Government of Western Australia
North Metropolitan Health Service
Sir Charles Gairdner Osborne Park Health Care Group

The Australian Inherited Retinal Disease Registry & DNA Bank (AIRDR)

Supporting the AIRDR: Leaving a Bequest

Inherited retinal diseases (IRDs) are a group of genetic eye conditions that can cause vision loss and blindness at any age, and are the leading cause of blindness among working-age Australians. With more than 300 genes linked to IRDs, **genetic research plays a critical role in improving patient care and developing future treatments**.

The Australian Inherited Retinal Disease Registry and DNA Bank (AIRDR) is **Australia's largest genetic IRD research resource**. We have approximately 10,000 DNA samples in our care, representing more than 4,600 Australian families affected by IRD. This invaluable program has enabled over 7,200 genetic analyses and provides an **important foundation for national and international research into IRDs**.

AIRDR continues to grow, collecting 300 to 400 new DNA samples each year. Where possible, genetic research findings are shared with participants' clinicians, helping families gain answers about the genetic cause of their IRD and supporting genetically informed patient care. On average, it costs AIRDR around $3,000 to genetically analyse a family's DNA, interpret the results and provide an informative research report. To date, **we have provided more than 2,500 genetic research reports for AIRDR participants, free of charge.**

While AIRDR works closely with clinicians and contributes to patient care, it is a research program rather than a clinical service. As such, **we rely on funding support from grant agencies, charitable foundations, private donations, and bequests** to continue this world-class program.

Our goal is to identify the genetic cause of IRD for every family enrolled in AIRDR to support development of personalised and other innovative treatments for relevant Australian families, and connect potentially eligible AIRDR participants with clinical trials and treatment programs.

Financial support in the form of donations and bequests, will help us achieve this goal sooner and advance research, opening pathways to potential treatments. **Every contribution makes a difference.**

If a bequest is something you wish to consider, the following wording may be used in your will:

I wish to gift the sum of $____ to the Australian Inherited Retinal Disease Registry and DNA Bank, Department of Medical Technology and Physics, Sir Charles Gairdner Hospital, Perth, Western Australia.

Thank you for your consideration of this idea.

Ms Terri McLaren
Principal Investigator
Australian Inherited Disease Registry and DNA Bank

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