

Minutes of the General Assembly of Rett Syndrome Europe London, 17th November 2012

Present

Danijela Szili, Hungary	Anna Vermeulen, Belgium	Johan Delaere, Belgium
Martine Gaudy France	Thomas Bertrand, France	Jordi Serra, Catalonia
Oliviero Dell' Oro, Italy	Julia Dell' Oro, Italy	Denis Galea, Malta
Stella Peckary, Austria	Gerard Peckary, Austria	Wilfred Ashalter, Germany
Karsten Larsen, Denmark	Marjorie Lamminen, Finland	Graeme Dallaghy, Scotland
Lorna Jaffa, UK	Michael Britton. UK	Paul Chapman, UK
Rob van der Stel, Netherlands		Nathalie Bouwman, Netherlands
Professor Angus Clarke, researcher		Laurent Villard, researcher.

Apologies were received from the following countries:-

Iceland Sweden Norway Russia. Greece Poland Ireland Estonia

Lorna Jaffa, representative from the UK welcomed the delegates to the meeting.

Ronnie Jaffa explained that during the lunch break we would be making a brief upbeat film about the work of each association. This would go on the RSE and Rare Connect websites. Each country would make a brief statement about one aspect of their work.

Minutes

The minutes of the last General Assembly on 6th November 2011 in Paris were agreed.

Introductions

Delegates introduced themselves and gave the name and age of their person who had Rett syndrome.

Activity report

Martine Gaudy, secretary and delegate from France introduced the Activity Report. (See attachment 1).

The highlights of the year for RSE were:-

- The setting up of a new website;
- The involvement with Rare Connect;
- An invigoration of the association.

Financial Report

Oliviero Dell' Oro presented the financial report (Attachment 2) which was approved by the GA. He requested associations to pay their annual membership fee before the end of the year if they had not already done so.

It was noted that November was very late in the year to present the accounts and it was requested that in future they are available in June. This would give us better access to funding streams. To facilitate this it was suggested that in future the accounts could be sent by email to member countries to be approved. They could then be ratified by the board and presented to the GA.

Activity reports

Altogether thirteen countries and two researchers, Angus Clarke and Laurent Villard were represented at the meeting.

Member countries each gave a brief report (written reports attached).

LUNCH

During lunch a delegate from each country made a short presentation to camera. This will be made into a short film about the work of RSE. The film will be up beat and will focus on activities from each country, without duplication, as far as possible. It is hoped to be able to put this film on the RSE and Rare Connect Websites.

RSE Website

After lunch Thomas Bertrand explained about the RSE website. It went live in June and is being viewed on a daily basis. Not all pulldown menus have been referenced yet. Contacts from all European countries are on the website. They can be seen when their country is clicked on and people are directed to the website of the country they have clicked.

Thomas keeps updating the site and encouraged members to send articles and photographs, including those from their own websites. Many articles have come from Danijela Szili in Hungary. He would like one article from each country every month.

Thomas asked the GA to let him know if we needed any more buttons or pulldowns.

Rare Connect

Thomas Bertrand explained about the Rare Connect website. It has been set up by Eurordis and is available to people in both Europe and America. It deals with many rare conditions and can be accessed in 5 European languages:- English, French, German, Italian and Spanish. At the beginning of a visit, one needs to click on the relevant condition and then the language icon.

There are 3 main tabs:- UNDERSTAND, MEET, LEARN. These are controlled by 2 moderators - Danijela Szili and Thomas. Bertrand.

Under the MEET heading one can ask a question. This is a forum and not a chat line. You can write a question in one of the five languages and it will be translated in one to three hours by a company (not Google). The response can then be shared by any other visitors to the site who can view it in one of the five languages.

LEARN contains articles and special events.

There are 106 registered members. Representatives from each country need to publicise Rare Connect to their members. Links can be shared on social networks.

Your own Rett syndrome story will be translated and published in UNDERSTAND within one day.

It is hoped that each month a professional from a different country will be available to chat.

There is a new tool entitled INFORM which will link to a complete article and is free. Material in Rare Connect and on the RSE Website needs to be balanced. We aim to have

families and professionals in discussion and national organisations should encourage their members to be involved.

On Rare Connect, there is access to other rare conditions. Information there can be helpful for those with Rett syndrome.

Thomas Bertrand and Danijela Szili choose articles in any area.

Jordi Serra has agreed to moderate in Spanish and Wilfried Asthalter has agreed to find someone to moderate in German. Johan Delaere will post articles from the Belgian magazine on Rare Connect for translation. The Care Pathway from Rett UK to be posted on the site.

European Congress 2013

Rob van der Stel of Stichting Terre, a foundation in the Netherlands told us of his plans for the European Congress. This will be from 17 - 19 October 2013 at the Maastricht Exposition and Congress Centre. It will deal with research update and preventative management. The scientific committee is being finalised. Currently ESRRRA (European Rett Research Association) and the Rett expertise team at Maastricht are involved. Laurent Villard and Angus Clarke have been invited to be on the scientific board Abstracts are scheduled for December.

Thursday 17

This will be a scientific session and so the language will be high level scientific language. This will be made clear to parents in advance. There is sensitivity around the confidentiality of the information and scientists will need to know if the sessions are private. There will be a wrap up session and there will be summary. The members thought that the scientific sessions should be open to families in all cases.

Friday 18 and Saturday 19

These sessions will be for professionals and parents. There is the potential to have 30 sessions on each of these days. They will cover history, genetics, clinical progress, communication, coping strategies, preventative management, CDKL5, FOXP1. Besides an opportunity to meet the experts, there will be a library and bookshop.

Currently the budget has not been set. The organisers are aiming for 300 people to attend.

The 2013 General Assembly of RSE will be held during the Congress.

The organisers would like all members of RSE to send them their logos and the names of doctors involved with RS.

The meeting will be conducted in English.

There are still many areas under discussion. Sponsorship is being sought. The need for sessions to be translated and financial support for poor families has not been resolved.

Any questions should be addressed to info@stichtingterre.nl

The next World Congress might be held in Moscow in 2016 and would be organised by the Russian Rett Syndrome Association.

Election to the board

Currently three members of the board are half way through their first term of office. They are Martine Gaudy, Thomas Bertrand and Lorna Jaffa. Oliviero Dell' Oro is halfway through his third term.

There is one vacancy and Danijela Szili was voted on to the board.

Jordi Serra expressed an interest in helping out and possibly becoming a board member in the future.

The board will discuss their roles and responsibilities at their first meeting.

World Congress, New Orleans 2012

Laurent Villard fed back on 7th World Congress in New Orleans, June 2012. (Appendix)

There were 3 aspects to his report:-

- 1 Basic research
- 2 Translational research
- 3 Networks

Following Laurent's presentation, there was a discussion. Researchers can obtain funds for their research but find it difficult to keep the database going.

Fish Oil

RSE has been approached by the Norwegian Fish Oil Company to promote their product. They say that their product is very pure. The company has made extravagant claims about the benefits of their fish oil. They say that the membrane in red blood cells is abnormal.

The product has been given to young girls and therefore it is difficult to see if the improvement is developmental or as a result of taking fish oil. It would need to be followed up scientifically. A trial costs a lot of money , for instance the clinical trial in France about desipramine for 36 people with RS costs about 500,000€. It is debatable if there is enough evidence to conduct a trial.

European Database

Angus Clarke talked about the European Database

Alessandra Reinieri in Italy has encouraged other European countries to pull all their national data together into a European Database. This would provide a better sample. Most data came from France, Spain and UK. Italy also contributed.

The precise data differed slightly from country to country but with a lot of time consuming and difficult work data was merged. This means that the Core database contains less information than national databases. It contains 1880 patients from 12 countries. The full database contains 293 clinical elements and 16 genetic elements. The Core data set contains 62 clinical and 7 genetic items. Subgroups can usefully be identified.

There needs to be a clear question or project for a national association to have access to the database.

To maintain the database will cost €5000 per annum. Besides this, €12,000 - €15,000 is outstanding. Money is also needed to develop the database in the future.

RSE requested that someone from the association should be on the database board so that the association can understand how the funding is organised. Better communication will help us to support the database. It will also be easier to get funding if members understand how the database is organised. Angus Clarke and Laurent Villard will convey the request that a parent representative would like to be on the board.

In Finland it is against the law for information to be stored on any database. Some countries, including Germany, have no entries on the database.

The InteRett and European databases were compared. InteRett contains parental data, which is not totally reliable, while EuroRett contains data which has been validated by a clinician.