



European Chromosome 11 Network e.V.

Activity Report 2016

Structure and development

The Board has been elected, at the conference in 2016 in Pforzheim. Gesa Bressel, Rick Pasma, Bettina Lehmann, Nina Kiventidou and Cindy de Klerk. Nigel Barrett is interim Treasurer, someone else will take this task in the near future. We thank Gaby Birle for her wonderful job as Secretary, Bettina has taken over her tasks.

The new logo was introduced and voted for.

We had 2 board meetings in 2016: at the conference and 9-11 September

We spoke of the division of tasks; Gesa is now president, Cindy is now vice-president, Bettina is secretary, Nina will do the tax reports and the funding from the German health insurance and Rick is supporting board member.

We evaluated the outcomes of the 2016 conference, which was very favourably received by all attendees. We planned the date for the next conference. Due to the fact it will be the 10th conference, we decided the it should be held 11-14 April 2019 so as not to clash with conference held in America will not be in 2018.

Homepage

www.chromosome11.org

Work on our homepage continues. The construction of the page and our webhost is in hands of the family Bressel (in Germany) It is completely renewed and updated. The translation in other languages is

in progress. Our Facebook page is working as a very useful communication aid between all the European members, and also with the American 11q Network.

Our Scientific Advisors

At the conference in Pforzheim in April 2016 we spoke to all our Scientific Advisors. They are very committed to the network and will continue their research. Dr Virgil Dalm showed the findings of his research to a very interested audience.

Prof Paul Grossfeld and Dr. Ken Parish from the USA held a presentation about the immune system as well. Paul Grossfeld also spoke about new findings: the link between chromosome 11 children and strokes, which could have a significant impact on future treatments for 11q children. In the upcoming years he will do more research into this subject – with the help of the European families.

We also invited a sexual therapist and the members were very enthusiastic about this.

At the conference in 2014 Karin Pasma collected data from the members and held a presentation about her findings

Finances

Donations were slightly down, although we had a very kind donation of €1,000 from Fam. Ziegler (Denmark) in memory of their daughter Julie. Membership fees were slightly up on previous years – we had no contributions from any Health Organisations. The conference was clearly the major cost event of the year – we spent just over €20,800 which was higher than previous years,

but the conference was very well received by all attendees!! Other costs were kept under control.

Because of the mix of the cost of the conference and the lack of funding from Health Organisations our cash resources were much reduced by the end of the year – down to just under €6,000. Much work needs to be done in the coming months to accumulate sufficient funds to be able to commit to the planned 2019 conference.

Best wishes
Nigel, Treasurer
Stafford, UK.

The Board
Bockenem, Germany