

# OPTN/UNOS PATIENT AFFAIRS COMMITTEE INTERIM REPORT

February 2, 2012

## I. Update on PAC work for 2011

The Committee reviewed the PAC Charge and the work that was assigned in 2011. The Executive Committee asked that the Committee review the existing patient notification bylaw for both substantive changes and changes to language for the purposes of clarification. The Patient Notification Subcommittee has reviewed the proposed language from the Policy Rewrite project. The policy rewrite project proposes to move patient notification from bylaw to policy. This was a major recommendation from PAC. The subcommittee will review the issue of patient notification and bring final recommendations to the Committee.

## II. Process for Identifying and Assigning Work

The Committee reviewed the basic criteria for new projects:

- Projects must address an OPTN Goal
- Fit with the PAC charge
- Time Limited
- Measurable

## III. Potential Projects for 2012-2013

The Committee received a presentation outlining potential projects for 2012-2013. Each project met the potential work requirements. Recommendations were as follows:

### A. Plain Language Histocompatibility brochure

The Committee received a presentation from the Histocompatibility Committee during the January conference call. The presentation included an excellent plain language explanation of histocompatibility and PRA. The Committee could work with the Histo Committee and Communications to develop this proposal into a brochure to be used with patients and families. PAC would provide the patient focused language, while the Histo Committee would provide the clinical/technical input. Both Communications and the liaison to Histo have endorsed this idea.

Strengths:

- The basic language and graphics are already in place.
- This writing of this project could be accomplished within 4 to 6 weeks

Challenges:

- The Committee questioned the universal value of this project across all organ groups

- The Committee questioned whether the goals of this project could not be met within the organ-specific WEP project – to be discussed next in this report.

## B. Organ Specific *What Every Patient Needs to Know* Series

Communications has been integrally involved with the newly completed rewrite of *WEP*. Both the Committee and Communications recognize the mammoth undertaking that a full rewrite can be. The further limitation of doing a large book is that it cannot easily be updated as changes occur. It is also difficult to incorporate the nuances of waiting for different types of transplant because of the generic nature of the resource. Communications has approached the Committee regarding developing individual organ-specific version of *WEP*. Organ-specific *WEP*'s would have an average length of 4 – 8 pages. Each book would highlight the psychosocial experiences of transplant unique to that organ.

### Strengths:

- Provides a more detailed explanation of waiting for each organ from the candidate perspective
- Can be nimbly updated when changes occur within the transplant community
- The basic style and format for *WEP* is already in place

### Challenges:

- This would be a long term project

## C. Teen Adherence

During a subcommittee call, members of the Committee began to relate their personal experiences with compliance and managing a teenage transplant recipient. The stories were reflective of anecdotal stories across the spectrum of health care about managing and parenting a teenager with a chronic illness. Management of a chronic illness is counterintuitive to the teen developmental tasks of movement towards normalcy and autonomy. This is further complicated by a general feeling of invincibility experienced by many teens. The focus of the discussion was on the need for more socially and culturally relevant educational resources and reminders to:

- Help teens to feel more independent in graft management
- Help teens to better fit in with their peers as they manage their grafts
- Provide education in ways that would be socially and culturally relevant

In compliance with the currently suggested process for identifying committee work, the group set about defining the problem by requesting a preliminary review of the literature and data.

The literature confirmed the issues raised in the initial discussion:

- Teens are less likely to adhere to the prescribed treatment regime. This in part is reflective of the developmental tasks of teenagers
- Non-adherence with medications leads to an increased incidence of graft loss among teens and persons in their early twenties.
- Having had a previous transplant is one of the three ways that patients are sensitized to HLA. The other two are pregnancy and blood transfusions
- Highly sensitized candidates wait longer for transplant
- Highly sensitized candidates are more likely to die while waiting for transplant

Transplant data further supports the initial thesis set forth.

A review of available data on graft survival 5 years post-transplant shows an average of 25 – 30% graft loss across solid organ groups between the ages of 11 and 34. In liver and heart recipients, the highest percentage of graft loss was found among 11 to 17 years-olds. While kidney recipients saw the highest percentage of graft loss in the 26 to 34 year old age group.

A significant number of candidates who lose their grafts at a young age will be re-listed. An analysis of the waiting list shows the highest numbers of candidates awaiting re-transplant are in the 11 to 17 year old and 18 – 25 year old groups.

***Candidates on the Waiting List on November 30, 2011:***

Age Group	Retransplant?				Total	
	No		Yes			
	N	%	N	%	N	%
<=5	568	95.6	26	4.4	594	100.0
<b>6-10</b>	304	85.2	<b>53</b>	<b>14.8</b>	357	100.0
<b>11-17</b>	621	76.5	<b>191</b>	<b>23.5</b>	812	100.0
<b>18-25</b>	2,293	74.1	<b>802</b>	<b>25.9</b>	3,095	100.0
<b>26-34</b>	5,862	77.7	<b>1,682</b>	<b>22.3</b>	7,544	100.0
<b>35-49</b>	22,860	80.9	<b>5,398</b>	<b>19.1</b>	28,258	100.0
<b>50-64</b>	45,770	89.5	5,392	10.5	51,162	100.0

Age Group	Retransplant?				Total	
	No		Yes			
	N	%	N	%	N	%
<b>65+</b>	19,308	93.9	1,257	6.1	20,565	100.0
<b>Total</b>	97,586	86.8	14,801	13.2	112,387	100.0

**Based on OPTN data as of November 30, 2011  
Data subject to change based on future data submission or correction**

A review of data on candidates who received transplants in 2010 shows a similar pattern, with the highest percentage of re-transplants being done in the 26 to 34 year old age group. It can then be inferred that those transplanted lost their grafts between the ages of 11 and 33; were re-listed and then transplanted. A cumulative review shows that 9.1% of all transplants in 2010 were re-transplants.

**Transplants by Age Group – January, 2010 – December 2010**

Age Group	Retransplant?				Total	
	No		Yes			
	N	%	N	%	N	%
<b>&lt;=5</b>	756	95.6	35	4.4	791	100.0
<b>6-10</b>	274	91.3	26	8.7	300	100.0
<b>11-17</b>	662	89.9	74	10.1	736	100.0
<b>18-25</b>	961	87.7	135	12.3	1,096	100.0
<b>26-34</b>	1,756	82.4	374	17.6	2,130	100.0
<b>35-49</b>	5,983	86.7	914	13.3	6,897	100.0
<b>50-64</b>	11,544	92.9	876	7.1	12,420	100.0
<b>65+</b>	4,113	95.8	181	4.2	4,294	100.0

Age Group	Retransplant?				Total	
	No		Yes		N	%
	N	%	N	%		
<b>Total</b>	26,049	90.9	2,615	9.1	28,664	100.0

**Based on OPTN data as of November 25, 2011  
Data subject to change based on future data submission or correction**

A study compiled by the Kaiser Family Foundation and published in the New York Times, January 20, 2010 reports that youth ages 8 – 18 spend more than 7 ½ hours per day using devices such as smart phones, computers and televisions. These same youth spend an additional 1 ½ hours per day texting and 30 minutes per day on cell phones. Through multi-tasking, youth were found to compress 11 hours worth of media content into 7 ½ hours per day. This data is supported by similar data in recent Neilson Studies for 2010.

It can then be inferred that any educational and instrumental or reminder resources must be electronic in nature to be culturally relevant and promote normalcy among youth and teens.

The project proposal, then, is to create an evidence based education tool for teens. This tool should incorporate:

- Instrumental supports in the form of guidance from the transplant team and family
- Emotional supports including online support networks and support groups
- Self-management resources including, but not limited to smart phone applications, graphic novels, computer based games etc.

The Committee Leadership has already identified Smartphone application developers who are also transplant recipients to work in product development. Committee Member transplant centers have tentatively agreed to be a part of any pilot of materials that may be indicated. Development feels that financial resources can be identified to support product development and program piloting. The liaison to the Pediatrics Committee has indicated that this is an issue that the Committee is concerned about.

Strengths:

- Addresses an issue that the transplant community is passionate about
- Potential to indirectly decrease deaths on the waiting list
- Potential to introduce an entirely new resource into the transplant community
- Resources would have application beyond the teen population
- Smartphone applications would be developed by transplant recipients

- All resources would be piloted in transplant centers before being introduced to the public

Challenges:

- This will be a multi-year project
- Skill and expertise in multiple areas will be required

#### IV. Discussion

The Committee found merit in each suggested project. The Committee unanimously chose to go forward with the Teen Adherence Project Proposal. The Committee would also like to propose moving forward with a graduated *WEP* Organ-Specific Project. This graduated process would include developing no less than one organ specific book per year. This graduated timeline would allow the Committee to also address other projects while looking at Organ-Specific *WEP*.

#### V. Upcoming Meetings

The next Committee Conference/Live Meeting Call will be on Thursday April 5, 2012 at 3:00 PM EST.

The Committee Face-to-Face meeting dates have changed to:

- Monday May 21, 2012
- Monday October 22, 2012