



General Assembly 2020

Activity report

RSE Board members

- Stella Peckary, Yvonne Milne, Wilfried Asthalter, Caroline Lietaer, Danijela Szili,
- Other volunteers: Laura Kanapieniene, Pedro Rocha



RSE aims of the statutes

- **AIM 1:** To make Rett syndrome better known in all European countries to the public, professionals, carers and those who are directly concerned
- **AIM 2:** To improve the communication within the European Rett Community
- **AIM 3:** To promote as a representative European organisation, the interests of people with RTT and families
- **AIM 4:** To expand RSE to all European countries and to assist, if necessary, in the creation of national associations
- **AIM 5:** To promote research into Rett syndrome

Building the Network

To make Rett syndrome better known to the public, professionals, carers

- News/Articles/Events on RSE website
- Report of international congresses
- Family days in the different countries, seminars
- Calendar of webinars organised by US rettsyndrome.org

Due to COVID-19 many European Rett organisations had to change the way of work.

- Many countries proposed very interesting online courses
- RSE tried to give an overview of these courses on our website
- For families stuck at home with their children this was very useful

European conference Tampere 27-28/09/2019

The 6th European Rett Syndrome Conference took place in Tampere, Finland on September 27th and 28th. The Finnish Rett Syndrome Association did an excellent job and was incredibly hospitable to around 180 participants from 18 countries worldwide: you can read our complete report on the website.





RETT RESOURCE

free for download now



An invaluable resource, written for you by European Rett experts,
with a focus on therapies and advice on day to day care and management of the complex problems of Rett syndrome.

Rett Resource project

Translated into Croatian (14), Dutch, French, German (10), Lithuanian, Macedonian (3), Russian*, Serbian (14), Swedish* and Turkish*

*new languages

Improving the communication

RSE communicates with its members and Rett community through their contact list, www.rettsyndrome.eu, Rare Connect platform www.rareconnect.org and Facebook.

To improve our communication, we have updated RSE website to work better on mobile devices and have acquired **official RSE email accounts, which are now as follows:**

- *General account for any official communication - info@rettsyndrome.eu*
- *Personalized email accounts for RSE board members to communicate on RSE matters - nsurname@rettsyndrome.eu. E.g. clietaer@rettsyndrome.eu, speckary@rettsyndrome.eu, etc. These personalized email addresses will be changed according to the status of the RSE board (new created, old suspended).*

Improving the communication

As there were SCAM attempts impersonalizing board members of RSE, we ask everyone to be attentive and always confirm the origin of the emails.

RSE will not be held responsible for any communication received from other than official RSE email accounts.

External Influence and Advocacy

- RSE is a member of EURORDIS: Allows RSE to vote at the GA of EURORDIS, during the European Congress for Rare Diseases, can apply for Eurordis Fellowships to support our members to attend our meetings and Eurordis/ECRD annual meeting
- Stella and Danijela attended the 10th European Conference on Rare Diseases & Orphan Products which took place online on 14-15 may
- Stella attended the Open academy digital school: Building engaged Online Communities 29 July and 29 September 2020 by a webinar

External Influence and Advocacy

- RSE board member Yvonne Milne is a rare disease European patient advocate for Rett Syndrome in the European Reference network ITHACA, (currently coordinated by France). She prepared a Patient Journey for RTT, that was presented to ITHACA members.
- RSE is involved in EURORDIS TASK FORCE (Dita drug information and transparency access Task Force). The Dita Task Force meeting in July was attended by board member Danijela Szili.
- RSE is involved in EUROPEAN MEDICINES AGENCY by Danijela Szili.



RSE research subcommittee

- Coordinator from the RSE board: Szili Danijela
- 10 volunteers from 8 countries
- Scope:
 - Mapping labs, hospitals and researchers involved in RTT research, starting with the research conducted in Europe.
 - Both medical and genetic research as well as clinical trials will be included.
 - Only genetic research involving MECP2 gene will be taken into account.

RSE research subcommittee

- Tasks
 - Searching published articles from 2014 in medical and scientific journals available online
 - Creating a list of RTT research categorized by: (country, type of research (genetic, medical, interventional or non-interventional), location and the date as well as the name of the scientific or medical journal where it was published.
 - Creating a list of scientists and physicians working on RTT categorized by country, type of research and location (name of the hospital, university, public or private institute).

Rett Centres Survey

- AIM: To collect data about different types of Rett Centres all across Europe, summarize the information and present it to Rett families and specialists.
- Targeted Rett Centres: Medical, Therapy and Research centres that have RS patients as their main target group or have sufficient expertise in the field.
- Form of the survey: An online questionnaire sent out by email to targeted Rett Centres and filled in by their representatives (only in English).
- We received very few answers which makes it difficult to draw any conclusions so far. We will do one last call for responses and then proceed to publishing the received information.

Rett Centres Survey

- The centres that filled in the questionnaire:
 - Evelina London Children's Hospital (UK)
 - Child Neurology, Medical University Hospital Vienna (Austria)
 - Multidisciplinary Rett clinic UZLeuven (Belgium)
 - Swedish National Center for Rett syndrome and related diseases (Sweden)
 - Rare Disease Centre for Rett syndrome and multiple disabilities (France)
 - Centre de référence Marseille (France)
 - Center for Rett syndrome (Denmark)
 - Hospital Niño Jesús (Spain)

Making RSE stronger

RSE applied for Microsoft NGO Program to get free tools for collaboration which include:

- Email accounts for organization
- OneDrive storage space
- Web applications of all Microsoft tools (Word, Excel, PowerPoint, etc.)
- MS Teams application

These tools allow more effective and safer organization of RSE documents and work process. It will also facilitate smoother RSE board transition.

We thank Laura and Pedro for their helping hand in this process.

Future plans - RSE Scientific Advisory Board

Within the RSE we are planning to create a European Scientific Advisory Board. We are very proud to work together with Gill Townend on this exciting project.

This advisory board would be made of 6/8 core members, representing a different area of medical, therapeutic and scientific expertise

Their possible tasks would consist of

- Review and comment on research requests received by RSE
- Keep abreast of new research publications
- Set up research collaborations
- Share education opportunities
- And many more...

RSE Financial Report 2019

Credits 2019	Amount in Euro
Membership fee 2019	4.200,00
Credit from Bank	50,00
Total	4.250,00

Debits 2019	Amount in Euro
Eurordis membership fee 2019	100,00
Travel expenses	1.975,32
Various expenses	1.319,34
Account charges and bank costs	246,10
Total	3.640,76

RSE Financial Report 2019

Balance of Account 31.12. 2018	23.936,12
Credits 2019	4.250,00
Debits 2019	3.640,76
Balance of Account 31.12.2019	24.545,36
Bank account as per 31.12.2019	24.545,36

Körle, 29.09.2020

Wilfried Asthalter Treasurer RSE

Approved for the discharge of the Treasurer and the Executive
Board of RSE by Horst Schneider