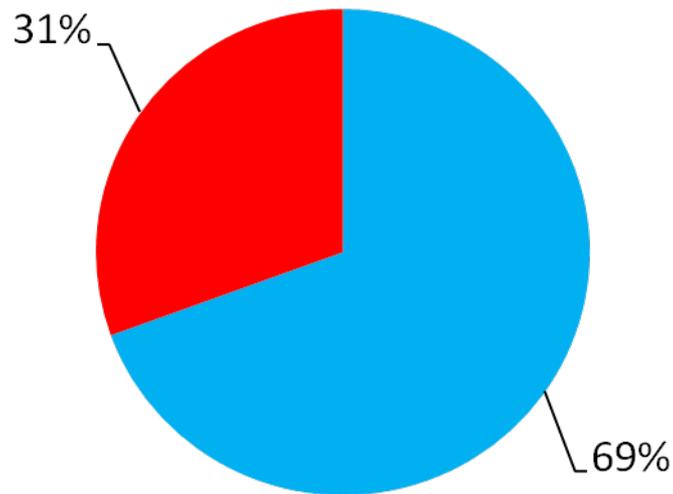
- Collaboration with the Operations and Safety Committee
  - Policy 3.2.1.9 Wait Time Transfer
  - Bylaw Appendix K Mass Wait Time Transfer
- Establish consensus on definitions
- Clarify policy and areas of responsibility
- Clarify definitions and processes for transfer of waiting time

# 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

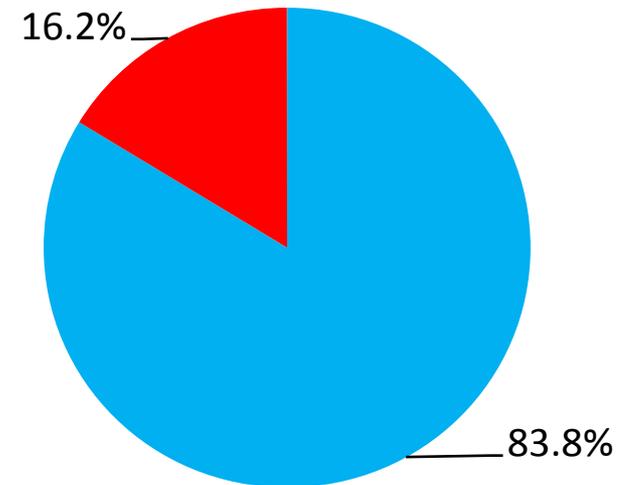
2010



Red – Non-compliance

Blue - Compliance

2012



# 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

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

# QUESTIONS

OPTN