

FSMA Iceland

Iceland



FSMA

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1. About

FSMA Iceland is a group of people with SMA and their families. The organisation was started around 2000 and was the main objective to support research for drug development, share information about treatments and raise awareness of SMA to the public.

2. Mission

The main goal for us over the last years has been to get drug access for every patient and to get everyone access to the best medical resources available. We aim to hold the group together so we can have communication with each other online or with meetings to share knowledge about the latest data or treatments that can benefit us.

3. Focus

Recently we raised a campaign in the media to push the government to allow adults to get access to drug treatment. In November 2023 the drug government agency decided to grant reimbursement to all adults with SMA which was a huge win for us.

4. Coming up

The next step is to celebrate the latest news. We have now started to share our experience with the drug treatment. We will continue to meet and share our knowledge and follow up on the latest data concerning treatments and therapies.

There have been some problems in the medical system for treating SMA patients, especially adults, a lack of knowledge with doctors and uncertainty about access to the right doctor or medical staff. We want to work with medical agencies to make sure that every patient has the support at hand whether a child or adult.

We have raised awareness with doctors about newborn screening and it is currently being discussed with doctors to start that process.