



RSE meeting

November 6, 2011

Paris



Agenda

Tour de Table

Meeting Secretary designation

RSE ordinary annual meeting

-Reports

-Decisions

-Board election

-Membership Fees

-Web site

-EuroRett EABR

-2012 & 2013 events

-Bylaws revision

Lunch Break

Perspectives

-RSE organisation and task distribution

-Eurordis Membership

-European and International institution involvement

-Collaboration with IRSF, Rett Trust

-Funds & Projects

-Commication

- **Introduction and adding topics**
 - Ireland : board member candidate, to improve attendance (RSE meeting) , good practices sharing, website, rep designation to meetings + feedback, to explore partnering (RD)
 - UK : RettUK,
 - Belgium: pb with membership fees payment, what was happening with RSE? Annual meetings, we are losing contacts, supports to some countries (Greece, Baltic...), communication
 - France: To join RD organisations
 - Italy: Communication policy, more attractive; Expectations: scientific committee, One central contact for countries, Project initiation, Website, to connect people
 - Spain catalonia: tasks
- **Meeting secretary** (Lorna)
- **2 parts**
 - Duties: GA, reports, decisions, vote
 - Prospectives, brainstorming, recommendations, action plan

- Question

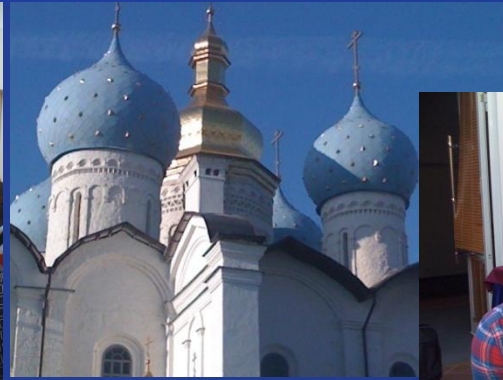
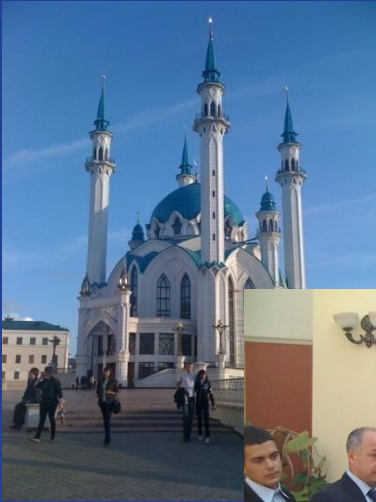
- Role and missions of RSE (along missions defined by Bylaws)

- To be stronger together, how?
 - Added value to national organisations ?
 - Umbrella federation ? European Good practice platform
 - Actor
 - More efficient
 - More professional
 - Partner and /or competitor vs USA

- Organisation of the 2nd European Congress in Edimburgh
 - Programme and logistics
 - Report by Dave Hewetson (Ireland) [Edimburgh\Edimburgh Report.pdf](#)
- Support for the creation of Rett Syndrome Russia
 - Olga Timutsa
 - 1st meeting in Kazan (september 2010),
 - to advocate the cause of Rett Syndrome and chil disability with Tatarstan Gov
 - To prepare the creation of the Russian association
 - To prepare the 2011 scientific meeting launching the Russian Association
 - With the support of Vera Zvonareva (WTA N°4)
 - No cost for RSE

Activity report 2010

- Kazan 2010



- External influence and advocacy
 - Member of EUCERD (European Union Committee of Experts in Rare Diseases)
 - Eurordis (pending membership)
 - Summer School on “Patient advocates in clinical trials and drug development”
 - Tasks forces
 - Workshop (registries)
 - DIA Eurometing patient fellowship programme
 - EMEA (European Medicine Agency)
 - in the PCWG (patient and consumer working group)
 - 4 meetings / year
 - Elected in PDCO (pediatrics committee)
 - One3 days meeting/month

- Website
 - Negative Audit by EMA (european medicine agency) and Eurordis
- EuroRett, EABR
 - Unsatisfaction of RSE silence
- Duplication of national organisations
 - Germany, UK ...
- Membership fees paiements
 - Unpaid fees?
 - Voting status
 - Revision of fees scale?
- Inexisting RSE Secretary
 - Minutes, activity reports, member list

- **Minutes** [RSE doc\Minutes RSE july 2011.doc](#)
 - EuroRett Data Base
 - Communication Logo
 - Website
 - Fees Scale
 - Funding policy

1 Non payment

- fees waive (art IX)

2 Scale (art VII)

- Over 300 members 400€
- Over 200 members (<300) 300€
- Over 100 members (<200) 200€
- 51 -100 members 100€
- Less than 50 members 50€

- To re-develop keeping the same domain
 - E mail adresses
- Including new graphic chart
- Dynamic web site
- Back end (access rights)
 - Administrator
 - Board
 - National president or authorised representative
 - Researchers
- Costs
 - Design: free
 - Development (under Joomla): 200€
- Front end



Perspectives

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- The European Syndrome
- How to to advocate, to develop better and best day to day practices?
- Research prioritization
- To fit with Rare Disease european policy
- 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?

- The Rare Diseases policy
 - EUCERD
 - Research policy
 - European reference (excellence) networks
 - Implementation into national plans (Europlan)
 - Eurordis
 - Advocacy
 - Drugs access
 - Off Label
 - Compassionate use
 - National alliances
- The orphan drugs policy
 - COMP (EMA)
- The EC research calls
 - FP7
 - ICT

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.

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 - ...

- On activity report
- On election of the board members
- On financial report
- On Fees scale
- On Website project
- On EuroRett & EABR demand
- On Eurordis Membership
- On 2012 World congress participation
- On 2012 Barcelona meeting
- On 2013 European Meeting in NL



Action

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- Definition of RTT
 - RTT is a Rare Disease...
- Affiliation to National Rare Diseases org

- Revision of ByLaws
 - Action
- Website Editorial Board
 - Action

- To mutualise expenses and to avoid duplication
- RSE research budget: joint action model
 - National participation in RSE research budget
 - National organisations: to vote an annual contribution
 - RSE calls
 - RSE Expenses on real costs of projects
 - RSE budget allows to participate to EC Calls (financial viability)

- Rett Syndrome
 - Barcelona 2012
 - World Congress New Orleans
 - Kazan 2012
 - 3rd European Congress 2013
- Advocacy
 - DIA Eurometing (patient fellowship)
 - PDCO
 - EMA PCWG (patient working group)
 - Eurordis
 - GA, annual scientific meeting, ECRD
 - Community network
 - Summer school on Clinical trial
 - EUCERD