

# Aplastic Anaemia and Other Bone Marrow Failure Syndromes Registry (AAR)

ACTRN12623000461695

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Status	RECRUITING
Sponsor	Monash University
Enrollment	1,000 participants

## Plain Language Summary

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Aplastic anaemia and other bone marrow failure syndromes (BMFS) are serious conditions where the bone marrow cannot make enough healthy blood cells. These rare diseases can be life-threatening, and there is currently very little Australian data on how many people are affected, what treatments are used, and what outcomes patients experience.

The Aplastic Anaemia and Other Bone Marrow Failure Syndromes Registry (AAR) is a national database collecting information from all Australian patients with these conditions over time. By joining the registry, your treatment details, test results, and health outcomes will be recorded (in a privacy-protected way) so that researchers and doctors can better understand these diseases and improve care for future patients.

Anyone with a confirmed diagnosis of aplastic anaemia or another bone marrow failure syndrome is eligible to join, including children. Blood relatives of people with inherited forms of these conditions may also be invited. There are no age restrictions. Joining simply involves giving your consent for your clinical information to be collected.

## Key Eligibility Criteria

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### Inclusion (2)

- Adult and paediatric patients with diagnostic features of aplastic anaemia (AA) on bone marrow biopsy (pancytopenia with a hypocellular bone marrow, absence of an abnormal marrow infiltrate and no increase in reticulin). Patients with AA that is acquired or due to inherited factors are included on the registry.
- The AAR now includes relatives of participants with a diagnosed BMFS.

### Exclusion (1)

- Patients who have chosen to 'opt-off' the registry. Also other causes of bone marrow failure (e.g. following chemotherapy or B12 deficiency) have been excluded.

## Locations (37 total)

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The Alfred - Melbourne, ACT,NSW,QLD,SA,TAS,WA,VIC, Australia  
Austin Health - Austin Hospital - Heidelberg, ACT,NSW,QLD,SA,TAS,WA,VIC, Australia  
Box Hill Hospital - Box Hill, ACT,NSW,QLD,SA,TAS,WA,VIC, Australia  
... and 34 more locations

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<https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=ACTRN12623000461695>

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