European RETT SYNDROME Conference Maastricht The Netherlands

Rett Syndrome Europe Activity Report

2012 - 2013

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RSE Board members (2013)

Martine Gaudy

Lorna Jaffa

Danijela Szili

Oliviero Dell'Oro

Thomas Bertrand

RSE aims

- **AIM 1 of the statutes:** To make Rett syndrome better known to the public, professionals, carers and those who are directly concerned in all European countries
- **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

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Building the Network

- **AIM 1 of the statutes:** To make Rett syndrome better known to the public, professionals, carers […]

1. Revitalise the network

Constant update of all the contacts in all countries to be able to communicate

2. Inform, advertise special events

News/Articles/Events on RSE website

Video of associations during last GA

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Building the Network

- **AIM 1 of the statutes:** To make Rett syndrome better known to the public, professionals, carers […]

Ms. Glòria Renom
Member of the Parliament of Catalonia
Mr. Thomas Bertrand
President of Rett Syndrome Europe
Dr. Josep Torrent
CEO of the foundation Dr. Robert
Dr. RoserValles
Advisor to the Office of the Ministry of Health
Ms. Monica Martinez
Chief of the Teknon Foundation
Dr. Jose MaPayà
Medical Director of the Medical Center Teknon
Mr. Jordi Serra
President of the Catalan Association of Rett Syndrome
Mr. D. Juan José García Fenoll
President of the Spanish Association of Rett Syndrome

On March 2, 2013 took place the 3rd Catalan Rett Syndrome Day: "Update on Research, Emotional Wellness, Disability and Guardianship at the Teknon Medical Center in Barcelona"

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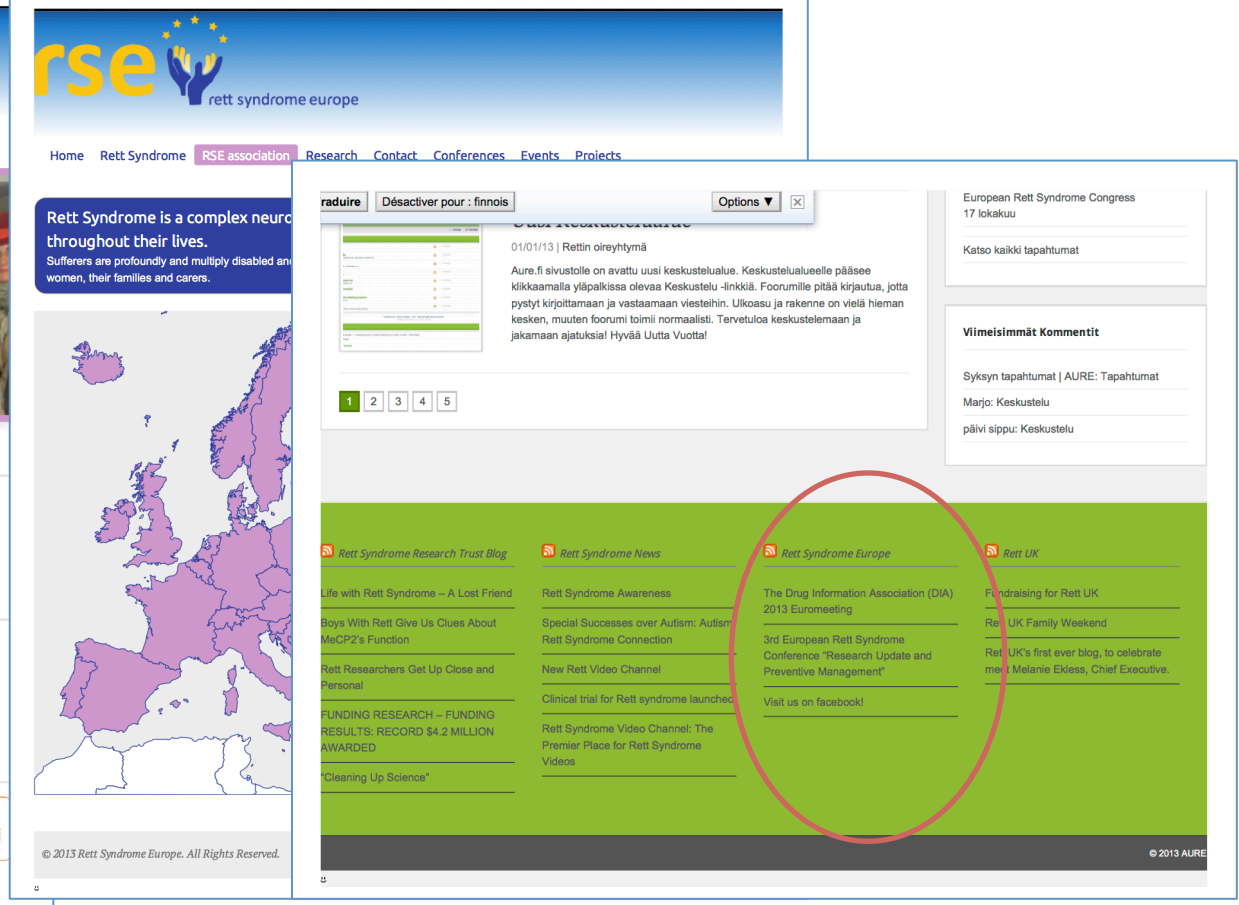
Building the Network

http://rettsyndrome.eu



http://aure.fi

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Website stats

Title	Views
Home page / Archives	5,850
Member Associations	951
RSE General Assembly 2012	435
Contact	420
History	417
Greece	407
Description	382
Slovakia	348
Board	287
Bosnia	273
History	258
Research Projects	251
Bulgaria	242
Croatia	221

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http://www.rettsyndrome.eu

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Building the Network

- **AIM 2:** To improve the communication within the European Rett Community

→ Discuss with other European parents and other Rare Diseases communities

RareConnect (June 2012)

Facebook (March 2013)

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Building the Network

https://www.rareconnect.org/en/community/rett-syndrome

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Facebook statistics

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RareConnect statistics (since June 2012)

RSE Moderators: Danijela Szili, Stella Peckary, Thomas Bertrand

- Since its creation the Rett Syndrome community has:
- **190** members
- **22** patient groups featured
- **16** articles
- **12** testimonials
- **50** forum topics
- **6** Documents

- **Who has visited the Rett Syndrome Community since its creation?**
- **7057** unique visitors

- **Where are visitors coming from?**

  Top 10 countries with most visitors:
- 1. United States 1,726
- 2. Italy 683
- 3. France 572
- 4. United Kingdom 487
- 5. Germany 477
- 6. Spain 432
- 7. Canada 224
- 8. Australia 204
- 9. Mexico 176
- 10. Netherlands 119

- **How are people finding the community on search engines?**

  Top 10 keywords (the words people use on a search engine to find the community):
- mi princesa rett
- rareconnect
- sindrome di rett
- rett syndrom
- ipad apps for rett syndrome
- syndrome de rett
- ulzibat
- sindrome de rett
- rett syndrome apps
- 3rd european rett syndrome congress

- **How did visitors find the community?**
- 1. google 3,381
- 2. (direct) 1,370
- 3. facebook.com 901
- 4. m.facebook.com 410
- 5. rettsyndrome.eu 269
- 6. eurordis.org 226
- 7. bing 91
- 8. twitter.com 89

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External Influence and Advocacy

- **AIM 3:** 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. **RSE is a member of EURORDIS:** Allows RSE to vote at the GA of EURORDIS During the EMM (EURORDIS Membership Meetings), *Martine and Danijela in Dubrovnik (June 2013)*

→ *EURORDIS fellowship was granted for Hungary, Croatia and neighbouring countries to attend this EMM*

→ *RSE was granted funds in EURORDIS "Support Rare Disease Federations" 2013 call for Eastern European countries to be able to attend today's RSE General Assembly*

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External Influence and Advocacy

Rare Diseases: an EU Public Health Priority

Improving access to quality care

Improving acces to Orphan Drugs

Deal with ethical issues

Member of EURORDIS Rare Diseases Europe

Promote Research and link patients to professionals acrosss country borders

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External Influence and Advocacy

2. EURORDIS Training resources:

- Summer School June on « patient advocates in clinical trials and drug development » June 2013, Barcelona, *Liana Murtazina (Russia)*
- Online learning tools
  - clinical trial and orphan medicinal products

3. EURORDIS Task Force:

- DITA Drug Information and Transparency Access Task Force June 2013, Dubrovnik, *Danijela*

4. EUCERD: European Union Committee of Experts in Rare Diseases – *Gérard Nguyen*

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External Influence and Advocacy

5. **EMA** European Medicine Agency (London, UK): RSE fulfils the criteria to be involved (letter of 14/11/11)

- Training programs for patients and patients advocates: Pharmacovigilance Workshop, *Danijela*
- PCWP: Patient and Consumer Working Group, *Danijela (Training Sessions)*
  - *RSE applied to the Call for expression of interest to eligible organisations to become a member of the PCWP – not granted 2013-2016*
- PDCO: Paediatric Committee
  - *New call for PDCO members from Academia / Health Care / Patient Representatives – deadline 8 November*

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External Influence and Advocacy

Danijela Szili
(President of the Hungarian Rett Syndrome Foundation)

DITA member (Drug Information, Transparency and Access)

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External Influence and Advocacy

6. **DIA**: Drug Information Association: Annual Euromeeting March 2013, Amsterdam, *Danijela*
   - *RSE applied for a DIA Philanthropy Grant Application for the translation of a book to be published by AFSR – Not granted*
7. **EUPATI**: European Patients Academy on Therapeutic Innovation: Workshop April 2013, Roma, *Olga Timutsa (Russia)*

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Our Network

- **AIM 4:** To Expand RSE to all European Countries and to assist, if necessary, in the creation of national associations

1. Russia

2. Greece

3. Romania

4. Iceland

5. Macedonia (contacts)

6. Bulgaria (contacts)

→39 contacts

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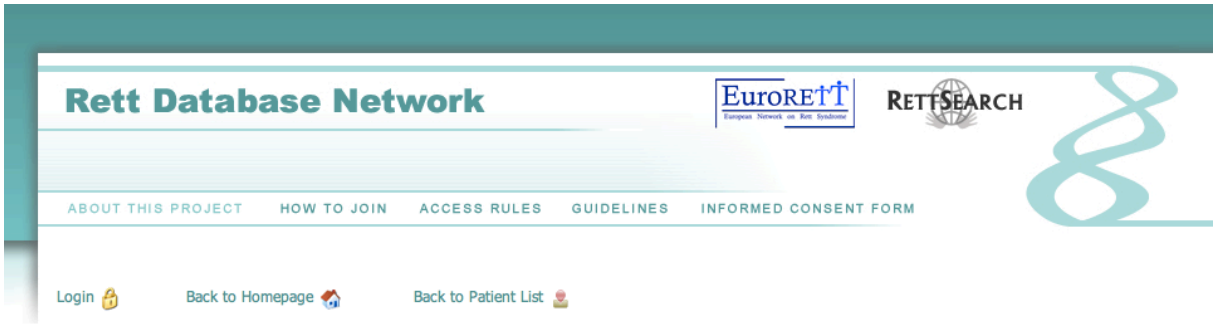
AIM 5: To promote research into Rett syndrome



http://www.rettdatabasenetwork.org

Oliviero Dell'Oro (Italy)
Jordi Serra (Catalonia)

«The aim of this project is to connect the already existing databases and to create a unified repository […] The data will be accessible to the participants and to the scientific community according to rules that assure transparency and equity […] This international effort will be of great value in order to perform genotype-phenotype correlations, to study modifier genes, and to select subgroups of patients for clinical trials.»

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Challenges and questions

- We now have the Network (we can still improve)
- We now have tools to advertise (Website)
- We have tools to communicate (Rareconnect/ facebook)
  - need for others? (twitter) – time consuming
- What's next: how can we use the network with the tools?
- New RSE Roles? Fundraising? For What? How?
  - (Role in advocating for research and/or care issues?)

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