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:

Parc Taulí Institut d'Investigació i Innovació I3PT
Parc Taulí Hospital Universitari
EUROPEAN JOINT PROGRAMME RARE DISEASES
asa asociación del sindrome de angelman
fast españa

Colaboration with:

- Hospedale Bambino Gesú (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

Parc Taulí Institut d'Investigació i Innovació I3PT
Parc Taulí Hospital Universitari
EUROPEAN JOINT PROGRAMME RARE DISEASES

Programa

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. Sofía 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
- Language and communication. Cindy Navis
- Neurorehabilitation in AS. Michaela Armando
- Non pharmacological treatments. Ariadna Ramírez

17:00 h End first day

DAY 2 (Friday, June 30)

MORNING

09:00h **Ongoing researd 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