

Children with Spinal Muscular Atrophy

Ukraine



csma.org.ua

Facebook: [ChildrenSMA](#)



Vitaliy MATYUSHENKO

csma.ua@gmail.com

1. About

Children with Spinal Muscular Atrophy (CSMA) is a voluntary, non-profit foundation in Ukraine whose mission is to provide support and information for anyone affected by or involved with Spinal Muscular Atrophy (SMA), works on equal access to treatment.

All adults with SMA were children, SMA is a hereditary disease.

2. Mission

The mission of the Foundation: to assist in the providing medical, financial, socio-legal, psychological, moral support to SMA patients - persons with disabilities and members of their families.

3. Focus

The main focus is on supporting the Patient Registry, keeping it with quality data and implementing it in the expert centers at the national level.

4. Coming up

The most important stage the work of the Foundation is the creation of SMA expert centers network, raising its professional level to international standards. Despite the national plan for rare diseases adopted by the State, rare disease doesn't became one of the priorities yet. As soon as the war ends, the Foundation will return to its main project - [the creation of expert center for patients with SMA and rare NMDs in native city Kharkiv.](#)