

## STOP SMA Macedonia - CTOΠ CMA

Republic of North Macedonia



<https://stopsma.mk/za-stop-sma/>



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### 1. About

The association STOP SMA was founded in 2018, by people who decided to join forces to build a support network for people with SMA and their families.

The association unites Macedonian patients with SMA and their families, represents their voice and tries to ensure better access to treatment, equipment, and necessary medical care. The association is entirely based on the volunteer work of people who are close to SMA issues, who work according to their knowledge and skills and act according to their free time, for the benefit of all those affected by this serious disease.

### 2. Mission

The mission of the STOP SMA Association is: Promotion and realization of the right to a quality and dignified life for people with Spinal Muscular Atrophy in the Republic of North Macedonia.

### 3. Focus.

Our focus among other is put on protection of the right to life as equals of persons with SMA, exercising the right to health care, access to treatment, right of access to assistive technology, social protection rights, inclusion in schools, the right to personal assistants, promotion of the rights and needs of people with SMA and other rare diseases, raising public awareness for an open and inclusive society for people with SMA and other rare diseases, support of newly diagnosed patients with SMA.

### 4. Coming up

- Increasing access to therapies
- Improving the condition of the multidisciplinary medical team for adult patients
- Facilitated transfer from paediatric to adult patients
- Increasing access to devices and assistive **technology**
- SMA day, at the neuro and paediatrics clinic with examinations by a multidisciplinary team.





