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Rare Awareness Rare Education (RARE) Portal

Rare Voices Australia (RVA) is leading the collaborative development of the RARE Portal for rare diseases. RVA is the national peak body for Australians living with a rare disease. The **RARE Portal** is one of the key deliverables of the **Australian Government's National Strategic Action Plan for Rare Diseases**, the first nationally coordinated effort to address rare diseases in Australia.

The RARE Portal:

- ✓ Is a digital library of verified rare disease information, services and resources
- ✓ Is customised for the Australian context
- ✓ Caters for all stakeholders in the rare disease sector and the general public
- ✓ Is a living website that is responsive to feedback and new knowledge
- ✓ Highlights strengths and gaps across the rare disease sector, which can inform policy and service development

Visit the RARE Portal: www.rareportal.org.au





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What's on the RARE Portal?

- ✓ General information about rare diseases
- ✓ Information for all stakeholders in the rare disease sector
- ✓ Services and resources available nationally and in specific states and territories
- ✓ Rare disease information customised for Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds and people living in regional, remote and rural areas
- ✓ Individual disease pages developed together with RVA Partner organisations (disease-specific groups)
- ✓ A-Z Support Directory of rare disease groups
- ✓ Opportunities for stakeholders to provide ongoing input via a Contribute page



How the RARE Portal is being developed

The RARE Portal is informed by an **extensive multi-stakeholder consultation process**, led by RVA. Development of the RARE Portal has been funded by the Australian Government.



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