

Dear Twin Registry Member,

We would like to invite you and your twin to participate in the **Australian Twins and Psychosis Study**.

What is the study about?

Psychosis is a mental disorder that disrupts the ability to distinguish between real experiences and imagined ones. The devastating symptoms include hallucinations, delusions, and extremely confused thinking. It is a common disorder, affecting an estimated 1% of the population, and may be a short-term condition or part of a long-term illness such as schizophrenia or bipolar disorder. Research has identified certain risk factors, including a family history of the illness, that increase a person's chances of becoming unwell, but the causes of psychosis are not fully understood.

The Australian Twins and Psychosis Study is part of the genetic research program at **The Queensland Centre for Mental Health Research (QCMHR)**. Over the past ten years, the program has been conducting family studies of psychotic disorders to investigate the inherited (genetic) and non-inherited (environmental) factors that cause psychosis. Studying identical and non-identical twins will help us to answer some of the most complex questions we have about the disorder. With the help of twins, we will be able to learn more about the risk factors for developing a psychotic illness and, just as importantly, investigate the genetic and environmental factors that may **protect** a person from becoming mentally ill, even if they have been exposed to some of the risk factors.

For this study, we need the help of twin pairs where at least one twin has a history of psychotic illness, but also the help of healthy pairs, where neither twin has experienced psychosis. Therefore, we hope you will consider taking part in the study regardless of your history of psychosis.

What does participating involve?

This study has two parts and involves an extensive list of procedures. **However, you only need to be willing to complete the minimum requirements for Part One in order to participate.**

Part One involves an interview, providing blood and cheek cell samples, a brief physical examination, and undergoing a series of short tests to investigate possible risk factors. All of this can be done in your home or at one of our participating clinics. If your parents are alive and willing to become involved, we would like to interview them about your mother's experiences while she was pregnant and about aspects of your birth and childhood.

Part Two of the study consists of more extensive clinical tests and the collection of additional physical samples. These may help us identify different risk factor groups based on physical differences. You may choose to participate in some, all, or none of the procedures.

The enclosed Information Sheet outlines Part One of the study in greater detail, including any risks that are involved. You should read this material thoroughly before making a decision about your participation.

You will be provided with a thorough explanation of the second part of the study once you have completed Part One, so you can decide whether or not you wish to participate in any of the additional tests.

You do not have to participate in both parts of the study or in all of the procedures to be of help. The minimum required from participants is completion of an interview, permission to access case notes and medical records (if applicable), and provision of a blood sample. All other procedures are optional.

If you prefer to have the various aspects of the study explained to you by a member of the research team, we would be very happy to do so over the phone or in person. Just contact a team member on one of the numbers listed below under "Further Information".

What are the benefits of participating in this study?

This study is unlikely to provide any immediate benefits to you. It will take years of work to find answers to the questions we are studying and ultimately develop better treatments for psychotic disorders. We try to be helpful

by answering questions about psychotic disorders, and by providing information about available treatment, if needed. Many patients and relatives find the interviews interesting and enjoy being able to help the study.

Participation is voluntary.

You are under no obligation to take part in this study and you are free to withdraw at any stage. Your decision will in no way affect your current or future access to available medical care. You may ask questions and request written information about the study at any time. Before deciding whether or not to take part, you may wish to discuss the matter with a relative or friend or with your doctor. Participating in this project will not result in any extra medical or hospital costs for you. You will be reimbursed for your time and any expenses incurred during your involvement in this study.

All information collected for the study will remain confidential.

All data collected for the study will remain confidential. It will be used only for the purposes of investigating the relationship between genes and psychosis. It will be stored securely, with access limited to members of the research team. The research team will not share personal information among family members without the approval of the individual concerned. The results of the research will be published in a form that will not allow individuals to be identified.

The material you provide to the study may be made available to other projects investigating genes and psychosis, but in a format that will not allow you to be identified. Some of these researchers may have commercial interests; in which case, you need to be aware that you will have no rights to a financial benefit from any subsequent use of your materials. In this respect, it should be noted that it is the whole collection of material from hundreds of participants that is of value and that in reality each individual contribution has no commercial value on its own.

If you are willing to take part in the study, please fill out the enclosed response form and return it in the enclosed reply paid envelope.

If you are not willing, or you are unable, to participate, please indicate this on the enclosed form and return it to us anyway, as this will let us know that you have received this letter and have made a decision about your involvement.

Further Information

If you have any questions, or would like further information about the study, please feel free to contact the member of the research team that is listed for your area, **or ring the QCMHR Freecall number: 1800 682 699 and we will have someone from the study contact you.**

Research Team Contact Numbers

Brisbane

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Thank you very much for your consideration. We look forward to hearing from you soon.

Yours sincerely,



Dr Bryan Mowry
Associate Professor
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