

Rare Diseases and Rare Disease Day

What is a rare disease?

- The most widely accepted definition is that a rare disease is one that affects less than five in 10,000 people.
- It is prominently cited that there are more than 7,000 different rare diseases.
- While individual diseases may be rare, the total number of Australians living with a rare disease is not. Approximately eight per cent of Australians live with a rare disease. Extrapolated to an Australian population of over 25 million people, this equates to around two million Australians.
- Approximately 80 per cent of rare diseases are of genetic origin.
- While there is large variation among rare diseases, people living with a rare disease face common challenges including timely and accurate diagnosis, limited care and support options and lack of research.

National Strategic Action Plan for Rare Diseases

In February 2020, Australia's Minister for Health launched the [National Strategic Action Plan for Rare Diseases](#) (the Action Plan), ahead of Rare Disease Day. Rare Voices Australia (RVA) led the collaborative development of the Action Plan, which involved extensive stakeholder consultation with all key stakeholders in the rare disease sector.

The Action Plan has three interrelated Pillars with Priorities, Actions and Implementation areas that work towards the best possible outcomes for Australians living with a rare disease. The three Pillars are:

1. Awareness and Education
2. Care and Support
3. Research and Data

'Developed by the rare disease sector, for the rare disease sector,' the Action Plan can drive and future-proof much needed reform.

Rare Disease Day

First launched in 2008 by EURORDIS – Rare Diseases Europe, Rare Disease Day 2021 (28 February) will mark the thirteenth time that rare diseases have been recognised globally. It will be the twelfth year the event will be commemorated in Australia.

The main objective of Rare Disease Day is to raise awareness among the general public and decision-makers about rare diseases and their impact on people's lives.

In 2020, thousands of events were organised in over 100 countries and regions to mark the day. The rare disease community united across borders to show that *Rare is many. Rare is strong. Rare is proud!* In Australia, a number of events were held including the Action Plan launch at Parliament House in Canberra, the Rare Together Expo in Perth, Rare Star Day, the Rare Disease Day Fun Run and Walk in Cairns and more. A number of buildings around the country were also lit up to mark the day.