



To all members of our network

Minutes of the general assembly of members

13. April 2019 - starting 3:15pm
in the large conference hall of the Hohenwart Forum
Schönbornstraße 25 - 75181 Pforzheim-Hohenwart

MINUTES

1) Greeting and election the person taking the minutes

3:15pm Opening by Gero Bressel as moderator of the meeting

Keeper of minutes: Robert Scherenberg

2) Formalities for opening the membermeeting

a) Determination of the proper invitation

It was dispatched in time taking into account the 4 weeks timeframe.

b) Resolution on the agenda

The agenda has been sent with the invitation and was accepted without changes.

c) Determination of the votes represented and the ability to constitute a quorum

22 voting members

d) Resolution of the minutes of the general meeting on 08.04.2016

The minutes were sent with the invitation and are accepted without objection.

Note from the ranks of the members: In the future the minutes are to be sent promptly after the meeting and then a second time with the invitation to the new meeting of the members.

3) Report of the Executive Board

- The following new member families are admitted to the association: Family Rabe, Family Auernhammer, Family Raguin, Family Immel and Family Drost.
- After the 2016 Conference, the first Board meeting took place in Sept 2016, at which Rick Pasman resigned as Chairman. Gesa Bressel was elected as the new president. This made it necessary to register an amendment at the registry court. A number of additional minutes and annual financial statements had to be submitted in order to finally receive the new notice of exemption for the coming years.
- There have been major difficulties in obtaining funds/grants from official bodies, so the conference has been postponed to 2019.
- Requests for grants have been made to treasuries, social organizations, and associations such as Rotary clubs.
- The homepage has been changed and will continue to be edited, also to improve its searchability. The expansion of multilingualism is planned.

- In 2017 Gero Bressel took over the office of treasurer.
- Donations: Dutch institutions have repeatedly refused donations and can only give grants to Dutch associations. In Luxembourg and France, too, official bodies have rejected grants. In Germany, applications were submitted to Aktion Mensch and the Verband der Ersatzkassen (vdek).
- In 2018 there was no change in the Board of Directors, the meetings were primarily concerned with conference preparations and raising funds.
- The attempt to raise funds did not have a great effect and an information letter was sent to all members.
- Gesa Bressel and Bettina Lehmann took part in two web seminars on association work and the basic data protection regulation.
- Facebook is very useful as a communication tool.
- A cooperation with the Erasmus University Rotterdam is to be expanded because of their ongoing research on blood platelets.
- Due to the tight budget, there will be no discount for chromosome 11 children in 2019, and childcare must be subsidised by families with 20€.

4) Financial report of the treasurer

a) Report of the Treasurer on the annual financial statements 2016 - 2018

Overview of the finances 2016 by former treasurer Nigel Barrett.

Conference costs 2016 amounted to more than € 20000.-.

European Chromosome 11 Network

Statement of Income and Expense 2016

		Sparkasse	HSBC £	HSBC €
	Total €	€	£	£ --> €
Income				
Membership Fees	656.16	600.00	48.00	56.16
Transfer	-	-	0.00	0.00
Donations	1,802.48	1,400.00	344.00	402.48
Interest	- 175.71	3.38	0.00	-179.09 currency loss
Total Income	2,282.93	2,003.38	392.00	279.55
Expenses				
Board Meetings	1,201.40	1,201.40		
Representation - Eurordis	150.00	150.00		
Banking and fees	175.00	175.00		
Conference cost	20,827.06	20,864.50	-32.00	-37.44
Transfer	-	1,168.22	1,009.00	1,168.22
Translation	600.00	600.00		
Total Expenses	22,953.46	21,822.68	977.00	1,130.78
Excess of Expenses over Income.	- 20,670.53	19,819.30	585.00	-851.23

2017: initial cash balance €5954.84, end of 2017 €9538.46

Membership fees are constant in every year - also by direct debit possibilities - €460.00

A large part of the donations was generated by two posts, that of Caroline van Heesewijk's father-in-law and one of his friends, who both collected donations for the network on their birthdays.

The nordic holidays GmbH has donated between 150-200 EUR for 4 consecutive years. Also these recurring donations make a big difference.

Einnahmen	Betrag
Mitgliedsbeiträge	460,00 €
Spenden	2.130,00 €
Übertrag HSBC zu SPK	539,81 €
Summe Einnahmen	3.129,81 €

Ausgaben	Betrag
Vorstandskosten	- 1.124,33 €
Mitgliedsbeiträge andere Vereine	- 75,00 €
Kontoführungsgebühr	- 7,49 €
Rechtsberatungskosten (Notar)	- 50,00 €
Übersetzungskosten	- €
Summe Ausgaben	- 1.256,82 €

Einnahmenüberschuss 1.872,99 €

Bilanz	Betrag
Sparkasse	11.411,45 €
Rückstellung Konferenz 2019	- 10.000,00 €
Total Eigenmittel 31.12.2018	11.411,45 €
Total Eigenmittel 31.12.2017	9.538,46 €
Summe Eigenmittel	1.872,99 €

2018: Membership fees as before, donations € 2130.00.

Bettina Lehmann and Camille Henny-Raguin have organized a bazaar for the network in 2018 and thus brought us the biggest part of the donations of the year.

Completion 2018: 11411.45€

2019 so far € 8762.00 Revenue

Einnahmen	Betrag
Mitgliedsbeiträge	460,00 €
Spenden	5.494,84 €
Summe Einnahmen	5.954,84 €

Ausgaben	Betrag
Vorstandskosten	- 669,55 €
Mitgliedsbeiträge andere Vereine	- 75,00 €
Kontoführungsgebühr	- 12,00 €
Rechtsberatungskosten (Notar)	- 48,91 €
Übersetzungskosten	- 1.300,20 €
Summe Ausgaben	- 2.105,66 €

Einnahmenüberschuss 3.849,18 €

Bilanz	Betrag
Sparkasse	9.538,46 €
HSBC (UK Währung Pfund Sterling)	
Rückstellung Konferenz 2019	- 8.500,00 €
Total Eigenmittel 31.12.2017	9.538,46 €
Total Eigenmittel 31.12.2016	5.689,28 €
Summe Eigenmittel	3.849,18 €

Money pledged: Grant for the conference by Aktion Mensch, a grant by the vdek is still in progress - a decision is expected in May. EUR 1400 was provided by EURORDIS for the work of the board.

Several large donations through companies.

b) Report of the cash auditor

All documents were in the correct form, the cash register was clearly arranged.

The cash auditor Nina Kiventidou applied for the ratification of the board.

c) Resolution on the financial statements 2016 - 2018

unanimously without dissenting vote

d) Resolution on the ratification of the actions of the Executive Board

unanimously in the abstention of the members of the Executive Board

5) Continuation of the network

The conference should take place at regular intervals, but possibly only every three years.

It would be very desirable for members to take over smaller and larger tasks: participation of members in project work within the network,

Making and keeping contacts: Passing on information via the website and Facebook. The multilingualism of the website is to be extended to: Italian, French, Spanish, Dutch.

6) New membership fees

Proposal from the Executive Board: Redesign from a fixed € 20.00 to a staggered € 20.00, - € 30.00, - € 50.00 and freely chosen - if possible by direct debit

There are registered over one hundred members, there pay only about 35 - 40. Here is the question of voluntariness and esteem, already now is a big difference between membership and paying members.

The decision about the membership fees will be postponed to the next conference, all members will be contacted.

7) Election of the Executive Board

Retiring from the Executive Board: Rick Pasman, Cindy de Klerk, Bettina Lehmann

Gero Bressel remains treasurer without standing for election to the board.

Readiness for the Board work: Camille and Olivier Raguin, Gesa Bressel, Nina Kiventidou and Kerstin Rabe

The new members of the Executive Board are elected:

Gesa Bressel, Nina Kiventidou, Camille Henny-Raguin, Olivier Raguin, Kerstin Rabe

in a block with no dissenting votes and abstention of the members of the Executive Board.

8) Questions from the Plenum

none

9) Miscellaneous

- Vote on interval of conferences: Vote: 17 votes for 2 year cycle 5 votes for 3 year cycle.
- The redesign of the homepage should go beyond the medical area, support offers, also country-specific information should be included.
- Questionnaires to supplement the data members should be collected, here in compliance with data protection provisions

- Paul Grossfeld will act as official medical advisor to the association and will be available for consultation.

End of the general meeting: 17:25 Uhr

Jesa Bressel