

PARENT INFORMATION SHEET

Dear Parent,

This is to introduce to you the plans for the five year follow-up visit for the W.A. Pregnancy cohort study (known as the Raine Study). As you know a lot of information was collected during your pregnancy and over the first three years of your child's life. You will remember that we planned to see all of the children again soon after their fifth birthday. Our specific aim in seeing the children at this age is to see if we can determine the influence of various factors, occurring during pregnancy and early life, on the development of asthma and allergies in children. Asthma is difficult to diagnose with certainty in children younger than five years old, hence the visit at this age.

Asthma is very common in our community, with up to 40% of children having symptoms of recurrent cough and wheeze, and as many as 20% of children being diagnosed as having asthma. Asthma is associated with a tendency to have sensitive airways, probably present from birth. Asthma symptoms occur when something from the environment triggers this tendency. While current asthma treatment is reasonably effective it can not "cure" asthma.

To be able to design treatments that may prevent children at risk from developing asthma, we need to know how to identify which children may be at risk. While we know that asthma runs in families there is evidence that it is triggered in early life and we need more precise information to enable us to know which children to treat so as to stop them developing asthma. To try and understand why some children develop asthma, we wish to study children at the age of five to see if we can identify any factors during pregnancy or early life that may help us understand why some children develop asthma.

As well as looking at asthma, we are also interested to know how children at this age perform in a hearing screening test. Often parents and children are completely unaware that a hearing problem exists and these hidden hearing problems can give rise to important learning difficulties. By screening all children in the study for hearing problems we hope to learn more about the causes of hearing loss in children at this age.

Once again you will be invited to bring your child to the hospital for a clinical examination. This will be similar to the previous examinations your child has had. In addition we will be offering a hearing screening test, measurements of lung function, and allergy tests. With the lung function and allergy tests it is important for us to collect this information on children with and without asthma so that we can identify differences that may go along with asthma.

The hearing screening test involves your child listening to various tones through the headphones of an audiometer and responding appropriately when a sound is heard.

The lung function tests consist of two parts. Initially we will ask your child to perform a series of "blows" through a spirometer, which measures how much and how fast your child can blow out. This may take a bit of practice but most five year olds can manage this test.

We then would like to measure how sensitive your child's airways are. This is done by giving them small amounts of a chemical called methacholine to breathe and measuring any change in the lung function tests. Methacholine is very similar to a naturally occurring body substance which is normally released from cells in the lungs. The action of methacholine wears off quickly but lasts long enough for us to measure. The "methacholine challenge test" is a test of airway sensitivity that is used in respiratory clinics all over the world and has proven to be safe and to provide useful information for

studies such as ours. Although most do not experience any significant symptoms, some children may develop coughing or wheezing during the test. These effects wear off quickly over a number of minutes but can be reversed almost immediately by giving the child ventolin. Any child who develops any symptoms or experiences discomfort will be given ventolin to breathe to reverse any effect of methacholine quickly.

The next part of the study involves allergy testing. We are offering both skin and blood tests to determine whether your child is allergic to the common environmental allergens important in Perth (house dust mite, cat, grasses, moulds and egg white). Blood tests are the more accurate allergy test, but we recognise that some families may not wish to have a blood test. To minimize any possible discomfort we will apply a local anaesthetic cream to your child's skin. There are no risks of infection from having a blood test when done properly, as at PMH. While skin tests are not as accurate as blood tests, they may be more acceptable to some families. Ideally we would prefer to do both blood tests and skin tests in the same children so that we can compare the results. This will provide us with the opportunity to find out just how accurate skin tests are. You will be advised of the results of the lung function and allergy tests when the results are available.

One of the things we would like to do with the blood we collect is to investigate the genetics of asthma. To do this we will study the DNA pattern in the blood sample. We will use this information to try to identify unusual DNA patterns that may be part of the cause of asthma. If such patterns can be found they could help to make future advances in the prevention, diagnosis and treatment of asthma. If you agree to your child's blood being used for genetic analysis this will *not* require an extra blood test. All the blood we need will be taken in one go, although the volume of blood we need will be slightly more (10mls = 2 teaspoonfuls more). If we find that your child has an important and unusual DNA pattern then we will advise what, if anything, you ought to do about it. Any DNA we collect will be used for no purpose other than investigating the genetics of childhood disease in the context of the Raine Study.

We will be asking you for separate permission for each part of the study so that you can feel free to participate in the study without feeling pressured to agree to it all. You may, of course, withdraw your child at any stage without prejudicing your child's right and access to the best medical attention available at the hospital.

If any of the screening tests indicate your child may have a problem we will refer you to your General Practitioner. We will also send a copy of the results of the hearing screening test to the Audiology Department at Princess Margaret Hospital if you should wish your GP to refer you there.

We would like you to feel free to ask any questions you may have about any aspect of the study. It is important that you understand why we are asking you to allow your child to participate in this part of the study.

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