{Date}

[Name]

[Role]

[Address]

[Suburb] [Postcode]

Dear [Name],

**Re: Australasian Shunt Registry – Imminent suspension or closure due to lack of funding**

The Australasian Shunt Registry (“Registry”) is a clinical quality registry managed by the Neurosurgical Society of Australasia. The Registry has been operational since late 2016 and is currently facing imminent suspension or closure due to lack of funding.

The Registry collects information about shunts - a medical device used primarily to treat hydrocephalus. Around 1 in 800 children are born with hydrocephalus in Australia every year and many more children and adults acquire the condition. It is estimated that several thousand procedures are performed annually. Hydrocephalus cannot be cured but it can be treated.

The failure rate of shunt devices is a significant issue. The consequences of shunt failure for patients and their families is devastating, often resulting in repeated brain surgeries, significant health issues, disability or death.

Suggestions:

Include your/your child’s name and age

When were you/your child diagnosed with hydrocephalus and what was the cause

When was your shunt inserted, have you had any revisions, how many?

What has this impacted your life (work, school, activities, family life etc)

The Shunt Registry is currently collecting data from both public and private, adult and paediatric hospitals throughout Australasia. There are currently over 2100 records in the Registry. Currently Registry data reports a failure rate of around 37%. Further information can be found at [www.nsa.org.au](http://www.nsa.org.au) -> Shunt Registry.

I have outlined below, my personal experience with hydrocephalus and the impact that it has had on my/ [my child’s] life.

The Registry urgently needs recurrent funding of $100,000 per annum to continue its important work. It would be a devastating outcome if the Registry, which is fully operational and collecting valuable information, is lost due to a lack of funding as any chance of reducing the impact of this condition on people, the health system and ultimately the budget will be lost.

This letter supports the formal request for funding sought by the Neurosurgical Society of Australasia.

Contact/sign off etc