

Inscription

For Registration, send an e-mail to Ester Freixa (efreixa@tauli.cat) containing the following information:

- Surname and given name
- E-mail
- Registration modality: Face-to-face or online

Venue

Fira Sabadell

Precinct access: Pl. de la Sardana, 7 08203 Sabadell
<https://n9.cl/dych0>



Hotel recommendations:

Catalonia Gran Hotel Verdi
Av. De Francesc Macià, 62, 08208 Sabadell, Spain
Phone: +34 93 723 11 11
E-mail: verdi@cataloniahotels.com

Organizer:



Collaboration with:

- Ospedale Bambino Gesù (Italy)
- Erasmus MC (Netherlands)
- MDKU Oxford neuromuscular center (UK)
- Attikon University Hospital (Greece)
- Hospital Archbishop Makarios III (Cyprus)
- Hospital Puerta de Hierro (Spain)



EUROPEAN WORKSHOP ON ANGELMAN SYNDROME



29 - 30th June 2023



This Networking event has received funding from the European Union's Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP N° 825575



DAY 1 (Thursday, June 29)

MORNING

08:45h Welcome, organizers and a representative of the families associations

09:00h How is it like to Access a specialized centre in different countries in Europe, the experience of parents from 3 different countries.

- Clinical Expertise Unit Sabadell, Spain. **Carme Manso**
- Experience from three European Families.

10:00h Coffee Break

10:30h Global care on AS (1)

Moderator: **Ana Roche**

- Update in Preclinical and clinical studies. **Laurent Servais**
- Genotype and phenotype. **Sofia Ourani**
- Epilepsy on AS
 - Epilepsy. **Marie Claire De Witt**
 - EEG features. **Federico Vigevano, Nicola Pietrafusa**
 - Practical aspects of EEG performance in AS children. **Susana Torres, Sandra Jara**
- Sleep disorders on AS. **Karen Bindels de Heus**

12:30h Discussion

13:30h Working Lunch

AFTERNOON

15:00h Global care on AS (2)

Moderator: **Argyris Dinopoulos**

- Global care children. **Karen Bindels de Heus**
- Global care adults. **Sabela Novo**
- Non pharmacological treatments. **Ariadna Ramirez**
- Language and communication. **Cindy Navis**
- Neurorehabilitation in AS. **Michelina Armando**

17:00 h End first day

DAY 2 (Friday, June 30)

MORNING

09:00h Ongoing research studies:

Moderator: **Neus Baena, Miriam Guitart**

- Basic research update. **Ugo Mayor**
- Self-promoted studies.
 - Natural History Study o AS in Spain. **Neus Baena, Debora Itzep**
 - Sleep and AS. **Marta Moraleda**
 - Hyperphagia, growth & puberty and bone Health. **Karen Bindels de Heus**

11:30h Coffe Break

12:00h Studies promoted by pharma companies. **Roche, Ultragenyx**

13:30h Working Lunch

AFTERNOON

15:00 – 17:00 h

Professionals forum:

- Clinical care consensus, clinical care units
- Compare resources in different countries (Spain, Cyprus, Greece, Netherland) and see what could be improved in the different places, from different experiences
- Discuss Angelman syndrome database
- "Nina" clinical expertise unit Netherlands
- Establish a virtual meeting calendar

Families forum:

- How to get straight and fast, how to keep together – Patients associations ASA and FAST-Spain, AS Alliance
- Contact patients associations from different countries