



# Fact Sheet 1

## Who are we and what do we do?

[www.rettaustralia.org.au](http://www.rettaustralia.org.au)

The Rett Syndrome Association of Australia Inc. (RSAA) was established in Melbourne in 1989 in response to the needs of Australian children and adults with Rett syndrome and their families. The Association does not have its own premises. Its Australian Business Number (ABN) is 55 128 238 122 and is managed by a committee of 13 volunteers (mostly parents) from across Australia.

### How to get in touch with RSAA

*Registered office:*

Rett Syndrome Association of Australia Inc.  
74 Peter St  
Grovedale Victoria 3216

Phone 0418 561 796

Email [info@rettaustralia.org.au](mailto:info@rettaustralia.org.au)

### What does RSAA do?

- Liaise with, and if possible provide assistance to, those involved in Australian studies on the syndrome
- Arrange regular gatherings of Rett syndrome families across Australia
- Represent the Association at selected local and overseas Rett conferences
- Raise awareness of the disorder
- Liaise with overseas Rett Syndrome Associations
- Support families affected by Rett syndrome
- Provide assistance to Rett syndrome research
- Conference organization, with our next event being the staging of the 9<sup>th</sup> World Rett Syndrome Congress. It was to be held in Surfers Paradise in 2020 but has been postponed to 29 September to 2 October 2021, subject to the situation regarding the COVID-19 virus
- Promotion of family participation in drug trials conducted in Australia together with provision of financial assistance with their accommodation and travel
- Collect, catalogue and share information
- Production of a newsletter
- Provision of an RSAA website [www.rettaustralia.org.au](http://www.rettaustralia.org.au) and Facebook site <https://www.facebook.com/rettaustralia/> and administration of the closed 'Rett Syndrome Australia' Facebook site <https://www.facebook.com/groups/15688775612/>