



AWARENESS AND EDUCATION

VISION:

The best possible health and wellbeing outcomes for Australians living with a rare disease.

CRITICAL ENABLERS:

Multi-stakeholder involvement and engagement.

Collaborative governance and leadership.

State, national and international partnerships.

High quality, comprehensive collection, and effective use, of rare disease data.

HOW WE ACHIEVE PROGRESS:

- Further develop RVA as the national peak organisation for rare diseases.
- Build on existing strengths to formalise centres of excellence throughout Australia.

WHY IS THIS IMPORTANT?

- Workforce and systems need to respond to current and future needs of those living with a rare disease.
- Increased awareness and education about rare diseases at the individual and community level is vital to empower people living with a rare disease to become active participants in their rare disease journey.
- Improved awareness will help reduce isolation and delays in diagnosis and treatment. Awareness activities must be supported by systematic identification, classification and a prioritised response to rare diseases and undiagnosed rare diseases.
- Rare disease organisations play a key role in raising awareness and providing person-centred information but are under-resourced.





AWARENESS AND EDUCATION PRIORITIES

Increase every Australian's awareness of rare diseases.

- National awareness and education activities.
- Awareness of relevant prevention measures.
- Targeted awareness and education for people in their preparation for conception and pregnancy.
- Awareness and education about testing and screening opportunities.

Access to information and education that enables people to be active participants.

- Awareness about rare disease services.
- A multi-purpose digital repository to detail available services and provide information.
- Improved communication between policy makers and the rare disease community.
- Resource and build activities of rare disease organisations.

Develop a national rare disease workforce strategy.

- Identify existing gaps in the rare disease workforce.
- Respond to current and future demands, including the impact of genomics.
- Equip and encourage frontline health professionals to consider, investigate and refer for a potential rare disease diagnosis.
- Australian guidelines that address the specific needs of people living with an undiagnosed rare disease.

