June 14, 2016



To all members of our association

Minutes of the regular general meeting of members

on April 8, 2016 – beginning 9:50 a.m. in the large event hall of the Hohenwart Forum Schönbornstraße 25 – 75181 Pforzheim-Hohenwart, Germany

Agenda

1) Welcome and election of the keeper of the minutes

After Rick Pasman, President, welcomed the members, Gero Bressel was appointed keeper of the minutes.

2) Formalities regarding the opening of the meeting

a) Verification that the members were duly summoned
 The members were duly summoned to the meeting of members.

b) Resolution relating to the agenda

The agenda was resolved as presented. There were no further items on the agenda.

- *c)* Verification of present votes and existence of quorum
 27 votes are present. The general meeting thus has a quorum.
- d) Resolution of the minutes of the meeting of members of March 29, 2014 The minutes of the general meeting of March 29, 2014 were adopted unanimously. It was motioned to send the items of the agenda of the previous meeting of members together with the minutes in the future.

3) Report of the board

In the last two years, four board meetings took place in Bockenem,
 Germany, which served the purpose of planning the conference, discussing
 the future of the association and planning the website.

- With respect to the upcoming conference, lots of work was put into improving child care and providing more capacities.

- Cindy DeKlerk and Rick Pasman participated in the 2015 EURORDIS meeting of members in Madrid, Spain: An important topic was, inter alia, the new European laws that intend to centralize European associations to the greatest extent possible.

- The new website is currently under development and will be finished as soon as possible.

4) Financial report of the treasurer

a) Report of the treasurer on the annual accounts of 2014

Report of the treasurer on the annual accounts of 2014 and 2015. Questions from the plenum: Which actions are taken with regard to members that do not pay? The board explained that one always had to consider whether it was more important to the association to lose a member (that does not pay) due to non-payment of the member fee or to keep a member and to possibly obtain the member fee later at a personal meeting.

b) Report of the annual accounts auditor

Stephan Kaiser as the annual accounts auditor – not present – recommended the formal approval of the actions of the board. There were no irregularities.

c) Resolution relating to the annual accounts of 2014 The annual accounts of 2014 and 2015 were resolved.

d) Resolution relating to the formal approval of the board for the accounting year 2014

The actions of the board were formally approved unanimously.

5) Continuation of the association

We need new members of the board. Newsletters, donations and fund raising are important key points for the association. There is more work to be done and the tasks should be distributed. Ton and Nigel retire from the board for personal reasons.

6) Election of the board

Nigel Barrett agreed to continue to keep the accounts until a successor has been found in the association.

The following board was elected unanimously: Rick Pasman (remains

European Chromosome 11 Network e.V. http://www.chromosome11.org/ President), Cindy DeKlerk (remains Vice President), Gesa Bressel, Bettina Lehmann and Nina Kiventidou.

7) Presentation of the new logo

It was noted that P and Q "is not missing a piece". Gesa Bressel: The Network also includes children who have a trisomy or a duplication. Casting of votes regarding the new logo: 16 votes for / 4 votes against / 1 abstention.

8) Questions from the plenum

Annet: Conny van Ravenswaaj sends her regards. Funds are required to translate 40-50 Unique brochures into Dutch. And also from Dutch into English. Several brochures will be reworked. The new brochure should have been online on the Unique website but is still missing. Languages unfortunately constitute one of Europe's problems.

Paul: There are many advantages when an association counts many members. He believes that the number of members amounting to 105 does not reflect the number of actual cases in Europe.

Nigel suggests that it is best to have only one "Chromosome 11" Facebook page and not the differentiation of Facebook pages according to the associations in the US/Europe.

9) Miscellaneous

- Facebook (Annet van Betuw): We should make sure that the page grows since this would surely also have the effect of obtaining more funds.

- The publication of photos of oneself or one's children on the group picture of the event and in protected groups on Facebook was not objected to by anyone.

Rick Pasman (President)

Cindy de Klerk

Gero Bressel (keeper of the minutes)

Cindy de Klerk (Vice President)

European Chromosome 11 Network e.V. http://www.chromosome11.org/

President and Vice President: Rick Pasman, Cindy de Klerk Members of the Board: Nigel Barrett, Ton Schouten, Gesa Bressel