

**8 May 2018**

Rare Voices Australia (RVA) welcomes tonight's Budget announcements related to the rare disease community. The Turnbull Government's announcements include:

- The Government will list Spinraza® on the PBS. This life-changing medicine treats the devastating illness, Spinal Muscular Atrophy (we congratulated RVA partner, Spinal Muscular Atrophy Australia, on this announcement and good work in this space last week). SMA patients would face costs of more than \$367,850 per year without subsidy.

These new listings give patients access to these medicines while paying a maximum of \$39.50 per script. Anyone with concession, including pensioners, will pay just \$6.40.

- The Turnbull Government has signed a landmark agreement with Medicines Australia to improve access to life saving medicines for rare disease through key reforms to the Life Saving Drugs Program.
- \$248 million worth of support will be dedicated to clinical trial activity through highly successful rare cancers, rare diseases and unmet need clinical trials and registry program.
- The genomics project, Mackenzie's Mission, will see \$20 million provided for a pre-conception screening trial for rare and debilitating birth disorders including Spinal Muscular Atrophy, Fragile X and Cystic Fibrosis.

RVA welcomes the Turnbull Government's Budget announcements and thanks Health Minister Greg Hunt for his ongoing support of the rare disease community.

Yours sincerely



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