

## RETT SYNDROME EUROPE

### MINUTES OF THE GENERAL ASSEMBLY OF RETT SYNDROME EUROPE HELD ON SATURDAY 31 OCTOBER 2015 AT THE BARCELO ARAN MANTEGNA HOTEL, ROME

The meeting opened at 13.10

#### 1. PRESENT

<b>Country</b>	<b>Name</b>
Armenia	Marina Parazyan
Austria	Stella Peckary
Cyprus	Petros Konstantinou
Czech	Lenka Kohoutkova and Michal Kozisek
Denmark	Iben Hjarso
Finland	Kirsi Peltonen
France	Thomas Bertrand ( <b>RSE President</b> )
Germany	Dr Charlotte Stein
Hungary	Danijela Szili ( <b>RSE Board member</b> )
Lithuania	Laura Kanapieniene
Norway	Hilde Friis and Sten Richard Larsen
Poland	Magdalena Partyla-Wojcik and Emilia Glazewska
Portugal	Sandra Madeira Cidade
Spain	Leticia Barreda
Catalonia	Pedro Rocha
UK	Yvonne Milne ( <b>RSE Board Member</b> ) and Lorna Jaffa
Scotland	Graeme Dallachy
France	Caroline Lietaer
Russia	Mark Tulchinskiy

#### **Observers**

Cyprus	Antonis Mouskos
Belgium	Paul Heymans and Hugo Pilate
France	Gerard Nguyen
Germany	Erwin Stein
Ukraine	Elena Khatina and Kateryna Lashko
Spain	Gonzalo Figueroa
UK	Chris Milne

#### 2. Welcome address and introduction of Board members

Thomas Bertrand opened the meeting, warmly welcoming all those attending. He introduced the members of the RSE Board who were present. Apologies were received from Martine Gaudy, (RSE Secretary, France) and Wilfried Asthalter (RSE Treasurer, Germany) who were both unable to attend due to family reasons. Apologies had also been received from the Swedish RSA

### **3. Draft minutes of the last GA of RSE, held on 15 November 2014 in Vienna, Austria**

These were approved as a correct record of the meeting, with the actions arising having been carried out.

### **4. 2014-2015 Activity Report**

Thomas presented this report on behalf of the Board, which is available in detail on the RSE web site. **Actions arising from this report were;**

- **Re Revitalising RSE network**, Thomas urged all members to be active in sharing any news or events held in their own countries with RSE. A few lines of explanation and photos would be ideal for posting on RSE home page, with links to Facebook and other social networks like RareConnect. He gave examples of meetings held during the year in Barcelona, Catalonia and Budapest, attended by RSE members, which spread the word and shared information globally. In January this year, Thomas attended the press conference to advertise and promote the forthcoming World Congress in Kazan, Russia May 13-17 2016. This resulted in the decision to open a new multi-disciplinary centre in Russia. This was an excellent example of significant effect of lobbying and raising awareness.
- **Re. RareConnect as EURORDIS social network for rare diseases** Thomas encouraged members to join this network, giving the opportunity to ask questions in one's own language and make contact with others. Members of RSE are moderators.
- **Re RSE is a member of EURORDIS** Danijela Szili, who represents RSE as a member, invited members to talk to her if they were interested in participating or becoming involved in any way with this important European organisation. Attending EURORDIS Summer School in Barcelona was mentioned as an example.
- **Re. Expanding RSE network** Thomas reported that there are already 44 family associations or family contacts known to RSE, although there were notable gaps, e.g. Albania, Azerbaijan and Georgia. He urged members to search for families in countries where Rett contacts have not been identified
- **Re. promoting research** The focus was particularly on the project Rett Networked Database. Thomas urged all countries to give consideration to funding this. A comment was made by Iben Hjarso (Denmark) that certain countries are unwilling to share their databases and that access to the data collected is not straightforward. Gerard Nguyen (observer, France) felt that RSE should be involved at a project's inception, rather than joining later on. Thomas explained that the demands on the Board's time made this very difficult.

**5. 2014 Financial Report for RSE** This had already been agreed. Thomas explained that the only income for RSE came from the membership fees paid by RSE member countries. Thomas reported that Wilfried Asthalter, (RSE Treasurer,) although unable to attend the GA had invited any questions on the accounts to be directed to him for a response.

**6. Elections to the Board.** As had already been notified to members, in line with RSE statutes, the Board members whose terms of office had come to an end, (Thomas Bertrand, Wilfried Asthalter and Yvonne Milne) were willing to serve for another 2 year

term and Danijela's term was still current. Martine Gaudy was not seeking re-election. The Board nominated Caroline Lietaer living in Belgium to fill this vacancy. These renewals and Caroline's nomination to the RSE Board were agreed unanimously by the meeting. Thomas paid tribute to Martine Gaudy, stating that her presence on the Board would be greatly missed.

#### **7. Any other business and Action Plan for the future**

Thomas explained that RSE needed to plan its activity for the future. 2016 would be a very full year, with input for the World Congress in Kazan in May and the planned celebration of Dr Andreas Rett's work in Vienna in September. The Board would look at ideas and consider proposals for future work, which could include running webinars as a way of sharing information

Lorna Jaffa (UK) proposed a vote of thanks to the RSE Board for their work and commitment to the organisation throughout the year. This was warmly supported by all the members.