



AHC
EUROPE

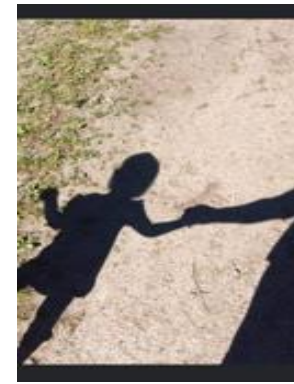
Thematic AHC Europe

1. How to connect AHC Families?





AHC Sweden



- The association AHC Sweden was formed in January 2020. The logo is inspired by a shadow image of Saga that has AHC.
 - In Sweden we know of eight people with Atp1a3 and one person with Atp1a2.
 - Four AHC-families are members of the association.
 - The association has approximately 60 members. Most are supporting members.
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Board members AHC Sweden



Carina Johansson
President



Alina Cirdei
Vice president



Catrin Lundgren
Secretary



Carola Johansson
Cashier



Veronica Lundgren
Social media manager



Maj-Inger Johansson
Bord Member



Denisa Lungu
Bord Member





How do you connect the families on a daily basis?

- We primarily use Facebook and Instagram to reach out to our members.
 - A closed Facebook group and Messenger group where we can share questions related to medication or other things
 - The problems we have are that families show little interest in sharing experiences with each other and participating in family meetings. Maybe they don't have the energy to get involved?
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Meetings with AHC families

- In 2023 we organized an online discussion group for AHC parents. The discussions were led by a psychologist. Only three parents participated but the discussions were good and we were able to share many different thoughts and feelings.
- In 2023 we also arranged a family meeting over a weekend. Two families from Sweden and two families from Denmark participated. The program mixed play and seriousness.







Family meeting 2026

- In August 2026 we are planning to organize a new family weekend for families in the Nordic countries.
 - Right now, three families from Sweden and two families from Denmark are registered to participate.
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Costs for family activities

- To participate in the activities such as a family weekends, families pay for the travel. AHC Sweden pays for food and accommodation.
 - To finance family activities, the association raises money through events such as a spring party, second hand markets and bingo walk. We also participate in local markets whiht lottery and chocolate wheels to raise money to the association.
 - We sell AHC Sweden merch like hats, caps, bracelets and more.
 - We have also applied and received money from various funds such as Nordic Welfare.
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