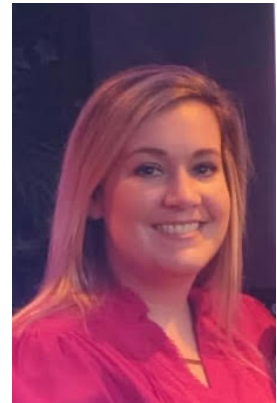


SMA Ireland

Ireland



www.smaireland.com



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1. About

Established in 2019, SMA Ireland is a voluntary organisation dedicated to raising awareness of SMA in Ireland and campaigning for access to treatment for all.

2. Mission

Our goals and activities include:

- Support families by providing information and a network of contacts.
- Raise awareness and campaign for the disease to be part of Rare Disease screening.
- Lobby for access to treatment and care.
- Serve as a liaison between pharmaceutical companies and patient families.
- Promote ongoing research and coordinate patient volunteers.
- Initiate and maintain connections with the major international SMA organisations.

Time is a critical factor when treating SMA, so one of our organization's top priorities is the introduction of SMA to newborn screening in Ireland.

3. Focus

SMA Ireland's main initiatives and achievements include:

- Offering information, support and community to the families of newly-diagnosed patients + to all people affected by SMA
- Advocating for treatment access by providing the patient perspective around the burden of SMA and the patient perspective on treatments
- Providing expert evidence to support reimbursement of SMA treatments in Ireland
- Advocacy for SMA to be added to the national NBS programme: generated substantial media coverage of the issue across top-tier newspapers, TV, radio, >20 parliamentary questions, and a successful event in Dublin attended by politicians and health system executives.

4. Coming up

We are currently working on the following:

- Moving from Minister of Health's announcement that SMA NBS should be implemented to actual implementation of SMA NBS by the health system in Ireland. This process could be delayed until 2026 and we are advocating for speedier implementation, together with exploring/creating implementation options together with the authorities.
- Supporting the training and professional development of Irish physiotherapists to support their SMA patients, including via visits to Utrecht, NL

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