Dear colleagues!

In order to ensure optimal care of children and adolescents with terminal respiratory insufficiency for whom lung transplantation might represent a life prolongation and quality of life improvement, the following requirements and recommendations must be guaranteed by the centres of post-transplant care:

1. Comprehensive and repeated education of the patient and the parents on the possibilities and limitations of a lung transplantation in children and adolescents (risk of transplant surgery procedure, mean organ survival of about 4 - 5 years, life-long medication with immunosuppressive drugs with repeated blood level measurements, repeated bronchoscopies with biopsies as needed, need of tight connection to a post-transplant centre for children/adolescents ensuring all diagnostic and therapeutic tools).

2. Clarification of the medical treatment options in the area the patients is living. In particular it must be required, that a specialized centre guarantees access to immunosuppressive drug level measurements has access to bronchoscopy during day and night, can process lung biopsies in a specialized histo-pathology unit, has access to microbiological, virological and parasitological culture conditions, can provide lung function measurement for children and adolescents by bodylethysmography. It is extremely important, that a nominated doctor or a team is assigned for the patient care.

3. Proximity of the parents living place to the centre should be clarified. The monetary burden should also be considered, since peri-transplantation costs are just covering a restricted part of the total costs. It should be permitted, that patients/families become welfare cases due to underestimation of the total costs of patient care.

4. Prior to potential eligibility for lung transplantation at the Thoracic Transplantation Centre in Vienna, a pre-evaluation with a 3-day hospitalization at the Children’s Hospital of the Medical University of Vienna has to be arranged.

Considering all the above mentioned points we hope to improve the quality of children and adolescents in the pre-, peri- and post-transplantation phase.

Kindly yours

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