

# CENTRE FOR CLINICAL RESEARCH IN NEUROPSYCHIATRY



*Gascoyne House, John XXIII Avenue, Mt Claremont, WA 6010*  
Mail: PO Private Bag No. 1, Claremont WA 6910 Tel: (08) 9347-6429 Fax: (08) 9384-5128  
<http://www.health.wa.gov.au/ccrn/>

## Genetic Testing and DNA Storage for Clinical Research

### INFORMATION SHEET FOR PARTICIPANTS

**On-site Chief Investigator:** Professor Assen Jablensky (08) 9224 0290  
**Chief Investigator:** Professor Vaughan Carr (02) 4924 6610  
**ASRB Manager and corresponding researcher:** Dr Carmel Loughland (02) 4924 6611  
**On-site Clinical Assessment Officer** Lisa Dawson (08) 9347 6415

#### What is DNA?

**DNA (DeoxyriboNucleic Acid) is a complex chemical substance that is present in the nucleus of every cell of the living organism and provides the 'blueprint' for its reproduction, growth, and function. The development and function of each organ of the body, including the brain, is under the control of specific segments of DNA called genes. A strand of DNA contains genes, areas that regulate genes, and areas that either have no function, or have a function we do not yet know. We inherit our entire DNA from both our parents.**

#### Why is DNA analysed?

**Human diseases, including schizophrenia, result from the interaction of environmental factors with the genes that underlie the hereditary predisposition of the person. Hereditary predisposition is often shared between members of the same family. This explains why close relatives often suffer from the same disorders, like asthma, diabetes, heart disease, or psychiatric illnesses, such as schizophrenia or bipolar disorder (manic-depression). Thanks to advances in genetic research, doctors now can better understand how certain physical illnesses are caused, or how they should be best treated and managed. Our project, funded by the National Health and Medical Research Council of Australia, aims to achieve such knowledge and understanding as regards the causes of schizophrenia.**

**Hereditary predisposition to a disease such as schizophrenia is likely to involve subtle alterations in specific genes that are passed from generation to generation. To pinpoint the altered genes, our research team uses sophisticated laboratory equipment to screen and compare DNA obtained from persons suffering from the disorder with DNA from their close relatives, as well as with DNA from persons and families where the disease is not present. Since the gene alterations we are looking for may be quite small and difficult to detect in the individual person, we need a very large number of individuals and families participating in this study.**

**One of the best ways of identifying such gene alterations is to study the genetic makeup of persons affected by the illness and compare it to individuals in whom the illness is not present. The first step in undertaking this work is to collect blood samples from people with schizophrenia and from people without the illness. These samples will be stored in a special way so that they last indefinitely, and we can extract from it DNA as necessary, without having to ask you for more blood in the future.**

#### Informed consent

We ask all participants, agreeing to participate in the Centre for Clinical Research in Neuropsychiatry-Australian Schizophrenia Research Bank (ASRB-CCRN), to provide a blood



sample. You will have the opportunity to speak with a member of our research staff, and ask for further information and clarification. Please note that you can refuse to participate or withdraw from the study at any stage. Your refusal or withdrawal will not affect in any way your access to medical care and treatment.

**Should you agree to donate a blood sample for the purposes of the clinical research described above, you will be given a Project Information Sheet and a consent form to read and sign.**

#### How is DNA obtained?

**A blood sample will be drawn by a qualified member of the research team in exactly the same way as any blood sampling for medical purposes. There may be some mild discomfort experienced with the insertion of the needle, and possible temporary bruising at the site of the draw. The test tube containing the blood sample will be given a code number and stored at the laboratory for DNA extraction. Please note that by consenting to donate a blood sample you understand:**

- **That donation of your blood sample for DNA analysis is voluntary, on the understanding that you will not receive, or be entitled to, any financial reward or remuneration.**
- **That our research results are meaningful only with regard to people suffering from schizophrenia as a group, and do not provide either a diagnosis or an assessment of risk of schizophrenia in the individual person. We therefore do not communicate results of DNA analyses to individual participants.**
- **That the blood sample is processed in such a way in order to provide the above-mentioned project with a constant supply of new DNA over many years.**
- **That the blood sample donated by you will be stored for the duration of the ASRB-CCRN, to be used solely for research into the genetic basis of schizophrenia and related disorders.**
- **That your identity will be kept confidential at all times and no identifying information will be disclosed to third parties, unless specifically required by Australian law (whenever possible, you will be informed, should this occur).**
- **That sometimes DNA is sent to other collaborating research institutions within Australia and/or overseas. If this occurs, your DNA sample will be identified by a code number only, and your identity will not be disclosed.**

#### Future use of your DNA

**As research into the causes of psychiatric disorders advances, there may be in the future new, currently unforeseen, uses for your DNA sample within the ASRB-CCRN research program – for example, looking for genes associated with certain physical disorders that occur in people suffering from schizophrenia, or genes that influence response to medication. As it is impractical to re-contact every participant for additional consent in relation to such new uses of their DNA samples, we are asking you now to allow the Chief Investigator of the ASRB-CCRN (currently Professor Assen Jablensky) to deal with such issues as appropriate, if they arise.**

#### What if I change my mind?

**You have the right to withdraw your consent at any time. If you wish to have your DNA sample withdrawn from further research, please notify the Chief Investigator in writing. We will then destroy your sample and inform you in writing when this is done.**

#### Do you have further questions?

If you wish to obtain additional information, or discuss any matter related to this research, you can contact, the Chief Investigator, Professor Assen Jablensky on (w) 9224 0290; fax number 9224 0285; or e-mail [assen@cyllene.uwa.edu.au](mailto:assen@cyllene.uwa.edu.au).

*Alternatively the following ethics committee has approved this project and all concerns can be addressed directly with them if you so wish.*

*Secretary, North Metropolitan Area Mental Health Services Human Research Ethics Committee, Private Mail Bag No 1, Claremont WA 6910 – (9347 6618)*

