



AHC
EUROPE

Thematic meeting AHC Europe

1. How to connect AHC Families?



Brief introduction of our association

- AHFA: our association serves the French AHC community with dedicated support and advocacy for families affected by Alternating Hemiplegia of Childhood.
 - 67 AHC families
 - No families with other ATP1A3 diseases yet (opened to other ATP1A3 diseases since December 2025)
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Board members AFHA

- Our board consists of dedicated volunteers who bring diverse expertise to support AHC families.
- Each member has specific responsibilities including medical liaison, family support, communications, and event coordination.
- This structure ensures comprehensive coverage of our community's needs while maintaining efficient decision-making processes.





How we connect the families on a daily basis

- Multiple channels ensure families can access support and information through their preferred methods, creating a comprehensive communication network:
 - Whatsapp: Multiple sub-groups for targeted discussions
 - Facebook: Closed group with messenger integration
 - Email support: Dedicated contact with 3 administrators
 - Open access: Support for members and non-members
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Information Sharing

MEDICAL & RESEARCH UPDATES

- Latest research developments
- Medical news and breakthroughs
- Treatment updates
- Clinical trial information
- Healthcare professional insights

COMMUNITY & SUPPORT

- Event announcements
 - Family experiences and stories
 - Practical advice and tips
 - Support resources
 - Educational materials
 - Advocacy updates
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Do you organize face-to-face meetings with your AHC families?

Annual meeting: family weekend

- Our signature event brings together AHC families for a comprehensive weekend of learning, sharing, and connecting. Held during holiday periods for maximum accessibility.
 - Weekend format: Saturday and Sunday
 - Held during winter holiday period
 - 18 in person: families attending physically at the venue attended
 - 13 remote: Families joining virtually for accessibility
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AFHA annual Meeting 2025



Annual meeting Program

Comprehensive agenda designed for families and professionals



SATURDAY PROGRAM

- Scientific updates with medical professionals
- Latest research presentations
- Association updates and planning
- Networking opportunities
- Welcome activities



SUNDAY PROGRAM

- Activities for AHC patients
- Family support workshops
- Planning for future initiatives
- Closing ceremony





Who Participates

Our diverse community of attendees and supporters



AHC families,
patients, parents,
and siblings



Healthcare
professionals,
neurologists,
researchers



Extended family,
grandparents,
care aids

Special programming ensures AHC patients remain engaged

- Patient Activities
- Adapted entertainment and peer connection opportunities for those less interested in medical discussions





Cost structure

Shared financial responsibility to ensure accessibility

AFHA ASSOCIATION COVERS

- One hotel night per family
- All meals during the event
- Venue and equipment costs
- Materials and resources

FAMILIES COVER

- Transportation to venue
 - Additional accommodation nights
 - Personal expenses
 - Optional activities
 - Travel insurance
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Current & Future Activities

Building more opportunities for family connections

CURRENT ACTIVITIES

- Annual General Meeting (AGM)
- Shared dinners during AGM
- Gathering of families during a long weekend
- Regular communication channels
- Support network maintenance

FUTURE OPPORTUNITIES

- Webinars (under consideration)
 - Local regional meetings (under consideration)
 - More frequent social gatherings
 - Online support groups
 - Educational workshops
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Problems and solution in connecting families?

Barriers We Face

Understanding and addressing the obstacles that prevent families from connecting helps us develop better solutions.

- Age Diversity: Different needs for younger vs older patients
- Travel issues: Distance and accessibility difficulties
- Medical: Some patients cannot travel long distances
- Financial: Cost barriers for some families

How We Address Challenges

Our strategies focus on inclusion and accessibility, ensuring every family can participate in our community.

- Flexibility: Multiple attendance and participation options
 - Remote Options: Hybrid events with virtual participation
 - Regional focus: Geographic considerations in planning
 - Financial aid: Assistance for families in need
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What we would you like to share and ask

○ **SHARING EXPERIENCES AND IDEAS!**

- Learning from each other across Europe
 - Open Discussion: your experiences and insights help strengthen our entire European AHC community. Every perspective matters.
 - What works: successful strategies in your country
 - Challenges: Obstacles you face connecting families
 - Innovations: Creative solutions you've tried
 - Support: What help do you need from others
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