

Spinal Muscular Atrophy Association of Australia Inc (SMA Australia) is Australia's peak body for the disease, proudly supporting Australians living with Spinal Muscular Atrophy for over 20 years.

August 2005	SMA Australia is founded.
August 2006	SMA Australia hosts our first Annual Fundraising Gala Dinner for SMA.
August 2015	SMA Australia hosts our first Million Steps for SMA fundraising walk.
August 2017	SMA Australia holds our first Parliamentary Event in Canberra, getting the condition on the radar of key decision makers in Federal Parliament.
November 2017	The Therapeutic Goods Administration (TGA) approves Spinraza (nusinersen) for the treatment of 5q SMA.
June 2018	Spinraza is listed on the Pharmaceutical Benefits Scheme (PBS) for the first time – the first treatment available for children with SMA in Australia. It is initially listed for those 18 years and younger at age of initiation with SMA types 1, 2 or 3a, demonstrating symptoms prior to three years of age.
August 2018	The first pilot program for Newborn Bloodspot Screening (NBS) for SMA is started in NSW and the ACT.
September 2019	SMA Australia holds our second Parliamentary Event.
December 2020	The PBS listing of Spinraza is expanded to include pre-symptomatic children with 1–2 copies of the <i>SMN2</i> gene.
February 2021	The TGA approves Zolgensma (onasemnogene abeparvovec) for the treatment of 5q SMA in eligible patients less than 9 months of age with symptomatic or pre-symptomatic SMA and 1-3 copies of the <i>SMN2</i> gene.
March 2021	The Federal government recommends SMA screening be rolled out nationally as part of the NBS program.
June 2021	The TGA approves Evrysdi (risdiplam) for the treatment of 5q SMA in children aged 2 months and over.
August 2021	Evrysdi is listed on the PBS for children with SMA in Australia. It is initially listed for those 18 years and younger at age of initiation with SMA type 1, 2 or 3a, demonstrating symptoms prior to three years of age.
April 2022	SMA Australia hosts the beSMAaware wellbeing conference.
May 2022	Zolgensma is listed on the PBS for the first time – the first gene therapy in Australia to be listed on the PBS. It is initially listed for the treatment of children less than 9 months of age genetically diagnosed with SMA Type 1 or pre-symptomatic children who have 1–2 copies of the <i>SMN2</i> gene.

July 2022	Screening for SMA is rolled out as part of the NBS program in NSW & ACT, following the completion of the pilot program.
August 2022	The PBS listing of Spinraza is expanded to include the treatment of adults whose symptoms appeared before 19 years of age – the first treatment available for adults with SMA in Australia.
September 2022	The PBS listing of Spinraza is expanded to include children with SMA Type 3b/3c.
January 2023	WA announces their NBS program will include screening for SMA.
March 2023	The TGA listing of Evrysdi is expanded to include people of all ages with 5q SMA.
May 2023	QLD (including northern NT) announce their NBS program will include screening for SMA.
August 2023	SMA Australia holds our third Parliamentary Event, providing an opportunity for our community to formally thank members of Parliament and their distinguished guests for supporting our efforts to gain PBS access to the latest SMA treatments over the past six years.
October 2023	<p>The PBS listing of Evrysdi is expanded to include adult patients who experienced SMA symptom onset prior to 19 years of age and did not initiate an SMA therapy in childhood, children with SMA Type 3b/3c, and children with confirmed genetic diagnosis of SMA who have 1–2 copies of the <i>SMN2</i> gene.</p> <p>The PBS listing of Zolgensma is expanded to include pre-symptomatic children less than 9 months of age genetically diagnosed with SMA who have 3 copies of the <i>SMN2</i> gene.</p>
November 2023	<p>Genetic carrier screening for SMA, Cystic Fibrosis and Fragile X syndrome is 100% covered by Medicare for anyone who is pregnant or planning a pregnancy and their reproductive partner.</p> <p>SA (including TAS and southern NT) announce their NBS program will include screening for SMA.</p>
March 2024	<p>Victoria announces its NBS program will include screening for SMA.</p> <p>The PBS listing of Spinraza is expanded to include pre-symptomatic children who have 3 copies of the <i>SMN2</i> gene.</p>
November 2024	The PBS listing of Evrysdi is expanded to include pre-symptomatic children with confirmed genetic diagnosis of SMA who have 3 copies of the <i>SMN2</i> gene.