

SMA Azerbaijan

Azerbaijan



[instagram.com/sma.azerbaijan](https://www.instagram.com/sma.azerbaijan)

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1. About

I am the lead of the Public Union of the SMA patients in Azerbaijan. The Public Union has an official registration status in Ministry of Justice of Azerbaijan. We are joined to the Union of the Patients Organizations in Azerbaijan. Our motto: “Together we can”.

2. Mission

Our goal is to create a government program for SMA patients to cover all the medical, legal and the social needs of the SMA patients.

What drives me? My daughter is SMA patient.

Our priorities are increasing the awareness of the people, public persons, doctors, etc. to the SMA disease.

3. Focus

We work in close collaboration with the other patients’ organizations, medical authorities and government members. We created an Advisory board of specialists. Our health insurance agency is ready to reimburse the treatment and the rehabilitation for the SMA patients.

4. Coming up

Planning the SMA school for the patients and the healthcare specialists.

Challenge- Low information on SMA between the people and specialists

Creating the single platform for all rare diseases areas.