

## **p. 1 Protocol Business meeting, Zaragoza, 160630**

### **Protocol of Business meeting EWGGD Zaragoza, Thursday, June 30, 2016**

**Date:** June 30, 2016

**Location:** Auditorium, Zaragoza, Spain

**Time:** 5.30 pm till 7.30 pm

**Participants:** Stephan vom Dahl (SD) - Andrea Dardis (AD) - Ari Zimran (AZ) - Beata Kiec-Wilk (BKW) - Carla Hollak (CH) - Eugen Mengel (EM) - Hanna Rosenbaum (HR) - Jeffrey Szer (JS) - Jeremy Manuel (JM) - Jörg Reinke (JR) - Kira Lukina (KL) - Maciej Machaczka (MM) - Maja di Rocco (MR) - Marc Berger (MBe) - Marieke Biegstraaten (MBi) - Mia Horowitz (MH) - Pilar Giraldo (PG) - Ricardo Feldman (RF) - Tanya Collin-Histed (TCH) - Pascal Niemeyer (PN) - Fiorina Giona (FG)

#### **1) Current and past activities**

- EWGGD meeting 2016:  
We had a very successful meeting in Haifa, with 280 registrations, thanks to HR and her team.
- Consensus project on management goals:  
Last year a Delphi study was performed among EWGGD members on the definition of management goals for GD1. The project was led by CH and MBi and the results have been submitted for publication.
- EWGGD membership:  
There is a possibility for official membership since 2012. At the moment we have 36 registered members.

#### **2) Financial report**

SD explains that the surplus of the 2010 meeting in Cologne was + €33.721. This amount has been used for EWGGD activities and reimbursements. MBi has been paid from this account as from November 2011. The current balance is around €2000. Therefore, this account will be closed in a few months. The balance of the Dutch EWGGD account is + €30.340 which results from the surplus of the Paris and Haifa meetings, membership fees, bank costs, website development and hosting costs, and the organization of a board meeting in Amsterdam in May 2015. The surplus of the Zaragoza meeting is expected to be around €20.000. The accounts have not been checked by non-board members yet. SD will make a proposal for two people.

SD explains that for the coming 2 years we need around €10.000 for secretarial work, and around €10.000 for travel expenses. He indicates that the rest can be used for f.e. a Roscoe Brady award, or for financial support of scientific projects. MH says that she is not sure if the EWGGD should go into prices. She argues that it would be better to use the money to support young scientists or doctors to attend the bi-annual EWGGD meeting. They should be offered not only a travel grant but also reimbursement of the registration fee. SD explains that this is part of the budget of the meeting, but we can increase the amount to €750 or €1000. Alternatively, we could decide to reimburse €500 registration fee through the budget of the meeting, and additional travel costs through the EWGGD account. CH proposes to use the money to financially support young doctors to travel to clinics/laboratories to learn from the experts. HR suggests to organize a "day of the experts". SD explains that this kind of activities is very expensive. JM mentions the possibility of organizing a master class in-between main meetings, particularly for young doctors. AZ emphasizes that it is important that young doctors commit themselves to the Gaucher field. By funding a research project this may be not the case. He supports the idea of CH to use the money for visiting trainings. CH argues that the board should come up with a good program with the rules and budget, and put it on the website. Otherwise it is not going to happen. In addition, it is important to support young scientists and doctors to come to EWGGD meetings. MH states that we need to be active and devoted as EWGGD.

It was concluded that the Board will first make a concept. For a laboratory visit a period of at least 3 months is needed. SD emphasizes that we are a non-for-profit organization, and therefore we need to spend the money.

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### **3) Publication of abstracts**

MBe asks if it is possible to publish the abstracts of the meeting. SD has approached Johannes Zschocke from JIMD, but Zschocke indicated that the EWGGD will need to pay money per abstract and he advised not to do it. AZ indicates that the abstracts can possibly be published in the special Gaucher edition of BCMD; shortly after the business meeting, however, he informed us that BCMD cannot publish the abstracts.

### **4) Change of the location of the 2016 meeting:**

SD explains why the location of the meeting was changed from Moscow to Zaragoza. The main reason for this decision was an upgrade of the selected venue from a 4-star to a 5-star hotel, while sponsors are not allowed to financially support meetings that are held in 5-star hotels. In addition, it appeared to be common practice in Russia that hotels receive a substantial pre-payment in advance (in contrast to previous meetings). The EWGGD, however, could not comply with such a request. Also, the hotel could only be paid in Russian Rubles, and, therefore, rates would be due to fluctuations in the exchange rate between Euro and Russian Rubles. Finally, to travel to Russia, each participant had to have a distinct visum. This is only a relative problem, but sufficient time is needed. KL explains that Russia put a lot of effort into the organization of the meeting. They are willing to organize the next meeting if the board offers them the opportunity, without voting. CH argues that the board needs to make a decision on whether or not to have a meeting in Moscow. This is supported by AZ who indicates that the chairman should decide on whether it is possible to overcome the problems. JS suggests to hire an agency from other country. MM wonders whether it is possible for the Russian team to organize the meeting outside Russia. SD suggests to put Russia on the voting list and to vote for the location of the 2018 meeting. CH says that she is not voting, since she cannot decide on Moscow as a location for the meeting. JM agrees that we cannot make a decision if we do not know if Russia can make it. In the end it was decided to ask Russia to make a concept for 2020, and to vote now for 2018.

### **5) Place and host of the next EWGGD meeting**

Both MM and MR are ready to host the next meeting in their country, respectively Sweden and Italy. Sweden received the majority of votes (11 out of 17). The next meeting will take place in Stockholm, Sweden. Maciej Machaczka will also be part of the board from now on as organizer of the next workshop.

### **6) Election of board members**

SD explains that four vacancies have arisen since he himself (Chairman), Helen Michelakakis (Vice Chairman) and Mia Horowitz (Board Member) have reached the maximum board period of 4 years. In addition, Nadia Belmatoug has decided to step back as a board member. There are 6 candidates for the board. SD is available for the chairman position. He is re-elected by acclamation. Helen Michelakakis decided not to be a candidate for the board. MH stands up for the position of vice-chairman. She is elected, again by acclamation. MBe, MBi, MR and Simon Heales explain why they are willing to be part of the board. MBe and MBi receive the majority of votes. The composition of the board is as follows:

- Chairman: Stephan vom Dahl
- Vice-chairman: Mia Horowitz
- Founder president: Hans Aerts
- Board member: Marc Berger
- Board member: Marieke Biegstraaten
- Board member: Hanna Rosenbaum
- Host 2018 Meeting: Maciej Machaczka
- EGA representative: Jeremy Manuel

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**Action items**

- Make a proposal for two (non-board) people to check the EWGGD accounts – SD
- Make a concept for rules and budget for visiting trainings and put it on the website - Board
- Planning of next board meeting in May or June 2017 - MBI



Stephan vom Dahl (Chairman of EWGGD), Düsseldorf, Tuesday, 27 September 2016