

Each year, around 15 children in New Zealand will be born with or develop life threatening liver disease. 6-7 of these will require a liver transplant in order to survive. While liver transplantation is life-saving, it requires frequent visits to out-patients and admissions to hospital. KIDS Foundation is there to help walk beside families during this time that can be both physically and emotionally draining for the whole family.

Why do some children need a new liver?

The liver performs so many important functions that we can not live without it. It makes proteins in our blood called clotting factors without which we would bleed with out stopping; destroys old red blood cells and some types of bacteria; breaks down toxic waste products that are produced by other cells in the body; stores important nutrients and can provide extra energy when the body needs it and it makes bile which is used by the intestine to break down and absorb fat.

The commonest reason for children to need a liver transplant is due to a condition called biliary atresia. This is where, for an unknown reason, there is a blockage in or absent bile duct. This results in bile not being able to drain into the intestine and so builds up in the liver causing irreversible damage.

Other conditions that can cause liver failure are alpha antitrypsin (ATP) deficiency, Wilson's disease and some other rare metabolic disorders. It can also be caused by long term use of Intravenous Total Parental Nutrition (TPN). All these conditions result in irreversible damage to the liver.

Without a transplant these children will die.

How can KIDS Foundation help?

KIDS Foundation is a not-for-profit organisation dedicated to providing New Zealand families with support, advocacy and education on liver disease, transplantation and living an immunosuppressed life.

Patient membership: We offer free membership as it is our belief that the price to be eligible to join is high enough.

Support: staff are available for direct support of members either by phone, email or physically when able. We organise regular family events to encourage families to support and get to know each other. We also offer financial support to liver children and their families.

Advocacy: The staff is available for help and support as you go through the process of transplantation especially if there are areas where an external advocate could be of help.

Education/Awareness: KIDS believe that it is vital that all families have access to up-to-date information available to them and work to ensure this is provided. We also work closely with all main hospitals to try and raise awareness of the importance of early diagnosis of liver disease.

Contact us:

Name _____

Address _____

Contact phone _____

Email _____

- I would like to be sent a patient member's application form.
Patient Membership is free.
- I wish to support the work of KIDS Foundation by becoming a supporter of KIDS member for an annual subscription of \$30.00. Supporters receive our newsletters and updates of activities and current issues.
- I wish to make a donation to KIDS Foundation for the following amount:
 - \$40.00
 - \$50.00
 - \$60.00
 - Other(please specify)

Please make cheques payable to:

KIDS Foundation
and post to:
PO Box 75-076, Manurewa, Manukau 2243.

Liver disease-What to look for!

In all new born babies jaundice is common and normal during the first few days of life. However if your baby is still jaundiced after two weeks of age then this must be checked out by your doctor. There are many reasons why your baby may still be jaundiced- a problem with their liver is one reason but is very rare. A simple blood test called a split bilirubin can tell if the jaundice is caused by the liver or some other reason.

An important check you can do is to look at the colour of the stools (Faeces) and the urine.

Newborn urine should be colourless-if it is persistently yellow this could indicate liver disease-tell your doctor, midwife or Plunket nurse even if your baby is not jaundiced.

The stools of breast fed babies should be green/daffodil yellow
The stools of bottle fed babies should be green/English mustard yellow

If they are pale yellow/cream in colour then tell your doctor, midwife or Plunket nurse no matter what the age of your baby.

If you have any concerns always check with your doctor.



The
**Kids
Foundation**
key immune deficiency support

KIDS Foundation / IDFNZ is a registered charity and Incorporated society AK403741, with charitable status under the New Zealand Income Tax Act and is GST registered.

For further information contact:

KIDS Foundation
National Health coordinator 0508 300 600

Or

Clinical Nurse Specialist, Liver team,
Starship Children's Hospital,
Auckland
09 307 4949

www.idfnz.org.nz

Liver Transplant

Support for children
and their families



The
**Kids
Foundation**
key immune deficiency support