# European Chromosome 11 Network e.V.



### Structure and development

We had several boardmeetings online and face to face:

- January 7<sup>th</sup> (video call)
- February 15<sup>th</sup> (video call)
- March 28<sup>th</sup> to 30<sup>th</sup> (conference preparation meeting in Luxembourg)
- April 24<sup>th</sup> (after-conference boardmeeting)
- September 15<sup>th</sup> (video call)

 $24^{\text{th}}$ April 21<sup>st</sup> to Hohenwart/hPforzheim (Germany).

At the conference a new board was elected. The board consists of:

Gesa Bressel (President)

Camille Raguin (Vice president) Work **Olivier** Raguin

preparations for the conference: finalizing the program, organizing logistics.

For the first time we held a hybrid networks like the American 11q conference, offering people could Network. not join physically to follow the speeches and ask questions online. Despite it being a huge Our Scientific Advisors load of work and a certain cost. we definitely would like to continue with this set up for the next conferences.

At the end of the conference, a new date was immediately set with the hotel. The planned date is from April 4<sup>th</sup> to 7<sup>th</sup> 2024. We also scheduled an in-person boardmeeting in January 2023 in We also collaborated in the past Luxemburg in addition to several years online meetings.

In July, Gesa and Camille attended the US conference in Washington D.C. They got to *Finances* meet with their colleagues from 11q Research and Resource As in all years with conferences, group: Linzee Thorpe Carroll and Jessica Curia Fekete and gathered useful information and inspirational ideas and tightened the bonds between the overseas communities.

The conference was held from Three newsletters have been sent: in January (regular). February (invitations and registration to conference), April (conference program).

### Homepage

on our homepage continues. The improvement of Gero Bressel serves as Treasurer the overall structure as well as the translation to other languages is First trimester was about the last still in progress. Our Facebook page proves to be a very useful communication aid between all the European members along with getting in touch with the other

We spoke to some of our scientific advisors (K. Paris, E. Huisman, P. Grossfeld, I. Herfs) at the conference in Pforzheim in April 2022. The researchers are still committed to the network. They continue to do several research on different topics.

with the University Hospital to set up new research about blood platelets. Dr

Elize Huisman conducted this research and the results have been presented during the conference.

Activity Report 2022

there were large expenses again this year. Since the conference was held as a hybrid conference with great technical effort, we had high costs for technology and personnel expenses for video and translator technology. For this reason alone the expenses amounted to  $14220.50 \in$ . The board decided not to charge a conference fee this year and to let the association cover the hotel costs for all chromosome 11 children. After deduction of the parents' own contribution, а further 20871.12 € are therefore still to be allocated as expenses of the conference.

This is opposed by donations of 7249.51 € and a grant of 1200 € from EURORDIS, some of which were received directly in conjunction with the conference. 10023.41 € grant the to conference is to be expected by "Aktion Mensch", but will only benefit the budget year 2023.

Income from membership fees was slightly higher than in previous years at 760 €.

## The Board

Gesa Bressel, President Olivier Raguin **Camille Raguin** Gero Bressel, Treasurer

Erasmus Bockenem, Germany