



Activity Report for 2011-2012

During last year, it was stated that:

- There had been a strong effort of the president, Dr Gérard Nguyen, to make RSE known by the European institutions:

- EURORDIS,
- EMA,
- EUCERD
- ...

- But the network had to be revitalised and a strong effort was needed in that prospect

- A new board was elected with a new president and a new secretary
 - Emmett Harten (Irish association)
 - Martine Gaudy

- But the president resigned after a few months, only 4 members of the board:
 - Martine Gaudy (France)
 - Lorna Jaffa (UK)
 - Oliveiro Del'Orro (Italy)
 - Thomas Bertrand (France)

Suggestions from members during GA of NOV 2011 which would revitalise the association (see 14 of minutes)

- Revisit statutes to assess our aims – get back to basics
- Improve communication:
 - Update website
- Ensure that the Annual General Assembly is a properly organised meeting with enough time for debate and socialising to revitalise the contacts between members
- Reinstate the social aspect of RSE. This will enable us to exchange informations and get to know each other

- Try to recreate links with countries where communication was lost
- Improve support to families
- Explore partnerships with other similar conditions e.g. Angelman's syndrome
- Does someone in RSE need to co-ordinate foreign projects?
- How do we support women with Rett syndrome?
- Strengthen RSE. Keep European research money in Europe.
- We need to add value to national associations
- Reports from national associations to be emailed to minutes secretary before the next meeting

Our Achievements

- **AIM 1 of the statutes: improve the communication within the European Rett Community**

1. Revitalise the network

- Updating all the contacts in all countries to be able to communicate
- Help from Danijela for Eastern Europe

Our Achievements: Building the Network

- **2. Build a new website**

Renewal of the website, keep the idea of a European map with all countries and links to their website and contacts of national associations when strolling on the country

- www.rettsyndrome.eu

- Please each country check your details

Our Achievements: Building the Network

- **3. New logo**, hands with the stars of Europe on a blue color. Logo « member of RSE » for associations that have paid their fee



- **4. Build a social network: RareConnect**
Owing to Eurordis support, we have developed a social network for RTT – Thomas Bertrand

Our Achievements: External Influence and Advocacy

- **AIM 2 of the statutes: to promote as a representative European Organisation, the interests of people with RTT and families**
Having RSE officially in the network of European institutions
- 1. We became officially member of EURORDIS:**
allows us to vote at the GA of EURORDIS and the ECRD (European Conference on RD)
Thomas and Danijela in Brussels

Our Achievements: External Influence and Advocacy

2. Working groups of Eurordis:

- Summer School June on « patient advocates in clinical trials and drug development » July 2012, Barcelona, Danijela
- Task Forces: DITA Drug Information and Transparency Access Task Force September 2012, Danijela

3. **EUCERD**: European Union Committee of Experts in Rare Diseases , G. Nguyen

Our Achievements: External Influence and Advocacy

4. **EMA** European Medicine Agency: RSE fulfils the criteria to be involved (letter of 14/11/11)
- Working groups of EMA in London:
Pharmacovigilance Workshop Feb 2012, Danijela
 - PCWP: Patient and Consumer Working Group Feb 2012, Danijela
 - PDCO: Pediatrics Committee

Our Achievements: External Influence and Advocacy

5. **DIA:** Drug Information Association - Annual Eurometing March 2012, G. Nguyen and Danijela, Copenhagen
6. **EUPATI:** European Patients Academy on Therapeutic Innovation - Workshop Sept 2012, Danijela, Frankfurt

Our Achievements

RSE at the 7th WRSC World Rett Syndrome Congress

Thomas and Martine present at the WRSC in New Orleans June 2012

On behalf of RSE address during the Family Reception

Our Achievements

RSE Publications

2 posters were presented at the ECRD and WRSC and accepted by the scientific committee: E-Patient and Modelling Family Outcomes

1 poster accepted for the BCPS, International Conference for Behavioural, Cognitive and Psychological Sciences in Bangkok

Our Achievements

- **AIM 3: Expand RSE to all European Countries and assist if necessary in the creation of national associations**

In september 2012, the Russian association held a family meeting. France and Finland attended and supported

Contacts made with Iceland 4 RTT girls

Challenges and questions

- How to make the RSE network live?
- How to develop the website even more? What kind of informations members would like to find?
- Rareconnect and other social media to develop?
- What should be the role of RSE?
- Problems of funding? Fundraising?
- Role in advocating for research and/or care issues?