

RETT SYNDROME EUROPE
MINUTES OF GENERAL ASSEMBLY MEETING
HELD AT HOTEL ANDEIS, BERLIN 4th November 2017

The meeting opened at 1030.

Present:

Austria – Stella and Gerhard Peckary
Czech Republic – Ivana and Philipp Hanns
Denmark – Iben Hjarso
Finland – Ella Helander
France – Thomas Bertrand and Caroline Lietaer
Hungary – Danijela Szili
Norway – Hilde Friis, Sten Larsen
Portugal – Sandra Madeira and Anna Dias
Russia – Olga Timutsa
UK – Yvonne Milne and Becky Jenner
Sweden – Anna Davidsson Kernevi
Germany – Wilfried Asthalter

In attendance:

USA – Paige Nues
France – Gerard Nguyen

Minute secretaries - Chris Milne and Riccarda Peckary

1. Welcome and address by the President – Thomas Bertrand

TB welcomed all delegates and thanked those country representatives that had presented posters summarising their current and proposed activities.

TB reminded all present that only fully paid up countries were able to vote and there was only one vote per country.

2. Minutes of the previous general assembly held on 17th September in Vienna.

These had been previously published on the RSE website. There were no questions and the minutes were approved unanimously.

3. 2016/7 Activity Report

TB confirmed that the full report had been posted on the website. He highlighted the following activities:

- Rett Resource – this is being lead by Caroline and will focus on the care management of the Rett person. It is based on the Rett UK guide, which is written by professionals for parents and carers. It will be available in several languages and 11 full texts have been received, which are now being proof read. The priority will be to make it available electronically first.
- ERN - ITHACA – Yvonne has been elected by EURODIS to serve on the Board of this European Reference Network initiative. The project mission statement is: xxxxxxx. RSE aims are very much aligned with those of this project and Rett is one of many diseases represented.
- Other – Some excellent older patient care guidelines produced in France have now been given permission for translation into English.

4. **Financial Report**

This was presented by Wilfried Asthalter – Treasurer. This has been approved by the auditor and the confirmation letter was displayed to the meeting, confirming the accounts without objection.

WA reminded the meeting that RSE's only regular source of income was membership fees.

New countries are joining and fee income is increasing, which is very positive.

The financial report was approved unanimously.

5. **Statute Changes**

TB announced recommended changes to the statutes, which are subject to Luxembourg laws.

- It is proposed to change Article 10 by extending Board member terms from 2 to 3 years. The number of Board members will remain at 5. In future a minimum of 4 the Board members must be carers or Rett family members.
- There are also some minor changes to requirements relating to names and addresses of Board members, the registered office address and article numbers.

These changes to the Statutes were approved by all member countries present with no votes against or abstentions. There were no further questions.

6. **Elections to the Board**

TB confirmed that he was standing down as President and as a member of the Board, but will continue to manage the website.

The following proposals were recommended:

- That Stella Peckary (Austria) should join the Board
- That the terms of office for Caroline Lietaer, Yvonne Milne and Wilfried Asthalter should be renewed.
- Daniela Szili is an active member and her term will be renewed at the next GA

All member countries supported the above proposals present.

Yvonne thanked The President for all the hard work and skill he had brought to his role with RSE and that his wisdom would be much missed by the Board.

7. Future meetings

- The Danish members confirmed that they would host the 2018 General Assembly meeting in Denmark at the Rett centre with visits available to the local school, where there are 8 Rett girls. The meeting would be open to all country members as well as anyone else who wishes to attend. The date will be confirmed but will probably be in November 2018.
- The Polish association with great regret had announced that it was unable to hold the 2019 European congress. Members were invited to consider their own ability to stage this event, which should include 1 day of practical sessions for local parents and carers and 1 professionals' day conducted by local professionals, not research presentations. Portugal expressed an interest in staging the 2019 event and will see if this is possible.
- It was noted that there will be a need to liaise with other countries outside Europe to ensure there is no duplication.
- WA informed the meeting that due to German law, drug companies were not allowed to sponsor such events, but this may be a possibility in other countries.

8. Any other business

- Denmark expressed concern about the development of the European database as money has been raised for this and nothing appears to have happened. TB confirmed that this had not progressed and that funds given need to be recovered. Yvonne has now taken this matter up as part of an ITHACA project, which aims to merge all databases. An application for EU funds has been submitted and decision is awaited. Yvonne will report back to members, when any decision is taken. TB recommended that for all countries who have sent money, that they should ask the European database directly to increase the pressure.

The meeting closed at 1130.