

https://chromosome11.org

Activity Report 2024

Structure and development of the Board

The new Board of Directors was elected in April as part of the general meeting at the conference in Hohenwart.

Gesa Bressel, Gero Bressel, Camille Raguin and Olivier Raguin offered to stand again for their current positions on the Board.

Bas Albers and Caroline Albers agreed to join the Board in addition to the Board members standing for re-election.

All six were elected unanimously by the meeting.

Work of the Board

We held several board meetings both online and in person:

07.01.24 Online

21.01.24 Online

02.02.24 - 04.02.24 Live board meeting replaced last minute by online meetings due to Covid.

19.02.24 Online

04.03.24 Online

17.03.24 Online

28.03.24 Online

25.06.24 Online

16.08.24 Online

06.09.24 - 08.09.24 Live board meeting in Luxemburg

07.10.24 Online

05.11.24 Online

17.12.24 Online

The first trimester was dedicated to finalizing conference planning, including handling registration and arrangements for families, organising childcare, and completing print materials.

After the conference and a much-needed break, the second half of the year focused on addressing feedback from the conference, uploading videos, issuing a newsletter and finally resuming work on the new website.

European Chromosome 11 Network e. V.

https://chromosome11.org/



European Chromosome 11 Network e. V. Winkel 1 31167 Bockenem

https://chromosome11.org

Conference

The preparation of the conference that took place in the first trimester. For this edition the board made a point to improve feedback gathering and analysis.

13 out of 27 families (excluding 3 board member families) answered the online feedback from. Throughout the rest of the year, these feedback and suggestions were analysed, resulting in a list of ideas for improvement for the next conference (covering topics such as registration process, program, day schedule, childcare, etc).

Additionally, the board spent the rest of the year sorting photos, making the photo gallery available, and uploading and preparing the videos for the YouTube channel in four languages.

Remark: for this conference and due to costs limitation, the board decided to only live broadcast the conference in English (compared to English, French, German and Dutch in 2022). No complaints were received about this, and videos posted on YouTube afterward do include all four languages.

It has also been decided to stop translating our communications to Spanish and Italian, due to a lack of interaction with those languages' speakers. Spain has had its own local network for several years. Italy also has a local group and only few interactions with our European group. All families are obviously still much welcome to the Conferences and can still receive the newsletter in another language. If there is interest in additional languages for the newsletter in the future, we will be happy to take this into consideration.

Website / IT

Work on our homepage resumed at the end of 2024. The website overall structure is 80% complete. Early next year, we will focus on the content and translations.

In the spring we migrated our emailing tool for sending newsletter from Mailchimp to Mailjet that offers more useful functions.

Webinars / education

The non-profit organization "Stifter helfen" once again offered a series of webinars for associations in October. Gesa Bressel has participated in the following webinars on behalf of the network:

11.09.24 Webinar "Social-media presentations"

24.09.24 Webinar "VOLUNTEERS AHEAD! Fundamentals of Promoting Engagement"

26.09.24 Webinar "AI tools for non-profit organisations"

19.11.24 Webinar "Did you say something? Better Communication with AI"

European Chromosome 11 Network e. V.

https://chromosome11.org/

Board of Directors: Gesa Bressel, Camille Raguin,



European Chromosome 11 Network e. V. Winkel 1 31167 Bockenem

https://chromosome11.org

Finances

For the 2024 conference, we have this time taken over the entire financial administration. The participation fees were therefore not paid directly to the hotel, but were settled by the association. As a result, income of around \in 14,113 from the conference was initially offset by the large expenditure total of around \in 54,856. However, as provisions before and grants after the conference largely covered this, it was only necessary to ensure liquidity. This conference was again heavily subsidized by Aktion Mensch - with a sum of \in 38457.

Other income for the year included membership fees of €1,160 and donations of around €2,886.

In addition to the conference, there were relatively low expenses for board costs amounting to \leqslant 205. However, not all expenses were reimbursed in 2024 - these will be reflected in 2025. Due to the changes at the Sparkasse, there were higher account management fees of \leqslant 178.35. An outgoing donation of \leqslant 200 was made at the request of our speaker Claus Diegel in connection with his presentation at the conference, for which he only wanted to be reimbursed in part.

This resulted in an income surplus of around € 1,760 as a positive result.

The Board of Directors

Gesa Bressel, President Olivier Raguin Camille Raguin Gero Bressel, Treasurer Caroline Albers Bas Albers

Bockenem, Germany, January 11th 2025

European Chromosome 11 Network e. V.

https://chromosome11.org/