

The National
fH
Registry

NEWSLETTER FOR THE NATIONAL FH REGISTRY

April 2026



FH Australia

Familial Hypercholesterolaemia Australia (FH Australia) is the patient-led national organisation, established in 2023 by individuals with lived experience of inherited high cholesterol. Our mission is to represent and advocate for people and families affected by Familial Hypercholesterolaemia (FH) and elevated Lipoprotein(a) [Lp(a)].

FH Australia is committed to improving awareness, understanding, and equitable access to timely diagnosis and effective treatment across Australia. Central to this work is a strong focus on patient advocacy. We provide a platform for individuals and families to share their lived experiences, helping to increase recognition of the real-world impact of these conditions, while also supporting patients to build their health literacy, navigate the healthcare system, and engage confidently in decisions about their care.

By elevating the patient voice, FH Australia contributes to a broader understanding of the challenges associated with inherited high cholesterol, including delays in diagnosis, variability in care, and the lifelong nature of management. These insights inform national conversations and support efforts to improve care pathways and outcomes for affected individuals and families.

FH and elevated Lp(a) are common yet significantly underdiagnosed conditions, both associated with an increased risk of premature cardiovascular disease. It is estimated that more than 90% of individuals living with inherited high cholesterol remain undiagnosed. Increasing awareness—across the community, primary care, and specialist settings and at all levels of government health policy—is critical to improving early detection.

FH Australia also plays an important role in fostering partnerships across the health sector, working collaboratively with clinicians, researchers, and advocacy organisations to strengthen education, awareness, and support services. Through these efforts, we aim to contribute to a more coordinated and effective national response to inherited high cholesterol. FH Australia was pleased to become a health alliance partner of the national Heart Foundation in early 2026.

If you are interested in getting involved with FH Australia, please consider becoming a “Friend of FH Australia”, our national patient network; you can also follow, like and repost us on social media, or consider becoming a State-based FH Australia Ambassador.

Learn more about FH Australia and/or become a Friend of FH Australia on our website: www.fhaustralia.org.au



Contact: info@fhaustralia.org.au



Opportunity to participate in new UNSW research study about potential changes to newborn screening

Researchers from UNSW Sydney are interested in hearing from parents of children diagnosed with Familial Hypercholesterolaemia (FH). The study aims to investigate parents' thoughts about possible changes to Australia's newborn screening programs, and ways to best support parents and families affected by FH and other conditions.

What does participation involve?

A **30–45-minute telephone or video-call interview** on the following topics:

- Your experiences with your child's FH diagnosis
- Your experiences of receiving support after your child's FH diagnosis
- Your opinions of potential changes to the ways FH is screened and the impacts on parents and families

Am I eligible to participate?

You are eligible if you are the parent/caregiver of a child (or children) currently under 18 years old, diagnosed with Familial Hypercholesterolaemia (any type).

If you are interested in participating, please contact the UNSW Research Team at neoscreen@unsw.edu.au or visit <https://redcap.link/7r13w3p6>.

You can also contact the study team directly: Dr Brittany McGill b.mcgill@unsw.edu.au or Professor Natalie Taylor natalie.taylor@unsw.edu.au.

[Link](#)



Dr Brittany McGill
Study Lead
The University of New South Wales



Professor Natalie Taylor
Principal Investigator
The University of New South Wales

Opportunity to participate in a University of Sydney study on improving care for people with familial hypercholesterolaemia (FH)

Researchers from The University of Sydney are inviting people living with familial hypercholesterolaemia (FH), or parents/carers of children with FH, to take part in a research study. The study aims to better understand people's experiences of diagnosis, treatment, and ongoing care, and to identify ways to improve support for individuals and families affected by FH.

What does participation involve?

You will take part in a one-hour online interview to share your experiences, including:

- Your experience of FH diagnosis and care
- Your interactions with healthcare services and professionals
- How you manage FH in daily life (including lifestyle and treatment)
- Your views on how support for people with FH could be improved

You will receive a gift card in recognition of your time.

Am I eligible to participate?

You may be eligible if you are an adult with FH, or a parent/carer of a child with FH, currently living in Australia and able to take part in an interview in English or Chinese.

How can I take part?

If you are interested in participating, please complete the short survey below:

<https://redcap.sydney.edu.au/surveys/?s=NEALNCW9LF4KYL74>

If you have any questions, please contact Ms Jinyan Shi,
jinyan.shi@sydney.edu.au

Link



Ms Jinyan Shi
PhD Candidate and Study Coordinator
The University of Sydney



Associate Professor Mitchell Sarkies
Principal Investigator
The University of Sydney



*everyone deserves
a better chance*

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