

Ensuring Children are a Focus in OPTN Modernization

September 2024



Background

The National Organ Transplant Act (NOTA) was established in 1984, creating the framework for the U.S. Transplant System. The Organ Procurement and Transplantation Network (OPTN) provides a public-private partnership to support the U.S. Transplant System, with the United Network of Organ Sharing (UNOS) as the current contractor of the OPTN. In 2000, the Final Rule gave HRSA further supervision over the U.S. transplant system, including the requirement of a board structure. In 2023, the Securing the U.S. Organ Procurement and Transplantation Network Act was signed into law, with the goal of modernizing the OPTN.

The OPTN Modernization Initiative started by HRSA separates the OPTN Board of Directors from the OPTN contractor. This means that a set of new contractors will be involved in the process. New contractors may not be as familiar or aware of the challenges pediatric patients face with organ procurement and transplantation. It is important to highlight the differences in transplantation issues between children and adults. The unique challenges a pediatric patient faces includes a scarcity of pediatric donors, unique size and anatomical challenges, and an increased emphasis on donor quality over operational efficiency. In the pediatric transplant community, we are not just focused on three-year survival, but providing a transplant that will last children a lifetime. These are among the many unique pressures in pediatric transplantation and speak to the essential need for children to be structurally and operationally protected by the OPTN.

We ask you to weigh in with HRSA using the information below and ask for specific mechanisms to ensure that operational changes to the OPTN do not impact the pediatric population in a negative way.

1. **Ensure transparency throughout the OPTN modernization process.** The OPTN is complex, making it important for organ transplant professionals to provide feedback on the process. This cannot be accomplished if there is a lack of transparency between HRSA, OPTN, transplant professionals, and the public. HRSA should contractually require all OPTN contractors to state how they will address the unique needs of children within their operations.
2. **Provide alignment across all awarded contractors on the importance of pediatrics in the OPTN.** We understand that new contracts will be awarded soon. Once contracts are awarded, HRSA and selected contractors need to align on the challenges pediatric patients and pediatric providers face during the organ procurement and transplantation process and ensure those issues are front and center.
3. **Include pediatric specific metrics in monitoring the performance of the OPTN.** Metrics that consider both adults and pediatrics together often create incentives that improve adult donation and transplantation but may negatively affect the pediatric population. Pediatric specific metrics need to be incorporated for performance, safety, and quality measures.
4. **Ensure the inclusion of pediatric patient advocates in the OPTN.** To guarantee that the needs of children are included in the OPTN modernization process, pediatric patient advocates must be involved in the OPTN. These advocates understand the needs of pediatric patients and policies that will help them. With the announcement of the board support contract to American Institutes for Research and a special election of a new board, it is urgently imperative that there are protections in that election to ensure pediatric patient advocate representation. A “regular” election does not benefit pediatrics due to the large number of voters in adult transplant.