ANGELMAN SYNDROME
COMMUNITY ADVISORY BOARD

The Angelman Syndrome Alliance (International), Angelman Syndrome Foundation (USA) and FAST (International) combine efforts in the global Community Advisory Board (CAB).

They are partnering with EURORDIS-Rare Diseases Europe to advance the work that is occurring in the Angelman Syndrome pharmaceutical and biomedical research space. CAB provides expert advice to all stakeholders involved in the research, development and service provision of biomedical treatments.

WHO IS ON THE ANGELMAN CAB

The Angelman CAB is a group of parent advocates and expert parents/carers. They will use their personal and/or professional knowledge and expertise to discuss and advise on the latest developments, challenges and issues related to Angelman Syndrome. There is an internal board of four voting members when votes are required. The other CAB members are there to advise and participate in crucial conversations. Each member takes part in hours of training with EURORDIS to prepare them for this role. The CAB members represent countries from all different corners of the world as listed on the right side.

THE CAB AIMS ARE AS FOLLOWS:

- **TO GUIDE** and facilitate the research and development pipeline for Angelman Syndrome treatments to better meet the needs of parents and carers.
- **TO INCREASE ACCESS** to, and justification for reimbursement of, Angelman Syndrome treatments globally.
- **TO IMPROVE AWARENESS** and understanding of Angelman Syndrome, within the healthcare system, academia, industry and institutions, and among the general public.
- **TO CREATE** a stronger voice for the Angelman Syndrome parent community.
- **TO RECRUIT, TRAIN AND SUPPORT** more parent advocates and experts in Angelman Syndrome to work within individual countries and across the globe as a whole.

IF YOU WOULD LIKE TO SET UP A TIME TO MEET WITH THE CAB, PLEASE CONTACT

Amanda Moore
CEO, Angelman Syndrome Foundation
amoore@angelman.org

Represented countries:

Argentina
Austria
Australia
Canada
Colombia
Czech Republic
Belgium
France
Germany
Greece
Hong Kong
Hungary
Ireland
Israel
Italy
Japan
Netherlands
Poland
Portugal
Russia
Spain
Ukraine
United Kingdom
United States of America

Partnering with

EURORDIS
RARE DISEASES EUROPE

COMMUNITY ADVISORY BOARDS (CABS)

are established, operated and maintained by parent advocates and expert parents. CABs are involved in scientific as well as policy- related issues in their disease area. They provide space to discuss the latest advances, challenges and issues related to medical treatments, medical devices, and procedures under development. This is an important initiative for the Angelman Syndrome community and for people affected by Angelman Syndrome globally.

WHAT WE CAN PROVIDE

PARENT PERSPECTIVES

on living with and caring for individuals with Angelman Syndrome at all ages.

LIVED EXPERIENCE

with different manifestations of Angelman Syndrome and issues unique to specific genotypes.

OUR EXPERIENCE

with different medicine and therapies. Guidance on how to best communicate with individuals with Angelman Syndrome.

GUIDANCE

on how to best conduct visits with as individuals in the clinic. Feedback on trial inclusion and exclusion criteria, informed consent forms, and retention of participants.

ASSISTANCE

with evaluating the appropriateness and meaningfulness of outcome measures for individuals with Angelman Syndrome.

INSIGHT

on regulatory contexts in different countries and overall community lens on all things AS.

ESTABLISH CONTACT

between pharmaceutical companies and clinicians/clinics.

ORGANIZING WEBINARS

to enable communication between pharmaceutical companies and clinicians and/or the Angelman Syndrome community.

COMMUNICATION

with parent association members about current and upcoming studies as requested.

BI-DIRECTIONAL

effective, transparent and reliable communication channel to the parents and their families.

Members of the Board

Betty Willemsen

- Aunt to Nina who was born in 2006, deletion +, struggles with epilepsy and obesity, and is good with large crowds.

Background: Appointed by His Majesty the King as 'Knight of the Orde van Oranje' for her international work in Angelman Syndrome. Founder of ASA, Founder of Nina Foundation and Initiator of Angelman Expertise Center at Erasmus MC with over 450+ AS patients (AS Clinic).

Catarina Costa Duarte

- Mother to Pedro who was born in 2010, deletion+
- Vice President of ANGEL - Associação Síndrome de Angelman Portugal

Background: Parents advocacy, global Collaboration.

Conny Schendler

- Mother to Rike who was born in 2009, mutation
- Board member of the Angelman e. V. Germany

Background: parent advocacy, global collaboration

Eitan Shay

- Father to Gil who was born in 2011, deletion+
- CEO of the Israeli Angelman Syndrome Foundation

Background: Parents advocacy, global collaboration, establishing clinical services to Angelman parent, and consulting on behalf of the Israeli community for clinical trials design and execution

Katie Cunnea, PhD

- Parent to Ruby who was born in 2005, deletion+
- Previous trustee of Angelman Syndrome UK

Background: Previous Science and Research Trustee and Principal Scientist in Structural based drug design, Evotec

Lara Hermann

- Mother to Alex who was born in 2000, UPD
- Secretary of Association Française du Syndrome d'Angelman (AFSA)

Background: parent advocacy, robust national network, cure & care perspective, support to caregivers.

Amanda Moore

- Mother to Jackson who was born in 2018, deletion+
- CEO of the Angelman Syndrome Foundation

Background: Parent advocacy, collaboration

Brad Schiele

- Father to Ali who was born in 2011, deletion+
- Board Chair of the Angelman Syndrome Foundation Canada (ASFC)

Background: parent advocacy, strategic planning, partnership building.

Daniel Harvey, PhD

- Parent to Matthew who was born in 1999, deletion+
- Member of the ASF Scientific Advisory Committee, and ASF Board of Directors.

Background: Has been involved in drug discovery research in both academia and industry for more than 30 years.

Dr. Elizabeth Jalazo- withdrew because of conflict

- Parent to Evelyn who was born in 2018, deletion+
- Clinic Director for the 15q Clinic Network

Background: Pediatrician and currently a fellow at UNC in the Genetics department.

Rebecca D. Burdine, PhD

- Parent to Sophie who was born in 2005, deletion+
- Member of the ASF Scientific Advisory Committee and Board of Directors
- Professor of Molecular Biology at Princeton University where I develop zebrafish models of human disorders

Background: Parent advocacy, clinical trial steering committees, consulting for clinical trial design and execution in Angelman Syndrome, research evaluation, communication.

Members of the Board

Meagan Cross

- Mother to Molly who was born in 2007
- Co-founder FAST Australia in 2010 and board member FAST US

Background: Information Science to develop the Global Angelman Syndrome Registry, which addresses critical data gaps across diverse populations worldwide. In addition to her work with FAST Australia, Meagan leads Rare Friends FNQ, a local charity dedicated to raising awareness for Rare Disease Day.

Karolina Pospieszyńska-Martysiuk MD, PhD

- Mother of Tymon who was born in 2017, mutation
- President of FAST Poland

Background: worked in Neonatal Intensive Care Units for many years, specialist in Augmentative and Alternative Communication, parent advocacy.

Stephanie Azout

- Parent to Michelle who was born in 2010, deletion+
- President and co-founder of FAST LATAM (will represent Colombia)

Background: AS Latin American network and part of patient advocacy groups in Latin America and AAC

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