

SMA Slovakia

Slovak Republic



www.sma-slovakia.sk (under construction)

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1. About

SMA Slovakia is newly established organisation that is focused on advocacy on patients and their families living with SMA. Our main goal is to provide the support and information for all families living with the disease, to communicate with medical providers on behalf of patients' needs and to represent the first contact for newly diagnosed families in Slovakia.

SMA Slovakia represents the SMA families and their everyday struggle with keeping their beloved ones in the best possible physical, psychological and social state. SMA Slovakia advocates for the ones, whose words haven't been heard yet.

The motto we came up with when establishing the first contact with medical providers was "Together in SMA, we are not alone, we need you!" - of course in Slovak equivalent. The biggest project that we are currently organising has the same motto "Together in SMA weekend", the aim of which is to start effective and better communication and trust between SMA families in Slovakia and the professionals responsible for the primary medical care of the SMA patients.

2. Mission

Each SMA patient is unique, each family have different story, nevertheless, we are all the same in our differences with one goal: BETTER LIFE for our beloved ones. SMA families in Slovakia need to understand, that we fight for the same goal. They are not alone. We are together in it.

We are just at the beginning of our journey with many projects and initiatives to come. However, we have managed to obtain and keep the consistent contact with medical providers in specialised SMA centres associated with hospitals in Slovakia. We have taken several meetings with the main pharmaceutical's companies where the collaboration on the needs of SMA patient have been discussed and promised. Representant of SMA Slovakia was invited to give lecture on The Care of SMA patient

in home environment, taking part at the congress on Rehabilitation of paediatric patients in Slovakia, December 2023. And it is just the beginning...

3. Coming up

The biggest project we are organising these days that should take place in June is the get together meeting designed for the needs of SMA kids and their parents. We have invited several professionals to have lectures on the newest trends in SMA (neurologist), respiratory physiotherapy, management of scoliosis and more. With numerous activities for kids (instructed swimming sessions, occupational therapy and other fun stuff), we believe that weekend “Together in SMA” will bring proper social and educational aspect for both, parents-caregivers as well as SMA youngsters and it will have so much needed psycho-hygienic effect. Since we are still at the beginning (SMA Slovakia is less than 1 year old) yet, we are trying to find optimal and proper ways how to bring SMA community in Slovakia together. We are talking and contacting families, discussing the weak sides of management of SMA from different points of view. Challenges are present on the daily basis, but hopefully more work we do, more trust we gain.

Picture from “Super vikend 2022”

