



## AHC Europe Thematic Meetings

**Topic:** Connecting Families

**Date:** Tuesday 24 March 2026

**Participants:** Alvaro Quintas (Portugal), Suffia Madsen (Denmark), Rebecca Verhoeff-Steenbergen (Belgium), Birgit Greiffenhagen (Germany), Rémi Orhant (France), Nienke Lentze (Netherlands), Anton Katsarov (Bulgaria), Ulrike Maschke (Germany), Alina (Sweden), Carina Johnsson (Sweden), Tatu (Finland), Filippo Franchini (Italy), Jacqueline Leite (Brazil), Vanessa Faria Cortes (Brazil), Bridget Vranckx (Spain)

### 1. Country updates

#### Germany (Birgit & Ulrike)

- **Composition:** supports 44 families total, including German-speaking families from Austria, Switzerland and Italy.
- **Family Connection:** Daily interaction via WhatsApp
- **Annual Event:** A four-day retreat (Thursday – Sunday) in Ura, in a specialised, disability-equipped centre. Programme focused on sharing. Activities include an AGM, music groups, sports and outings. The last meeting was attended by around 20 families. Dr. Rosewhich attended a couple of times in last 10-15 years, as well as Prof. Brockman. Families pay for the weekend (accommodation, food & drink), the activities are organised and covered by AHC Germany.
- **Challenges:** Families with recent diagnoses often feel overwhelmed and afraid of the long-term prognosis, making them hesitant to attend meetings.

#### Portugal (Alvaro)

- **Composition:** 2 families diagnosed with AHC. Both families also belong to AHC Spain.
- **Status:** Association newly founded in November 2025.



- **Strategy:** Focused on building a website and establishing a network with the College of Neuropediatricians in Portugal to identify and reach new patients early.

#### **Brazil** (Vanessa Faria & Jacqueline Leite)

- **Composition:** 28 families identified in Brazil and one in Argentina.
- **Status:** Not yet a formal organization due to lack of funds; currently operating as a committee within a national epilepsy association to increase visibility. Led by two scientists, not families.
- **Strategy:** Looking for ways to make the association bigger. In contact with Brazilian association for epilepsy.
- **Meetings:** once a trimester.
- **Initiatives:** Created an AHC e-book and are involved in biological research partnerships.

#### **Spain** (Bridget Vranckx)

- **Composition:** 25 families (23 AHC and 2 CAPOS). 5 board members.
- **Status:** 2004
- **Family Connection:** Shared **WhatsApp** group, social media & informative webinars organised between 2022 and 2023 for Spanish-speaking community (including Latin America) covering research updates and adult transitions.
- **Meetings:** not formally organised since Covid. Last family meeting coincided with ATP1A3 Symposium held in Barcelona in 2024 and was attended by 5 families. Two years earlier, an impromptu family meeting coinciding with data collection for Treat-AHC project (Barcelona) was successfully attended by 13 families.
- **Challenges:** Geographical distance to the Barcelona reference centre; engagement (especially of ageing families), organisation capacity.

#### Italy (Filippo Franchini)

- **Composition:** Supports 50 families, including some with CAPOS. Missing at least 10-15 patients in Italy. Some families not part of association.
- **Status:** Established in 1999
- **Strategy:** an annual weekend meeting in Genoa (the university centre location). Activities include an AGM (also online).
- **Challenges:** Very difficult to have families to come in person, so pay accommodation and meals. The rest is paid by families
- **Inclusivity:** The association covers accommodation and meals to encourage attendance; AGMs are also held online to ensure those who cannot travel are included.

#### Denmark (Suffia Madsen)

- **Composition:** 6 member families, though approximately 15 people are known to have AHC in Denmark.
- **Status:** Founded in 2004
- **Connection:** email, Facebook, Zoom meetings.
- **Meetings:** Used to have three-day family meetings, now moving toward one-day events as most patients are now adults with different interests. These events include outings to amusement parks, restaurants, etc. Currently working closely with AHC Sweden to host joint events.

#### Sweden (Alina & Carina)

- **Composition:** 8 families with ATP1A3 and 1 with ATP1A2. 60 supporting members. 7 Board members.
- **Status:** Formed in January 2020.
- **Connection:** Active closed Facebook Messenger group for members.
- **Meetings:** weekend family meeting organised together with AHC Denmark (2 families from Sweden + 2 families from Denmark) – mixed programme. Planning family meeting for families in Nordic countries, including Sweden, Denmark, Norway, Finland. Accommodation and food costs are covered by AHC organisation funded by specific fundraising activities. Families pay for travel.



- **Initiatives:** In 2023, they piloted an online discussion group for parents led by a psychologist.
- **Challenges:** Some families show low interest in sharing, potentially due to lack of energy.

#### **Bulgaria** (Anton Katsarov)

- **Composition:** 1 family
- **Status:** Board consists of AHC family, friends and family members.
- **Context:** Two other Bulgarian families have been identified but currently reside in Germany and Ireland.

#### **Netherlands & Belgium** (Rebecca & Nienke)

- **Composition:** Supports 16 families (19 patients total) : 11 in The Netherlands, 5 in Flemish-speaking Belgium. 5 board members (all except one are parents). Newly created expert/scientific team.
- **Status:** Officially became a joint association for The Netherlands and Belgium in 2023.
- **Family Connection:** Email, WhatsApp, Newsletter. Closed the closed Facebook group due to lack of interaction.
- **Annual Event:** A "Family Day" every summer focused on sharing experiences. Since 2022, researcher Arn van den Maagdenberg has attended to provide scientific updates and hope to families. Costs covered by association.
- **Initiatives:** A first "Consultation Day" at the hospital in Antwerp is scheduled for July 14, 2026, to facilitate doctor-family interaction.
- **Challenges:** Older AHC patients and parents in different phase. Younger families don't reach out to the association.

#### **France** (Rémi & Mirjana)

- **Composition:** 68 families
- **Status:** Established in 1991



- **Family Connection:** Website and Facebook are important, but WhatsApp is the most effective tool.
- **Meetings:** Two-day event (Saturday–Sunday). The first day features scientific presentations from 4–5 doctors, and the second day includes the AGM and a fundraising raffle. Families can join remotely. Association covers one night’s accommodation and all meals.
- **Medical Liaison:** Maintains a regular email exchange with doctors and professors. Doctors are asked to instruct new families to contact the association immediately.
- **Challenges:** age diversity, travel distances, medical and financial barriers.

## 2. Insights & Suggestions

- **Multilingual Support:** Larger associations often provide a home for families in countries without local support (e.g., France supporting Morocco; Germany supporting Austria and Switzerland).
- **Contact Accessibility:** AHC Europe should maintain a designated contact for each country on its central website to assist newly diagnosed families.

## 3. Closing consensus

Participants described this first thematic meeting as constructive, inspiring and a symbol of unity within the European AHC community.

### Words used to describe the meeting:

Hopeful, Good exchange, Inspiring (x3), Knowledgeable, Together, Stronger, Interesting, Unity (x2)