

Due to the significant advantages of transplantation over dialysis in a child, dialysis is a bridge to transplant for the vast majority of children with end-stage renal disease (ESRD), and transplant referral is critical for optimal pediatric ESRD care. Efforts to strengthen the accountability and transparency of the transplant system have the potential to improve the health of this vulnerable patient population. It is important that HRSA ensure the needs of pediatric patients, and their families, pediatric nephrologists, and pediatric centers are considered in the OPTN modernization effort. It is important that pediatric transplant patients and pediatric nephrologists, not just pediatric transplant surgeons, have a voice in any changes being made to the OPTN; this will help ensure that any new policies or systems put into place do not negatively impact pediatric patients and their families.

The current multidisciplinary committees are a strength of the current OPTN system. These committees are key to weighing in on allocation priorities and setting policy. We ask that HRSA maintain this committee structure in OPTN. In order to strengthen the voice of pediatric transplant patients, we request that there be a required pediatric representative on each of the organ-specific committees. This will allow pediatric specialists to have input on each allocation change and ensure that the policies protect pediatric patients. The families of children who are eligible for transplants should also be included.

For this modernization effort to improve the health of these vulnerable children, publicly available data must break pediatric data out from adult data. Specifically, ASPN recommends that HRSA's publicly available data include pediatric data for organ transplantation and waitlists by organ. Transplant requirements and considerations differ between children and adults. Without pediatric data, it is impossible to have a complete picture of how the transplant system is functioning for children with ESRD.