Further information

If you wish to enquire further before sending this form, please contact one of our research assistants on the details below:

Phone: +61 8 9346 2866
Email: scghmtp@health.wa.gov.au
Website: www.irdregister.org.au

To participate

Please mail your completed form to:

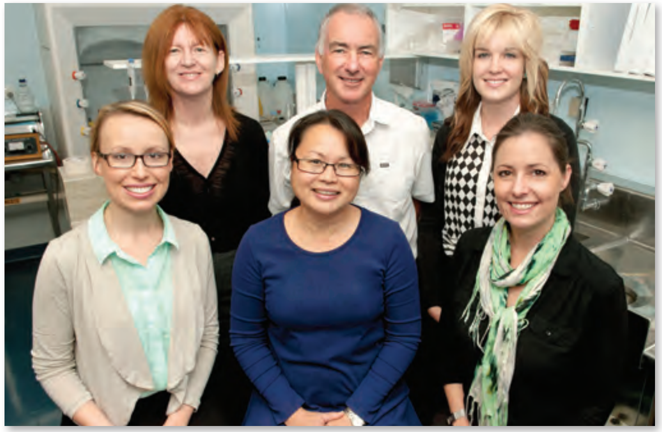
AIRD Register and DNA Bank
Department of Medical Technology and Physics
Sir Charles Gairdner Hospital
Hospital Avenue, Nedlands WA 6009

Funding for this research is generously supported by grants from Retina Australia (WA) (www.rawa.com.au) and Retina Australia (www.retinaaustralia.com.au).

Ethics & confidentiality

The Sir Charles Gairdner Hospital Human Research Ethics Committee has given ethics approval for the conduct of this project. If you have any ethical concerns please contact the Secretary of the Sir Charles Gairdner Hospital Human Research Ethics Committee on (08) 9346 2999. All study participants will be provided with a copy of an information sheet for their personal records.

Note that in accordance with these ethics approval conditions, your DNA can be used only for research into inherited retinal disease. The results must be kept strictly confidential and may not be released to anyone else in a way that may identify you. You may withdraw from the study at any stage, and upon your written request, your stored DNA will be destroyed.



The AIRDR Team

Australian Inherited Retinal Disease Register & DNA Bank

LCA
Retinoschisis
Choroideremia
Usher syndrome
Stargardt disease
Macular disorders
Retinitis pigmentosa
Rod & cone dystrophies

Government of **Western Australia**
Department of **Health**

About our research

Inherited retinal disease is a leading cause of visual impairment in Australia. The Australian Inherited Retinal Disease Register and DNA Bank was established as a national resource in 2009.

The aim of this study

The aim of this project is to establish a comprehensive Australian Inherited Retinal Disease Register and DNA Bank, and to progressively analyse stored DNA samples to identify IRD causing mutations in our population.

What you will be asked to do

If you choose to participate, you will be asked to answer some questions regarding your relevant clinical and family history, and to supply a small quantity of blood or saliva. Your DNA will be extracted from the blood or saliva, and will be stored by us until we genetically analyse it. Your genetic results (which may include the specific genetic mutation causing your IRD) are also recorded in this resource, as they become available. Only IRD related genetic information is stored.

The benefits of participating

As the molecular mechanisms leading to inherited retinal disease become more clearly understood, novel therapies are being developed which will in time prevent or ameliorate loss of sight and improve visual function. The early establishment of your genetic diagnosis is a prerequisite for potential participation in emerging therapies. If the genetic cause of your IRD is established and is of medical importance to you or your family, we will contact you.

This resource is actively used by clinicians and researchers to identify participants who may be suitable for emerging gene-specific clinical trials, to improve our understanding and treatment of inherited retinal diseases, and to facilitate clinical counselling of patients. Under no circumstances will a participant's identifying information be provided to other research groups without your written consent.

Expression of interest to participate in the Australian Inherited Retinal Disease Register and DNA Bank

Please note: This form is for new participants only.

I would like to know more about this project and may wish to participate by donating a small amount of blood or saliva and by answering some questions about my medical condition and family history.

Please contact me on the details below:

Surname: ______________________

Given Names: ______________________

Title: ________ Sex: ________ DOB: ________

Best known IRD Diagnosis: ______________________

____

Address: ______________________

____

Phone - Home: (   ) ______________________

Phone - Work: (   ) ______________________

Mobile: ______________________

Email: ______________________

I understand that while I receive feedback of a general nature, it is possible that I may never receive feedback about my case specifically.

Signed: ______________________

Date: ______________________