



RSE Annual General Assembly

October 9, 2010

Edinburgh

Article IV. Aims

- The aim of RSE is to represent the interest of people with Rett syndrome and their families, especially in the following areas:
 - 1.To make Rett syndrome better known to the public, professionals, carers and those who are directly concerned in all European countries.
 - 2.To improve the communication within the European Rett community.
 - 3.To promote, as a representative European organisation, the interests of people with Rett syndrome and their families.
 - 4. To expand the RSE to all European countries and to assist, if necessary, in the creation of national associations.
 - 5.To promote research into Rett syndrome.
- These aims are to be especially attained by:
 - 1. Co-operation with Rett syndrome associations within Europe and Worldwide.
 - 2. Co-operation with other relevant international and national institutions.*
 - 3. Co-operation with other social groups.
 - 4. Exerting influence on decisions concerning legislation in relation to medical, health, and education in professional and social fields.

- External cooperation, influence and advocacy
 - Elected in the EUCERD (European Union Committee of Experts in Rare Diseases)
 - Eurordis
 - Summer School on “Patient advocates in clinical trials and drug development”
 - GA and task forces
 - EURPLAN
 - DIA Eurometing patient fellowship programme
 - EMEA (European Medicine Agency)
 - in the PCWG (patient and consumer working group)
 - Meetings
 - Elected in PDCO (pediatrics committee)

- Organisation of the 2nd European Congress
 - Programme and logistics
- Godmother
 - Vera Zvonareva (N° 4 WTA)
- Support for the creation of Rett Syndrome Russia
 - Olga Timutsa
- Involvement in the **EuroRett** project
 - European research network funded by EC
 - Board Meetings

OPENING BALANCE on 2008.01.01.	4.815,30
Revenues (membership fees paid by patient organizations)	1.900,00
Expenses (World Rett Congress – Paris, website maintenance cost):	702,54
CLOSING BALANCE on 2008.12.31.	6.012,77

Financial Forecast 2009

OPENING BALANCE on 2009.01.01.	6,012.77 EUR
Revenues (membership fees paid by patient organizations):	4,500 EUR
Expenses	
• Website improvement	2,000 EUR
• Support to economically weak countries	2,400 EUR
• Membership fees (EURORDIS, etc.)	500 EUR
• Projects (EABR, etc.)	500 EUR
• Miscellaneous	500 EUR
TOTAL expenses:	6,400 EUR
CLOSING BALANCE on 2009.12.31.	4,112.77 EUR

- On activity report
- On election of the board members
 - To renew
- On financial report

- Fragile organisation
 - Division, dimergers in some countries
 - Reduction of funds
 - Unpaid membership fees
 - Poor reactivity
 - Questionnaires on organisation profile
 - Duplication
 - Organisation and cooperation to be improved

Article IV. Aims

- The aim of RSE is to represent the interest of people with Rett syndrome and their families, especially in the following areas:
 - **1.**To make Rett syndrome better known to the public, professionals, carers and those who are directly concerned in all European countries.
 - **2.**To improve the communication within the European Rett community.
 - **3.**To promote, as a representative European organisation, the interests of people with Rett syndrome and their families.
 - **4.** To expand the RSE to all European countries and to assist, if necessary, in the creation of national associations.
 - **5.**To promote research into Rett syndrome.
- These aims are to be especially attained by:
 - **1.** Co-operation with Rett syndrome associations within Europe and Worldwide.
 - **2.** Co-operation with other relevant international and national institutions.*
 - **3. Co-operation with other social groups.**
 - **4.** Exerting influence on decisions concerning legislation in relation to medical, health, and education in professional and social fields.

- How to to advocate, to develop better and best day to day practices?
- We are entering the drug development phase (the challenge of Orphan Drug): are we ready?
 - Informed?
 - Eurordis charts (relationship with industry, CT)
 - Trained?
 - To be an active partner ?
 - Our role?

- To each country
 - To change the definition of Rett Syndrome
 - To become member of national alliance for Rare Disease
- Membership fees
 - Country = sum of 10€ per member
- Organisation
 - Board
 - External representatives
 - Board of WG pilots
- Projects

Working groups

- Working group on communication
 - preparation of the next european congress in 2011 in Kazan
 - New website and web portal
 - PR plan
- Working group on guidelines and best practice recommendations
- Working group on fund raising and charity actions
 - Under the partnership with Vera (european Tennis Federations?)
- Working group on research (patient-driven research)
 - interface with EABR
- Working group on European High Level Advocacy