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Acute post streptococcal glomerulonephritis in New Zealand children

Information Sheet for Parents

7 July 2007

Dear Parent,

Background

You and your child are invited to take part in a surveillance study of acute post streptococcal glomerulonephritis (APSGN) in New Zealand. Your paediatrician has been diagnosed APSGN in your child. APSGN is a major cause of acute kidney problems in childhood

This is condition is caused by a streptococcal bacteria infection. The infection occurs in the throat ("strep throat") or in broken skin such as eczema (impetigo/school sores). About 7-14 days after the onset of the infection, the kidneys become inflamed and the child passes dark brown tea coloured urine. The inflammation of the kidneys (both kidneys are affected) is caused by the body's immune system reaction to the strep infection. There may be reduced amount of urine passed and rarely in severe cases the kidneys stop making urine altogether. As you will know the kidneys act as filters to clean the blood of wastes and toxins. Inflammation of the kidneys will reduce the kidneys ability to filter the blood and levels of toxins build up in the blood. Salt and water also builds up in the body and this leads to high blood pressure. (hypertension) This may cause headaches and in severe cases convulsions. The build up of salt, water and toxins is usually temporary. The treatment of APSGN is supportive and is by giving medicines to encourage the kidneys to get rid of more salt and water and by using blood pressure lowering medicines. Although most children make a complete recovery from this illness, those who have very severe disease are at risk of long term kidney complications such as high blood pressure, protein loss by the kidneys and reduced kidney function.

Aim of Study

The aim of this study is to record population information, clinical features, the result of laboratory tests and complications of APSGN. The information gained in this study will help your paediatrician and other doctors to have a better understanding of APSGN in a large group of New Zealand children. It offers the advantage of information based on New Zealand children and not studies performed on American or British children.

The study will not involve any additional blood or urine tests or procedures that your child would normally receive following the diagnosis of APSGN. No <u>additional tests</u> will be done on your child. There will not be any storage of blood or urine samples for genetic testing

What does the study involve

Your paediatrician will ask for your consent to record the clinical information in a questionnaire sent out by the Principal Investigator. This will be done at the time of initial presentation. Your paediatrician will remain in charge of your child's medical care and will treat your child in the usual manner. The Principal Investigator will not have any part in your child's medical care unless it is deemed clinically necessary by your child's paediatrician

Confidentiality

Principal Investigator will store the information on a database and all identifying names will be removed to protect the privacy of the participants. Only the Principal Investigator will have access to this information. Publications and reports resulting from the study will ensure that confidentiality of participants is protected.

Participation

Your child's participation is entirely voluntary (your choice) You do not have to consent for information on your child's medical condition to be sent to the Principal Investigator. If you agree to take part, you may withdraw at any time. If you chose to withdraw or not to take part, this will not affect any healthcare your child may require in the future. Results of the study will be made available to your paediatrician and a copy will be available to you if requested.

If you have any questions relating to you and your child's rights as a participant in this study, contact Health Advocates Trust on 0800 205 555

Statement of Approval

This research has received the approval of the Auckland Ethics Committee

If you have any questions regarding the study, please contact your child's local paediatrician or **Dr William Wong**, **Paediatric Nephrologist**, **Department of Nephrology**, **Starship Children's Hospital**, **Auckland**, **09 307 4949 pager 93 4823**

Thank you for taking part in this study.