

## RETT SYNDROME EUROPE

### DRAFT MINUTES OF GENERAL ASSEMBLY HELD ON 26 OCTOBER 2018 IN COPENHAGEN, DENMARK

#### PRESENT

**Board members** – Caroline Lietaer, President, France; Danijela Szili, Secretary, Hungary; Wilfried Asthalter, Treasurer, Germany; Yvonne Milne, U.K.; Stella Peckary, Austria.

**Country representatives** – Louise Lund, Denmark; Iben Hjarsoe, Denmark; Ella Helander, Finland; Kirsi Peltonen, Finland; Oliviero Dell’Oro, Italy; Laura Kanapieniene, Lithuania; Pavel Kwiecien, Poland; Ana Teixeira, Portugal; Sandra Madeira, Portugal; Paula Bolzani Prunes, Catalonia; Yolanda Coron, Spain; Anatoly Savchenkov, Russia; Becky Jenner, U.K.; Hanna Rymo, Sweden; Peter Karltwist, Sweden; Anna Davidsson-Karnevi, Sweden; Carina Klasman, Sweden; Maria Dellskog, Sweden; Katarina Oryd, Sweden.

**Observers** – Giulia Dell’Oro, Italy; Dr Martina Semino, Italy; Helena Wandin, Sweden; Claudia Petzold, Germany; Gerhard Peckary, Austria; Pedro Rocha, Portugal; Chris Milne, U.K.

**The meeting commenced at 1420.**

#### 1. **President’s opening remarks**

CL thanked the Danish Rett Center and the Danish representatives for their excellent organisation and for the use of the venue for the meeting.

CL stated that 15 countries are represented today with the aim sharing how we are all dealing with Rett Syndrome. She welcomed all the representatives attending for the first time.

#### 2. **Minutes of 2017 General Assembly**

The draft minutes were approved unanimously.

#### 3. **Activity report 2017-2018**

3.1 CL thanked the Board members for their excellent work in a very heavy year. She also thanked the two former Presidents, Gerard and Thomas, and the Rett Resource collaborators. CL presented the Activity Report using a pre-circulated slide pack.

3.2 **Statute changes** – CL explained that 2 major and some minor changes to the Statutes have had to be made for legal reasons.

3.3 **Aim 1 - Rett Resource** – CL reported that this had been completed and was available on line in English at no cost. It has been written by the best Rett experts available. It is also available in Croatian, Dutch and Lithuanian, with French and German coming soon. It was also announced that 3 new countries had joined RSE – Turkey, Ukraine and Tunisia (the latter by special request as the only other African country with a Rett organisation was South Africa).

3.4 **Aim 2** – A new Rett centre had been established in Paris and there has already been a joint meeting with the Maastricht centre on a project on aging. A new

French diagnostic protocol has been published, but this is currently only available in French. This may be translated in the future. A Catalan association meeting has been held in Barcelona.

3.5 **Aim 3** – RSE is a voting member of EURODIS. Yvonne is a Rare disease patient advocate on the European reference network ITHACA. Yvonne attended the new winter school in Paris, which will run again in 2019. She also explained that the leadership of ITHACA will be transferring from the U.K to France in 2019. Danijela continues to be involved with the EURODIS task force and the European Medicine Agency. Danijela asked for more volunteers to attend such meetings as the more such meetings we attend, the more effective we can become.

3.6 **Aim 4** – The Ukranian Rett Syndrome Association was founded on 8<sup>th</sup> May 2018 in Kiev. The Turkey Rett Syndrome Association has been re-established after closing in 2015. A new association for Angelman and Rett syndrome has been established in Tunisia and will have observer status in RSE. This is the first known association in an Arab country.

3.7 **Aim 5** – (see later item 7 on the future of research.)

#### **4. Financial report**

**WA** (Treasurer) summarised the 2017-18 accounts which had previously been made available. He confirmed that a few countries had not yet paid their 2018 subscription, but that he expected all countries to have paid by the end of 2018. He showed the statement of the auditors, confirming the accounts. There were no questions and the financial statements were approved with 18 votes in favour and none against.

#### **5. Statute changes and legal status of RSE.**

**DS** (Secretary) stated that a lawyer familiar with Luxembourg law had to be employed to make the necessary changes to the Statutes. This was completed on 28<sup>th</sup> February 2018 and backdated to November 2017. In the future, annual returns will need to be made in French and the 3 year mandate will end in November 2020 when new Board elections will be required.

DS proposed a vote of thanks to Caroline for her work as President, which was endorsed by the meeting.

#### **6. Rett Resource Project**

This is currently available in English, Croatian, Dutch and Lithuanian. It will soon be available in French and German. In response to a question about further translations, CL said that it needed professional translation, which then needed further checking before publication. The costs for each language are about 4000eu. It also must be in the same format and is only to be available on the website. CL invited country representatives to contact her about further translations.

**Action: Country representatives**

## **7. Proposal for RSE subcommittees to be formed for specific projects.**

DS identified areas in which subcommittees could be formed to help the development of RSE activity and to achieve its aims. These are research, awareness (particularly in the area of social media such as Twitter), fundraising and communications.

DS suggested that countries could donate, say, 1000eu and they could agree what they wanted to research in areas such as scoliosis, respiratory and epilepsy. DS asked members for their views on whether other organisations could be asked to collaborate on research projects.

A discussion followed specifically on the subjects of fundraising and research.

Comments included:

- A clear brief of each individual project would be required before fundraising could take place
- We don't know what is being done in each country
- The Board needs to draft a strategy for this
- Other organisations will be protective about their own activity
- Fundraising is means to an end. The first step is to prepare a strategy
- The Board needs more people to help to achieve this
- Portugal has contacted universities to find out what is going on. We need to use their methods which will be free of charge i.e. get professional help.
- We need a scientific committee
- We do not have list of potential researchers
- There is a problem of the RSE operating in isolation. We must take account of work being done in the US etc.
- Catalonia reported that they had been using subcommittees successfully in joint working with the Spanish association on fundraising.
- WA asked the members to note that RSE had no charitable status in the EU which allowed for fundraising, but applying for grants is allowable

In conclusion the members agreed unanimously that the Board should have the authority to create sub-committees to move projects and ideas forward, which could include country members and others who can provide specific expertise.

Volunteers who wished to act on such committees were asked to notify DS. Paula (Catalonia) agreed to volunteer.

## **8. Rett Centres survey**

LK introduced the topic by saying that small countries have little professional help and support within their countries and need to look abroad for that assistance. What is needed is a database of available resources in the larger countries, such as Rett centres, other specialist clinics and schools with Rett expertise.

An on-line questionnaire is being made available and all countries are asked to help to ask their centres of best practice to complete it. Country representatives were asked to contact Laura by e mail at [laura.kan@outlook.com](mailto:laura.kan@outlook.com) if they wished to discuss this further.

### **Action: Country representatives**

CL agreed to send out the questionnaire which needs final improvements made to it. The board will include Laura in all further discussions on this.

PR stated that it would be important that the information was always up to date and that a mechanism would be needed to maintain the currency of the database.

Members agreed to support this project to move forward.

## **9. New communication technology project**

(presented by Dr Martina Semino – Italy)

The aim of Airett is to provide new tracking software system, and the project is called Project Amelie. The new software will be Rett specific.

Having verified that eye tracking is an ideal system for Rett girls, it was felt that new software was required that, unlike Tobii, is designed for people with complex communication needs.

The first year of the project has been completed. The outcomes have been:

- Increase in attention span
- Increase in choices made
- Increased usage at home and integration with school usage
- Activity sequences have been timed

In response to questions Dr Semino responded that:

- There are current discussions taking place about the compatibility of the new software with current systems. A decision will be made by December 2018.
- It is planned to be launched in Italian and then English.
- Its USP is that it will be Rett specific.

CL thanked DR Semino for her presentation and confirmed that further information on this project will be posted on the RSE website.

**Action: Board**

## **10. Rett Database**

(It was planned to include Alessandro from Italy via Skype for this item, but the link failed).

Pedro Rocha asked for brief update on the project in Alessandro's absence. It seems to be a very ambitious project and interesting as a concept but has design constraints. YM confirmed that there is currently a Geneda database for families only which is being populated, Further work on the overall database is required.

Pedro offered his assistance to the Board from a technical point of view.

**Action: Board to progress**

## **11. 2019 meeting**

Finland have volunteered to host the General Assembly on the 27<sup>th</sup> and 28<sup>th</sup> October 2019 in Tampere, Finland. The preliminary programme will be made available in Spring, 2019. The aim is to promote Rett Syndrome in Finland, where there is limited expertise.

**Action: All countries were asked to place a link to the event on their websites.**

The General Assembly closed at 1700.