

INTERIM REPORT OF THE OPTN/UNOS PEDIATRIC TRANSPLANTATION COMMITTEE

November 20, 2008
Chicago, Illinois

The OPTN/UNOS Pediatric Transplantation Committee met on November 20, 2008, and considered the following items:

Update Regarding Actions from the November 17-18, 2008 Board of Directors Meeting

The Committee discussed actions from the November 2008 Board of Directors (BOD) meeting. The report highlighted the most recent proposals the BOD passed. In particular, the BOD passed the Membership and Professional Standards Committee's proposal to better define functional inactivity; and the Living Donor Committee's proposal to require transplant centers to accept only those living donor organs that have been recovered at an OPTN member transplant hospitals. The Living Donor Committee's proposal was an issue for one pediatric center which does living donor recoveries at a non-OPTN member hospital. As that center was the only member specifically affected by this, the BOD thought it prudent to support the proposal. The UNOS Membership Department will work with this center in hopes of addressing its needs. In parallel with the extended conversation around this center, the BOD conferred that the responsibility of following up with living donor falls on the recovery center. This approach should shield pediatric centers from the challenges of following living donors.

The Committee liaison proceeded to report that the bulk of the meeting revolved around dissolving alternative allocation systems (AAS). The BOD dissolved a number of liver AAS's; however, it sent the Ohio statewide AAS back to the Liver Committee on account of new data presented to the Executive Committee that the Liver Committee had yet to review. The BOD also sent the Tennessee statewide pancreas variance back to the Pancreas Committee for further discussion, as it also contained new data that the Pancreas Committee had not reviewed. The BOD decided that the LifeSource Upper Midwest OPO pancreas AAS will stay in place for three years, at which point it will be reevaluated. The BOD voted to remove all other AAS's that it discussed from the system.

Review and Consideration of Public Comment Proposals Released October 10, 2008

1. *Proposal to allow candidates who need a pancreas for technical reasons as part of a multiple organ transplant to be listed on the pancreas waiting list – Policies Affected: Policy 3.2.7 (Pancreas Waiting List Criteria) and Policy 3.2.9 (Combined Kidney-Pancreas Waiting List Criteria) Pancreas Transplantation Committee*

The Committee's discussion of this proposal focused on follow up and forms that would need to be completed for the recipients of a pancreas for technical reasons. The Committee had concerns that the proposal does not fully address how graft outcomes are to be followed after classifying these patients as pancreas transplant recipients. The expectation as the proposal currently stands is that these forms will likely be completed as "lost to follow up." A Committee

member proposed that upon a pancreas being denoted as transplanted for technical reasons, that the requirement for follow-up forms for that pancreas is eliminated. In response, a SRTR representative indicated that one would want to be able to capture the pancreatic graft loss. Conversation focused on when to indicate the pancreas is lost, and the Committee elicited that it would be best for a pancreas transplanted for technical reasons to be considered lost at the time of the transplant. In terms of multi-visceral transplants, discussion indicated that it is likely necessary to include the classifications: transplanted for technical reasons-function not required and transplanted for technical reasons- function required.

A Committee member raised a final question as to whether the remainder of a pancreas that is transplanted for technical reasons could be used for islets. Another Committee member responded that whole organ prep for islets is likely better, but a segment would be potentially usable and that this is something that could be considered.

The Committee approved a motion to support the proposal as written, but suggests when it is time to make changes to the follow-up forms that revisions are made to minimize the impact on transplant centers that are taking the pancreas solely for technical reasons. The revision of the forms should also include questions which will give some meaningful data as current forms do not provide any questions that can be answered for a pancreas used for technical reasons. (Committee Vote: 14 in favor, 0 opposed, 0 abstentions)

2. *Proposal to clarify islet allocation protocol – Policy Affected: Policy 3.8.1.6 (Islet Allocation Protocol) Pancreas Transplantation Committee*

The Committee briefly reviewed this policy proposal and agreed that although this is an interesting topic for discussion, it has no pediatric relevance. Accordingly, there was no further discussion and no vote.

3. *Proposal to increase the safety of allocations to candidates who do not appear on the match run – Policies Affected: Policy 3.1 (Definitions), Policy 3.2.4 (Match System Access), and Policy 3.9.3 (Organ Allocation to Multiple Organ Transplant Candidates) Membership and Professional Standards Committee (MPSC)*

The Committee discussed this policy proposal, and conversation focused on the multi-organ implications of this proposal. The Committee had concern that this policy will add a layer of complexity to an already complex process, likely yielding inefficiencies in the system. It is felt that a bigger, all inclusive perspective is necessary to analyze multi-organ transplant listings and matching from top to bottom. Rather than put band aides on the system to make it more complex, the Committee suggested that UNOS should look at multi-organ transplants and redesign the system to solve these problems more clearly.

The Committee voted to support the proposal, making note that it believes a complete analysis and redesign of multi-organ listing, matching, and allocation needs to be approached.
(Committee Vote: 14 in favor, 0 opposed, 0 abstentions)

4. *Proposal to clarify, reorganize and update OPO policies to align with current practices – Policy Affected: Policy 2.0 (Minimum Procurement Standards for an Organ Procurement Organization) Organ Procurement Organization (OPO) Committee*

The Committee briefly reviewed the proposal. There were no comments as the Committee felt this was not necessarily a pediatric issue, and it did not vote on the proposal.

Discussion of the OPTN Final Rule Requirements for Organ Allocation Policy

Status of Kidney Allocation Policy Review

Dr. Sharon Bartosh, the Kidney Working Group Chair, led the discussion surrounding the ongoing review of the effects of Share 35. Dr. Bartosh reported that the Kidney Working Group met in September, and has been concentrating on the effect that Share 35 has had on kidney allocation to pediatric patients. There have been very positive effects as a result of Share 35:

- The number of pediatric kidney refusals has declined.
- Transplant rates for children (transplant rate per active patient years on the wait list) has improved for children except for those highly sensitized (PRA \geq 80%).
- Median waiting time for children has decreased for in all age groups.

The Kidney Working Group has also carefully looked at whether or not there has been much utilization of donors above the age of 35. This appears to not be an issue, thus the pediatric patients are receiving young, presumably healthy, deceased kidney donors.

Dr. Bartosh reported that there has not been any detriment to graft survival in children, post Share 35. In addition, the group has looked at graft survival for recipients of living donor transplants as compared to recipients of deceased donor transplants. Although members have not seen any decrease in graft survival for children, the data does reflect a decrease in the percentage of children who are receiving living donor transplants. The decrease in living donation transplants in children is being seen both in the absolute number and overall percentage, and spans across all the age groups (with adolescents being affected the most). These data looking at the decrease in living donor donation was presented at the March PAS meeting (Hawaii) and May ATC meeting (Toronto).

Following Share 35, the data shows no increase in the percentage of the highly sensitized children who are getting transplanted. The percentage of children receiving zero antigen mismatched kidneys went from six percent before Share 35 to three percent following Share 35. This is a focus of the Kidney Working Group. At past meetings the Kidney Working Group, and Pediatric Committee as a whole, debated whether to address the unintended consequence of highly sensitized pediatrics mixed in with highly sensitized adults with the Kidney Allocation

Score based system (KAS) . Since KAS is progressing slowly, the issue needs to be addressed in the interim. The Kidney Working Group is searching for solutions to tweak the system to give highly sensitized pediatrics priority instead of simply saying priorities that had been taken away from pediatrics should be reinstated.

- *KPSAM assessment of the impact of run 3b on the number of kidney transplants in highly sensitized adults (PRA >= 80%) – Consequences of Increased Pediatric Priority (SRTR Presentation)*

Dr. John Magee, SRTR Liaison, presented data based on the most recent iteration of a KPSAM assessment of the number of kidney transplants in highly sensitized adults (PRA>=80%) under the assumption of regional sharing for highly sensitized pediatric patients (PRA >=80%) for all deceased donors. SRTR generated two runs, their assumptions were:

- First Requested Run (Run 3a)
 - Prioritize highly sensitized (PRA>=80%) zero antigen mismatch pediatric candidates over highly sensitized zero antigen mismatch adults in the kidney allocation algorithm for all standard criteria (SCD) deceased kidney donors, regardless of donor age.
- Second Requested Run (Run 3b)
 - In addition to the allocation changes made in the first requested run, classifying regional sensitized (PRA>=80%) non-zero antigen mismatch pediatric kidney candidates with local non-zero antigen mismatch candidates according to points (Regional Sharing) for all SCD deceased kidney donors.

These two runs produced the following results:

Expected Number of KI Alone Transplants			
Mean and Standard Deviation of 3 runs			
Transplant	Current Rules	1. 0MM PRA ≥ 80% pediatric patients over PRA ≥ 80% adults	2. Add Regional sharing for pediatric PRA ≥ 80%
Total Pediatric KI:	584 (26)	603 (9)	641 (9)
Pediatric PRA ≥ 80%	39 (5)	42 (6)	67 (3)
0MM Pediatric PRA ≥ 80%	4 (2)	6 (3)	6 (2)
Total Adult KI:	7670 (43)	7692 (53)	7625 (34)
Adult PRA ≥ 80%	988 (8)	1040 (19)	998 (46)
0MM Adult PRA ≥ 80%	142 (9)	150 (16)	137 (2)
Total KI:	8254(68)	8295(54)	8266(43)

SRTR

Following Dr. Magee's presentation of the data, the Committee proceeded with discussion. A Committee member posed the question whether regional sharing was investigated for pediatric and adult highly sensitized patients, with preference given to highly sensitized pediatrics over highly sensitized adults. The concern is that regional sharing for pediatrics alone will likely be unpalatable within the kidney transplant community as a whole, and that some benefit for adults should be included in any proposal. Dr. Magee responded this was not considered in the KPSAM run; however, his prediction is that those changes would not affect pediatrics and may increase the transplant number of highly sensitized adults while decreasing the number of unsensitized adult transplants, but ultimately keeping the total numbers the same.

Considering these assumptions, another Committee member expressed concern that highly populated, urban areas within a region may become "kidney sinks" due to an overwhelming number of highly sensitized patients compared to the rest of region. Other Committee members responded that they did not believe this would be an issue. The rationale being that most transplant centers have patients on their waiting lists waiting for a re-transplant, and accordingly, highly sensitive patients are spread throughout.

The Committee concluded the discussion by deciding to wait for the data including highly sensitized adults participation in regional sharing before sending these ideas and information elsewhere. This will then be discussed in the Kidney Working Group, which is expected lead to a Joint Pediatric-Kidney Subcommittee.

- *Analysis of Inactive pediatric Kidney Waiting List Registrations*

Dr. Wida Cherikh presented data pertaining to the Committee's concerns with the increasing number of inactive pediatric registrations on the waiting list. The data is stratified by age at listing (<1, 1-5, 6-10, 11-17) and included reason for inactivity, length of inactive time and time on the waiting list, and removal status. To summarize the data:

- Of the 1,137 pediatric kidney registrations on the wait list in December 2007, 618 (54%) were inactive as of 12/31/07.
- The percentages of inactive registrations were higher than the active registrations in the 1-5 year (63%) and 11-17 year age groups (54%).
- The most common reasons for inactive status were incomplete work-up (31%) and temporarily too sick (19%).
- Nearly a third of the registrations that were on the kidney wait list for one year or more and were inactive on 12/31/07 had never been active.
- Of the 618 inactive registrations from 12/31/07, as of 10/17/08:
 - 359 (58%) were still waiting in inactive status.
 - 53 (9%) were still waiting in active status.
 - 140 (23%) had received a kidney transplant.
 - 10 (2%) had died.

The Committee Chair led the discussion by stating that these data are startling, but why is this important? What are the problems with leaving the system as is?

A Committee member opined that the volume of inactive registrations is not disadvantaging other patients; however, prematurely listing patients while they are young only to capitalize on pediatric priority could be perceived as taking advantage of the system. This Committee member felt that arbitrary listings should be investigated and transplant centers should have some set of established waitlist criteria. Another Committee member retorted that she did not think that was an issue, except for those adolescents about to turn 18. Another Committee member pointed out that this does disadvantage patients- every candidate that is listed after the "questionable listing" is potentially affected. He also contended that no patient should be waitlisted until their workup is complete, and that tightening waitlist requirements may be beneficial to both pediatric and adult candidates.

Another point raised by a Committee member in discussion of the pediatric inactive registrations was the accuracy of the data. The volume and time of inactivity is correct, but the reasons given could be inaccurate. Those filling out the forms may be entering data for the sake of completion, as they may not know the complete reason a patient is inactive. This elicited a response from another Committee member that forms gathering information about inactivity should be altered to assure there are honest categories that provide valuable data. The forms should include a serial estimate of renal function to determine if patients are actual transplant candidates or listed inappropriately. Ideas were presented that GFR at listing or dialysis dates could be investigated. The Committee agreed that if the prolonged pediatric patients could be better categorized, this would assist in developing any beneficial policy changes. Along the lines of further analyzing these inactive patients, a Committee member proposed that the distribution of inactive pediatric patients be examined. In theory there should be an even distribution across the country, but it would be telling if a significant number of inactive pediatric patients are only at a couple of transplant centers.

A Committee member hypothesized that some of the inactive patients could be inactive as a function of that patient waiting for a living donor. Working up a living donor takes time, and certain situations arise which would extend those time frames even greater. If this is a significant reason for pediatric inactivity, an idea was posed (in the spirit of more helpful data) that there be another category for "Inactive- Waiting for a Living Donor."

Another Committee member brought forth three unique comments. First, he stated that in moving forward with this discussion is important to keep in mind that KAS is going to alter the dynamics of waiting list in terms of getting to transplant (although more so for adults than pediatrics). Second, this issue is not unique to pediatrics and it might be helpful to confer with the Kidney Committee about their perception of the issue and how it would apply to adults. The final comment was that the Committee may want to refer this to the MPSC for them to consider not only looking at functional inactivity of programs, but also inactivity of the patients on their

list at any given time. Dr. Bartosh, who is also a member of the MPSC, stated she would bring this final comment to the attention of the MPSC Chair.

The discussion around this topic concluded with notion that the Committee should tread carefully in pursuing this topic. The Chair noted that it must be remembered that the current system may in fact be serving pediatric patients best. A Committee member cautioned bringing undue attention to the fact that patients who are waitlisted before their 18th birthday receive pediatric priority, regardless of how long they stay on the wait list. This is a great advantage for pediatric patients, but continually spotlighting it may bring questions and criticism that could ultimately disadvantage pediatric patients. This provoked a comment that the progression from childhood to adulthood should be seen as a continuum. The idea that one's 18th birthday is a biological cut off is impractical, and hopefully this issue will be built into KAS.

- *Characteristics of Living donors pre- and post-Share 35 policy implementation (SRTR Presentation)*

Ms. Kathryn Meyer of SRTR presented a table of data that investigated pediatric transplants from living donors before and after Share 35's implementation. The data presented and discussed can be found below.

	Mean		SD	
	Pre	Post	Pre	Post
Donor male	50.6%	45.2%	50.1%	49.8%
Donor race: Black	8.8%	9.0%	28.4%	28.6%
Donor race: Asian	2.1%	3.3%	14.3%	17.9%
Donor race: Hispanic/Latino	16.5%	15.6%	37.1%	36.3%
Donor race: White	72.4%	71.6%	44.8%	45.2%
Donor age in years at time of recovery	37.3	37.6	8.7	8.6
Donor age >35	64.0%	66.5%	48.0%	47.3%
Donor weight in kilograms	80.1	77.8	16.4	15.9
Donor BMI	27.0	27.4	4.3	4.6

The data show that while there are small differences, in no case does the difference approach a single standard deviation. Also, none are statistically significant. The Committee agreed that this data was not helpful in deciphering the decrease in living donors, and did not provide insight as to if pediatric decreases in living donors are the same reasons as a decrease in adult living donors.

Committee members hypothesized some explanations to the living donor decrease. One suggestion is that centers are becoming more stringent in who they will accept as a living donor, out of concern for the living donor. Another idea was that transplant centers are not pursuing living donation as much.

The discussion of this topic concluded with the intentions of setting up a Joint Pediatric-Kidney-Living Donor Subcommittee to investigate all the reasons behind these trends.

Status of Liver and Intestinal Organ Allocation Policy Review

- *Liver-Intestine Working Group Update*

The Committee Chair led the discussion. It is thought that enough time has elapsed since the implementation of policy to identify splittable livers and there should be significant data that can now be analyzed. The Chair made a point to say that this needs to be in the forefront of the Liver Committee as their input is crucial to this potential avenue of increasing the number of patients that receive a liver transplant. The Chair suggested that it may be helpful if ACOT made the same overtures to the Liver Committee as it did the Pediatric Committee. This may aid in increasing the priority of raising the number of split liver transplants. Part of the split liver discussion must include revisions to OPTN Policy 3.6 **Allocation of Livers** (i) & (ii), to achieve plain language for this section of policy. The Liver and Policy Oversight Committees have reviewed the entire liver policy, and the Liver-Intestine Working Group could likely borrow heavily from those reviews so as to not duplicate efforts.

During this conversation a Committee Member made an inquiry about one-year graft and patient survival of split liver transplants and the age breakdown (pediatric vs. adult) of recipients of split liver transplants. The Committee also requested that the splittable liver policy implemented in late 2007 be evaluated with regard to how often both segments were actually transplanted or one segment was discarded when the livers met the splittable criteria.

A Committee member raised the question if requirements could be made to mandate splitting livers in certain circumstances. The Chair responded that the current climate in the liver transplant community is such that it is unlikely this would ever happen. Another Committee member suggested an idea that would essentially make splitting mandatory. His idea was to increase the age that pediatrics received preference. For example, all pediatrics would receive priority for a donor aged <18, and 0-11 year old recipients would receive priority for all donors <35, similar to kidney. In this example the pediatric patients that received priority from donors aged 18-34 would not likely use the whole liver, and accordingly would yield more splits. Other Committee members express some concern with this approach. Those being some liver's anatomy render them unable to be split, not all pediatric centers split or are able to split livers, and an overall concern of the adult community's reaction to such an idea. To solve some of those problems, it could be included in policy that this allocation schema would only apply if a split liver transplant is to occur. A Committee SRTR representative indicated that modeling could be done for this concept. The discussion concluded that the Committee would wait to see the data that is generated, and then proceed to refer this topic to the Liver Committee.

This discussion led to the summary and conversation of Liver and Intestine Working Group's teleconference review of the MPSC's proposal to alter the bylaws pertaining to conditional status of living donor liver programs. The question posed to the Committee is whether those conditions should be revised for pediatric programs. The Working Group supported the proposal, but had a lot of discussion as to the volume thresholds that were set. Multiple other

Committees echoed this same sentiment. The MPSC is interested in forming a joint subcommittee with the Pediatric and Living Donor Committees. A Committee member provided feedback from the Liver Committee meeting, which convened the previous day. He stated that the Liver Committee chair is pushing to separate completely pediatric center qualifications. The Committee member reported that the Liver Committee's Chair's feelings are that the only requirement for a pediatric living donor program is a transplant surgeon. He continued that no one at the Liver Committee meeting disagreed that you needed anything more than a single transplant surgeon to if a center is only performing left lateral segment living donor transplants.

Status of Thoracic Organ Allocation Policy Review

- *Thoracic Working Group Update*

The Vice Chair of the Committee led the discussion updating the group on the Thoracic Working Group. During the last teleconference call in September, the group primarily discussed the implementation of the broader sharing of heart and lungs, and the status changes that are coming for <12 year old heart-lung and lung candidates. Much of the conversation dealt with housekeeping issues and addressing UNOS IT's questions.

Aaron Powell, representing the UNOS IT department, explained the difficulties that have been uncovered with the lung broader sharing as it stands. He stated the policy as written is relatively prescriptive as to how the design of the system should work. Difficulties were noticed in tracking time at a status for candidates, and working through which patients are the sickest of a relatively small cohort. This is an extremely large effort for the relatively limited circumstances when these distinctions are required considering the small volume of candidates. There are concerns about folding this data into LAS for such a small number of patients, and suggested more of a "justification form" approach, creating a second page for this documentation rather than putting it within the structure of the LAS forms in UNetSM. This will be discussed in further detail at an upcoming conference call with the Heart-Lung Working Group and UNOS IT. It is believed that changes that need to be made will be relatively minor from a policy perspective, and should be able to go straight to the Executive Committee for approval.

Status of Pancreas Allocation Policy Review

- *Pancreas Waiting List Criteria Policy Revision Memo*

The Pancreas Committee sent a memo to the Committee in response to its feedback regarding an edit to OPTN Policy 3.2.7 **Pancreas Waiting List Criteria**. This topic was covered earlier during the public comment documents review. The summary of that discussion can be found above.

- *Allocation of Deceased Donor Kidneys from Donors <35 – FINAL REVISED Data from the Joint Pediatric-Pancreas Subcommittee*

The Committee had reviewed a data set at its last meeting as a result of efforts from the Joint Pediatric-Pancreas Subcommittee. There have been some minor revisions and the data was included in the Committee Packet for all those that were interested. The Committee had no further comment or discussion. The updated data can be found below.

Table 1. Kidney Allocation Pre- and Post-Share 35

Recipient Group	09/28/2005 – 06/30/2008		12/27/2002 – 09/27/2005		Total	
	#	%	#	%	#	%
One Tx: Both Kidneys to Adult Multi-organ Recipient	8	.1	8	.1	16	.1
One Tx: Other	760	10.2	660	9.8	1420	10.0
Two Tx: Both Adult Multi-organ Recipients	171	2.3	136	2.0	307	2.2
Two Tx: Both Adult Recipients	5249	70.8	5239	77.6	10488	74.0
Two Tx: Both Pediatric Recipients	175	2.4	47	.7	222	1.6
Two Tx: One Pediatric Recipient, One Adult Recipient	1053	14.2	660	9.8	1713	12.1
Total	7416	100.0	6750	100.0	14166	100.0

Joint Pediatric-OPO Subcommittee Update

- *Donor Management Guidelines Memo, dated October 14, 2008 from the OPO Committee*

The Committee received a response from the OPO Committee pertaining to the ongoing discussion between the two committees. The OPO Committee reported that it does not feel best practices guidelines for conflict resolutions in the OR are necessary. The OPO Committee’s opinion is that the medical director from an OPO should be utilized to negotiate such situations appropriately, and should always be available for consultation. The memo from the OPO Committee, as well as the resulting conversation among the Committee, stressed that open communication between teams is imperative.

The Committee’s discussion continued and highlighted that the few instances that have come up seem to be individual and isolated- not a common issue that can be legislated. Rather, a process should be established which the memo touches on and lays out a method of adjudication. A Committee member posed the question that instead of a blanket resolution protocol, could it be expected that each OPO establish its own guidelines. Another Committee member questioned the practicality of this, stating he was not sure the guidelines would be followed even if set up considering seniority, politics, and other factors in the operating room.

The Committee’s OPO representatives drove the remainder of the conversation indicating that it is every OPO’s goal to recover and transplant as many organs as possible; to do something

counterproductive just doesn't make sense. Furthermore, the issue at hand could be a result of coordinator inexperience.

The Committee concluded this conversation by ultimately deciding to wait and see if similar situations occur before it pursues the matter further.

- *Definition of Multi-System Organ Failure Memo, dated October 20, 2008 from the OPO Committee*

The Pediatric Committee's Chair and OPO representatives led this discussion. The OPO representatives explained some of the expectations of OPOs pertaining to imminent and eligible deaths, as well as the challenges of varying interpretations of multi-system organ failure. As the discussion surrounding the requested input progressed, a Committee member stated multisystem organ failure is a syndrome of altered organ function in the situation of a severely systemically ill patient often, but not necessarily, due to sepsis. It is not the sum of individually failing organ systems. A Committee member suggested that good definitions can be found in text books and that attempting to recreate those definitions is unnecessary, and will not ultimately help to achieve the OPO Committee's objectives. Furthermore, multiple Committee members indicated that each scenario is different, therefore rendering it difficult to form an absolute and useful definition of specific organ failure. Based on this, the Committee continued a somewhat confounded discussion as it was not sure of the OPO Committee's goals or exactly what type of feedback it seeks from the Pediatric Committee. The Committee concluded the discussion of this item without a formal response to the questions posed for consideration. The Committee agreed that if the OPO Committee would like to provide a representative to explain its goals regarding this memorandum and what type of feedback it requests, then the Pediatric Committee will conduct additional discussion to provide further feedback.

- *Comments from Region 10 Meeting Related to the Increasing Difficulty Involved in Multiple Organs Using the More Complex Allocation Algorithms*

The Committee Liaison brought forth a conversation that she had with a hospital administrator who was sent to the Region 10 Meeting in the stead of the Committee's Region 10 representative, who was unable to attend. She expressed many concerns regarding the placement of combined organs. She noted that it is becoming increasingly difficult to place multi-visceral organs due to current allocation algorithms and policies. The central tenant to her concerns was a fear that pediatric patients were being disadvantaged and missing multiple organ transplants that they needed. Her suggestion was a multi-visceral list for pediatric patients. The Chair asked that these comments be incorporated with a complete discussion of multi-organ recipients that was alluded to earlier in the meeting. The Chair was not convinced that separate lists for every organ combination possibility are the best path forward.

Discussion Items Not on the Agenda

- Dr. Wida Cherikh presented a slide set that introduced the timeline for the upcoming review of OMB forms that are set to expire in November 2009. The Chair indicated that since the forms were categorized recently to include pediatric fields, unless there are glaring omissions (possibly guided by intuition) then changes would probably be minimal; however, one change that can be made are those suggestions that resulted from the Pediatric Committee's proposal pertaining to pancreas for technical reasons. Discussion continued that there isn't a great deal to be gained by reviewing all the forms that were recently implemented. It was thought to be more prudent to wait for a year to eighteen months of data to be compiled and then analyzed for questions and issues that Research and/or the Help Desk have encountered. The Committee concluded the conversation agreeing to participate in a conference call to discuss this matter further and provide any of the current forms' glaring omissions.
- The Committee received a letter from an OPTN member children's hospital bringing to its attention a recent interaction with SRTR. The letter stated that pediatric centers were expected to pay for sample risk adjustment data; however, adult programs could receive these reports free of charge. The Chair suggested that the letter be given to the Committee's SRTR representatives to review, investigate, and provide a response. The SRTR liaison stated he thought that was a great path forward.
- As the meeting was concluding, the Chair asked if there were any other comments or ideas that Committee members wanted to express. Dr. Bartosh took the floor and indicated that a lot of centers are reviewed for inactivity- within a particular organ and often for pediatrics. This led her to question what is the definition of a pediatric center and is it better to have multiple centers within a highly populated area struggling with outcomes and inactivity, or a couple of excellent centers serving the same population? Is it necessary to have hundreds of pediatric centers? Dr. Bartosh continued that smaller centers make it difficult to statistically prove anything and centers often use this as an excuse when they fall below the set thresholds. In response to this other Committee members voiced their support, but questioned how, outside of harm, it could be justified shutting down centers. The Chair commented that data does not prove these changes are necessary or wise, and it will be difficult to pass this idea on to the transplant community as small centers get one vote just like large centers, but there are many more small centers than large centers. Another Committee member noted that it is not unusual to hear about patient access and how important it is, but quality of transplants is very important as well. Conversation then focused on the definition of a pediatric center, and who is and should be qualified to perform pediatric transplants. The Committee agreed in discussion that technical abilities to perform the surgeries are not the main question; it is all the other necessary follow-up which is critical. The Chair concluded this conversation reminding the Committee that it must proceed cautiously and deliberately in its addressing of this topic. If the Committee tries to answer the questions in terms of survival, it will fail like other attempts in the past. Accordingly, the Chair asked the Committee to give this topic further thought and it can be discussed again

later when there is time as the agenda allows and if other approaches are brainstormed. The Chair then reiterated the complications of moving forward considering the imbalance of small centers compared to large centers.

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