Press release OdySMA launch: Not to be published before 1st of February 2023

# From SMA Europe we are excited to announce that our OdySMA project goes live !

## Today, the 1st of February 2023, a date that also marks the beginning of 2023 Rare Disease Month, we want to celebrate with you the official launch of our OdySMA project. OdySMA is an initiative that aims at one and only goal: that no one is left behind in the access to treatment journey.

### OdySMA is a dynamic tool that we are using to create an SMA atlas that visualises systematically collected data to illustrate access pathways. The goal is to reveal the 'quest to access' of people living with SMA by mapping, visualising and centralising knowledge and data around access issues.

Please visit OdySMA website for more: <https://www.sma-europe.eu/>

### Laura Gumbert, Project Manager of OdySMA states:

“I am very grateful to be part of this unique project. The launch of the OdySMA project makes the intensive work of many months visible and gives all people in Europe living with SMA, as well as their families and patient advocacy groups, a powerful tool to facilitate policy work and to accelerate access to healthcare provision.

But there's more to it than that: This platform shows also at a glance all the already made achievements of our strong community. I would like to thank everyone who has contributed to this huge project, our community, our partners from the industry, and our IT partner. Without you, this would not have been possible! Today’s step is an important milestone, and I am looking forward to now maintaining the platform but also expanding it so we have a helpful, sustainable advocacy tool for our community.”

All together. One goal.

### Spinal muscular atrophy (SMA)

​SMA is a rare genetic and progressive neuromuscular condition occurring in approximately 1 in 6,000 to 10,000 live births. Characterised by the degeneration of nerve cells in the spinal cord (motoneurons), SMA leads to progressive muscle weakness and atrophy.

​SMA has many faces. It is characterised by a wide spectrum of how severely children and adults are affected. The symptoms vary from person to person. SMA may affect daily activities such as breathing, eating, hugging, grabbing, nodding, sitting and walking.

​SMA is caused by a fault in a gene called Survival Motor Neuron 1 (SMN1; i.e., homozygous mutation or deletion). This gene carries the information required for the production of an important protein called SMN. When there is not enough of this protein, the nerve cells that help control the muscles for moving and breathing become damaged.

To date, no cure has been developed for SMA. However, three disease-modifying SMA medicines received EMA approval and many other drugs are in development with varying mechanisms of action and administration routes.

**More useful resources:**

<https://www.sma-europe.eu/living-with-sma>

### SMA Europe

SMA Europe is a non-profit umbrella organisation of spinal muscular atrophy (SMA) patient organisations from across Europe. Together with our 26 member organisations from 24 countries, we strive for creating a better world for all those living with SMA.

Together, we work to bring effective treatments and optimal care to everyone living with SMA acting through the following main areas:

* Research
* Advocacy
* Raising awareness

SMA Europe partners with the following European and international not-for-profit organisations to work on transversal issues to improve the lives of people with SMA and their families. Our partners are: EURORDIS, SMA Foundation, Cure SMA, Cure SMA India, EURO-NMD, EMA and European Neuromuscular Centre.

For more information, please consult our website: <https://www.sma-europe.eu/>

### Sponsors of the OdySMA project:

Biogen, Novartis, Roche, Scholar Rock

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### Additional information:

**SMA Europe website**: <https://www.sma-europe.eu/>

**OdySMA website:** <https://odysma.sma-europe.eu/>

### Social Media SMA Europe:

LinkedIN: @SMA Europe; Facebook: @SMAEurope1; Twitter: @SMAEurope; Instagram: @SMAEurope