



AHC
EUROPE

Thematic meeting AHC Europe

1. How to connect AHC Families?



Give a brief introduction of your association

- AHC Foreningen, Denmark
- There are 6 patient & families who are members of the association.
We know of about 15 people with AHC in Denmark.
- There are no members with other ATP1A3 mutations.
- 20 paying memberships, including both family memberships and supporting memberships.
- The board has 3 members and 1 substitute member.
The president is responsible for all administrative work and organizing the association's events.
The treasurer is responsible for the finances and accounting.



Board member Benthe, president Suffia, member Dorthe, and substitute member Lise Lotte



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

- The president is always available by phone.
- All important information is shared by email.
- We have an open Facebook page where we share news, AHC Day, and Rare Disease Day.
- We also have a closed Facebook group where parents can ask questions and share experiences.
- We use Zoom – online meeting, for board meetings and the Annual General Meeting if physical attendance is not possible
- Website - <https://ahckids.dk/>



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

- AHC Denmark was founded in 2004.
- For many years, we organized family weekends for patients, parents, siblings, and grandparents.

During these weekends, doctors, psychologists, AHC researchers, and physiotherapists gave talks.

We learned a lot about AHC and shared our experiences with each other.

At the same time, babysitters took care of the children and kept them entertained.



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

Årstal	Sted	
Juni 2003	Fuglebjerg	Samledes 6 AHC familier, 7 AHC patienter - for første gang
23.-25.jan 2004	Pindstrup	Hjernens funktion, anfald, episoder, symptomer på AHC, motorik. Stiftende generalforsamling
3.-5. juni 2005	Pindstrup	Neuroscreening, opdragelse, sanser, trimmulation
1.-3. dec 2006	Pindstrup	Opdragelse og konfliktløsning
17.okt 2009	Fuglebjerg	Høstfest -fælleskab og hygge
23.-24.jan 2009	Karlsunde	Hverdagsproblemer med AHC, sygdomsforklaring, forskning
18.-21okt 2012	Slette Strand	Fællesskab og erfaringsudveksling, hygge
15. feb 2014	Næstved	10 års jubilæums fest
21.-23.nov 2014	Billund	Familie-weekend i Lalandia
12.-14.juni 2015	Karrebæks-minde	Weekendhygge
6.mars 2016	Odense	Koncert med Rasmus Seebach
8.okt 2016	Næstved	Bio – Danmarks premier filmen Human Timebombs

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

2017	Slagelse	Temadag AHC Forsker fra Århus Universitet, Karin L.-Hartmann
26.maj 2018	Slagelse	Temadag AHC forskning, Karin L.-Hartmann, søsken-fortælling
19.aug 2018	Næstved	Koncert med Rasmus Seebach
18.sep 2019	Sørup Herregård	Forskning og erfaringsudveksling
10.-11.okt 2020	Sørup Herregård	Vi unge, oplæg og samtaler
20.juli 2021	København	Tur til Den blå Planet, Færøsk kunst på Bryggen og restaurant Flammen
19.-21.nov 2021	Billund	Familie-weekend i Lalandia
19.-20.nov 2022	Skælskør	Temadag på Kobæk Strand Konferencecenter Sanser, motorik og søvnproblemer
26.nov 2022	Herlufmagle	Julefrokost
18.-19.nov 2023	Skælskør	Forskning med Karin Lykke Hartmann Personlige beretninger: mit liv med AHC Teater Besøg på Ellegård Göttinge Minipigs
16.juni 2024	Ruds Vedby	Besøge Birkegårdens Haver
13.juli 2025	Bjæverskov	Sommerudflugt Pangea Park – Restaurant Stacys i Køge
5.okt 2025	København	Tur i Tivoli – Halloween
30.nov 2025	Århus	Jul i Tivoli Friheden

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

- Today, most of our patients are adults (18+).
- Since there is no specific treatment that works, we now focus more on social activities.
- Most people prefer one-day events.
- We have visited places like botanical gardens, amusement parks, zoos, theaters, water parks, concerts, and restaurants.







Do you organise other activities to connect families?

- During the COVID-19 pandemic, we arranged online activities like shared meals and bingo on Zoom. This worked well, especially for people who live far away.
 - Over the past 3-4 years, we have worked together with AHC Sweden and joined each other's events.
 - All our events are free for members because we receive funding from the Danish Social Authority to support our work.
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What problems/ issues do you experience with connecting families?

- Young patients have different interests and often do not want to join the events.
 - No new families are joining, and we are not sure if there are more children with this condition.
 - Travel distances
 - Although we are a small country, all patients have different doctors. We lack expertise and collaboration in this area.
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What else would you like to share or ask (in relation to connecting families)?

- Friends forever...



Events 2025

