

CONSENSUS PERSPECTIVE

A Perspective on Referral and Selection for Pediatric Lung Transplantation



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1. BACKGROUND

After its introduction as a treatment option for children with end-stage lung disease in the 1980's,¹ pediatric lung transplant (LTx) rapidly expanded to 100 or more consistently performed throughout the world annually starting in 2005.² In late 2019 and early 2020, the advent of highly effective cystic fibrosis (CF) transmembrane conductance



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regulator gene modulator therapy (HEMT) for individuals with CF and the COVID-19 pandemic dramatically impacted pediatric LTx, with a significant reduction in the number of transplants being performed in children.^{3,4} Prior to these 2 events, CF was the primary indication for LTx in children, but that changed essentially overnight as very few patients with CF, regardless of age, required LTx anymore, with childhood interstitial lung disease and pulmonary vascular disease quickly becoming primary indications for LTx in children in countries with HEMT availability.^{3,4} As the landscape of pediatric LTx was evolving and the number of children undergoing LTx significantly dropped, there were concerns this specialized niche of pediatric care was vanishing, as there was a lack of guidance for the referral and selection of children for LTx.⁵ Although previous International Society for Heart and Lung Transplantation (ISHLT) consensus documents on the selection of LTx candidates provided some pediatric-specific recommendations,^{6,7} most of these focused on a limited number of pediatric lung diseases and could not expand on key issues that may have limited LTx candidacy for children, primarily due to word count limitations in these adult-focused publications.

As aforementioned, in 2021, the ISHLT released an update on the selection of LTx candidates via consensus that included brief comment on pediatric considerations.⁶ This was an important set of pediatric-specific recommendations, as it highlighted certain principles for LTx selection in children—including the theme of early referral, given the propensity for longer wait times for small children and infants compared to adults. This also highlighted crucial points on consent, adherence, transitions of care, and certain rare pediatric-specific diagnoses such as alveolar capillary dysplasia and pulmonary veno-occlusive disease. It is certainly this kind of consensus-based approach that helped pave the way for our pediatric lung transplant community to develop specific broader guidance around infants, children, and adolescents.

As a result, in April 2022, a representative expert group of ISHLT members focused on pediatric advanced lung disease and LTx assembled and generated the idea of an international document to establish guidelines for the referral and selection of pediatric LTx candidates to advance the field. Due to the recent transformative events impacting pediatric LTx, it is the general opinion of the panelists involved in the development of this consensus document that it will go beyond providing guidance for the referral and selection of children for pediatric LTx and also serve as a key part in the advancement of the field of pediatric lung failure and LTx.

2. TOP TAKEAWAYS

1. Children with advanced lung disease that are potential LTx candidates should be referred early, with the timing based on their primary diagnosis and trajectory of their lung disease, ideally forming a professional partnership between the referring center and the LTx center.
2. Listing for LTx in pediatrics should be considered for chronic, end-stage lung disease if there is progressive lung disease without available medical or surgical therapy or not responding to optimal treatment, and if there is an increased chance of death (> 50% mortality) from primary lung disease within 2 years.
3. Pre-LTx optimization in children is often different than in adults, as this involves ensuring patient and family goals are aligned and considering psychosocial factors beyond the child's control with the need for detailed instructions regarding candidacy and timing for re-referral if not presently a candidate.
4. Under specific circumstances, pediatric patients could be listed for LTx with an unknown cause for their lung disease (eg, infants with presumed fatal surfactant dysfunction but pending genetic testing and too clinically unstable to obtain a lung biopsy), if there are no other contraindications such as systemic disease and/or second end-organ failure.
5. Based on center policy, refusal of nationally recommended vaccinations is generally considered a contraindication for pediatric LTx.
6. Referral for LTx of children with end-stage lung failure requiring extracorporeal life support (ECLS) in the setting of acute/chronic respiratory failure associated with pre-existing advanced lung disease without



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reversible cause should be considered if the patient has shown no signs of improvement after minimum of 2 or more weeks of support.

7. Prior to ECLS, all the following factors should be considered and optimized, including vascular access, bleeding risk, neurological concerns, infectious concerns, use of anticoagulation, need for paralysis/sedation (ideally minimal), participation in rehabilitation with physical and occupational therapy, nutrition (ideally predominantly enteral), psychosocial supports, waiting period, and allosensitization.
8. For severe forms of pulmonary hypertension that may not be amenable for waiting for donor lungs, alternative procedures should be discussed within a multidisciplinary team, such as a pulmonary-to-systemic arterial shunt ("reverse Potts shunt"), atrial septal intervention (creation or enlargement), and pulmonary artery-to-left atrium shunt with artificial membrane (Novalung, Quadrox) should be considered as a palliation or a means to transplant based on each individual patient's hemodynamic condition and the center's experience.
9. Unmodifiable non-adherence and lack of sufficient care providers to support transplantation are contraindications to LTx.
10. Timing for referral for pediatric candidates being considered for multi-organ transplantation with LTx should be as early as possible, given the additional evaluation time needed and the scarcity of pediatric multi-organ donors.

With these takeaways, the panelists strongly believe that the single most important goal of LTx in children with respiratory failure who continue to progress despite optimal medical therapy or who have poor quality of life from their primary pulmonary condition is not to get to transplantation, but to be alive and healthy after LTx. Regardless of the respiratory support employed for sustaining life for these children, including ECLS, these patients need optimal management to allow the best chance for an optimal outcome and maximizing overall survival in the setting of limited pediatric donor organs globally.

3. CONCLUSION

With this consensus document, the ISHLT and its membership, for the first time, have created comprehensive guidance on managing children with advanced lung disease who may be considered for LTx as their ultimate therapy option. Importantly, this document addresses factors unique to children that often need addressing as LTx is discussed as a treatment option with patients and caregivers based on individual desires for the remaining part of their life.

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APPENDIX A. SUPPORTING INFORMATION

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.healun.2025.08.004](https://doi.org/10.1016/j.healun.2025.08.004).



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