Minutes of 2025 AHC EUROPE ANNUAL MEETING

Date: 9 December 2025

Attendees: Anton Katsarov, Mirjana Pavlicek, Sigurdur Johannesson (Siggi), Nienke Lentze, Michael Kabicher, Verena Haas, Suffia Madsen, Rémi Ohrant, Alvaro Quintas, Marjorie Godines, Abhishek Behl, Tsveta Schyns-Liharska, Bridget Vranckx

Apologies: Filippo Franchini

Moderator: Siggi + Bridget

Secretary: Bridget

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1. Reading of AGM 2024 Minutes

Presented by Bridget Vranckx, AHC Europe Board member

- The minutes were accepted unanimously.

2. Annual Report 2024

Presented by Siggurdur Johannesson, AHC Europe president

Membership Growth

- The association welcomed three new member associations: Portugal, Austria, and Les Rêves de Thalia.

Awareness

- The association celebrated AHC Day on January 18th and Rare Disease Day (RDD) on 28 February 2025 with a social media campaign (Raise Index Finger for AHC Day and official Rare Disease Day posters for RDD).

Internal Organisation

- A new identity—**AHC Europe**—and a new website were implemented.
- We created working groups and spent the last half of the year getting more organised with these groups.

Research

- AHC Europe finalised the agreement to jointly fund the 5-year **ATP1A3 project** spearheaded by Arn van den Maagdenberg at Leiden University.
    - 9 AHC associations are funding this project, including 6 European associations, plus the Canadian AHC organisation and the two USA organisations (AHC Foundation and Cure AHC).
    - There are already some good results, which will be published soon.
    - **Oxygen Study (France):** Rémi Orhant provided an update on the oxygen study led by Prof. Flamand-Roze. The study will be able to continue following the successful recruitment of missing AHC patients, with results anticipated at the next symposium (September 2026).

Events

- The association participated in the Washington Research meeting (November) and is involved in **ATT Now**, a group of parents and scientists who meet regularly online and twice yearly face-to-face.
- Attempts to organise family meetings in Holland and Denmark were unsuccessful, but the association remains committed to trying again.
- AHC Europe was invited to present at the 13th ATP1A3 Symposium in Australia.
- AHC Europe president attended the **Rare Hope Gala**, a fundraising event hosted at the Washington Cathedral by Rare Hope (a new organisation formed by Simon and Nina Frost). The event raised $1.3 million in one night.

3. Financial Report 2024

Presented by Siggurdur Johannesson, AHC Europe president

- All amounts are presented in EUR (€) using a fixed exchange rate of **1 EUR = 145 ISK**, as the association’s accounts are held in Iceland.
- The association is **financially stable** after completing the first year of collecting annual membership fees (€200 per member). In previous years, most expenses were covered by AHC Iceland, resulting in limited fixed costs.

- **Account Structure:** The association holds one operational structure in Icelandic Krona (ISK) and one operational account in EUR.

- **Financial Results**

  Income is derived from **annual membership fees** and funds received for the **Leiden Research project**. Expenses during the year primarily related to payments made in connection with the Leiden Research project.

- **Transfer Fees**

  A question was raised by Nienke concerning the income received for the Leiden Leiden Research Project being slightly lower than the amount paid. Siggi explained this was due to the bank transfer fees, which amount to approximately €20. This is why Siggi proposed each organisation adds €20 to the total amount transferred.

- The **account balance to date** stands at **€4,459**, representing ta positive year-end position and the strongest balance achieved so far.

Account	Income (€)	Expenses (€)	Net Result (€)
ISK Account (converted)	€ 19.862	€ 17.241	€ 2.621
EUR Account	€ 59.509	€ 60.049	€ 540
Combined Total	**€ 79.371**	**€ 77.291**	**€ 2.080**
Annual fee-bank cost	*€ 2.757*	*€ -49*	*€ 2.708*
Funding research project	*€ 59.373*	*€ -60.000*	*€ -627*

4. Annual Fee

Presented by Siggurdur Johannesson, AHC Europe president

- It was suggested and agreed upon to **maintain the current annual fee of €200**.

5. Bylaws Amendments

Presented by Siggurdur Johannesson, AHC Europe president

- No suggestions for amendments to the bylaws were received. Siggi reminds attendees that suggestions need to be presented to the board at least 4 weeks prior to the AGM.

6. Presentation of Board Members

Presented by Siggurdur Johannesson, AHC Europe president

- The current Board Members are: Sigurdur Johannesson, Filippo Franchini, Mirjana Pavlicek, Abhishek Behl, Anton Katsarov, Alvaro Quintas, Nienke Lentze, and Bridget Vranckx.
- The bylaws state the board is made up of a minimum of 3 and a maximum of 8 board members and allows for substitute board members up to a total board number of 16.
- Rémi Orhant has requested to be part of the Board and was voted in unanimously as a substitute member.

7. AHC Europe Roadmap

Presented by Nienke Lentze, AHC Europe Secretary

Reminder of AHC Europe mission (to support and unite AHC families and accelerate research into effective treatments) and clarification that although we talk about AHC, the association also advocates for ATP1A3-related diseases.

Goals and Key Actions:

1) **Build a professional and sustainable AHC Europe association**
   This goal is focused on our internal organisation and aimed at creating a strong, well-structured and visible organisation.
   Some key actions include:
   - Increase our **visibility and awareness** to all AHC organisations. This will be a strong focus of Q1, with a clear communication strategy, quarterly meetings and the annual AGM, and presence on socials.
   - Ensure **financial stability** and **optimise internal processes** (emails, Google Docs) for better collaboration.

- **Patient Overview:** Develop a standardised format to collect an overview of AHC patients per country to be shared with countries in Q1.

2) Support European Associations

In order to be strong and united, we need to share and learn from each other.

Some key actions include:

- Organise regular thematic meetings for knowledge sharing and best practices (e.g., fundraising, family meetings). Nienke asked attendees for some ideas – non-board members (Michael, Marjorie and Suffia) all mentioned how to raise awareness of AHC among families and healthcare professionals and how to be more informed.

3) Strengthen collaboration among European (and US) AHC associations

With research moving forward fast, we want to be ready and in a strong position to be able to move at same speed as research.

Some key actions:

- Quarterly meetings with main USA organisations to stay in the loop and ensure collaboration.

4) Advocacy for AHC patients and families

Ensure AHC Europe has a strong, coordinated voice at European level.

Some key actions:

- We want to make an overview of all European Rare Disease organisations to see who will represent AHC Europe in the relevant organisations.

5) Progress Research

Advance and promote scientific research at European level

Some key actions:

- Establish a **scientific and medical committee** for AHC Europe and set up quarterly meetings with this group.
- **Support researchers** through an online application form to request funding or patient participation in new research studies.

- Investigate how to simplify the **legal process of research agreements** by setting up a single, standardised agreement to support cross-border collaboration.
- Share information about ongoing research through committee members, the website, social media, and a newsletter (the initial newsletter will be in layman's terms for AHC families).
- **Liaise with International AHC Research Consortium** (IAHCRC) and discuss ways of simplifying collaboration and access to patient data for international research projects.
- Researcher collaboration & family experiences: find ways to get researchers interested and collaborating with each other and collect valuable lived experiences.
- Funding of research projects to be carried out by individual AHC organisations. To be discussed in quarterly meetings.

6) **Improve treatment by healthcare professionals**
How are our children treated today?

Some key actions:

- Develop European treatment guidelines and share with AHC healthcare professionals. The guidelines can be adapted for each country.
- France is currently creating French treatment guidelines which they hope to be able to present at the next symposium.

Working Groups: Working groups have been established to drive the organisation forward. The current structure and members are:

- **Communication:** Alvaro, Anton, Bridget, Abhishek, Marjorie.
- **Research & Treatment:** Mirjana, Siggi, Rémi, Marjorie.

  One vacancy: filled by Michael Kabicher.
- **Family support, collaboration and advocacy:** Nienke, Bridget, Mirjana.

  Two vacancies: one filled by Suffia Madsen.

Summary of actions for AHC Europe members to help us reach our goals:

1. Sign up for our newsletter
2. Pay the yearly fee

3. Fill out AHC overview document
4. Join thematic meetings
5. Join family meeting on 24 September 2026
6. Submit names of neurologist/reference centres in your country

8. Announcement 14th ATP1A3 Symposium

Presented by Rémi Orhant, president of AHC France

- **Details:** The 14th Symposium on ATP1A3 in disease will be held in **Paris in 2026**.
- **Organising Medical Team:** Dr. Eleni Panagiotakaki, Dr. Boris Chaumette, and Pr. Emmanuel Flamand-Roze.
- **Programme:** The programme will include scientific presentations and a European family meeting.
- **Family Meeting** on **24 September** before the symposium.
  - Rémi Orhant requested input for things to be discussed. Nienke suggested we discuss how to be prepared for when a treatment becomes available.
  - AHC Europe will assist with the organisation, and Rémi will organise a dinner. The meeting is open to all family representatives (Europe and international).
  - Anton suggests adding family meeting attendance in the registration form.

9. 2026 AHC Day Campaign

Presented by Álvaro Quintas, AHC Europe Board member

- AHC Foundation (AHC Kids) is leading the social media campaign.
- The campaign aims to gather pictures of hands to create a large mosaic spelling the word **"Hope"** on AHC Day.
- Families are encouraged to be creative by sharing photos of their hands, drawings, or paintings for the "Hands of Care" theme.

- A discussion took place regarding the translation of the "Hands of Care" graphics. Álvaro and Siggi will follow up with AHC Kids.

10. Any Other Business (AOB)

No other business.

Conclusion: The President commended the work done by the association.

Next AGM: A proposal was accepted to move the next AGM to **January 2027** to allow the full year to conclude before the meeting.