LUNG TRANSPLANT

What is Lung Transplant?
A lung transplant is an operation where one or both of a person's lungs are removed, and lungs from someone else are put in, in their place. It is a big operation and one which is not suitable for all patients. Before a child can have a lung transplant they (and their parents) will need to undergo a careful selection process to decide if they are suitable to receive donor lungs.

Who needs a Lung Transplant?
Lung transplant is considered in those children in whom the risk of dying from their lung disease is greater than the risk of dying from undergoing a transplant. As a general guide, children in whom there is a 50% risk of dying within the next 2 years have reached a stage where lung transplant needs consideration. Transplant may also be performed where a child's lung disease alone is so restricting to their quality of life, that it is felt that the risk of dying from the transplant is outweighed by the benefit to quality of life.

How do I know if my child needs a lung transplant?
Your child's Respiratory Specialist will be aware of the clinical indicators for when transplant should be considered. The Specialist will discuss the issue of transplant at a time when it is a possibility, but not a necessity.

Are some children turned down for transplant?
Yes. Certain underlying illnesses or problems may mean a transplant is contra-indicated (not appropriate), for example:

- Children who have chest problems secondary to a neuromuscular disorders;
- Those with severe failure of more than one other organ (liver, kidneys, immune system etc);
- Children with severe blood infections, TB, AIDS or Hepatitis C liver disease.

In addition, certain other problems may make the transplant too risky (e.g. severe malnutrition, bone disease, renal [kidney] impairment, rib cage deformity, multi-resistant airway organisms). Also, the transplant team may decide that for a child where there has been difficulty in doing the previously recommended treatments is also unsuitable for a lung transplant.

Why are some children denied a lung transplant?
Sadly, in order for a child to get a lung transplant, another child or adult has to die. In this case, the grieving family have to give consent that the lungs of the child who has died can be used in a transplant. Understandably, at such a painful and tragic time, most parents find it too hard to agree to their child's organs being used in this way. For this reason, only a few suitable lungs are available for transplant in children. Also, the team can only use lungs from someone who has died *without* infection, malignancy, or organ failure (i.e the lungs cannot have been damaged by the cause of the donor child's death).

As you can imagine, these factors will limit the number of suitable pairs of lungs that are available. A pair of lungs can only be transplanted once, and cannot be used again. The transplant team has a duty to ensure that such a precious resource is used in children with the highest chance of success from their transplant. It is for this reason that the transplant team is very strict about who they will accept onto the transplant waiting list.

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How is it decided that my child is suitable for transplant?
When your child's Respiratory Specialists think your child's illness may be deteriorating over time, and they may be a possible candidate for lung transplant, they will discuss this with you. If, after this discussion you think a transplant might be in your child's best interests (and at this stage some parents decide that a transplant *is not* in their child's best interests), then your child will be referred to the transplant team.

The initial assessment will be done by the Adult Lung Transplant team in Auckland. After this, they will decide if your child is big enough (at least of small adult size) to possibly be listed for transplant here, or if your child needs to be referred to the team in Melbourne. There will need to be a further transplant assessment performed in Melbourne. The assessment is a very thorough process which takes 2 or 3 days. Your child will be clinically examined, undergo some tests they will have had before (e.g. lung function test) and some they may not have had (e.g. bone density scans, echocardiogram). In addition the child and responsible adults in the household will also be assessed psychologically to try and predict how the family will cope after the transplant. After this assessment, the team will decide how best to proceed.

To have a transplant means that part of one child's body is put into another child. This can often create difficult and complicated questions in the minds of the families going through this process. Some people may have great difficulty in coming to terms with there being a part of a child who has died being put inside their child; others may not be troubled by this at all. It can also sometimes happen that one adult in a household is comfortable with these issues, while the other adult is not.

The psychological assessment is intended to identify these moral dilemmas, and understand whether a particular family will be able to cope with the reality of what happens or not. In those families who are unlikely to cope, there is a risk that the outcome of the transplant will not be as successful. Given the limited availability of lungs to transplant, it is essential that all efforts are made to avoid lungs being used in situations where a poor outcome is very likely.

What then?
After the assessment has been performed the child's case will be discussed amongst all the transplant team. They will then decide into which of three categories to enter the child:

Active waiting list: The transplant team feel the need for transplant is pressing, and so will actively consider your child whenever a pair of lungs becomes available. The decision to give a pair of lungs to any child is then based on the tissue match (compatibility) between the donor and recipient. The lungs will always be offered first to the person in whom the match is closest. A child who is on the active waiting list must move to Melbourne to live. This is so they can be within easy reach of the hospital whenever a set of lungs become available

Inactive waiting list: The transplant team thinks the need for transplant is not urgent, but is likely to progress to this within 2 or 3 years. Between the Auckland respiratory paediatric team and the transplant teams we will keep your child under review, but will transfer him/her to the "active list" at a later stage, when it is right to do so.

Unsuitable for transplant: The team feels that there are clinical and/ or psychological factors with your child; or factors within the immediate family, which would make successful transplant very unlikely. If your child is not accepted for transplant, and the factors which prevented listing then resolve, then your child can be re-referred at a later date. If your child is assessed as being unsuitable for transplant, the reason(s) for this will be clearly and carefully explained to you.

Where can I find out more about Lung Transplant?
There is a massive amount of complicated information to digest when considering lung transplant. A number of hospitals in the US, which have paediatric lung transplant programmes, have posted information on the Internet. However, given the complexity of information it is probably best to discuss any concerns you have about a need for transplant with your child's Respiratory Specialist initially. If your child is *not* in need of transplant referral, and is unlikely to do so in the next 6-12 months, then your specialist can reassure you about this.

Will a transplant cost me money?
The medical costs of the transplant, and some of the social costs to stay in Melbourne, are met by the New Zealand Ministry of Health. However, if a parent has to give up their job to move to Melbourne, there is no money to cover this loss of earnings.

This information sheet is produced to answer some of the questions parents ask about Lung Transplant. It is not intended to replace discussion with your child's Respiratory Specialist and you are encouraged to discuss your child's condition with the specialists when you attend clinic.