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## **Re: Revised INVEST Board of Directors Bylaws and Management and Membership Policies**

On behalf of the nation's children's hospitals and the patients and families we serve, thank you for the opportunity to comment on the revised OPTN bylaws and management and membership policies. We appreciate your efforts to modernize the OPTN and urge you to ensure adequate pediatric representation on the INVEST Board of Directors.

The more than 200 children's hospitals that comprise the Children's Hospital Association (CHA) are dedicated to the health and well-being of our nation's children. Children's hospitals provide vital care to pediatric transplant patients. There are key differences in organ transplantation between children and adults. For example, there is a scarcity of pediatric donors. There are often size and anatomical challenges for pediatric transplant candidates, and since children often need more than one organ during their lifetime, there is a critical need for a focus on donor quality over operational efficiency. The many unique considerations for optimizing pediatric transplantation access and outcomes speak to the need for pediatric representation on the INVEST Board of Directors. CHA has previously expressed concerns with the OPTN Modernization Initiative started by HRSA as it separates the OPTN Board of Directors from the OPTN contractor. New contractors may not be familiar with the challenges pediatric patients face with organ procurement and transplantation, making it even more critical that there is increased pediatric representation on the INVEST Board of Directors. We need to ensure there can be alignment between contractors so that children are not overlooked or disadvantaged in the process.

### **Increased Inclusion of Pediatric Patient Advocates**

It is critical for HRSA to include adequate pediatric transplant representation on the INVEST Board of Directors and the larger committees. While we appreciate that the revised bylaws and management and membership policies require that the At-Large Directors must include at least one pediatric specialist, we urge HRSA to increase this number. The current Board of Directors bylaws and management and membership policies are the exact same, however, there are five pediatric representatives currently sitting on the Board. We urge HRSA to ensure that this number stays the same or increases. To guarantee that the needs of children are included in the OPTN modernization process, more than one pediatric specialist must be involved on the Board of Directors. These advocates understand the needs of pediatric patients and the policies that will support them. The specific needs of pediatric transplant candidates vary by organ and across age groups from infancy to adolescence. Further, caregivers of children in need of transplant face unique challenges accessing transplant with variable access around the country. In the United States, children under the age of 18 make up approximately 22% of the population. If only one of the potential 34 members is a pediatric specialist, this is approximately 3% of the board, which would create substantial under-representation of the pediatric population. There would be further misrepresentation if the INVEST Board of Directors had a full 42 individuals, with only one pediatric specialist. We have specific concerns about the lack of pediatric representation, if the new bylaws do not require increased pediatric patient advocates. Lack of pediatric representation does not support achieving equity for children in the transplant community since there are differing definitions of optimal access and outcomes for children with end-stage organ failure. The majority of children will need multiple transplants over their lifetime. As such, the classification of "high-quality" organs for children differs from adults. Transplant equity for children is not solely about reducing wait times; it involves children receiving organs that will last as well as receiving these organs expeditiously. Lastly, there is a lack of resources and staffing shortages within the pediatric transplant community. The pediatric workforce, including those who dedicate their time and expertise to transplantation, is in crisis and access to pediatric transplant varies across the nation, with some families having to travel far distances to obtain access to life-saving organ transplantation for their children. The board must consider the increased challenges children, and their families face in obtaining life-saving transplants. As the OPTN and the INVEST Board of Directors move forward, the best way to ensure that children's voices are heard is to secure broad pediatric representation in the Board's composition.

CHA asks HRSA to ensure that there is adequate pediatric representation during the OPTN Modernization process by:

- Requiring the minimum number of pediatric specialists on the Board of Directors be increased to at least 3 pediatric specialists and at least 5 total members who are knowledgeable about pediatric transplantation.
- Require that at least one pediatric representative be included on the Nominating Committee.
- Require that at least one pediatric representative be included on the Executive Committee.
- Require that at least one pediatric representative be included on each of the Permanent Standing Committees.

We thank you for the opportunity to provide comments and look forward to continuing to work with you to improve children's health care. Please contact Natalie Torentinos at [Natalie.Torentinos@childrenshospitals.org](mailto:Natalie.Torentinos@childrenshospitals.org) or (202) 753-5372 for more information.