

Advocacy Beyond Borders

Australia



www.advocacybeyondborders.com



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1. About

Advocacy Beyond Borders is a not for profit charity based in Australia that supports rare disease patient organisations in their country (Asia Pacific, Middle East and Africa) to develop and support local solutions. We work with all relevant stakeholders and utilise best practice resources, advocacy strategy and tactics and delivery models to support local efforts and aspirations.

“Empowering the voice of change”

2. Mission

Create a connected community of patient advocacy groups around the world that will together create significant and positive change for patients and families living with SMA. IN 2024 we plan to hold region meetings to connect with patient organisations within our region to find out the priority areas they want to focus support on.

3. Focus.

Our focus is connecting the community. As we are relatively new we have a website and some resources to support organizations can automatically download to help them. Our focus is to consult organisations in the region with the view of holding a conference in Asia Pacific late in 2024.

4. Coming up

Just looking to connect with as many organisations as possible to help those countries that may not have access to treatments right now. Working on a survey to find out what countries have access to treatments, newborn screening or genetic testing.