

WeCareJourney Association

Malaysia



wecarejourney.org



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1. About

We're the pioneering SMA patient group in Malaysia that truly celebrates diversity. This means our committee, community, and even our medical board of doctors come from all walks of life. We believe this variety of perspectives makes us stronger and more effective in supporting families with SMA.

We're not afraid to speak our minds. We believe in having open and honest conversations, even when they're tough. We're respectful, but we're also firm in our commitment to getting the best possible care and support for families.

We partner with a wide range of stakeholders and believe that by working together, we can make a real difference in the lives of families with SMA.

We're proud of the progress we've made, but we know there's still more to do. We're committed to continuing to work hard until every family with SMA has access to the care and support they need to thrive.

2. Mission - C.A.R.E

Imagine a future where everyone with SMA gets the best possible care and families with SMA live happy and healthy lives. That's what we are working towards!

- **Connect** patients, families, and healthcare providers together. We share knowledge, resources, and helpful connections. We also build a strong support network where everyone can feel encouraged and understood.

- Augment healthcare providers and partners. We're like the extra boost for them by offering extra resources, support, and expertise to help them do their best work for people with SMA.
- Raise Awareness. We speak up for unmet needs, broader access to treatment and better healthcare standards for everyone with SMA in Malaysia.
- Equip families by giving them the capability to be in charge of their loved one's care and their own well-being. We believe every family should have the tools they need to thrive.

3. Coming up

- **Everyday Lifelines:** We know that things like emergency use BiPAP and MEI devices, home physio, hydrotherapy, and help with breaks and assisted living are crucial for families with SMA. They're like lifelines, so we'll keep them strong and even improve them over time.
- **Team SMA:** We're joining forces with doctors, HCPs, and anyone else who wants to make a difference for people with SMA. Together, we'll push for better treatment and raise the bar for how everyone with SMA is cared for in Malaysia.
- **Growing Our SMA Family:** We're building a strong, inclusive team of leaders from different backgrounds and experiences. This way, we can keep fighting for better care and support for everyone with SMA, now and in the future.