

Further information

If you wish to enquire further before sending this form, please contact us on the details below:

Phone: +61 8 6457 2866

Email: scghmtp@health.wa.gov.au

Website: www.scgh.health.wa.gov.au/Research/InheritedRetinal.html

To participate

Please mail your completed form to:

AIRD Registry 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 and its state branches.



Ethics & confidentiality

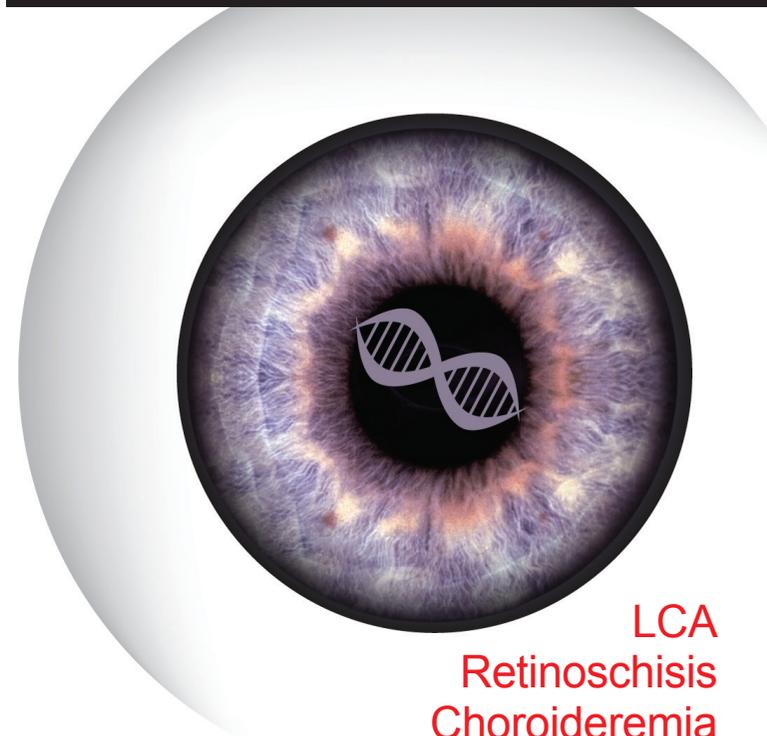
The Sir Charles Gairdner Hospital Human Research Ethics Committee has given ethics approval for the conduct of this project. If you have any ethical concerns please contact the Secretary of the Sir Charles Gairdner Hospital Human Research Ethics Committee on (08) 6457 2999. All study participants will 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 Registry & 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 Registry and DNA Bank was established as a national resource in 2009.

The aim of this study

This project established the national inherited retinal disease (IRD) registry and DNA bank, and currently aims to facilitate research on Australian families by developing the registry and progressively analysing stored DNA samples for IRD-causing genetic changes. This work is expected to encourage and expedite Australian-based clinical trials, inform patient management, improve patient outcomes and expand the current genetic knowledge regarding IRDs.

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 until it is ready to be genetically analysed. 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 IRDs 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 IRDs, 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 Registry 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 may receive feedback of a general nature, it is possible that I may never receive feedback about my case specifically.

Signed: _____

Date: _____