



## AUSTRALIAN FUNCTIONAL GENOMICS NETWORK Participant Information Sheet

### What is the AFGN?

The Australian Functional Genomics Network (AFGN) is made up of experts in clinical genetics and functional genetics research. The AFGN is designed to “match” clinicians and their patients with researchers who can do studies to better understand the genetic basis of their disease.

### What is functional genomics?

Genomics is the study of all of a person’s genes, also known as the genome, and how they interact in the body.

Functional genomics is an area of research that focuses on how individual genes work and interact to perform different jobs in the body. The aim of functional genomics studies is to help figure out whether a specific change in a gene disrupts the normal function of the gene in a way that could cause disease.

One way of exploring this is by copying these variants in an animal or cell model, this is known as model organism research.

### What is involved?

1. Your clinical team will ask for your verbal consent to submit a connection application on your behalf.
2. This application will be reviewed by our experts to try and match you to a research project.
3. Not all applications will be matched, however, as the Network grows your application may be matched in the future. We will store your application for a minimum of five years.

Understanding the genetic basis of your condition may help inform your diagnosis which may provide important information for your clinical care and access to treatment and management options. Resolving a diagnosis can also help alleviate feelings of uncertainty.

### What happens if a match is found?

If a match is found, your de-identified data will be shared to the research group. In all instances your information will be treated with confidentiality.

You may be contacted by the research team for further consent or access to samples of your DNA. These may be new or previously stored samples.

Due to the wide variety of models and techniques used in functional genomics research, we are unable to provide detail on what your research project will involve. This information may be provided to you by the research team at the commencement of the project. The AFGN will ensure that research projects will be ethically approved.

### Potential Outcomes

Results may provide information about your condition and its management. However, they may also remain uninformative.



### How will the results be provided to me?

Research findings will be returned to your clinical team who will be responsible for passing clinically relevant results on to you.

Due to the nature of this research, we are unable to provide a timeframe for results. Many studies may take years to produce significant results. This means that results may not be returned if the research team cannot contact your primary clinician.

### What will happen to information about me?

Your information will remain confidential. Your data will be stored electronically in the AFGN study database. Only the project team will have access to your identifiable information to ensure results can be linked back to you.

During the matching process your de-identified information will be shared with the AFGN clinical and scientific committee to ensure that they are able to find the most appropriate research team.

If a match is found, this information will be shared with the research team.

Your de-identified information and functional genomics results may be shared with national and international databases to advance scientific knowledge.

### Withdrawing from the project

You can withdraw from the project at any time. You just need to tell us so. If you leave the research project, we will continue to use the information we have already collected about you. If you do not want us to use this information, please tell us. In this case, we will **stop using** your information. We may securely destroy the information as required by law.

### Contact us

If you would like more information about this project, you can contact:

|                  |                                                                                             |
|------------------|---------------------------------------------------------------------------------------------|
| <i>Name</i>      | <i>Ebony Matotek</i>                                                                        |
| <i>Position</i>  | <i>Project Officer</i>                                                                      |
| <i>Telephone</i> | <i>0410045818</i>                                                                           |
| <i>Email</i>     | <a href="mailto:functional.genomics@mcri.edu.au"><u>functional.genomics@mcri.edu.au</u></a> |