

PEDIATRICS

Pediatric recipients of solid organ transplants have unique and specific medical, surgical, and programmatic needs that must be met to elevate the quality of their post-transplant lives. The etiology and sequelae of organ failure in childhood differs substantially from adults, and directly affect growth, development, and cognitive performance. While we strive to perform "one transplant for life," a child currently has a high likelihood of incurring the increased morbidity and mortality risk of re-transplant, possibly even before reaching adulthood.

Thus, as a primary objective, children and adolescents must receive top priority for allocation of all suitable donor organs and access to qualified pediatric transplant healthcare to eliminate waitlist mortality and improve their post-transplant quantity and quality of life.

A child, by default, will have a longer exposure to immunosuppressive agents as compared to adults. Clear differences in absorption and metabolism of key immunosuppressive agents have been identified, starting as early as infancy. Thus, the potential adverse consequences of longstanding immunosuppression on bone health, cognitive development, and reproductive potential will generate a lasting impact on body growth, immune function, and self-imagery. Given the specific needs of children at the various developmental milestones and oscillating requirements for immunosuppression, the use of customized and innovative immune monitoring and immunosuppressive regimens must be vigilantly pursued and implemented.

Adolescents represent a unique and challenging population with disproportionately high incidence of graft failure and mortality directly related to inadequacies in the transition to independent care process and adherence to overall healthcare recommendations. Gaps in insurance coverage, and access to primary care and essential medications, continue to be a significant problem as post-transplant children transition to adulthood. These patients require structured, evidence-based protocols and psychosocial programs that support individualized, pediatric transplant patient needs.

These issues, many of which are unique to the vulnerable pediatric transplant population, require special study and focused prioritization. Increased funding for both basic science and clinical research is needed to better understand and develop innovative strategies that maximally benefit children with organ failure and transplants. Pediatric patients have much to gain from a successful transplant, including the optimization of growth, neurocognitive, and psychological development, the ability to attend school with their peers, pursue higher education, safely reproduce, and ultimately to become productive, independent members of society.

The American Society of Transplantation (AST) has strongly supported past legislative efforts to improve the field of pediatric transplantation, including medical research provisions included in the Children's Health Act of 2000, 106th Congress, P.L. 106-310, Title XXI, Special Needs of Children Regarding Organ Transplantation and the FDA's pediatric rule published in the December 2, 1998, Federal Register (63 Fed Reg 66631). This rule, which became effective April 1, 1999, ensures that all medications are tested for safety and efficacy in pediatric patients.

In summary, the AST supports the following initiatives:

- Prioritization for children to have optimal, equitable access to donor organs for transplant, and qualified transplant healthcare.
- Support for research that specifically addresses the special needs of children who have undergone organ transplantation, and promoting studies that provide for the successful transition of care into adulthood
- Guaranteed comprehensive insurance coverage for all pediatric organ transplant recipients



Approved by the AST Board of Directors on February 15, 2006
Revised and approved by the AST Board of Directors on April 13, 2009
Revised and approved by the AST Board of Directors on September 6, 2011
Revised and approved by the AST Board of Directors on August 12, 2015
Revised and approved by the AST Board of Directors, March 3, 2020

American Society of Transplantation (AST)

1120 Route 73, Suite 200 Mount Laurel, NJ 08054 Phone: (856) 439-9986 Fax: (856) 439-9982

Email: info@myAST.org Website: www.myAST.org

Contact:

Shandie Covington, Executive Director, scovington@myast.org; 856-316-0924

Bill Applegate, Director of Government Relations, bill.applegate@bclplaw.com; 202-258-4989