

# The Haemophilia Osteoporosis Registry (THOR): Identifying Mechanisms of Bone Loss in Haemophilia

ACTRN12621001397808

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Status	RECRUITING
Sponsor	Monash University
Enrollment	176 participants

## Plain Language Summary

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Haemophilia A is a bleeding disorder where the blood doesn't clot properly. Thanks to major advances in treatment over the past few decades, people with haemophilia are living longer than ever. But a longer life means new challenges — including osteoporosis, a condition where bones become weak and fracture more easily. Research suggests people with haemophilia break bones more often than the general population, but the reasons why are not fully understood.

This study — the Haemophilia Osteoporosis Registry (THOR) — uses advanced bone imaging technology to look in detail at the structure, density, and strength of bones in men with moderate to severe haemophilia A, compared to healthy men without haemophilia. The goal is to understand when and how bone loss starts in people with haemophilia, so that future screening guidelines can be created.

You may be eligible if you are an adult male, weigh under 160 kg, and have been diagnosed with moderate to severe haemophilia A. Healthy men without major medical conditions may also join as controls. Participants need to be able to lie still during imaging scans and communicate effectively in English. The study is conducted at a hospital-based research centre and involves bone density scans and a research visit.

## Key Eligibility Criteria

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### Inclusion (12)

- Eligibility for inclusion as a participant in this study will require a potential participant to satisfy all of the following eligibility criteria:
- Aged 18 years or older
- Male
- Body weight less than 160 kg (maximum rating of imaging machines).
- At least one side of the body must be free from any metal, or other material in limbs or surrounding locations, that could interfere with imaging.

... and 7 more (see full listing online)

### Exclusion (4)

- For all participants:
- Have other medical condition that in the opinion of the investigators may deem inclusion unsafe or inappropriate (e.g., recent exposure to nuclear medicine; conditions that may reduce ability to remain supine during DXA (e.g., vertigo); conditions that may reduce ability to remain still during scans (e.g. Parkinson's disease, motor-neuron disease).
- Control participants:
- On medications that targets bone health e.g., Alendronate (Fosamax), Risedronate (Actonel), Ibandronate (Boniva), Zoledronate (Aclasta), Denosumab (Prolia), Teriparatide (Forteo) and Romosozumab (Evenity).

## Locations (2 total)

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Monash Medical Centre - Clayton campus - Clayton, VIC, Australia  
The Alfred - Melbourne, VIC, Australia

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<https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=ACTRN12621001397808>

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