



Children's Hospital Association Statement for the Record

U.S. House Energy and Commerce Subcommittee on Oversight and Investigations "A Year Removed: Oversight of Securing the U.S. Organ Procurement and Transplantation Network Act Implementation"

September 11, 2024

On behalf of the nation's children's hospitals and the children and families we serve, thank you for holding the hearing, "A Year Removed: Oversight of Securing the U.S. Organ Procurement and Transplantation Network (OPTN) Act Implementation." We applaud your efforts to ensure the U.S. transplant system is working effectively and equitably. It is important to consider the impact of "Securing the U.S. Organ Procurement and Transplantation Network Act" on pediatric health care. Pediatric patients face unique challenges with organ procurement and transplantation that include scarcity of pediatric donors, unique size and anatomical challenges, and an increased emphasis on donor quality.

We ask Congress to work with the Health Resources and Services Administration (HRSA) to address the needs of pediatric patients and providers when implementing the OPTN Modernization Initiative. It is critical that Congress examine opportunities to connect with HRSA to ensure interests of pediatric transplant candidates are at the forefront of OPTN governance structure and operations.

Congressional Action Needed

Several key opportunities for bipartisan Congressional action to protect pediatric patients are highlighted below. We focus on topics that Congress can weigh in on with HRSA that are relevant to children's needs in organ procurement and transplantation.

Ensure transparency throughout the OPTN modernization process. It is important that organ transplant professionals can provide feedback on the modernization process. This cannot be accomplished if there is minimal transparency between HRSA, OPTN, transplant professionals, and the public. HRSA should contractually require all future OPTN contractors to state how they will address the unique needs of children within their operations.

Provide alignment across all awarded contractors on the importance of pediatrics in the OPTN. Once contracts have been finalized, HRSA and selected contractors need to align on the challenges pediatric patients and pediatric providers face during the organ procurement and transplantation process.

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.

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 with the OPTN. With the announcement of the board support contract to American Institutes for Research and a special election of a new board, it is imperative that there are protections in that election to require pediatric patient advocate representation.

In conclusion, efforts to address organ procurement and transplantation issues throughout government must be aligned to support the needs of pediatric patients. We ask Congress to work with HRSA on the OPTN Modernization Initiative to help provide transparency, accountability, and inclusion for pediatric patients and pediatric providers.

Thank you again for your commitment to ensuring “Securing the U.S. Organ Procurement and Transplantation Network Act” works for children, supports access to needed organs, and highlighting the challenges that have risen during the process. Children’s hospitals stand ready to partner with you to advance policies that will make measurable improvements in the lives of our nation’s children.