

# NSW HEARTS: The NSW Inherited Cardiomyopathy Cohort Study

ACTRN12622000772741

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<b>Status</b>	RECRUITING
<b>Sponsor</b>	Garvan Institute of Medical Research
<b>Enrollment</b>	3,000 participants

## Plain Language Summary

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Inherited cardiomyopathies are a group of heart muscle diseases — including hypertrophic, dilated, and arrhythmogenic cardiomyopathy — that are passed down through families and can cause serious heart problems, including sudden cardiac death. The NSW HEARTS study aims to build one of the largest, most detailed databases of people with these conditions in New South Wales, bringing together clinical records, cardiac MRI scans, blood samples, and whole-genome sequencing.

By collecting in-depth data from over 2,500 participants and following them over time, researchers hope to identify patterns in how these diseases progress, uncover the genetic variants responsible in families where the cause is unknown, and ultimately improve how these conditions are diagnosed and treated. The data will also be used to develop better guidelines for managing complications.

You may be eligible if you are 17 or older, reside in NSW, and have a confirmed or suspected inherited cardiomyopathy — including being an asymptomatic gene carrier. There are no exclusion criteria for this study. The research is led by the Garvan Institute of Medical Research in Sydney.

## Key Eligibility Criteria

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### Inclusion (4)

- (1) Diagnosis of inherited cardiomyopathy (hypertrophic cardiomyopathy, dilated cardiomyopathy, arrhythmogenic cardiomyopathy, left ventricular noncompaction, restrictive cardiomyopathy, undiagnosed but familial cardiomyopathy, genetically confirmed heritable
- cardiomyopathy not already eligible, asymptomatic gene carrier)
- (2) Resident in NSW at time of consent
- (3) Aged 17 years and older

### Exclusion (1)

- Nil

## Locations (3 total)

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Royal Prince Alfred Hospital - Camperdown, NSW, Australia  
St Vincent's Hospital (Darlinghurst) - Darlinghurst, NSW, Australia  
Westmead Hospital - Westmead, NSW, Australia

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<https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=ACTRN12622000772741>

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