

# SMA Patientenvertretung Österreich

Austria



<https://www.smaoesterreich.at/>



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## 1. About

The SMA Patient Representation Association Austria was founded in July 2020 to represent the interests of SMA patients in Austria.

## 2. Your mission

- Association of all Austrian patients;
- Collaboration and strengthening of the network with other organizations locally and also in international level;
- The promotion of research work and support of therapy development (e.g. through cooperation with doctors, representatives of the health system and politics, pharmaceutical companies);
- Organising community-building events;
- Represent the interests of SMA patients to all important stakeholders;
- Strengthening the media presence;
- Contacts with international patient organisations and research centres;
- Sharing of current information on treatment options and promotion of exchange between those affected

## 3. Campaigns

- **NEW BORN SCREENING / 2021**  
Supporting the Campaign for integrating SMA into NBS in Austria / 2021

<https://www.smaoesterreich.at/ngs> (German)



Babys retten – JA zum SMA Neugeborenen-Screening

- **Uniform financing system for medicines / 2022**  
We are committed to a nationwide funding pool for medications to treat SMA. Access to essential medicines must no longer be regulated differently at country or insurance level!
- **Campaign: #Stop suffocation / 2020**  
Our campaign ensured that many SMA patients were able to start treatment with Spinraza. Treatment contracts were also concluded in Vienna, but in most cases the hospitals do not honor them.

<https://www.smaoesterreich.at/projekte>

#### 4. Coming up

- **SMA ÖSTERREICH FAMILY DAY 2024**

Last year we have managed to organise our first Event. It was a great day full of networking, exchange and updates from medical point of view; sports, travelling with a wheelchair, etc.

2024 stands for even more exchange. We are preparing an event with the focus also on caring relatives and the whole network support around one SMA Patient. Our challenges are mostly on the financial side.



1st SMA MEMBERS AUSTRIA MEETING in GRAZ / Sept 2023