

# Indonesian Spinal Muscular Atrophy Community

Indonesia



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## 1. About

Indonesian SMA Community is an Indonesian community of people with SMA, their family, health professionals and anyone who is concerned about SMA in Indonesia. We are a non-profit organisation and have been working voluntarily to raise SMA awareness throughout Indonesia since 2017.

I am chairwoman of Indonesian Spinal Muscular Atrophy Community and also mother of children with SMA. I represent my organisation, especially parents and family that live with SMA in Indonesia. I believe that everyone has the right to get access to medicine and any treatment for SMA so they have a good quality of life.

## 2. Mission

I want to learn from other people and organisation experiences and strategies from many different countries how to deal with stakeholders in their country to get access to any treatment. I also want to build a network with them.

SMA is not a priority in Indonesia, so person with SMA in Indonesia don't get access to SMA's medicine. Early detection also has not yet become attention for the government. Test DNA is expensive and we have to pay it out of pocket. I am hoping from this event I can get enlightenment and encouragement to do more for people with SMA in Indonesia.

### 3. Focus

We are sharing information about living with SMA including any treatments and clinical trials that are available within our members. We provide support for patients and family members for the grieving process. We are collaborating and advocating with academic, health associations and other disability organisations to improve better quality of life for people with SMA.

We provide the families of SMA patients with a space to meet, to learn, and to console each other in our journey. We provide in depth information on SMA for health professionals to ensure wider early detection. We provide the general public with SMA awareness.

### 4. Coming up

Right now, we are also focusing on advocacy of regulations that can better accommodate the needs of people with disabilities, especially people with rare diseases like SMA. Our biggest challenge is getting access to affordable SMA's medicine.

