

18 August 2023

**PBAC POSITIVE RECOMMENDATION**  
**Spinraza and Zolgensma for pre-symptomatic babies with 3 copies of the SMN2 gene**

We are excited to bring you the news that the Pharmaceutical Benefits Advisory Committee (PBAC) announced a positive recommendation today for both Spinraza and Zolgensma to be extended for pre-symptomatic babies with three copies of the Survival of motor neuron 2 (SMN2) gene.

We are working closely with the sponsors – Biogen for Spinraza and Novartis for Zolgensma – and the Hon Mark Butler MP, Minister for Health and Aged Care, for a timely announcement regarding the listing date(s) on to the Pharmaceutical Benefits Scheme (PBS).

New generation SMA is rapidly making life easier for families, and even more so with the extension of these treatments. Currently there is a requirement that babies with three SMN2 copies are asked to wait until symptoms develop before they can access either Spinraza or Zolgensma treatments. With the PBS listing extensions, children that would have previously missed out due to the number of backup SMN2 copies they have, may have the same successes as those who have been treated at birth, and families will be save the heartbreak of knowing that there is a treatment available but you're not able to access it.

If you have any questions, please don't hesitate to email us at [smaa@smaaustralia.org.au](mailto:smaa@smaaustralia.org.au).

Yours sincerely,



**Julie Cini**  
Spokesperson



**Seona Donald**  
President



**Gavin Old**  
Vice President