

**SMA  
EUR  
OPE**

# Global SMAAdvocacy Event

**13 March 2024  
Ghent, Belgium**

**“Patient advocates are the force behind many achievements for people living with SMA. At the Global SMAAdvocacy Event, patient advocates from all over the world will come together to learn and grow stronger together.”**

**Nicole Gusset**  
CEO & President  
SMA Europe

[www.sma-europe.eu](http://www.sma-europe.eu)

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Together, through greater understanding,  
we will create a better world  
for all those living with SMA.

**All together. One goal.**



The Global SMAAdvocacy Event brings together patient advocates from all over the globe to engage with current issues in SMA patient advocacy. Participants share advocacy experiences and learn from each other while elaborating strategies towards concrete advocacy goals.

Discussions will focus on challenges like equity in access to SMA therapies and standards of care, reimbursement for SMA treatments and new-born screening, but also on how to make the best of national registries or influence policy.

**Teach each other, learn together.**



## Agenda

09.00 - 10.30 Welcome and morning workshop

10.30 - 11.00 Coffee break

11.00 - 12.30 Morning workshop

12.30 - 13.30 Lunch

13.30 - 14.30 Vernissage of SMA Awareness Campaign 2023

14.30 - 16.00 Afternoon workshop

16.00 - 16.30 Coffee break

16.30 - 18.00 Afternoon workshop

18.30 - 21.00 Dinner

### Ankita Batla

Event moderator

Medical Strategy and Patient Engagement Consultant

### Alice Larotonda

Community Research and Education Manager

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# #WeAreUnique

## 2023 Awareness Campaign Vernissage

SMA has many different faces.

Our SMA Europe community is an example of how diverse the condition is, and how many different manners exist when it comes to living with it.

Traveler, Explorer, Journalist, Rebel... eleven individual stories which, together, resonate in one powerful poem that we want to share with you.



Join us at the official opening:  
13 of March at 13.30hrs. ICC Ghent, 1st floor.

Emilia Debska

Communication Manager  
emilia.debska@sma-europe.eu





## The Global SMAAdvocacy Event is sponsored by:

### **Biogen**

Founded in 1978, Biogen is a leading global biotechnology company that has pioneered multiple breakthrough innovations including a broad portfolio of medicines to treat multiple sclerosis, the first approved treatment for spinal muscular atrophy, two co-developed treatments to address a defining pathology of Alzheimer's disease, the first treatment to target a genetic form of ALS, the first oral treatment approved for postpartum depression, and the first approved treatment for Friedreich's ataxia. Biogen is advancing a pipeline of potential novel therapies across neurology, neuropsychiatry, specialized immunology and rare diseases and remains acutely focused on its purpose of serving humanity through science while advancing a healthier, more sustainable and equitable world. We routinely post information that may be important to investors on our website at [www.biogen.com](http://www.biogen.com).

### **Novartis**

At Novartis, our commitment to our purpose of reimagining medicine to improve and extend peoples' lives remains unwavering. We're focusing our energy on disease areas where there is significant need for new treatments and where we have deep expertise and capabilities. We're also building on our strengths in advanced new technology platforms - including gene and cell therapy - that will help us deliver the next generation of medicines for patients.

Science will always be core to who we are. We will continue to unravel the mysteries of biology and develop new technologies to fight disease. We recognize there is more to do in helping people navigate the human experience of disease and helping them achieve a better quality of life. This also involves working on solutions to help address the evolving needs of healthcare professionals and healthcare systems as they navigate the introduction of novel technologies, increasing burden of disease and economic pressures. We aspire to build on our scientific heritage and expand our impact on human health through a deeper understanding of patients' needs and strengthening collaborations with key stakeholders who share our mission. We know our collective impact will be greater than anything we could ever achieve alone. The only way to reimagine medicine is to do it together. [www.novartis.com](http://www.novartis.com)



## **Roche**

You are warmly invited to our symposium and booth at the 4th Scientific International Congress on spinal muscular atrophy (SMA):

- Join us at our satellite symposium (Should all adults with SMA receive treatment? An experts' debate | Thursday, 14 March 2024 | 13:10-14:10) where we will explore the benefits of and barriers to adults receiving treatment for SMA.
- In the form of an exciting debate, our faculty speakers will debate the case on whether all adults living with SMA can and should receive disease-modifying treatment. An individual living with SMA will serve as the moderator and share their perspectives on this important issue, followed by the opportunity for audience participation
- Visit us at our booth to learn more about our commitment to SMA and for the opportunity to speak with our representatives!

We look forward to seeing you there!

M-XX-00015893 (Date of preparation: January 2024)

[www.roche.com](http://www.roche.com)

## **Biohaven**

[www.biohaven.com](http://www.biohaven.com)

## **Scholar Rock**

[www.scholarrock.com](http://www.scholarrock.com)

# Thank you!



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