

**RETT SYNDROME EUROPE**  
**DRAFT Minutes of Annual General Assembly**  
**17<sup>th</sup> September 2016, Vienna, Austria.**

**Members attending:**

Portugal – Ana Paula Deus (Treasurer), Sandra Cidade (President)  
Poland – Magdalena Partyila-Wojcik (Board member)  
Russia – Olga Timutsa (Chairman), Anatoly Sauchenkov (observer)  
Finland – Ella Helander (Board member), Topi Helander (Observer)  
Sweden – Katarina Oryd (Board member), Anna Davidsson Karnevi (Vice chairman)  
Norway – Sten Richard Larsen (Treasurer), Therese Steinnes (Board member)  
Austria – Stella Peckary (Board member),  
Belgium – Peter Vanherck (Board member), Margaretha De Wit (observer)  
Italy – Oliviero Dell’Oro (Associate), Alberto Romano (Associate)  
United Kingdom – Chris Milne (Observer & Minute taker), Yvonne Milne (RSE), Becky Jenner (CEO Rett UK)  
Catalunya – Pedro Rocha (Board member)  
Lithuania – Laura Kanapieniene (Director)  
France – Caroline Lietaer (RSE), Thomas Bertrand (RSE & Board member)  
Hungary – Danijela Szili (RSE)  
Germany – Wilfried Asthalter (RSE & representative)  
USA – Paige Nues (observer)  
Australia – Claude Buda (Vice President)

**Apologies**

Armenia  
Cyprus  
Czech Republic  
Malta  
Spain  
Scotland

**1. Welcome address and introduction of members**

Thomas Bertrand (TB) welcomed all country representatives and observers from other countries and organisations. All Board members and other attendees introduced themselves.

TB also welcomed members of the Communication project which is led by Gill Townend (GT) from Maastricht University and announced that this would be an exceptional item on the agenda.

**1.1 Communication Project**

GT explained that the aim of the project is to develop international clinical guidelines for the management of communication in individuals with RTT.

After awaiting funding, the project started earlier in 2016 with a full search for any reports or other information on communication in Rett syndrome that already exist. This preliminary stage has now been completed.

The second stage is to gather information from professionals. All country representatives will have received a request from GT to encourage known speech and language therapists to complete the survey. Members were asked to ensure that this was being carried out. **Action ALL**

GT stated that there was a Project information card in the conference pack and any country requiring further information should contact her by email at [g.townend@maastrichtuniversity.nl](mailto:g.townend@maastrichtuniversity.nl).

The next stage will be to gather information from family members, probably via a survey form. A pilot form has been developed in Chicago and this needs to be translated in to a number of key languages. It will be available on line from the 1<sup>st</sup> October 2016. Representatives from the following countries agreed to have the form translated and returned to GT:

- Poland
- Spain
- Sweden
- Italy
- Netherlands
- France
- Russia
- Germany
- **Action all of the above**

Once this process is completed, the form needs to be circulated to and completed by as many families as possible.

Responses not received in English will be translated by the University authorities under strict ethical rules.

Finally, the steering group will review all professional and family responses and develop draft guidelines which the stakeholder group and some parent representatives will review. The final draft guidelines will be presented and available at the Berlin conference in November 2017.

## 2. **Draft minutes 2015 and action points**

The minutes were agreed by country representatives with no comments. Members were asked to note that Caroline Lietaer was representing the French Association and not the Belgian one and the minutes would be amended.

## 3. **2015-2016 Activity report**

TB indicated that the full report had been made available on the website and reflected the 5 aims of RSE.

**Aim 1** – TB requested that all country representatives should send any articles about RTT that are published in their country to RSE for publication on the RSE website.

TB requested that greater use of Rare Connect should be made. **Action ALL.**

**Aim 2** – no comments

**Aim 3** – Discussion took place about the EURORDIS Summer School in Barcelona. This was a fully funded course of 4 days which prepared delegates to serve as, for instance, EMA representatives. Good English language skills are required.

**Aim 5** – Numbers in the Rett database had risen from 2020 to 2046, but TB said that this was not enough, the reason probably being that the database has too many limitations ([www.rett-databasenetwork.org](http://www.rett-databasenetwork.org)). It was agreed that RSE needs to put pressure on to resolve this unsatisfactory situation. Pedro Rocha volunteered to do this at the October Board meeting. **Action Pedro Rocha.**

It was also noted that doctors do not have the time to download data, but parents should be able to do this, but are unable to do so currently.

#### 4. **2015 Financial report**

This was presented by Wilfried Asthalter – Treasurer.

The current bank balance is 19304 euros.

Pedro Rocha still reported difficulties in his association paying without an invoice.

WA stated that all countries receive a request for payment, which should suffice.

Peter Vanherck (Belgium) asked for more information on the travel expenses. WA explained that the most of these were a contra entry to the EURORDIS grant, which required a full report and detailed analysis of how the grant had been spent.

#### 5. **Elections to the Board**

As no other nominations were received, Danijela Szili was re-elected to the Board for a further 2 years.

TB announced that he would be retiring at the Berlin conference, having completed his 3 x 2 year terms.

It was agreed that it would be useful for members interested in joining the Board in the future, to shadow existing Board members and listen in to the monthly Skype discussions. Pedro Rocha expressed interest and others interested were invited to contact a Board member. **Action All.**

#### 6. **Any other business**

Katarina Oryd (Sweden) thanked the Board for their work and stated how useful RSE was for smaller countries that cannot have any influence on their own.

Yvonne Milne suggested that RSE should be acting as a forum for the collection of “good ideas”, such as specialist equipment that has been developed. **Action All.**

It was also agreed that RSE will support any country who wants to set up a national meeting for parents and professionals.

The meeting closed at 1745.