

Minutes of the General Assembly of Rett Syndrome Europe

Maastricht, The Netherlands,

18 October 2013

Present

UK (Rett UK) – Yvonne Milne, Janet Best

UK (Cure Rett) – Paul Beaumont, Elisabeth Hartford, Kori Dryhurst Coates

France (AFSR) – Thomas Bertrand, Martine Gaudy, Gerard Nguyen

Hungary (Magyar Rett Szindroma Alapitvány) – Danijela Szili

Germany (Elternhilfe für Kinder mit RS) – Wilfried Asthalter

Germany (Rett Syndrome Verein für Forschungsförderung) – Claudia Petzold

Belgium (BRSV) – Anna Vermeulen, Els Maes

Norway (Norsk Forening for RS) - Sten Richard Larsen

Austria (ORSG) - Stella Peckary

Sweden (RSIS) – Katarina Oryd, Anna Davidsson-Karnevi, Monica Petterson

Finland (Autistien ja Rett henkilöiden Tukiryhmä) – Antti Rautio

Malta – Denis Galea

Russia (Rett Syndrome Association of Russia) – Natalia Lohmanova

Slovakia – Ron Edes

Denmark (Landsforeningen Rett Syndrome) – Iben Hjarsoe

Iceland (Rett Syndrome Iceland) – Fridrik Fridriksson

Cyprus – Petros Konstantinou

The Netherlands (Stichting Terre) – Rob Van der Stel

The Netherlands (NRSV) – Marielle van der Berg

Australia (Rett Syndrome Association of Australia) – Bill Callaghan

USA (International Rett Syndrome Foundation) – Page Nues

Apologies

Lorna Jaffa RSE Board member (Rett UK), Oliviero Dell'Oro RSE Board Member and Treasurer (Italy Associazione Italiana Rett – AIRETT).

Minutes of the last meeting

Minutes of the General Assembly of Rett Syndrome Europe, held in London on 17 November 2012, which had been posted on the RSE web site were agreed as a correct record.

Welcome and Introductions

RSE President, Thomas Bertrand welcomed the delegates to the meeting.

Presentations had been made the previous day by most of the RSE member countries, outlining details relating to their organisations, such as size of population, the history, activities and projects, how many people with RS and their aims and wishes. The presentations were then posted up for display throughout the conference for all delegates to see the work of the European parents' associations.

Activity report for RSE for 2012/13

Thomas Bertrand, as President of RSE, introduced the Activity Report for RSE for the past year, which is to be posted on the RSE web site. He reviewed the aims of RSE and linked these to the achievements over the past year. The highlights were:

- Revitalising the RSE networks, helping communication between countries. A breakdown was given of the web site statistics
- Now 40 contacts in the RSE network
- Work on the RSE web site to improve interest and access, with up-to-date information
- RSE is a member of Eurordis and takes an active role in the work of this organisation, as an important advocate for rare diseases in Europe
- A number of RSE members have used their eligibility to participate in events organised by Eurordis by attending several throughout the year
- Joining RareConnect, (set up by Eurordis and NORD) in June 2012 and Facebook (March 2013), to discuss with other European parents and other rare disease communities

The presentation ended with a slide on challenges and questions for RSE for the coming year.

Finance report for RSE for 2012/13

In the absence of the Treasurer, Oliviero Dell'Oro, Martine Gaudy presented the current cash balance of RSE of **11,624.38 euros** (to the end of 2012).

Note for the minutes

Oliviero Dell'Oro, the current RSE treasurer, is to stand down after three consecutive terms until 31 December 2013, (the end of the RSE financial year).

The issue of obtaining funds from European Union was discussed. It was agreed that to secure large grants there was a need for collaboration between countries and all applications had to be extremely well presented and supported with well-argued business cases. Gerard Nguyen (AFSR) pointed out that there is also a European RTT research network, although RSE itself is not recognised as a research organisation. He felt that RSE's family support role was strong, but it lacked the strength in fundraising.

RSE Membership fees

Martine Gaudy presented the list of organisations who had paid their RSE membership fees up-to-date. A list is available of those organisations who are excused the fee (through the small size of their organisation or financial hardship).

Action: It was pointed out that only those countries who pay their fees or are excused can be members - Countries who wish to be members of RSE and who have not yet paid their annual membership fees are requested to do so.

Elections of RSE Board Members

Martine Gaudy presented the current position relating to the membership of the RSE Board. In line with RSE statutes, Oliviero Dell'Oro, (Treasurer, Italy) had served three terms of office and was due to stand down. Lorna Jaffa (UK) also wished to stand down.

Yvonne Milne (UK) was proposed as a new Board member and Wilfried Asthalter (Germany) was proposed as Treasurer. They were duly elected to serve on the Board of RSE.

Next GA of RSE

It was announced that the next GA would take place in 2014 in Vienna, Austria. Date and venue to be advised.

Next (8th) World Congress on Rett syndrome

This is to take place in Moscow, from 13 to 17 May 2016 and will be hosted by the Russian RSA.