

Cure SMA Foundation of India

India



www.curesmaindia.org



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1. About

Cure SMA Foundation of India is a registered public charitable trust with pan India representation. Since the humble beginning of 10 families, we have grown to represent SMA families and individuals across the country. Each year we support SMA families through our newly diagnosed care and counselling, resource pool, SMA camps and supportive services, patient advocacy and many other direct family support services. We are extensively working to empower SMA patients and enabling them to access existing services and facilities. We have augmented our effort to bring the lifesaving SMA therapies to India.

2. Mission

We are committed to bringing the treatment and cure for SMA to India, making healthcare accessible, inclusive, and insured for all, and creating awareness about SMA and the significance of genetic screening so that we can accomplish a world without genetic diseases. Our Vision: We dream of a SMA free world and a barrier free universal healthcare for all.

3. Focus

We aim to build a robust Ecosystem for SMA individuals, families and Caregivers in India. We are also supporting our neighbouring countries. Currently 8 SMA multi-disciplinary SMA clinics are running in India in collaboration with hospitals and HCPs. We have formed a SMA task force with 40 clinicians of various specialities to guide us in improving SMA care infrastructure and treatment access. Our advocacy efforts have been instrumental in bringing various compassionate use programmes for treatment access in India. Our advocacy with government and pharma has resulted in partial treatment access in India. We are focused in bringing broader treatment access across the all SMA Type and age.

4. Coming up

We are working on developing a model to bring 360-degree solution to SMA and other rare disease through a program: Cradle to Livelihood.

Pictures of other founding members of Cure SMA Foundation of India



Ms Archana Panda
Co-founder &
Director Patient
Advocacy



Dr Razeena
Sethunath
Co-founder &
Director Patient
Empowerment



Ms Srilakshmi
Nalam
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