

**OPTN/UNOS Pediatric Transplantation Committee
Report to the Board of Directors
June 23-24, 2014
Richmond, Virginia**

**Heung-Bae Kim, MD, Chair
Eileen D. Brewer, MD, Vice Chair**

Contents

Action Items	2
1. Proposal to Change Pediatric Heart Allocation Policy	2
Committee Projects	3
2. General Principles of Pediatric Allocation	3
3. Pediatric Transplant Training and Experience Considerations in the Bylaws	4
4. Pediatric Lung Allocation Policy Review	4
5. Pediatric Classification for Liver Allocation	5
6. Revisiting the Pediatric End Stage Liver Disease (PELD) Score	6
Committee Projects Pending Implementation	7
7. Pediatric Liver: Remove ICU Requirements and Modify Hepatoblastoma Requirements...	7
Implemented Committee Projects	7
8. Evaluation of ABO-Incompatible Heart Policy	7
9. Evaluation of Kidney Share 35 Policy: Inactive Status and Refusal Reasons among Candidates Aged 0-5.....	8
Review of Public Comment Proposals	9
10. Proposal to Continue Adolescent Classification Exception for Pediatric Lung Candidates (<i>Thoracic Organ Transplantation Committee</i>)	9
11. Proposal to Notify Patients Having an Extended Inactive Status (<i>Transplant Coordinators Committee</i>)	10
Other Committee Work	11
12. Heart-Lung Allocation Policy	11
13. Pancreas as a Part of a Multivisceral	12
14. Vascular Composite Allograft (VCA) Update	12
Meeting Summaries	12

**OPTN/UNOS Pediatric Transplantation Committee
Report to the Board of Directors
June 23-24, 2014
Richmond, Virginia**

**Heung-Bae Kim, MD, Chair
Eileen D. Brewer, MD, Vice Chair**

This report reflects the work of the OPTN/UNOS Pediatric Transplantation Committee from November through April 2014.

Action Items

1. Proposal to Change Pediatric Heart Allocation Policy

Public Comment: March 15 – June 15, 2013

The *Proposal to Change Pediatric Heart Allocation Policy* includes four recommendations:

- 1) redefine Status 1A and Status 1B criteria;
- 2) increase the maximum qualifying isohemagglutinin titer to 1:16 for determining eligibility to accept an ABO-incompatible heart offer for candidates who are one year of age or older but registered before their second birthday;
- 3) change the allocation priority of urgent candidates younger than one year of age and potential transplant recipients eligible to receive ABO-incompatible heart offers by changing their blood group classification; and
- 4) eliminate the option to register heart candidates as *in utero*.

The Thoracic Committee and Pediatric Transplantation Committee reviewed the “plain language” version of the policy proposal to ensure there were no substantive changes from the version distributed for public comment, as well as to ensure that all post-public comment changes were incorporated. After careful review, the Thoracic Committee (15 approve, 0 oppose; and 0 abstain) and the Pediatric Committee (11 approve; 0 oppose; and 0 abstain) recommend the following modified policies for consideration by the Board of Directors:

RESOLVED, that Policies 3.4.H (In Utero Candidate Registrations); 5.3.C (Pediatric Heart Acceptance Criteria); 6.1 (Status Assignments); 6.1.D (Pediatric Heart Status 1A Requirements); 6.1.E (Pediatric Heart Status 1B Requirements); 6.1.F (Pediatric Heart Status 2 Requirements); 6.3 (Status Exceptions); 6.3.A (RRB and Committee Review of Status Exceptions); 6.4 (Waiting Time); 6.5.A (Allocation of Hearts by Blood Type); 6.5.B (Sorting Within Each Classification); 6.5.C (Allocation of Hearts from Donors at Least 18 Years Old); and 6.5.D (Allocation of Hearts from Donors Less Than 18 Years Old) are modified, as set forth in Exhibit A of the Thoracic Organ Transplantation Committee report, effective pending programming and notice to the OPTN membership.

FURTHER RESOLVED, that the congenital heart disease diagnoses are approved, as set forth in Exhibit A of the Thoracic Organ Transplantation Committee report , effective pending programming and notice to the OPTN membership.

Committee Projects

2. General Principals of Pediatric Allocation

Public Comment: n/a
Board Review: November 2014 (Estimated)

Ethical support has not been publically articulated for balancing the principles of allocation in pediatric allocation policy to accommodate the special needs of pediatric patients, thus rendering those policies vulnerable to future scrutiny and liabilities. In light of the emergency action that resulted in the "Proposal for Adolescent Classification Exception for Pediatric Lung Candidates," the Ethics and Pediatric Transplantation Committees formed a joint subcommittee to address the need for an ethical framework for developing and evaluating pediatric allocation policy for all organs

The Joint Subcommittee has begun to outline ethical considerations that may ultimately lead to an amendment to the "[Ethical Princiles to be Considered in the Allocation of Human Organs](#)" (Board approval: June, 2010) or a guidance document that the organ specific committees may reference as they consider changes to allocation policy.

NOTA and the OPTN Final Rule both provide for an equitable allocation of organs with special consideration of pediatric transplant candidates. The Joint Subcommittee discussed a number of unique ethical considerations when applying the principles of justice and utility to determine pediatric priority in organ allocation.

Subcommittee members noted that this is based upon a utilitarian approach. There is an inherent duty to care for our children that applies to society as a whole. There is also a social psychology aspect of this. One of the stages of becoming an adult is nurturing children from a psychological perspective. Children are seen as a vulnerable population.

While it is important to recognize that moving one person or population up on a match run inevitably bumps someone down on the list, there has to be a recognition that the pediatric population is small in comparison to adults. There are more pediatric donor to adult recipient transplants than there are adult organs being used for pediatric transplants. It was noted that this is not so straightforward in kidney allocation, where there is competition for every organ. These principles may be challenging to use in the kidney world, and a great deal of scrutiny may be expected due to the potential impact on this group. It was argued that this same group of principles could apply to geriatrics or young adults. A member countered that fair innings and autonomy concepts would be very different for these populations. Balancing justice and utility will be very challenging. These are arguments that will be heard from other committees and stakeholders. The principles may need to be articulated very clearly prior to Board consideration, as controversy should be expected.

A member questioned whether it would be less self-serving for the Ethics Committee to take this proposal to the Board. While this Committee certainly wants to promote and advocate for the principles, there was concern regarding how this will be perceived by the Board and others considering the document for approval. A member countered that the Pediatric Committee should be leading the charge to advocate for this population, with backing from the Ethics Committee. The Joint Subcommittee will reconvene with plans to complete a proposal for Board consideration in November 2014.

3. Pediatric Transplant Training and Experience Considerations in the Bylaws

Public Comment: *Fall, 2014 (Estimated)*
Board Review: *June 2015 (Estimated)*

Pediatric transplantation is a specialty within the field of transplantation; however, the Bylaws are silent regarding any pediatric training and experience requirements. As such, transplant hospitals that predominately serve pediatric candidates may have professionals without any pediatric transplant experience approved for key personnel roles (primary surgeon and primary physician). A secondary issue associated with this larger problem is that the Bylaws do not define what constitutes a pediatric transplant program. The Committee is working with the Membership and Professional Standards Committee (MPSC) to create Bylaw language to address this.

The Committee continued discussions related to the development of pediatric specific training and experience conditions in the Bylaws. The Committee discussed:

- Allowing an intensivist to fill the role of primary physician (which was declined).
- Developing a conditional pathway for those not meeting the pediatric patient transplant volume requirements set forth in a two year period.
- Adding language to allow transplant of acute pediatric patients at adult programs due to extenuating circumstances, but requiring MPSC review.
- Removing alternative pathway for predominantly pediatric programs across all organ groups.
- Updating and seeking feedback from the regions throughout the development of this proposal.
- Engaging the professional societies, which is already underway, during the development of this proposal.

The Committee plans to have a proposal ready for public comment in fall, 2014.

4. Pediatric Lung Allocation Policy Review

Public Comment: *Spring, 2015 (Estimated)*
Board Review: *November, 2015 (Estimated)*

The Thoracic Organ Transplantation Committee's Lung Working Group is conducting a comprehensive review of pediatric lung allocation. While the Pediatric Committee crossover representatives are already involved in the Working Group, the Thoracic Committee has requested additional pediatric representation for this effort. The main concerns will be the proposal for adolescent allocation for pediatric patients (as related to an index allocation event from last summer), larger sharing for adolescent donors, and broader sharing with adult patients. There will also be discussion related to ex vivo lung perfusion (EVLP) and simultaneous heart-lung allocation and transplant allocation.

For more information, see the **Thoracic Organ Transplantation Committee's Report to the Board**.

5. Pediatric Classification for Liver Allocation

Public Comment: *Fall, 2014 (Estimated)*
Board Review: *June 2015 (Estimated)*

Current policy requires pediatric liver candidates with a MELD score who remain on the waiting list after their 18th birthday to submit a request to the Regional Review Board (RRB) if they wish to retain their "pediatric classification." An RRB request is not necessary if the candidate is listed as Status 1A or Status 1B. Similarly, pediatric liver candidates who were removed from the waiting list for any reason and then relisted for transplant after their 18th birthday may request "pediatric classification" from the RRB. If the candidate meets pediatric Status 1A or pediatric Status 1B criteria, then RRB approval is also unnecessary. The Committee has identified two issues in current policy:

- Eliminating a candidate's "pediatric classification" the day of their 18th birthday is inconsistent with how other organs (i.e., kidney, heart) treat "pediatric classification."
- With the exception of a previously listed pediatric liver candidate who returned to the list after their 18th birthday, the RRBs have approved every submitted pediatric classification request (10). The Committee believes this is an inefficient use of RRB resources.

As a result of this practice, there was an influx of RRB requests, asking for continued pediatric classification for their candidates about to turn 18. The group learned that RRB requests in this scenario are always approved, but adult requests for pediatric status upon returning to the match run have been turned down.

This policy is inconsistent among organs. It is also inefficient for centers applying for these classifications, UNOS staff managing these requests, and RRB representatives reviewing the requests. A suggestion was made to automate this process. If a candidate is about to turn 18, this continuation would automatically occur. Additionally, the request for pediatric classification as an adult might be removed. Committee members believed that, if there is a need for re-listing as an adult, it would be in a patient's best interest to be treated as an adult and receive adult offers. A memo was sent to the Liver Committee outlining these suggestions in preparation for a February 14, 2014, teleconference.

The Liver and Intestinal Organ Transplantation Committee was generally supportive of this idea. The Liver Committee did recommend a three-year cap to extending pediatric classification, with this option ending for these candidates at age 21. To fully implement this policy change, programming would be required. In light of the programming delay, this could be managed manually in the interim to eliminate the RRB review.

Pediatric classification provides priority to pediatric donors. It also gives a candidate the ability to be listed as Status 1B. A question regarding the magnitude of this issue was raised. Twelve to fifteen requests have been received in the last year. The Committee found this number to be negligible. The three year cap seemed reasonable to some members. If you are sick enough as a pediatric candidate and have not been transplanted, this three year window should allow for your transplant in this time period. This age 21 cut off makes sense for freestanding children's hospitals who must transfer patients at this age to adult care. Members questioned whether the cap should be set and then subsequent data evaluated, or whether no cap should be placed until post-implementation data are studied. Other organs do not have this cap.

There was discussion regarding whether this is worth the effort it will entail based upon the low number potentially affected. One member noted that it may have more significant impact going forward. The Committee was asked whether it should continue work to address this now with low yield or fold it into another larger liver-related effort, such as a comprehensive review of pediatric liver allocation and pediatric end-stage liver disease (PELD). Members agreed it may be wise to address this as part of a larger effort. A full review of PELD may also address sizing concerns, including adolescent candidates that may be more suited to smaller pediatric organs due to candidate failure to thrive.

Discussion then moved to considering adolescent candidates that may be more suited to smaller pediatric organs due to failure to thrive, similar to earlier discussion related to lung candidates. This may be a more comprehensive proposal to address as a standalone concern. This is an inconsistency that will somehow need to be addressed, and may be a cause for discussion when revisiting the PELD score.

6. Revisiting the Pediatric End Stage Liver Disease (PELD) Score

Public Comment: Fall, 2015 (Estimated)

Board Review: June 2016 (Estimated)

The PELD score has not been modified since it was implemented in 2002. A high proportion of pediatric patients are transplanted in Status 1 or with a PELD exception, which indicates that review is needed.

The Committee received an update from its Liver and Intestinal Organ Transplantation Committee crossover representative. He noted that a working group was tasked with assessing the efficiency, effectiveness, and limitations of the current PELD allocation system. The group was asked to explore changes to PELD that will decrease the number of children transplanted under an exception score and optimize the ranking of liver candidates by their medical urgency.

The Working Group identified the following issues with the current PELD allocation system:

- A large number of pediatric candidates are listed with exceptions rather than actual scores.
- There are regional differences in the PELD score of transplant recipients.
- Policy lacks of standard criteria for exceptions.

Challenges were recognized related to revising PELD. The original calculation included both death and transfer to the ICU as endpoints, but the latter is considered subjective. Additionally, waiting list mortality, while important for children, does not recognize the significant long-term morbidity faced by pediatrics when transplantation is delayed. Members of the working group suggested that a power calculation be requested to determine how many deaths must be included for a revised PELD to be more accurate. Members felt that the number will always be too small to have statistical power.

Current practices include requesting PELD exception scores (>40) that will place a child below Status 1, but above all adults on a match run (because they are capped at a MELD score of 40). This provides access to split livers for small children. The exception requests and scores granted by the RRB are not standardized across the country. The working group questioned if there was a biomarker to indicate that growth failure was likely to occur

that could be used as an endpoint, but noted that this may be impossible to prove statistically due to small sample size. Members agreed that PELD needs to be replaced, but noted that its replacement was also dependent on the availability of organs. Some members also questioned the appropriate amount of pediatric priority over adult candidates, though the impact of modifications to pediatric allocation on adults is thought to be minimal.

Overall, 90% of initial PELD exceptions submitted from 5/1/2012 through 4/30/2013 were approved by the RRB. Of the 300 initial PELD exception applications, biliary atresia accounted for 40%. Metabolic liver disease and genetic conditions accounted for another 18%.

The working group concluded that a revised PELD score based on methods used for MELD (with the end point of waiting list mortality risk) is not feasible due to the small number of deaths in the pediatric population and lack of another end-point as a proxy for mortality. Exceptions sought for the pediatric population are motivated not only by the desire to decrease short-term risk of mortality, but also to reduce the risk of lifelong problems associated with growth and developmental failures (as seen in metabolic liver diseases).

A member noted that there is great variation in exception scores across the regions. Additionally, this may be an appropriate time to address split livers again, though this remains a prominent topic in the liver community. Pediatric priority may be a viable option here, in much the same way Share 35 is used for kidneys.

It was suggested that leadership between the two committees should get together to discuss a path forward with this group until liver redistricting is settled, as this will be a high priority for the community. This pediatric effort may ultimately be put on hold for a period of time.

Committee Projects Pending Implementation

7. Pediatric Liver: Remove ICU Requirements and Modify Hepatoblastoma Requirements

<i>Public Comment:</i>	<u>March, 2011 (Remove ICU Requirements)</u> <u>March, 2011 (Modify Hepatoblastoma Requirements)</u>
<i>Board Approval:</i>	November, 2011(both)
<i>Implementation:</i>	January 2015 (estimated)

Both of these projects were individually approved by the Board in November 2011, but bundled for the purposes of programming and implementation. Programming is scheduled to begin on this effort in fall 2014.

Implemented Committee Projects

8. Evaluation of ABO-Incompatible Heart Policy

<i>Public Comment:</i>	February, 2006
<i>Board Approval:</i>	September 20, 2006
<i>Implementation:</i>	November 22, 2010

The Committee reviewed data evaluating the ABO-Incompatible heart policy (**Exhibit B**). This policy, implemented on November 22, 2010, allows Status 1A and 1B pediatric candidates less than two years of age at listing and *in utero* candidates for whom blood type is unknown to accept a heart from a donor of any blood type, provided they meet the

eligibility requirements set forth in Policy 3.7.8. A candidate's anti-A and anti-B titers must be reported at the time of listing (except for in utero candidates), monthly after listing, at transplant, and in the event of graft loss or death within one year of transplant.

Early results indicate that ABO-incompatible heart transplants, performed most often in recipients less than a year of age, have comparable patient survival with transplants using ABO-identical or compatible organs. Long term survival and secondary outcomes will need to be examined as more ABO-incompatible transplants and follow-up information becomes available.

A member noted that severity of cardiac listing and regional distribution impact the frequency of these transplants. The system was set up to take a very cautious approach, making offers of incompatible organs only after primary and secondary blood groups were exhausted. In the new proposal, ABO-incompatible offers are considered in the primary group in infants, and titer level cut offs will increase from 1:4, to 1:16. To date, the proposal has been well received. This has not necessarily increased the number of transplants, but redistributed organs to sicker kids. The proposed heart allocation changes may ultimately transplant more organs and reduce discards.

9. Evaluation of Kidney Share 35 Policy: Inactive Status and Refusal Reasons among Candidates Aged 0-5

Board Approval: November 18, 2004
Implementation: September 28, 2005

UNOS Research staff presented data requested by the Committee as part of an ongoing discussion related to refusal reasons and the proportion of inactive registrations for the 0-5 year old candidates as compared to other pediatric age groups (**Exhibit C**). Under this policy, candidates less than 18 years of age at listing receive local priority for kidneys from donors < 35 years of age.

The proportion of inactive candidates on the waiting list is greatest in the 0-5 age group. On December 31, 2013, 69% of registrations 0-5 years old were inactive, while 56% of those 6-10 and 58% of those 11-17 were inactive. Of local kidney offers made to pediatric candidates from donors less than 35 years old from 2009 to 2013, 14% of offers made to 0-5 year old candidates were refused due to donor size or weight. This is compared to only 6% of offers to 6-10 year olds and 5% of offers to 11-17 year olds. In candidates age 0-5 years of age, the most common reasons for refusal were donor age or quality (29%), patient ill, unavailable, refused, or temporarily unsuitable (16%), and donor size/weight (at 14%). The percentage of offers refused for reasons other than donor size/weight were similar among all pediatric age groups.

When considering acceptance rates among local kidney offers made to pediatric candidates from Share 35 donors during this same 2009-2013 time period, 0-5 year old candidates had the lowest percentage of offers accepted (14%) as compared to those aged 6-11 (19%) or 11-17 (27%).

After reviewing the data, Committee members agreed that speculations within the committee related to 0-5 year-old candidates were proven true by this analysis. It is difficult, due to the obesity epidemic, to find kidneys that are not too large to transplant into these smaller children. Some of the inactive status reports may also be related to living donor work up.

Reasons for inactive status were not reviewed as part of this analysis. Varying program practices dictate use of this inactive status, and this would be an interesting area to delve into for a clearer understanding. Another member noted that his region reviews organ offers based upon KDPI due to the lower than expected acceptance rate. He speculated that there is probably a great deal of variation across the regions in this area. Additionally a number of Share 35 organs are absorbed into dual organ transplants, leaving less desirable kidney alone offers for programs to consider in some regions. Members noted that KPDI may be a better indicator of quality than assuming that a donor less than 35 years of age is more desirable.

Review of Public Comment Proposals

The Committee reviewed 2 of the 17 proposals released for public comment from March – June, 2014. The Committee intends to review 4 additional proposals before the end of the public comment cycle. Time constraints prevented completion of review during the Committee's April 8, 2014, meeting.

10. Proposal to Continue Adolescent Classification Exception for Pediatric Lung Candidates (Thoracic Organ Transplantation Committee)

After hearing its presentation, Committee members acknowledged that, if this proposal is not approved, the system will revert back to young pediatric candidates receiving offers based upon time waiting, losing the opportunity to also be considered for organ offers based upon adolescent allocation. The number of candidates impacted here is very small. Approval of this change would make the policy modifications approved by the Executive Committee last year a permanent change. These cases would continue to be considered by the Lung Review Board (LRB).

The Chair noted that last year the Committee voted unanimously against the Executive Committee's decision to make this change without the benefit of data and thorough due process. To date, only ten candidates have requested this exception, and all have been approved. To benefit from the double listing, candidates would have to be of an appropriate height and weight to be able to accept an adult lung.

A member questioned whether it may be wiser to just write the height requirement into policy if any pediatric candidate meeting an appropriate height be approved for adolescent status rather than having this issue go to the LRB each time.

A crossover representative to the Thoracic Organ Transplantation Committee noted that this group weighed extending this emergency action for another year to allow for further data collection before a change in pediatric lung allocation is made permanent. It was suggested that the data may not be of adequate quality for consideration due to small sample size. The Thoracic Committee also discussed a height requirement rather than an exception on the basis of age. Ultimately, the Thoracic Committee believed that this was the most appropriate path forward at this time.

A member suggested that a height requirement could be perceived as arbitrary. An additional concern was that some adolescents with failure to thrive would benefit more from a young pediatric donor lung rather than an adolescent donor based upon size. These small adolescent candidates must currently wait for refusals from all pediatric candidates before

receiving offers for these smaller lungs based upon the current system. Additionally, there were concerns that very small adult candidates could be impacted by these changes, as very small and very tall adult candidates often have extended waits for organs due to size constraints.

Most of the ten candidates that applied for the exception ultimately received pediatric lungs, but additional care must be taken when considering cut downs of adult lungs to use lobes. At the time of this meeting, only one of the ten candidates had accepted adult lungs. This is a very center-specific choice. Small children receiving a lobar transplant may potentially impact allocation to adults.

In kidney allocation, all candidates less than 18 years old receive preferential offers for donors less than 35 years of age. The center has discretion to accept an organ based upon donor and pediatric candidate size. Similarly, this proposal seems to give the programs discretion to consider a broader donor population based upon size. From an ethical perspective, there is inconsistency in how children are prioritized. There is a joint working group trying to resolve some of these discrepancies. (See above.) There are different concepts of what is equitable by organ in terms of sickest first or waiting time, but also by how children are categorized. More guidance on this topic may be helpful to this discussion in the future as this effort develops. The Committee asked for more information about whether these patients are receiving and turning down adult organ offers.

Based upon the small number of patients that this proposal impacts that will result in limited work for the LRB. For this reason, and recognizing that pediatric lung allocation is being reviewed, a member noted that it makes sense to support this proposal. This gives lung programs discretion to make decisions. Concern remained for small adolescents who do not have the reciprocal option and must wait for all Zone B pediatric offers before receiving these small organ offers. This, too, will be considered in the overall pediatric allocation review.

The Pediatric Committee unanimously supported this proposal but recommends an ongoing assessment of the pediatric and adolescent lung allocation system and wishes to participate in these discussions (15 yes, 0 no, 0 abstentions).

11. Proposal to Notify Patients Having an Extended Inactive Status (Transplant Coordinators Committee)

After listening to the presentation, the Committee raised a number of concerns. A member asked what leads the Transplant Coordinators Committee to believe that a patient does not understand what it means to be inactive. The presenter noted that there is scientific data chronicling studies in this area. It was suggested that these patients hear so much information that they often do not understand that being inactive means they will not receive organ offers.

Another Committee member asked if patients were notified at the time that they were made inactive. If so, why shouldn't this education follow the initial inactivity versus waiting a year to follow up and educate? The presenter noted that, once you are made inactive, there is no current policy requirement related to following up with these patients. It was noted that some programs are already very good at this.

A Committee member noted that understanding what inactivity means is important for patients but thought that this intervention may not be a useful tool to use in trying to grow a

patient's health literacy. A letter in the mail well after the fact may ultimately cause more confusion. Is there a better way to achieve this goal?

A Committee member asked if there was a sense of why this many patients are inactive. It could be because someone is early in the disease process, needs other testing, needs to lose weight, or does not meet some other center-specific criteria for listing. The presenter referred to the literature as a source of information, and noted that the letter may prompt a patient to call the center and follow up on the reason for inactivation if they are not understanding the situation. A question related to the language required in the current notification letter was posed. Would receiving a letter saying you were listed for transplant, but then receiving another letter saying you were inactive (perhaps because you had not completed the last of any required screening or testing) further confuse organ candidates? Members suggested that the following should be considered:

- Ninety days seems to be an administrative burden, and there is no data to support the selection of this number. The original public comment proposal suggested a one-year follow up letter.
- Consider including language on why a patient is inactive and what he or she can do to become active on the waiting list.

The Committee chose not to vote on the proposal but rather to share feedback with the sponsoring committee. While some thought that this was a nice effort that comes with good motives to improve patient and transplant program communication, it does place an administrative burden on the transplant program.

Other Committee Work

12. Heart-Lung Allocation Policy

The Committee's crossover representative to the Thoracic Organ Transplantation Committee updated the Committee on confusion related to generating the match run for combined heart-lung candidates. There are match runs for heart, lung, and combined heart-lung allocation. OPOs have some confusion regarding the combined list sometimes forget to run this match. As a result, thoracic transplant programs are encouraged to list candidates for all three organ types to ensure that candidates are not overlooked. In most cases, the lungs will follow the heart (a lifesaving organ). This listing practice was seen as a temporary measure prior to improving the listing requirements in Policy. The Thoracic Committee wants to clarify this language, and has requested advice from the Pediatric Committee.

The Thoracic Committee requested at least two Pediatric representatives for a joint subcommittee to address this issue. A lung and heart representative from the Committee volunteered to represent on behalf of the pediatric community. The goal of this group, led by the Thoracic Committee, is to make sure the listing process captures all candidates eligible for heart-lung both from a logistical standpoint and also in considering that the listing criteria are appropriate for these patients. Additional representation may be considered as new appointments to this Joint Subcommittee are finalized for terms starting July 1, 2014.

For more information, see the **Thoracic Organ Transplantation Committee's Report to the Board**.

13. Pancreas as a Part of a Multivisceral

The Chair updated the Committee on discussions related to centers using the pancreas for an *en bloc* transplant if they are not approved to transplant pancreata. The Pancreas Committee was amenable to updating policy language to allow for this scenario, permitting the listing of patients for pancreas if it is part of an *en bloc* procedure. It was noted that all candidates receiving a pancreas as part of a multi-visceral transplant must be listed for a pancreas in addition to the other organs. Currently the MPSC follows up in these instances. Additional concerns were shared regarding the OPO's standard acquisition charge for the pancreas as well. The Chair plans to join a pancreas bylaws review teleconference next month to address this issue.

For more information, see the **Pancreas Transplantation Committee's Report to the Board**.

14. Vascular Composite Allograft (VCA) Update

UNOS will oversee vascular composite allografts (VCA) when modifications to the OPTN Final Rule are effective on July 1, 2014. As a result, a new VCA Committee has been formed to begin work on the infrastructure needed to support allocation of these organs, including policies and bylaws. The Chair of this new committee requested that this Committee be alerted to the development of the VCA Committee, as pediatric allocation will be a part of this effort and input will be requested early in the process. There is already a children's hospital that has started to develop a VCA program. This is on the horizon, and this Committee will be asked to participate early in the process of considering concerns and impacts specific to pediatric VCA recipients.

Meeting Summaries

The committee held meetings on the following dates:

- January 15, 2014
- February 26, 2014
- April 8, 2014

Meetings summaries for this Committee are available on the OPTN website at:

<http://optn.transplant.hrsa.gov/members/committeesDetail.asp?ID=15>

Evaluation of ABO-Incompatible Heart Policy

Prepared for:

OPTN Pediatric Transplantation
Committee Meeting
April 8, 2014

By:

Wida S. Cherikh, Ph.D.,
Marissa A. Clark, M.S., and
Yulin Cheng
UNOS Research Department

Table of Contents

BACKGROUND/PURPOSE 2

WORK PLAN ITEM ADDRESSED 2

COMMITTEE REQUEST 2

DATA AND METHODS 2

 Data Sources 2

 Cohort and Methods 2

RESULTS 3

 Pediatric Registrations Added to the Heart Alone Waiting List during 11/22/2010-12/21/2013 3

 Waiting List Removals among Pediatric Registrations Added to the Heart Alone Waiting List during 11/22/2010-12/21/2013 and Willing to Accept an ABO-Incompatible Transplant 4

 Pediatric Registrations on the Heart Alone Waiting List on February 28, 2014 4

 Deceased Donor Heart Alone Transplants Performed during 11/22/2010-12/21/2013 for Recipients Less Than 2 Years Old at Listing 5

 Graft and Patient Survival for Pediatric Deceased Donor Heart Alone Transplants during 11/22/2010-12/21/2013 6

 Recipient Deaths of ABO-Incompatible Heart Alone Transplants Performed during 11/22/2010-12/21/2013 6

SUMMARY 7

APPENDIX 1 8

BACKGROUND/PURPOSE

On November 22, 2010, an ABO-incompatible pediatric heart policy was implemented. This policy allows Status 1A and 1B pediatric candidates <2 years of age at listing who meet the eligibility requirements set forth in Policy 5.3.C, including *in utero* candidates for whom blood type is unknown, to accept a heart from a donor of any blood type. Under this policy, born candidates who elect to receive a donor heart of an incompatible blood type must have a medical urgency status of 1A or 1B. Anti-A and anti-B titers must also be reported at the time of listing (except for *in utero* candidates), monthly after listing (all eligible candidates), at transplant, and in the event of graft loss or death within one year after transplant. See Appendix 1 for Policy 5.3.C and Policy 6.5.A. The current analysis was performed as part of on-going policy evaluation for the Committee.

WORK PLAN ITEM ADDRESSED

Access to transplant and good outcomes for pediatric candidates.

COMMITTEE REQUEST

Provide listing and transplant outcomes for the eligible candidates.

DATA AND METHODS

Data Sources

Information provided in this report is based on OPTN data as of February 28, 2014. Data are subject to change based on future submission or correction.

Cohort and Methods

Waiting List Analysis:

- The number of Status 1A or 1B pediatric registrations <2 years old at listing with a non-AB blood type who were added to the heart alone waiting list during the 37 months after policy implementation (11/22/2010-12/21/2013) was tabulated by medical urgency status at listing, age at listing (in utero, <1 year, 1-<2 years) and the registrant's willingness to accept a donor heart of an incompatible blood type; additionally, removal codes for registrations willing to accept an incompatible heart were tabulated.
- The number of Status 1A or 1B pediatric registrations <2 years old at listing with a non-AB blood type still waiting on February 28, 2014 was also tabulated by medical urgency status at month end, age at listing, and the willingness to accept an ABO-incompatible donor heart.

Transplant Analysis:

- The number of deceased donor, heart alone transplants performed in the 37 months since policy implementation (11/22/2010-12/21/2013) who were <2 years old at listing, had a non-AB blood type and a medical urgency status of 1A or 1B at transplant was tabulated by age at listing, age at transplant, and the ABO compatibility of the transplant.
- Unadjusted graft and patient survival rates within 12 months of transplant were computed for deceased donor, heart alone transplant recipients during the 37 months since policy implementation (11/22/2010-12/21/2013) who were <2 years old at listing, had a non-AB blood type and a medical urgency status of 1A or 1B at transplant using the Kaplan-Meier method and compared using the log-rank test.

RESULTS

Pediatric Registrations Added to the Heart Alone Waiting List during 11/22/2010-12/21/2013

Table 1 tabulates the number of pediatric registrations who were <2 years old at listing with a non-AB blood type and an initial medical urgency status of 1A or 1B who were added to the heart alone waiting list in the 37 months since policy implementation (11/22/2010-12/21/2013) by medical urgency status at listing, age at listing, and the willingness to accept a donor heart of an incompatible blood type at listing.

- 251 (38%) of the 668 pediatric registrations during this period indicated a willingness to accept a heart of an incompatible blood type at listing, of which 225 (90%) were listed as Status 1A.
- 598 (90%) of additions were listed with a medical urgency status of 1A, and 555 (83%) of additions were less than a year old at listing.
- Of the 251 registrations willing to accept a heart of an incompatible blood type, 236 (94%) were less than a year old at listing.
- Only twelve registrations listed between the ages of 1 and less than 2 indicated willingness to accept an ABO-incompatible heart at the time of listing, of which ten were listed as Status 1A and two were listed as Status 1B.
- The majority (91%) of registrations willing to accept an ABO-incompatible heart at the time of listing did not receive any treatment that may have reduced their titer values to 1:4 or less (data not shown in table).

Table 1. Pediatric Registrations <2 Years at Listing, with a non-AB Blood Type, and a Medical Urgency Status of 1A or 1B Added to the Heart Alone Waiting List during 11/22/2010-12/21/2013 by Status at Listing, Age at Listing, and Willingness to Accept a Donor Heart of an Incompatible Blood Type

Medical Urgency Status at Listing	Age at Listing	Willing to Accept an Incompatible Blood Type at Time of Listing?						Total	
		Yes			No				
		N	Row %	Col %	N	Row %	Col %	N	Col %
Status 1A	In Utero	2	100.0	0.9	0	0	0	2	0.3
	<1 Year	213	42.7	94.7	286	57.3	76.7	499	83.4
	1 - <2 Years	10	10.3	4.4	87	89.7	23.3	97	16.2
	Total	225	37.6	100.0	373	62.4	100.0	598	100.0
Status 1B	In Utero	1	100.0	3.8	0	0	0	1	1.4
	<1 Year	23	41.1	88.5	33	58.9	75.0	56	80.0
	1 - <2 Years	2	15.4	7.7	11	84.6	25.0	13	18.6
	Total	26	37.1	100.0	44	62.9	100.0	70	100.0
Total	In Utero	3	100.0	1.2	0	0	0	3	0.4
	<1 Year	236	42.5	94.0	319	57.5	76.5	555	83.1
	1 - <2 Years	12	10.9	4.8	98	89.1	23.5	110	16.5
	Total	251	37.6	100.0	417	62.4	100.0	668	100.0

Waiting List Removals among Pediatric Registrations Added to the Heart Alone Waiting List during 11/22/2010-12/21/2013 and Willing to Accept an ABO-Incompatible Transplant

As of February 28, 2014, removal reasons among the 251 pediatric registrations who were <2 years old at listing with a non-AB blood type and an initial medical urgency status of 1A or 1B who were added to the heart alone waiting list in the 37 months since policy implementation (11/22/2010-12/21/2013) and willing to accept an incompatible donor heart at listing are as follows:

- 170 (68%) were removed for transplant
 - 31 (18%) received ABO-incompatible hearts
 - 19 (11%) received ABO-compatible hearts
 - 120 (71%) received ABO-identical hearts
- 27 (11%) were removed for death
- 23 (9%) were removed for too sick
- 16 (6%) were removed for other reason
- 15 (6%) were still waiting

Pediatric Registrations on the Heart Alone Waiting List on February 28, 2014

Table 2 tabulates the number of pediatric registrations <2 years old at listing with a non-AB blood type and a medical urgency status of 1A or 1B who were on the heart alone waiting list on February 28, 2014 by medical urgency status at month end, age at listing, and the willingness to accept a donor heart of an incompatible blood type.

- Of the 58 registrations waiting on February 28, 2014, 26 (45%) indicated a willingness to accept a heart of an incompatible blood type.
- Among the 26 registrations willing to accept a heart of an incompatible blood type, 24 (92%) were waiting in Status 1A.
- Two of the 26 registrations (8%) willing to accept an ABO-incompatible heart were listed between the ages of 1 and less than 2 years old; both were waiting in Status 1A.
- The majority (96%) of registrations willing to accept an ABO-incompatible heart at the time of listing did not receive any treatment that may have reduced their titer values to 1:4 or less (data not shown in table).

Table 2. Pediatric Registrations < 2 Years at Listing, with a non-AB Blood Type, and a Medical Urgency Status of 1A or 1B on the Heart Alone Waiting List on February 28, 2014 by Status, Age at Listing, and Willingness to Accept a Donor Heart of an Incompatible Blood Type

Medical Urgency Status at Month End	Age at Listing	Currently Willing to Accept an Incompatible Blood Type?						Total	
		Yes			No				
		N	Row %	Col %	N	Row %	Col %	N	Col %
Status 1A	<1 Year	22	57.9	91.7	16	42.1	57.1	38	73.1
	1 - <2 Years	2	14.3	8.3	12	85.7	42.9	14	26.9
	Total	24	46.2	100.0	28	53.8	100.0	52	100.0
Status 1B	<1 Year	2	50.0	100.0	2	50.0	50.0	4	66.7
	1 - <2 Years	0	0	0	2	100.0	50.0	2	33.3
	Total	2	33.3	100.0	4	66.7	100.0	6	100.0
Total	<1 Year	24	57.1	92.3	18	42.9	56.3	42	72.4
	1 - <2 Years	2	12.5	7.7	14	87.5	43.8	16	27.6
	Total	26	44.8	100.0	32	55.2	100.0	58	100.0

Deceased Donor Heart Alone Transplants Performed during 11/22/2010-12/21/2013 for Recipients Less Than 2 Years Old at Listing

Table 3 tabulates the number of deceased donor heart alone transplants performed in the 37 months since policy implementation (11/22/2010-12/21/2013) where the recipient was <2 years old at listing, had a non-AB blood type, and had a medical urgency status of 1A or 1B at transplant, stratified by age at listing, age at transplant, and the ABO compatibility of the transplant.

- 44 (10%) of the 423 deceased donor heart transplants were ABO-incompatible and were performed at 18 different transplant centers.
- 42 of the ABO-incompatible transplants were performed in Status 1A recipients less than a year old at both listing and transplant, where recipients were listed between the ages of 0 to 11 months old.
- One ABO-incompatible transplant was performed in each of a Status 1A and Status 1B recipient aged 1-<2 years old at both listing and transplant.
- Times spent on the waiting list for these 44 ABO-incompatible transplant recipients ranged from 2 to 260 days.
- These 44 recipients received transplants from donors between 0 and 7 years old; 26 donors were less than a year old (between 0 and 10 months), nine were aged 1-<2 years old, four were aged 2-<3 years old, and five donors were between 3 and 7 years old (data not shown in table).
- The sequence number on the match runs for these 44 ABO-incompatible transplant recipients ranged from 1 to 15, and the maximum number of potential recipients on the match run ranged from 1 to 25 (data not shown in table).

Table 3. Deceased Donor Heart Alone Transplants Performed during 11/22/2010-12/21/2013, where the Recipient was <2 Years at Listing, had a non-AB Blood Type, and had a Medical Urgency Status of 1A or 1B at Transplant, by Age at Listing, Age at Transplant, and the ABO Compatibility of the Transplant

Age at Listing / Age at Transplant		Incompatible ABO		Identical/Compatible ABO		Total	
		N	%	N	%	N	%
<1 Year	<1 Year	42	13.2	276	86.8	318	100.0
	1 - <2 Years	0	0	19	100.0	19	100.0
	2 - <3 Years	0	0	1	100.0	1	100.0
	3+ Years	0	0	1	100.0	1	100.0
	Total	42	12.4	297	87.6	339	100.0
1 - <2 Years	1 - <2 Years	2	3.1	63	96.9	65	100.0
	2 - <3 Years	0	0	18	100.0	18	100.0
	3+ Years	0	0	1	100.0	1	100.0
	Total	2	2.4	82	97.6	84	100.0
Total	<1 Year	42	13.2	276	86.8	318	100.0
	1 - <2 Years	2	2.4	82	97.6	84	100.0
	2 - <3 Years	0	0	19	100.0	19	100.0
	3 Years	0	0	2	100.0	2	100.0
	Total	44	10.4	379	89.6	423	100.0

Graft and Patient Survival for Pediatric Deceased Donor Heart Alone Transplants during 11/22/2010-12/21/2013

Table 4 summarizes the Kaplan-Meier unadjusted graft and patient survival rates within 12 months of transplant for deceased donor heart alone transplants performed in the 37 months since policy implementation (11/22/2010-12/21/2013) where the recipient was <2 years old at listing, had a non-AB blood type, and had a medical urgency status of 1A or 1B at transplant, stratified by the ABO compatibility of the transplant.

- There were no significant differences in the unadjusted graft or patient survival rates for pediatric recipients of deceased donor hearts, regardless of the ABO compatibility of the transplants.
- Among ABO-incompatible transplant recipients, one year patient survival was 92% as compared to 83% for compatible and 88% for identical transplants.

Table 4. Kaplan-Meier Graft and Patient Survival for Recipients of Deceased Donor Heart Alone Transplants during 11/22/2010-12/21/2013, where the Recipient was <2 Years at Listing, had a non-AB Blood Type, and had a Medical Urgency Status of 1A or 1B at Transplant, by the ABO Compatibility of the Transplant

Survival Type	ABO Compatibility of Tx	No. of Tx's	Months Post Transplant	No. Alive or No. with a Functioning Graft	Survival Rate (%)	95% CL of Survival	Log-rank test p-value
Graft	Incompatible	27	6	25	96.3	[82.52,100]	0.5396
			12	19	92.4	[76.96,100]	
	Compatible	30	6	23	82.8	[65.56,100]	
			12	17	82.8	[65.56,100]	
	Identical	216	6	195	91.2	[86.85,95.52]	
			12	143	86.9	[81.87,91.93]	
Patient	Incompatible	27	6	25	96.3	[82.52,100]	0.4981
			12	19	92.4	[76.96,100]	
	Compatible	30	6	23	82.8	[65.56,100]	
			12	17	82.8	[65.56,100]	
	Identical	216	6	195	92.1	[87.92,96.26]	
			12	143	88.2	[83.37,93.09]	

Recipient Deaths of ABO-Incompatible Heart Alone Transplants Performed during 11/22/2010-12/21/2013

Table 5 displays the primary and contributory causes of death, titer values at the time of death, and survival times of the recipients who died within one year following an ABO-incompatible, deceased donor, heart alone transplant performed during 11/22/2010-12/21/2013.

- Of the 44 ABO-incompatible heart transplants performed in the 37 months following policy implementation, six recipients (14%) have died.
- Four of the six deaths occurred within a year of transplant while the other two occurred between one and less than two years post-transplant.
- Of the deaths within a year of transplant, titer values at the time of death were all 1:2 or less.

Table 5. Recipient Deaths within 1 Year of Transplant for ABO-Incompatible Deceased Donor Heart Alone Transplants Performed during 11/22/2010-12/21/2013

Survival Time (Days)	Primary Cause of Death	Contributory Cause(s) of Death	Titer Value at Time of Death
0	Graft Failure: Primary Failure		1:0
51	Cerebrovascular: Hemorrhage (Non-Stroke)	Renal Failure, Multiple Organ Failure	1:2
56	Graft Failure: Hyperacute Rejection	Renal Failure, Infection: Clinical Sepsis, no organism identified	1:0
209	Cardiovascular: Cardiac Arrest	Non-compliance	1:1

SUMMARY

- The majority of candidates willing to accept an ABO-incompatible heart were Status 1A infants less than 1 year at listing.
- Among candidates willing to receive an ABO-incompatible donor heart, the majority actually received an ABO-identical heart.
- The vast majority of ABO-incompatible transplants were performed in Status 1A recipients less than a year old at both listing and transplant.
- Early results of ABO-incompatible heart transplants, performed mostly in pediatric recipients less than one year old, suggest comparable patient survival with ABO identical/compatible transplants.
- Long-term survival and secondary outcomes also need to be examined as more ABO-incompatible transplants and follow-up information become available.

APPENDIX 1

Policy 6.5.A. Allocation of Hearts by Blood Type. Within each heart status, hearts will be allocated to candidates according to the primary blood type matching requirements in *Table 6-5* below:

Table 6-5: Primary Blood Type Matching Requirements

Hearts from Donors with:	Are Allocated to Candidates with:
Blood Type O	Blood type O <i>or</i> blood type B
Blood Type A	Blood type A <i>or</i> blood type AB
Blood Type B	Blood type B <i>or</i> blood type AB
Blood Type AB	Blood type AB

After hearts are allocated to primary blood type candidates, they are allocated to any secondary blood type compatible candidates, then to any eligible incompatible blood type candidates.

Allocation to *in utero* candidates eligible for any blood type deceased donors is initiated after all eligible born candidates have received offers

Policy 5.3.C. Pediatric Heart Acceptance Criteria. A transplant hospital may specify whether a candidate is willing to accept a heart from any blood type deceased donor. The candidate will be eligible for heart offers from deceased donors of any blood type if the candidate meets at least *one* of the following conditions:

1. Candidate is *in utero*
2. Candidate is less than one year old, and meets *both* of the following:
 - a. Is registered as status 1A or 1B.
 - b. Has reported current isohemagglutinin titer information for A or B blood type antigens to the OPTN Contractor within the last 30 days.
3. Candidate is at least one year old, and meets *all* of the following:
 - a. Is registered prior to turning two years old.
 - b. Is assigned status 1A or 1B.
 - c. Has reported current isohemagglutinin titer levels less than or equal to 1:4 for A or B blood type antigens to the OPTN Contractor within the last 30 days.
 - d. Has *not* received treatments within the last 30 days that may have reduced titer values to 1:4 or less.

If a transplant hospital indicates that a pediatric candidate is willing to accept a heart from any blood type deceased donor, and the candidate meets at least one of the eligibility conditions, anti-A or anti-B titers must be reported as follows:

- At the time of registration (except *in utero* candidates).
- Every 30 days after registration (except *in utero* candidates).
- At transplant (all candidates).
- If graft loss or death occurs within one year of the transplant (all candidates transplanted with an incompatible blood type heart).

Evaluation of Kidney Share 35 Policy: Inactive Status and Refusal Reasons among Candidates Aged 0-5

Prepared for:

Pediatric Transplantation Committee
Committee Meeting
April 8, 2014

By:

Wida S. Cherikh, Ph.D.,
Marissa A. Clark, M.S., and
Tim Baker
UNOS Research Department

Table of Contents

BACKGROUND/PURPOSE.....2

WORK PLAN ITEM ADDRESSED.....2

COMMITTEE REQUEST2

DATA AND METHODS.....2

RESULTS3

 Pediatric, Kidney Alone Additions during 2009-2013 and Pediatric, Kidney Alone
 Registrations on the Waiting List on December 31, 2013 by Waiting List Status and Age
 at Listing..... 3

 Local Kidney Offers Made to Pediatric Candidates from Donors Less than 35 during
 2009-2013 by Candidate Age at Listing 4

SUMMARY.....5

BACKGROUND/PURPOSE

The Pediatric Committee has been monitoring the Share 35 Kidney Policy implemented on September 28, 2005. Under this policy, kidneys from donors less than 35 years old that are not shared mandatorily for zero HLA mismatching, for renal/non-renal organ allocation, or locally for prior living organ donors shall be offered first for transplant candidates who are less than 18 years of age at listing irrespective of the number of points assigned to the candidate relative to candidates 18 years of age and older, with the exception of candidates assigned 4 points for CPRA levels of 80% or greater.

Data presented on a December 11, 2013 conference call showed that the overall median waiting time to a non-zero HLA mismatch, deceased donor, kidney alone transplant for kidney alone additions following policy implementation only decreased from 948 to 806 days for registrations aged 0-5 at listing as compared to the decrease in registrations aged 6-10 or 11-17 at listing, from 671 to 516 days and from 894 to 418 days, respectively. The Committee discussed the long median waiting times pre- and post-Share 35 for the 0-5 year candidates and requested additional data on refusal reasons and proportion of inactive registrations among 0-5 candidates.

WORK PLAN ITEM ADDRESSED

Access to transplant and good outcomes for pediatric candidates.

COMMITTEE REQUEST

As a follow-up to the December 11, 2013 conference call to present data as part of regular policy evaluation, the Committee requested to look at the number and percentage of inactive patients aged 0-5 on the waiting list as well as organ refusal reasons for candidates aged 0-5 at listing as reported on the Potential Transplant Recipient (PTR) records.

DATA AND METHODS

Data Sources:

Information provided in this report is based on OPTN data as of February 28, 2014. Data are subject to change based on future submission or correction.

Cohort and Methods:

Waiting List:

- Pediatric, kidney alone registrations added to the waiting list during 2009-2013 were tabulated by waiting list status and age at listing, where waiting list status reflects the status at 4 weeks after listing or removal, whichever came first.
- Pediatric, kidney alone registrations on the waiting list on December 31, 2013 were tabulated by waiting list status at year end and age at listing.

Kidney Refusals:

- Kidney match runs during 2009-2013 where the kidney was ultimately transplanted were examined. Local offers made to pediatric candidates (age at listing <18) from donors less than 35 years old were tabulated by whether the offer was accepted or, if not, the reason for refusal.
- Zero mismatch offers were excluded as well as any offer that the candidate could not have accepted.

- Each donor organ is weighted equally, regardless of the number of refusals for that organ. As offers are made, organs are refused for multiple reasons. In order to accurately capture a single refusal reason per organ, the total number of refusals, per organ, are taken into consideration and weighted. For example, if a kidney is refused 7 times for donor size and 3 times for donor quality, the kidney would have 7/10 of a refusal for donor size and 3/10 of a refusal reason for donor quality.

RESULTS

Pediatric, Kidney Alone Additions during 2009-2013 and Pediatric, Kidney Alone Registrations on the Waiting List on December 31, 2013 by Waiting List Status and Age at Listing

Table 1 tabulates the number and percentage of pediatric, kidney alone registrations added to the waiting list during 2009-2013 by waiting list status at 4 weeks after listing and age at listing and pediatric, kidney alone registrations on the waiting list on December 31, 2013 by waiting list status at year end and age at listing.

- Additions aged 0-5 at listing had the highest percentage of registrations inactive, at 58%, compared to 48% for those aged 6-10 and 47% for those aged 11-17 at listing.
- Of those registrations aged 0-5 at listing and still waiting on December 31, 2013, 69% were waiting in an inactive status, followed by 58% of those listed at age 11-17 and 56% of those listed at age 6-10.

Table 1. Pediatric, Kidney Alone Additions during 2009-2013 and Pediatric, Kidney Alone Registrations on the Waiting List on December 31, 2013 by Waiting List Status and Age at Listing

Age at Listing	Additions					Snapshot				
	Active*		Inactive*		All	Active		Inactive		All
	N	%	N	%		N	%	N	%	
0-5	395	42.5	535	57.5	930	74	30.8	166	69.2	240
6-10	370	52.0	341	48.0	711	91	44.4	114	55.6	205
11-17	1,503	52.6	1,357	47.4	2,860	336	41.7	470	58.3	806
All	2,268	50.4	2,233	49.6	4,501	501	40.0	750	60.0	1,251

* Reflects waiting list status at 4 weeks after listing or removal (whichever came first).

Local Kidney Offers Made to Pediatric Candidates from Donors Less than 35 during 2009-2013 by Candidate Age at Listing

Table 2 displays the weighted response percentages for refusals among local kidney offers made to pediatric candidates from donors less than 35 years old during 2009-2013.

- Pediatric candidates aged 0-5 at listing had the lowest percentage of offers accepted, at 14%, compared to those aged 6-11 or 11-17 at listing, at 19% and 27%, respectively.
- In candidates aged 0-5 at listing, the most common reasons for refusal were donor age or quality, at 29%, patient ill, unavailable, refused, or temporarily unsuitable, at 16%, and donor size/weight, at 14%.
- Of the offers made to 0-5 year old candidates, 14% were refused because of donor size or weight, as opposed to only 6% of offers made to 6-10 year olds and 5% of offers made to 11-17 year olds.
- The percentage of offers refused for reasons other than donor size/weight were similar amongst 0-5, 6-10, and 11-17 year old candidates.

Table 2. Local Kidney Offers Made to Pediatric Candidates from Donors Less than 35 during 2009-2013

Note: Excludes zero MM offers and offers the candidate could not accept and includes only kidneys that were transplanted

Offer Response	Candidate Age at Listing		
	0 - 5	6 - 10	11 - 17
	Weighted %	Weighted %	Weighted %
Accepted	14.30	18.68	27.42
801 - Patient ill, unavailable, refused, or temporarily unsuitable	15.93	16.68	14.26
811 - Number of HLA mismatches unacceptable	5.30	5.67	5.52
812 - No serum for crossmatching	5.23	3.31	4.60
813 - Unacceptable Antigens	1.49	1.90	2.38
814 - High PRA	0.00	0.00	0.01
815 - High CPRA	0.00	0.11	0.11
820 - Heavy workload	0.13	0.00	0.02
823 - Surgeon unavailable	0.15	0.15	0.16
824 - Distance to travel or ship	0.12	0.11	0.07
825 - Operational – transplant center	0.05	0.00	0.02
830 - Donor age or quality	28.72	30.69	25.46
831 - Donor size/weight	13.57	6.15	4.91
833 - Donor social history	7.31	8.46	8.06
834 - Positive serological tests	1.35	1.07	0.93
835 - Organ Preservation	0.84	0.60	0.72
836 - Organ anatomical damage or defect	1.42	1.56	1.19
837 - Organ-specific donor issue	2.54	3.35	2.47
898 - Other Specify	1.56	1.50	1.70
All	100.00	100.00	100.00

SUMMARY

- Pediatrics aged 0-5 at listing had the highest percentage that were inactive on the waiting list.
- Pediatric candidates aged 0-5 at listing had the lowest percentage of offers accepted.
- The percentage of offers refused because of donor size or weight was much higher among 0-5 year old candidates as compared to 6-10 or 11-17 year old candidates.
- The percentage of offers refused for reasons other than donor size/weight were similar amongst 0-5, 6-10, and 11-17 year old candidates.