Twins and Psychosis Study Information Sheet

What is the Twins and Psychosis Study?  
This research study has been established at The Queensland Centre for Mental Health Research (QCMHR), The Park - Centre for Mental Health, Wacol, Queensland. The goal of the study is to find factors, both inherited (genes) and non-inherited, that play a part in causing psychosis. To do this, we need the help of more than 150 Australian pairs of twins: 100 pairs of twins where at least one twin has a psychotic illness and 50 pairs of twins where both members have never experienced psychosis.

Why is the study important?  
No cause has yet been found for serious mental illnesses such as schizophrenia and mood disorders. However, research has shown that there are factors that increase a person's risk of becoming unwell. For example, there is a higher chance of developing a psychotic illness if someone else in your family has the illness, suggesting genetic factors are involved. Possible environmental risk factors have also been identified.

It is helpful to study risk factors for illnesses by looking at twins because identical twins share their genes and all twins have shared their environments to varying degrees. This study aims to examine risk factors for developing a psychotic illness in both identical and non-identical twins from Australia, where at least one of the twins has a history of psychosis or twins where both members have never experienced psychosis. We are also interested in both genetic and environmental factors that may protect a person from developing mental illness even if they have been exposed to some of the risk factors.

When studying risk factors for illnesses it is important to be able to identify different groups of people who may all have the same illness but with different causes. In the second part of this study we want to look at a number of tests that may help us identify different groups within the psychotic illnesses. Two of the tests involve collection of skin and nerve cells. Growing cells in the laboratory allows us to study how these cells function and thus helps us to understand how changes in cell functioning may lead to illness.

How are families contacted?  
In accordance with strict rules for research studies, we have received permission to work with staff members at many clinics and hospitals. These staff members tell us about twins who might be able to help with this study. We ask the staff member who knows the twin to phone or write to them to ask permission for us to make contact.

Why do we need your help?  
The major problem in this study is finding enough eligible twins to participate. If you and your twin fit the criteria for this study, then your help could be very important. We believe that professionals, patients and families can cooperate to find answers to psychotic disorders.

Will you benefit from the study?  
It will take years of work to find better answers for psychotic disorders. This study will not provide any immediate benefits. We try to be helpful by answering questions about psychotic disorders, and if needed, by providing information about available treatment. Many patients and relatives find the interviews interesting, and enjoy being able to help the study.

What can you do to help?  
All participation is voluntary and confidential. This study involves two parts. If you choose not to join the study, your standard of treatment will not be affected. You are free to change your mind and withdraw at any stage during the interview or in the future. Participation in this project will not result in any extra medical and hospital costs to you. You will receive reimbursement for any expenses incurred during your involvement in this study.

In the first part:
1. We would like to speak with you about your life experiences and your observations about other relatives. The interview can be at your convenience. We can come to your home if you prefer, or provide your transport to and from the research centre. Most interviews last between 1-2 hours and with your permission will be videotaped.
2. With your permission a 20ml (4 tspns) blood sample will be collected. DNA will be extracted from the blood cells in order to examine the links between genes and psychotic illness.
3. It may be necessary to review your medical records and we may need to contact you at a later date to obtain more information.
4. We will do a brief physical examination (eyes, mouth, hands), head measurements and finger and palm prints. This examination gives us information about your growth during pregnancy.
5. We will also carry out a brief neurological evaluation scale that involves investigating your reflexes, memory and handedness. This examination gives us information about the functioning of your central nervous system.
6. If your parents are alive, we would like your permission to interview them in order to ask for information about your mother's pregnancy, you and your twin's childhood, and you and/or your twin's illness. We may ask your parents for a blood sample to look at their genes.

7. We will test your sense of smell, as there can be changes in this associated with psychotic illnesses. You will be asked to identify a number of odours on patches provided by the interviewer.

8. We will ask you to undertake a test to see how your skin reacts to a Vitamin B test. The vitamin B is placed on four patches at differing strengths, which are then placed briefly on your arm. We then check your arm over the next 20 minutes to see how your skin responds.

9. We will ask you to respond verbally to eight different pictures. Your speech samples will be used to assess form of thought and language. With your permission we will videotape your responses.

In the second part:
There are several tests we would like to carry out on you and your twin. They would be conducted at a time that is suitable to you and you are free to choose to participate in, or decline any or all of the tests.

1. Eye tracking involves a series of tasks that check your eyes and how you can keep track of certain things on a computer screen. For these tests you will be required to put on a headset with cameras attached, and look at a computer screen. This will take approximately one hour.

2. Binocular Rivalry measures how fast you can switch attention between the two sides of your brain. This will take approximately half an hour and involves looking at a computer screen while wearing goggles and signalling according to whether there are vertical or horizontal lines appearing on the screen.

3. Neurocognitive Assessment involves a number of computerised and paper and pencil tasks. This tests memory, attention and concentration and should take approximately one hour.

4. Evoked Response Potentials. During this part of the assessment you will be asked to sit in a chair while some electrodes are attached to your head to record the electrical activity of your brain while you listen to some sounds over an audiotape. This part of the assessment will take approximately one hour.

5. Magnetic Resonance Imaging scan involves using a magnetic field around a tunnel-shaped scanner to form an image of your brain. This gives a clear picture and does not use any radiation. This takes approximately 40 minutes.

6. Skin Biopsy - Skin cells are grown from a small piece of tissue that will be taken from the skin on the inside of the upper arm. This will involve a local anaesthetic and the amount of skin taken is about the size of a match head. The procedure takes about ten minutes.

7. Nasal Biopsy - In order to grow nerve cells, small pieces of tissue will be taken from inside of your nose. The cells there are involved in our sense of smell. For this procedure an Ear Nose and Throat specialist will spray on a local anaesthetic to numb the inside of your nose and two tiny pieces of the tissue will be collected, each less than the size of a match head.

You are free to participate or decline to participate in this study. All information collected in the study is treated in strict confidence and only members of the clinical research team will know your name. All information, the blood sample and buccal smear will be collected and analysed in coded form to make sure that you cannot be identified. The clinical information will be processed and securely stored at the Brisbane coordinating centre. The blood, cell lines, DNA and buccal smear will be stored at the Queensland Institute of Medical Research, Brisbane. We intend to publish the results only in scientific journals. You or your family will in no way be identified by name in any publication. When the study is completed the material you have provided may be made available to other projects investigating genes and psychosis. Some of these researchers may have commercial interests, in which case, you need to be aware that you will have no rights to any subsequent use of your materials. Individual results of DNA analysis will not be provided to participants or their relatives.

Are there any risks?
There are some possible adverse effects or risks related to participation in this project, which include:

1. Very occasionally, talking about family illness can be upsetting. If by chance the interview causes distress in individual patients or family members, the interview will be terminated and support provided. If a subject indicates a potential for self-harm, the interviewer will report these responses immediately to the treating clinician.

2. Complications associated with blood sampling are infrequent and minor, and include local bruising and inflammation of the vein used. Persons drawing blood will be trained in venipuncture techniques to minimize these complications. There is a possibility of some minor abrasion from buccal smear and/or minor skin irritation from the niacin test.

3. The major potential side effects of this study involve the skin and nose biopsies. Minor discomfort or bleeding may be experienced after the procedure, which settles with rest. Trained staff will be present to monitor your health after the biopsies. The small biopsy from your nose will not affect your sense of smell afterwards. The amount of tissue removed from your skin and nose is very small and no problems with healing are expected.

4. At present, the Policy on Genetic Testing of the Life Insurance Federation of Australia states that companies will not initiate any genetic tests on applicants for insurance. However, there is a possibility that at some time in the future, once genes predisposing to schizophrenia have been identified, insurance companies might wish to genetically test people before issuing policies.

Who is conducting the Study?
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