

**OPTN/UNOS Patient Affairs Committee  
Meeting Summary  
August 7, 2014  
Conference Call**

**Kristie Lemmon, Chair  
John Fallgren, Vice Chair**

*Discussions of the full committee on August 7, 2014 are summarized below and will be reflected in the committee's next report to the OPTN/UNOS Board of Directors. Meeting summaries and reports to the Board are available at <http://optn.transplant.hrsa.gov>.*

**Committee Projects**

**1. Project to clarify the language for Individual Wait Time Transfer Subcommittee Update**

The Committee received an update on the work of the Individual Wait Time Transfer Subcommittee. The Subcommittee is completing a draft of proposed policy language to present to the Committee during the October Chicago Meeting.

**2. Update of *What Every Patient Needs to Know***

The Committee received an introduction to the new project to update the existing patient resource, *What Every Patient Needs to Know (WEP)*. The Committee has been involved in the writing, design and update of WEP since its inception in the 1990's. WEP is a patient-focused resource which is intended to cover the transplant process, from diagnosis through listing for transplant from the perspective of patients and families. WEP uses a short, question and answer and list format. During the 2010 rewrite, the Committee hoped to develop a resource which could easily be followed by persons with limited focus due to poor health.

The Committee will collaborate with UNOS Communications and other departments within UNOS to update WEP to reflect changes in policy and accepted transplant practice since the 2010 rewrite. The goal of the project over the next month is to convene a subcommittee to begin defining the work for the project.

**Committee Projects Pending Implementation**

**3. None**

**Implemented Committee Projects**

**4. None**

**Review of Public Comment Proposals**

**5. None**

## Other Significant Items

### **6. VCA (Vascular Composite Allograft) Policy Implementation Process: Surgery used to reconstruct tissue damaged typically by trauma, infection or sepsis. Typically refers to hand and facial transplants.**

In a Federal Register Notice published July 3, 2014, the U.S. Department of Health and Human Services announced that vascular composite allografts (VCAs) would be added to the definition of organs covered by federal regulation (the OPTN Final Rule) and legislation (the National Organ Transplant Act). VCA includes hand and facial transplants.

VCA is a new concept to many within the transplant community. Donation for hand and facial transplants has potential to illicit a strong emotional response from both donor families and the public at large. The Committee is always concerned with anything that has potential to erode public trust in the transplant system. Therefore, the Committee seeks to collaborate with the VCA Committee in shaping the message that goes to the general public and the methods used to approach potential donor families.

This is the second presentation the Committee has received on VCA, in preparation for the expected VCA policy proposals that will be released for Public Comment, Fall, 2014.

The presentation provided a broad overview of the following:

- Definition of VCA
- VCA transplant activity to date
- Introduction to the VCA Committee
- Historical perspective on current VCA policy
- VCA Allocation

The Committee followed the presentation with active discussion around the following areas:

- Emotional impact of pictures
- 'Miraculous' recovery of function and form for recipients
- Value of in-depth psychosocial evaluation for candidates
- Psychological impact on the general public when initially introduced to VCA
- Importance of sensitivity in the approach to living donors

The VCA Committee asked that the Patient Affairs Committee review the current VCA Guidance Document in preparation for the final presentation to the Board. A subcommittee was formed. The Committee will have follow-up discussion at the September Committee call.

### **7. Resource Review**

The Committee is currently involved in the review of the following resources:

- Liver Concept Document
- Policy Rewrite Quick Fix
- OPTN Website Review

These are continuing projects. The Committee will complete each project before the October Face-to-Face meeting.

**Upcoming Meetings**

- September Conference Call
- October 20, 2014 – Face-to-face Meeting in Chicago