

Press release. 18th of October 2022.

This Friday, the 21st of October, kicks off the 3rd International Scientific Congress on Spinal Muscular Atrophy. Barcelona is the city chosen for this occasion. The main goal of the Congress is to bring together an international and multidisciplinary group of scientists and health-care professionals and provide a venue for them to present and exchange their breakthrough ideas relating to SMA, especially also in light of the patient-relevance of their findings, and to cement existing and stimulate new collaborations.

- Her Majesty, Queen Letizia, is the Honorary President of the Congress.
- The congress has 7 plenary sessions that will finish on the 23rd of October. The venue for the event is CCIB - Centre de Convencions Internacional de Barcelona.
- SMA Europe is the organiser of the event and FundAME Foundation acts as the hosting organisation.

21st of October. Save the date.

Around 800 researchers, healthcare professionals, and patient representatives will meet on the 21st of October during the 3rd International Scientific Congress on SMA. The congress is organised by SMA Europe and is kindly hosted by FundAME Foundation.

Nicole Gusset, President of SMA Europe:

“The goal of our scientific congress is to bring together an international and multidisciplinary group of scientists and healthcare professionals. We provide a venue for them to present and exchange their breakthrough ideas relating to SMA, especially also considering the patient-relevance of their findings, and to cement existing and stimulate new collaborations.”

Antonio Hitos, President of FundAME:

“We are very proud that this 3rd International Scientific Congress on Spinal Muscular Atrophy will be celebrated in Barcelona. It is also a great honour to have Her Majesty, Queen Letizia, holding the presidency of honour. Her support matters a lot when it comes to raising awareness and advocacy actions regarding rare diseases, in this case, SMA, and helps to reinforce the importance of the work conducted by patients’ organisations such as ours, especially regarding the research and its future.”

Véronique Van Assche, SMA Europe Adult Committee Coordinator and SMA Belgium delegate.

“We are all driven by the same objective: to continue to find innovative solutions to relieve and treat SMA. As a representative of the adult committee within SMA Europe, I think it is essential to talk about this disease, to exchange our points of view, and to create connections so that new ideas arise.”

The Scientific Programme of the 3rd International Congress on Spinal Muscular Atrophy.

The Congress will begin on Friday, 21st of October with the session “Spinal Muscular Atrophy: New horizons beyond the disease” conference, organised by Dr. Eduardo Tizzano, director of the Clinical and Molecular Genetics Area and the Rare Diseases Unit at Vall d'Hebron Hospital and winner of the Queen Sofia Award for Prevention, and by FundAME.

It will be followed by the session taught by Yasemin Erbas, Vice-president of SMA Europe, called “SMA Europe’s evidence-based patient advocacy: Bridging the gap between clinical research and patient experience.”

The scientific programme includes both scientific sessions and poster presentations. During the event, diverse workshops and symposia will be held. The programme takes into account the patient’s perspective and aims to bring together researchers, healthcare professionals as well as patients and their carers in order to keep on working on the strategic vision of SMA Europe: to create a better world for all those living with SMA.

The goal of the 3rd International Scientific Congress on Spinal Muscular Atrophy is to bring together an international and multidisciplinary group of scientists and health-care professionals. SMA Europe, as the main organiser, and FundAME, as the hosting organisation, provide a venue for them to present and exchange their breakthrough ideas relating to SMA, especially also in light of the patient-relevance of their findings, and to cement existing and stimulate new collaborations.

The programme of the Congress has been developed by prestigious neurologists and researchers, members of SMA Europe Scientific Advisory Board. The Scientific Advisory Board (SAB) is composed of an international group of neuroscientists and neurologists with particular expertise in Spinal Muscular Atrophy (SMA) research.

The professionals that will be participating in the Congress are, among others, Tom Gillingwater (UK), George Mentis y Umrao Monani (USA), Michela Rigoni (Italy), Andreas Ziegler and Mert Karakaya (Germany). Moreover, different workshops will be conducted by Richard Finkel (USA), Stefania Corti (Italy), Cécile Martinat (France), Danilo Tiziano (Italy), Heike Koelbel (Germany), Sonia Messina (Italy) & Renske Wadman (The Netherlands).

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. SMA 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>

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Organisers

SMA Europe

SMA Europe is a non-profit umbrella organisation of spinal muscular atrophy (SMA) patient organisations from across Europe. Together with our 24 member organisations, 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 on 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/>

FundAME

Spinal Muscular Atrophy Foundation (FUNDAME) is a non-profit, private foundation, established in 2005 and made up of patients affected by SMA and their relatives. FundAME strives to find ways to improve the quality of life of those affected by SMA and to promote research into this disease.

FundAME supports research at both national and international level, in order to bridge the gap between today and the day a cure for SMA is available. In the meantime, FundAME seeks ways to improve the quality of life of those affected by the disease.

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Additional information

Congress website: <https://barcelona2022.sma-europe.eu/index.php>

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

Social Media SMA Europe:

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

FundAME website: <https://www.fundame.net/>

FundAME Social Media:

LinkedIn: @FundAME; Facebook: @fundameAME; Twitter: @FundAMEnet; Instagram: @FundAMEnet