

## Japan SMA Family Association

Japan



[www.sma-kazoku.net](http://www.sma-kazoku.net)



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### 1. About

The president of the JAPAN SMA Family Association, the mother of a 15-year-old son with SMA Type 1. The association was established in 1999 and consists of 300 members (patients, families, specialized doctors, therapists). We manage SMA Future Conferences with multiple stakeholders and provide support for parents of children and adult patients.

### 2. Mission

Our goal is to provide screening test for all newborns by free, enabling early detection and pre-symptomatic treatment of all SMA patients. We also aim to create a comprehensive follow-up manual for after treatment and specific physical function assessment criteria.

### 3. Focus.

We've successfully obtained approval for three treatments and secured a budget for NBS through lobbying and government appeals. We've held numerous seminars and meetings for patients and families, fostering collaborative relationships with stakeholders.

We've also engaged with the media to raise awareness about our initiatives.

### 4. Coming up

We're working on establishing a nationwide system for NBS and early treatment, conducting physical function assessments, setting up follow-up procedures after treatments, and addressing challenges in inclusive education.