PREFACE

Why a monograph on pediatric lung transplantation? Since the first pediatric lung transplant nearly 30 years ago, lung transplantation in children has evolved as an accepted therapy in selected children with end-stage lung disease, as it offers a prolongation of life and an improved health-related quality of life. Even though only approximately 1,500 pediatric lung and heart-lung transplants have reported to the ISHLT Registry, numbers are increasing. There are more than 30 centers worldwide that report pediatric lung transplant to the ISHLT Registry, but the vast majority of centers perform less than five transplants in children (<18 y) annually. It is important to understand that pediatric lung transplants present a specific challenge as children who undergo such a procedure are not ‘just small adults’, but they show distinct differences regarding their underlying lung disease, a challenging operative approach, and the impact of immunosuppressant drugs and opportunistic infections on the developing immune system and the child’s somatic growth.

To date, the published literature in the field of pediatric lung transplantation consists mostly of single-center retrospective reports including small patient cohorts. Current practice is typically based on extrapolated adult data, and many unanswered questions exist in the field of pediatric lung transplantation. Therefore, on behalf of the ISHLT, we put together a selected team of experts to produce this Monograph on Pediatric Lung Transplantation as an experience-based guide or handbook rather than an evidence-based document, to offer a reference for established pediatric lung transplant centers, but in particular to those being newly established at present or in the near future, i.e., in countries in Eastern Europe, South America or Asia. In addition, information is provided for adult lung transplant programs performing lung transplants in older children. Specific pediatric issues such as adherence and compliance to therapy are addressed in detail.

This Monograph comprises topics such as timely referral of children for lung transplantation, their evaluation and listing, aspects of peri-transplant management, post-transplant complications and comorbidities, and outcomes following pediatric lung transplantation. Chapters on specific issues such as living donor lung transplantation and infant lung transplantation were included. There is a particular emphasis on growth and development and psychosocial issues such as cognitive development, adherence and quality of life after transplantation. Further, there is a chapter explicitly devoted to end of life care in children. As care for children after lung transplantation is provided by a multi-disciplinary team, experts contributing to this Monograph on Pediatric Lung Transplantation include physicians and surgeons, and allied health professionals such as nurses and psychologists.

Finally, we intend this Monograph on Pediatric Lung Transplantation as a reference to assist efforts in the pediatric lung transplant community to harmonize management protocols and current practice and to enable the multi-center collaborations that are required to achieve our common goal to improve outcomes in children and adolescents after lung transplantation.

Samuel B. Goldfarb
Christian Benden
Stuart C. Sweet