

What is hydrocephalus?

Hydrocephalus is caused by an excess amount of cerebrospinal fluid in the brain.

Every year in Australia 1 in 500 children are born with hydrocephalus and many more adults and children acquire this condition.

There is no cure for hydrocephalus but it can be managed successfully with surgery.

The most common treatment of hydrocephalus and associated disorders is the insertion of a shunt. A shunt is a tube that takes fluid from the cranial compartment to another body compartment (usually the abdomen) where the fluid is absorbed.

How can I support the registry?

There is currently no provision for ongoing Government funding for the Shunt Registry. We welcome and appreciate your support. Please email the registry for further details

CONTACT DETAILS

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The Australasian
Shunt Registry

What are the aims of the Registry?

The key objectives are:

- Determination of the current indications, frequency and outcomes of CSF shunt related procedures
- Measurement of CSF shunt longevity
- Early identification of particular CSF shunt components associated with unexpectedly high failure rates
- Quality of clinical care - allowing benchmarking of outcomes between deidentified individuals and neurosurgical units
- Risk mitigation: immediate rebuttal when inaccurate information is published about the safety of CSF shunts
- Research: the registry will provide an opportunity to study methods of improving the performance and outcomes of CSF shunts and their components.

How is the information collected?

Hospital staff complete a registry data collection form at the time of surgery and forward it to the Neurosurgical Society Office in Melbourne where the registry is housed. Registry staff then enter the data into the database

Registry data will provide information to improve patient safety and quality of care. The overall aim is to reduce the probability of adverse outcomes for those with CSF shunts. Large numbers are needed to make this possible

What information is collected

- Patient Name, Date of Birth & Gender
- Medicare Number
- Contact address
- The reason the shunt was needed
- The name of the Surgeon and Hospital
- Shunt information such as name and type
- Antibiotic use
- The reason why a shunt may need to be removed, replaced or revised

How is the information kept secure?

Your privacy is very important to us.

All information will be handled in accordance with the New Zealand Privacy Act 1993 and the Australian Commonwealth Privacy Act (1988) including the Privacy Amendment (Enhancing Privacy Protection) Act 2012 and all other State and Territory laws and regulations.

No patient will ever be identified in any reports or publications produced by the Registry

Participation

Participation is voluntary. Your decision whether or not you want to be involved does not affect your treatment in any way. If you would like to participate then you do not need to do anything. If you do not wish to participate then you can have some or all of your information removed. If you have not received an "optout" form, please email shunt.registry@nsa.org.au and one will be sent to you.