

## RETT SYNDROME EUROPE

### MINUTES OF GENERAL ASSEMBLY OF RETT SYNDROME EUROPE HELD ON SATURDAY 15 NOVEMBER 2014 IN VIENNA, AUSTRIA

The meeting opened at 0945.

#### 1. PRESENT

|  |                   |   |
|--|-------------------|---|
| <b>GAUDY Martine</b>                       | France            | RSE Secretary   |
| <b>BERTRAND Thomas</b>                     | France            | RSE President   |
| <b>MILNE Yvonne and Chris Milne</b>        | UK                | RSE Board President and founder of Rett UK            |
| <b>SZILI Danijela</b>                      | Hungary           | RSE Board Hungaria Chairwoman                         |
| <b>EDINGER Katalin SZUCS Alesandra</b>     | Hungary           | Hungaria Asso Board Member                            |
| <b>HEGYI Marta Pediatric Neurologist</b>   | Hungary           | Hungary Neurologist                                   |
| <b>ASTHALTER Wilfried</b>                  | Germany           | RSE Board Treasurer- Elternhilfe Board                |
| <b>WOJCIK Piotr GLAZEWSKA Emilia</b>       | Poland            | Polish Association President                          |
| <b>HJARSO Iben</b>                         | Denmark           | Danish Association Former Treasurer                   |
| <b>EDES Ron</b>                            | Slovakia          |   |
| <b>KOHOUTKOVA Lenka KOSIKEK Michael</b>    | Czech Republic    | Chairman and Board member of the CZ Asso              |
| <b>SVATON Vratislav</b>                    | Czech Republic    | Individual  |
| <b>FREILINGER Michael Dr</b>               | Austria           | Child neurologist                                     |
| <b>PECKARY Stella</b>                      | Austria           | Board members of the Austrian Asso                    |
| <b>PAINSI Mr and Mrs</b>                   | Austria           | Chairman of the Austrian Association                  |
| <b>DELL ORO Oliviero</b>                   | Italy             | Chairman AIRett                                       |
| <b>ASUNEN Mira and Jarno</b>               | Finland           | Board members of the Finish Asso                      |
| <b>BISGAARD Anne Marie</b>                 | Denmark           | Kennedy Rett Centre                                   |
| <b>NUES Paige</b>                          | USA               | IRSF Family Director                                  |
| <b>DALLACHY Graeme</b>                     | Scotland          | Chairman of the Scottish Association                  |
| <b>JAFFA Lorna</b>                         | UK                | RETT UK Chairwoman of the Board of Trustees           |
| <b>MALZER Romana and Markus</b>            | Austria           | Austrian Association                                  |
| <b>TIMUTSA Olga</b>                        | Russia            | Chairwoman of the Russia Association                  |
| <b>ROCHA Pedro</b>                         | Catalonia         | Vice President of the Catalonia Association           |
| <b>CELESTIN Elisabeth</b>                  | France            | President of the French Association                   |
| <b>PARAZYAN Marina</b>                     | Armenia           | Executive Director of Source Foundation               |
| <b>SZAROTA Zuzanna</b>                     | Sweden and friend | RSIS Board member                                     |
| <b>BERGSAKER David K</b>                   | Norway            | Med Officer Frambu Ressource centre for rare diseases |
| <b>FRIIS Hilde and Sten Richard LARSEN</b> | Norway            | President and Treasurer of the Norwegian Association  |
| <b>WENZEL Irmgard</b>                      | Austria           | Member  |

## **2. APOLOGIES**

Martine Gaudy reported that apologies had been received from the following countries: Iceland, Malta, Netherlands, Belgium and Greece.

## **3. WELCOME**

Yvonne Milne welcomed all attendees to the meeting on behalf of the Board, explaining the planned structure and timing of the day, before handing over to Thomas Bertrand, RSE President.

Gunther Painsi, President of the Austrian Rett Syndrome Association announced that they were very pleased to host the meeting and hoped that the focus on Rett Centres and clinics would provide a vision for associations in the future.

## **4. MINUTES OF THE 2013 MEETING**

These were approved.

## **5. 2013-14 ACTIVITY REPORT**

Thomas Bertrand presented a detailed report, which is attached to these minutes.

Matters arising from the report were:

- Re Rare connect, Danijela requested moderators fluent in Spanish and Italian as well as English. It was agreed that Danijela would discuss this with Pedro Rocha and Oliviero Dell Oro. **ACTION DANIJELA SZILI**
- Any delegate that is interested in the Eurodis network should speak to Danijela. **ACTION: ALL**

## **6. FINANCIAL REPORT**

This was presented by Wilfried Asthalter and a summary was circulated to all delegates. Delegates were reminded that annual subscriptions were due before the General Assembly and that only member countries that had paid were entitled to vote at the meeting. Only 10 countries had paid so far.

Denmark stated that they had not seen any request for payment. Both Wilfried and Martine confirmed that more than one request had been sent to each country.

Both Austria and Denmark said it would be helpful if an invoice for the amount required could be sent, so a formal payment could be made. Wilfried said that this was difficult, if he did not know how many members a country had.

There were no further questions.

**ACTION: WILFRIED AND MARTINE TO AGREE A REVISED PROCESS FOR 2014-15**

**ACTION: WILFRIED TO ENSURE THAT THE BANK DETAILS ARE ON THE WEBSITE**

## **7. ELECTIONS TO THE BOARD**

Yvonne Milne reminded delegates that Board members could have 2 x 2 year terms and that most would be coming to the end of their second term next year. Delegates were asked to consider putting their names forward for the Board before the next general assembly.

**ACTION: ALL**

Delegates were informed that Danijela Szili had completed her first term and was willing to stand for a further term of two years. There were no other nominations. This was proposed by the UK and seconded by Poland. It was agreed unanimously that she should be elected for further 2 year term.

**8. ANY OTHER BUSINESS**

Lorna Jaffa (UK) proposed a vote of the thanks to the Board of RSE for all they have done for the organisation throughout the year. This was supported by all delegates.

The meeting closed at 1045.