

## Sjögren Europe General Assembly - Minutes

Sunday 13 September 2020, 1400-1600 CET (1300-1500 BST)

The attached slides were shown as an illustration of the work of SE *Appendix 1*

### 1. Welcome

The president, Alice, welcomed all those attending

### 2. Introduction of Board members

Alice Grosjean, President; Mascha Oosterbaan, Vice president; Katy Antonopoulou, Treasurer; Linda Stone, Secretary; Ana Viero; Coralie Bouillot; Joyce Koelewijn-Tukker  
Each Board member has one vote excluding for items where the vote 'discharges the Board'.

### 3. Attendees listed (for the record).

Observing, ie not entitled to vote: Sara Badger, Vivienne Brown, Adela Gaia, and Frederic Gomez

### 4. Member organisations: representatives' names noted as only the official representatives of Member organisation may vote.

Each Representative has one vote.

Finland - Leena Ahtila

France – Maggy Pincemin

Greece – Katy Antonopoulou

Israel – Ram Bols

Netherlands - Mascha Oosterbaan

Portugal – Ana Viera

Switzerland – Antonella Spada

United Kingdom – Liz Faulkner

### 5. Minutes of the 2019 General Assembly. *Appendix 2*

Linda presented the minutes. It was noted that certain names of attendees had been corrected afterwards. Also, the category of Supporters (minute 5) has not yet been introduced. There were no questions.

*Vote:* All Board member and Representative votes were in favour of accepting the minutes.

### 6. Annual report. *Appendix 3*

Alice presented the Annual report. There were no questions.

*Vote:* All Representatives voted to accept the Annual Report.

### 7. Financial report. *Appendix 4*

Katy presented the Financial report. In answer to a question, she explained that the very small amounts referred to the first year. It is anticipated that additional funds will be forthcoming.

8. Auditors report. *Appendix 5*

Katy presented the Auditor's report.

*Vote:* All Representatives voted to accept the Financial report and the Auditor's report.

9. 2020 budget. *Appendix 6*

Katy presented the budget for 2020. She highlighted that the budgeted income was anticipated to come from membership subscriptions, contracting with a pharma company and sponsorship for activities.

In answer to questions, she accepted that 2019 was an error, it should read 2020. The 2-day workshop will be virtual and expenses will be for the technical costs and payment/expenses for speakers.

Ram volunteered that some clinicians are willing to speak without pay. This is accepted but varies depending upon the event and subject. The offer of help from Israel was welcomed. It was stressed that the Board will not spend money that it does not have. Projects will not be started without confidence that the funding is in place.

*Vote:* Board members and representatives were eligible to vote and the result was unanimous in accepting the budget for 2020.

10. Planned activities. *Appendix 7*

- a. Joyce presented plans for a conference, hopefully in 2021.
- b. Ana reported on Sjögren Awareness month in April. She pointed out that SE did not have the capacity to post every day throughout the month as members were also active in their own countries.
- c. Mascha reported about the very successful social media World Sjögren's Day campaign highlighting the invisibility and hidden burden of Sjögren's. The 'iceberg' image was translated into several languages and widely welcomed and used.
- d. Katy highlighted the details of the Webinar scheduled on 3 November 2020.
- e. Coralie outlined the significant involvement of Board members in a number of relevant research studies and projects. The importance of bringing the patient voice to research sharing information.  
SE is now an associate member of EURORDIS and will become a full member in 2021.

Linda reported on the following:

- f. She reminded the meeting that SE has an active social media presence. There are frequent posts on Facebook, Instagram, and, in the future, Twitter.
- g. An e-newsletter is published three times a year.
- h. A virtual Board meeting is held monthly (more often if necessary) with an agenda and minutes.
- i. The website is regularly updated to ensure it is contemporary, eg World Sjögren's Day.

- j. SE shares information and resources if appropriate with member organisations and others, sharing experience, ideas and knowledge and encouraging involvement in research to improve care and welfare for Sjögren's sufferers.  
SE liaises with clinicians, including the medical board, to identify speakers as required, eg for the Webinar.  
SE has had discussions with Pharma companies, seeking sponsorship via discretionary grants, and discussing the possibility of supporting relevant research. When required and/or relevant, SE will enter dialogue with regulators.  
SE participates in relevant Congresses eg EULAR  
SE has been co-opted to PARE.

11. Discussion of any issues raised by full members. (Must be received by 31.08.2020).  
No issues had been raised.

12. Thankyou

End of formal meeting.

## **Open Question and Answer session.**

A general discussion covered various areas.

Maggy suggested contacting Germany, Dutch Belgium and Sweden. It was commented that normally, contacts are made when attending conferences but this is very difficult when meetings are virtual.

Leena responded to Ana's query about a registry saying that there is a registry for hospital knowledge only.

Attendees shared some positive examples around keeping members together during Coronavirus when meetings are impossible. These ranged from virtual meetings including speakers to local WhatsApp groups, increased email contact.

Maggy also suggested involvement with EMA (not possible for UK).

*Zoom sign in code and password*