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PBAC POSITIVE RECCOMMENDATION Spinraza over 18s

Today is another historic day for those living with Spinal Muscular Atrophy (SMA) especially for those who are over 18 years. The outcomes from the March 2022 meeting have been published by the Pharmaceutical Benefits Advisory Committee (PBAC) this afternoon, and we are beyond excited to announce that Spinraza for those over 18 years has been given a positive recommendation.

The SMA community have been eagerly awaiting this recommendation for several years and we are thrilled to be able to bring you the news of this announcement. We are hoping for an imminent announcement from the Heath Minister regarding the Pharmaceutical Benefits Scheme (PBS) listing date and are working hard in the background to ensure there is minimal delay.

The journey to get this across the line has been a long five years, but as the peak body, we continued to fight for the adult community, even when some had lost all hope.

This is a huge change in the landscape for SMA, and we urge anyone who is over 18 years and not receiving treatment to start the conversation with your neurologist as soon as practicable to ensure you gain access once listed on the PBS. If you don't have a neurologist, please reach out to us as we can assist you in connecting with someone. We encourage you to start treatment now instead of waiting for other treatments to be approved in the future, this will ensure your optimal health and wellbeing.

If you have any questions, please do not hesitate to reach out to us at smaaa@smaaustralia.org.au.

Kind Regards

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Julie Cini – CFO

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