The 2023 OPTN ABO-incompatible heart transplantation policy changes explained

Joseph P. Hillenburg

When we think about "disparity" we often assume that it is referencing race, socio-economic status, or other social determinants of health. However, disparities in transplantation take many forms. In pediatric heart transplantation, this can include factors such as initial diagnosis (ie. the reason for listing), transplant center volume, and ABO blood type.

If you are reading this article (whether a provider or caregiver of a patient) you are likely intimately familiar with the fact that solid organs typically are matched so that the blood groups of the donor and recipient do not cause an acute immune response to the transplanted organ. What is often surprising to nearly every non-provider I know, and even to many providers outside the "transplant public" is that many babies have safely received blood group incompatible (so called ABO-incompatible or ABOi) heart transplants. These patients thrive and have similar outcomes with ABOi transplantation, often leading others to react in amazement and awe, and proclaiming the wonders of modern medicine.

Initial steps by the US Organ Procurement and Transplantation Network (OPTN) over a decade ago allowed for ABOi heart transplantation, after other countries had been using the procedure. The initial policy allowed for titer levels of 1:4 or below, and as a result, my son (Type B) was listed for and received an AB heart in 2011, with an excellent outcome.

This technology, largely borne out of necessity by our Canadian colleagues, has been slow to be adopted by the OPTN. These researchers, as well as a number in the US, have demonstrated through careful research that there is no demonstrable difference in outcomes.

Subsequent changes in 2016 loosened OPTN policy to allow for titer levels of 1:16 for children under age 2. Between these changes and reduced hesitancy, more children were listed with the option for receiving an ABOi heart, but still some hesitancy persists, affecting both willingness to further liberalize policy and to list potentially eligible children.

Finally, and more recently, the OPTN Pediatric and Heart Committees worked together to examine what more could be done to help younger children, particularly those who might be older than age 2 but with lower titer levels. These changes, approved at the June 2023 OPTN Board of Directors meeting, include:

- *Eliminate the 24-month age cap, making all pediatric recipients eligible, provided the child's titer level are 1:16 or less.*
- *Include Status 2 candidates (previously only 1A and 1B were included).*
- *Include simultaneous heart/lung candidates. · In the event of listing for a second transplant, pediatric candidates may be eligible to receive an offer of both their compatible and original incompatible types.*
- *Add data collection points that will provide data on outcomes for older patients who receive ABOi heart transplants to inform further practice and policy changes.*

OPTN Public Comment, though overwhelmingly supportive, indicated a number of potential issues which were left on the table, and hopefully the community will consider further liberalization in time. Some of the comments reflected points such as:

- *When all other factors that impact organ priority are the same (distance from donor, urgency status, weight/height ranges, time on waiting list), organ offers will go first to ABO-compatible (ABOc) transplant candidates and then ABOi transplant candidates for children aged 1 and older.*

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- *Adults who received ABOi hearts as a child are not eligible to be listed for incompatible blood types once they turn 18. While this population is likely currently near 0, it will only increase as children like my son continue to thrive.*
- *Allow for the use of newer and more advanced assays.*
- *Potentially removing the 1:16 titer cap and need for monthly blood draws to check titers while listed and leaving this to center discretion.*

Unfortunately, none of the modifications proposed in public comment were included in the final policy, and it will be up to the pediatric heart transplant community (ie. us) to ensure that the OPTN further advances policy to follow clinical advancements. The inclusion of additional data collection by the OPTN will form the basis for further changes in the future.

With all of that said, our community has much to be hopeful for in the passing of this policy change. The OPTN contract is administered by the United Network for Organ Sharing (UNOS), whose Information Technology (IT) department estimated a 12–18-month implementation schedule. I look forward to more young lives being saved once implementation is complete, so other children will have the same opportunity as my son.

Joseph Hillenburg is the father of an 11-year-old heart transplant recipient. His son was diagnosed with Dilated Cardiomyopathy in 2011, and transplanted with an ABO-incompatible heart at what is now Ann & Robert H. Lurie Children's Hospital of Chicago. Mr. Hillenburg currently serves as Strategy Advisor for Transplant Families, an advocacy and support organization for families of pediatric transplant recipients. He also serves as a parent representative on the PHTS Scientific Committee and has served on the OPTN/UNOS Board of Directors.

Links:

https://optn.transplant.hrsa.gov/policies-bylaws/public-comment/modify-heart-policy-for-intended-incompatible-blood-type-aboi-offers-to-pediatric-candidates/

https://www.nejm.org/doi/full/10.1056/NEJM200103153441102

https://pubmed.ncbi.nlm.nih.gov/33743201/

https://www.jhltonline.org/article/S1053-2498(20)31525-4/fulltext

https://www.youtube.com/watch?v=HfXX5BSiUnA

**Special thanks to Dr. Brian Feingold for vetting the science*