



AHC
EUROPE

Thematic meeting AHC Europe

1. How to connect AHC Families?



Give a brief introduction of your association



Asociación
Española del
Síndrome de la
Hemiplejía
Alternante de
la Infancia

25 Families

23 AHC

1 CAPOS

5 Board
Members

President: Bridget Vranckx
(International & communication)

Vice President: David Muruais
(Research & website)

Secretary & Treasurer: Marc
Gambús

Board Member: Gloria Moreno
(family support)

Board Member: Rafaela Muñoz
(adults & liaison Latin America)





How do you connect the families on a daily basis? What kind of information do you share?



One **WhatsApp** group for members where we share questions, events, fundraising initiatives, news



Do you organize face-to-face meetings with your AHC families?

Last family meeting: 2024

Coincided with ATP1A3 Symposium held in Barcelona that year.

Five families joined (one without son)

This meeting was **informal**. Held in a hotel meeting room. No programme, just lunch together and then a space for children to be comfortable and families able to talk to each other. Afterwards walk around the neighbourhood.

Cost was covered entirely by AESHA. This included travel, accommodation and catering.





Do you organize face-to-face meetings with your AHC families?

October 2022

Data collection for Treat-AHC project.

Ten families joined, plus 3 that are not AESHA members.

This meeting was **informal** and organised by doctors.

We met in hospital and had a chance to talk to each other while we waited for our turn to talk to doctors.

Travel and accommodation costs were partially covered by AESHA for AESHA families.





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Do you organise other activities to connect families?



SJD Sant Joan de Déu
Barcelona - Hospital



Webinars:

Between September 2022 and November 2023, we organised **three webinars for the Spanish-speaking community**, connecting Spanish neurologists and AHC specialists with the Latin-American AHC community.

Topics included treatment and project updates, adult transition, setting up an AHC patient organisation, summary of XI ATP1A3 Symposium, Q&A.

AGM:

Every year we have an AGM.

Before Covid, this was in person and coincided with a family meeting the day before.

Since 2020, the AGM is online.



What problems/ issues do you experience with connecting families?

- The reference centre is located in Barcelona, which is not a central location in Spain.
 - Very long distances in Spain and often families have to either drive or take different forms of transportation (car, train, plane) to get to Barcelona.
 - Ageing families: many no longer engaged because don't think anything will happen after so many years.
 - Complex medical issues of some patients
 - The Board is stretched very thin and does not have capacity to organise the family meetings every year along with everything else.
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**What else would you like to share or ask
(in relation to connecting families)?**

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