KOLPING
WIEN-ZENTRAL

ÖRSG
Österreichische Rett-Syndrom Gesellschaft

Rett Syndrome Europe Activity Report

2013 - 2014

rse
rett syndrome europe

RSE Board members (2014)


Martine Gaudy


Yvonne Milne


Danijela Szili


Wilfried Asthalter


Thomas Bertrand

RSE aims of the statutes

- **AIM 1:** 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:** 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

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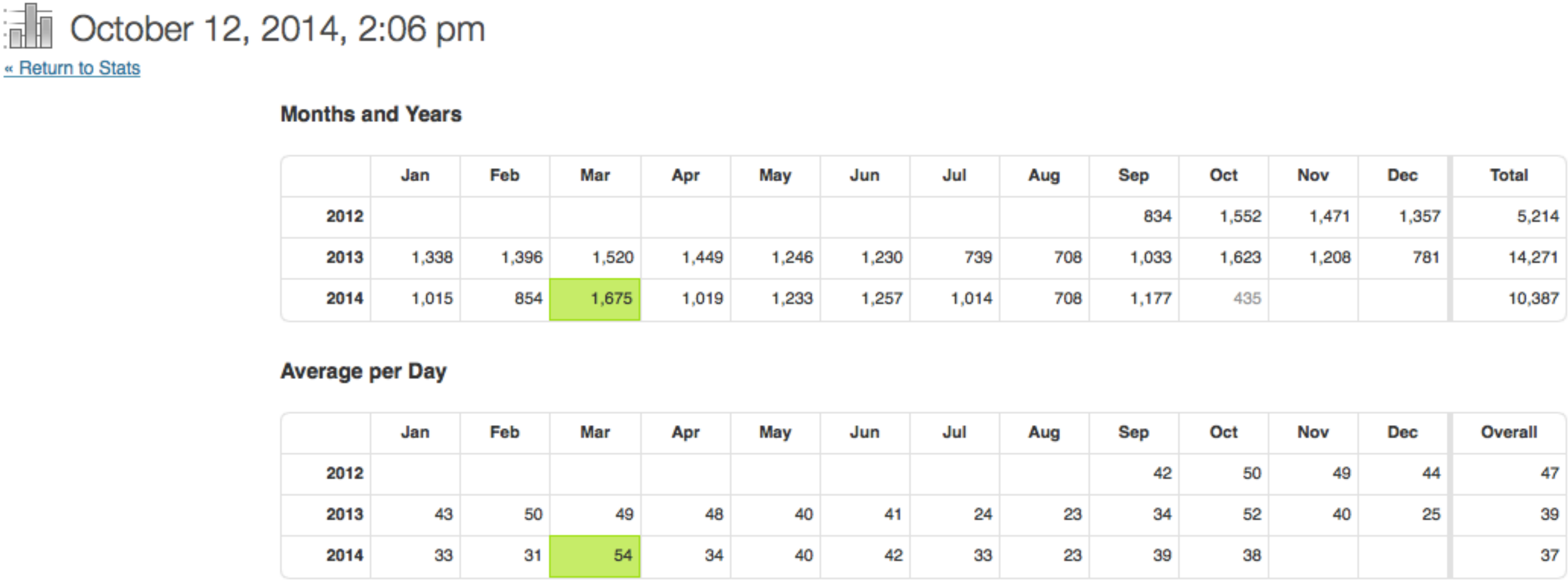
RSE website stats



October 12, 2014, 2:06 pm

« Return to Stats

Months and Years

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total
2012									834	1,552	1,471	1,357	5,214
2013	1,338	1,396	1,520	1,449	1,246	1,230	739	708	1,033	1,623	1,208	781	14,271
2014	1,015	854	1,675	1,019	1,233	1,257	1,014	708	1,177	435			10,387

Average per Day

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Overall
2012									42	50	49	44	47
2013	43	50	49	48	40	41	24	23	34	52	40	25	39
2014	33	31	54	34	40	42	33	23	39	38			37

Building the Network

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

On 8th March, took place at the Centro Médico Teknon in Barcelona, the 4th Catalan day on Rett Syndrome. The main topic was "From Research to Assistance in Adulthood".

This year, in addition to offering all the updated information necessary for early diagnosis and better treatment, it emphasised the importance of the regulation of care model for girls with Rett syndrome in Catalonia and the ability to replicate in other autonomous regions of Spain.

During one day, a broad community of politics led by the Catalan Ministry of Social Security, researchers, patients' associations, directors of centres of expertise, multidisciplinary centres, private foundations, day centres, social workers, etc… performed presentations.

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

- Eurordis Photo Exhibition

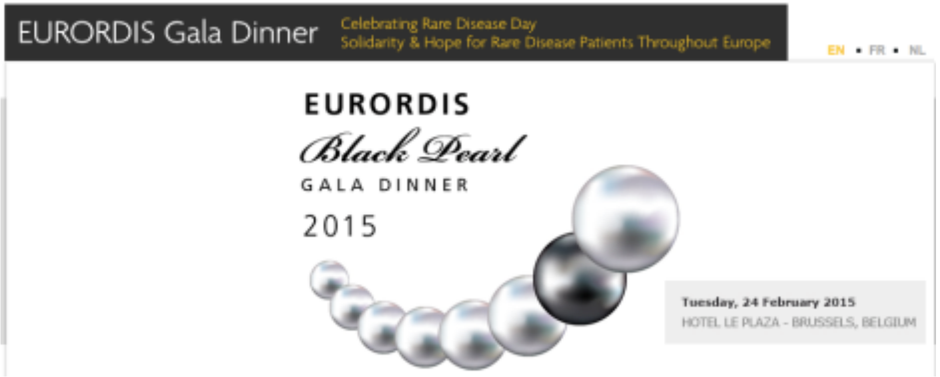
"Come closer"

Black Pearl Gala

(February 2014)

Magyar Rett Szindróma Alapítvány

MRSZA



EURORDIS Gala Dinner

Celebrating Rare Disease Day

Solidarity & Hope for Rare Disease Patients Throughout Europe

EN • FR • NL

EURORDIS

Black Pearl

GALA DINNER

2015

Tuesday, 24 February 2015

HOTEL LE PLAZA - BRUSSELS, BELGIUM

THE VOICE OF RARE DISEASE PATIENTS IN EUROPE

EURORDIS - European Rare Diseases Organisation

Bureau

EURORDIS Photo Contest 2014 participants

Living with a rare disease

This Photo Contest is open to anyone with an interest in rare diseases.
Vote for your favourite photo(s) below, or send your own photo(s) and try to win one of our 3 iPad!

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

- Eye-tracking and AAC workshop in Paris (March 2014)

tobii

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 (2012)

Facebook (2013)

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Building the Network

Rett Syndrome Europe

Organisation à but non lucratif

is a network of National Rett Associations which promotes research and aims to improve the quality of life of all individuals with Rett syndrome in Europe.

301

5 amis aiment Rett Syndrome Europe

Rett Syndrome Europe a partagé un lien.

EURORDIS eNews: IRDiRC conference advances research collaboration

Je n'aime plus · Commenter · Partager

Écrire un commentaire...

Rett Syndrome Europe a partagé un lien.

Be informed! Read about the most important events in the Rare disease field! http://www.rarediseaseblogs.net/

Voir la traduction

Rare Disease Blogs. International opinion on Rare Diseases & Orphan Drugs

Je n'aime plus · Commenter · Partager

Écrire un commentaire...

Stimuler la publication

Rett Syndrome Europe a partagé un lien.

Did you know that the future drug therapies for Rett Syndrome as orphan drugs will have to go trough Centralised authorisation procedure at the EMA (European Medecines Agency) in London in order to be marketed in EU?

Voir la traduction

What is an orphan drug?

'Orphan drugs' are medicinal products intended for diagnosis, prevention or treatment of life-threatening or very serious diseases.

Je n'aime plus · Commenter · Partager

Rett Syndrome Europe a partagé un lien.

Watch this informative video about European Patients' Academy for Therapeutic Innovation, with Jan Geissler, EUPATI Director!

Voir la traduction

About EUPATI, its objectives, benefits for patients – and its upcoming conference

J'aime · Commenter · Partager

Communautés de malades atteints de maladies rares

Accueil / Le syndrome de Rett / Accueil de la communauté

Bienvenue – Communauté Le syndrome de Rett

Qu'est-ce que Le syndrome de Rett ?

Le syndrome de Rett est un désordre neurologique complexe, congénital et d'origine génétique qui affecte principalement les filles. Les enfants atteintes sont profondément handicapées et sont totalement dépendantes pour tous les actes de la vie quotidienne.

Source: associations de patients participantes visibles ci-dessous

Ressource Le syndrome de Rett

Les dernières expériences de membres

Plus d'expérience de membres

Conférence européenne sur le Syndrome de Rett 2013

par Dutch_rett_syndrome_foundati publié il y a environ 1 mois Aucun commentaire

L'ERSCM 2013 est une initiative du GKC (Gouverneur Kremers Centrum), du Stichting Terre (Fondation hollandaise pour le Syndrome de Rett) et NRSV (A...

En savoir plus

Action march on Rare Disease Day in Vienna

par stellppeckary publié il y a environ 1 mois Un commentaire

With the motto - achieving more together - the action day for the worldwide Rare Disease Day was held on 28-29 February in Vienna. On 2 March, the ...

En savoir plus

Partenaires et associations de malades

RareConnect est une initiative d'EURORDIS et de NORD. Les associations suivantes y participent en tant que partenaires.

- Rett Syndrome Europe
- Asoc. Española del Síndrome de Rett
- Assoc. Nacional de Pais e Amigos Rett
- Landsforeningen Rett Syndrom
- Österreichische Rett-Syndrom Gesellschaft
- Assoc. Française du Syndrome de Rett
- MAGYAR RETT SZINDRÓMA
- Belgische Rett Syndroom Vereniging
- Rett Syndrome Poland
- Associazione Italiana Rett
- Rett Syndrom i Sverige
- Rusian Rett Syndrome Association
- Rett UK
- Asoc. Catalana del Síndrome de Rett
- Rett Syndrome Ireland
- Norsk Forening for Rett Syndrom
- Rett Syndrome South Africa
- Ontario Rett Syndrome Association

Vous êtes membre de cette communauté

Je veux...

- Raconter mon expérience >
- Démarrer une discussion >
- Rencontrer d'autres membres >
- En savoir plus sur la maladie >

Rencontrer nos membres

Afficher tout

Activité communitaire la plus récente de Le syndrome de Rett

Raptor Pharmaceutical Licenses IP for Rett Syndrome from French Research Institutes
sujet publié il y a environ 20 heures
Voir la transcription

ULZIBAT - Methode
sujet publié il y a 4 jours
Voir la transcription

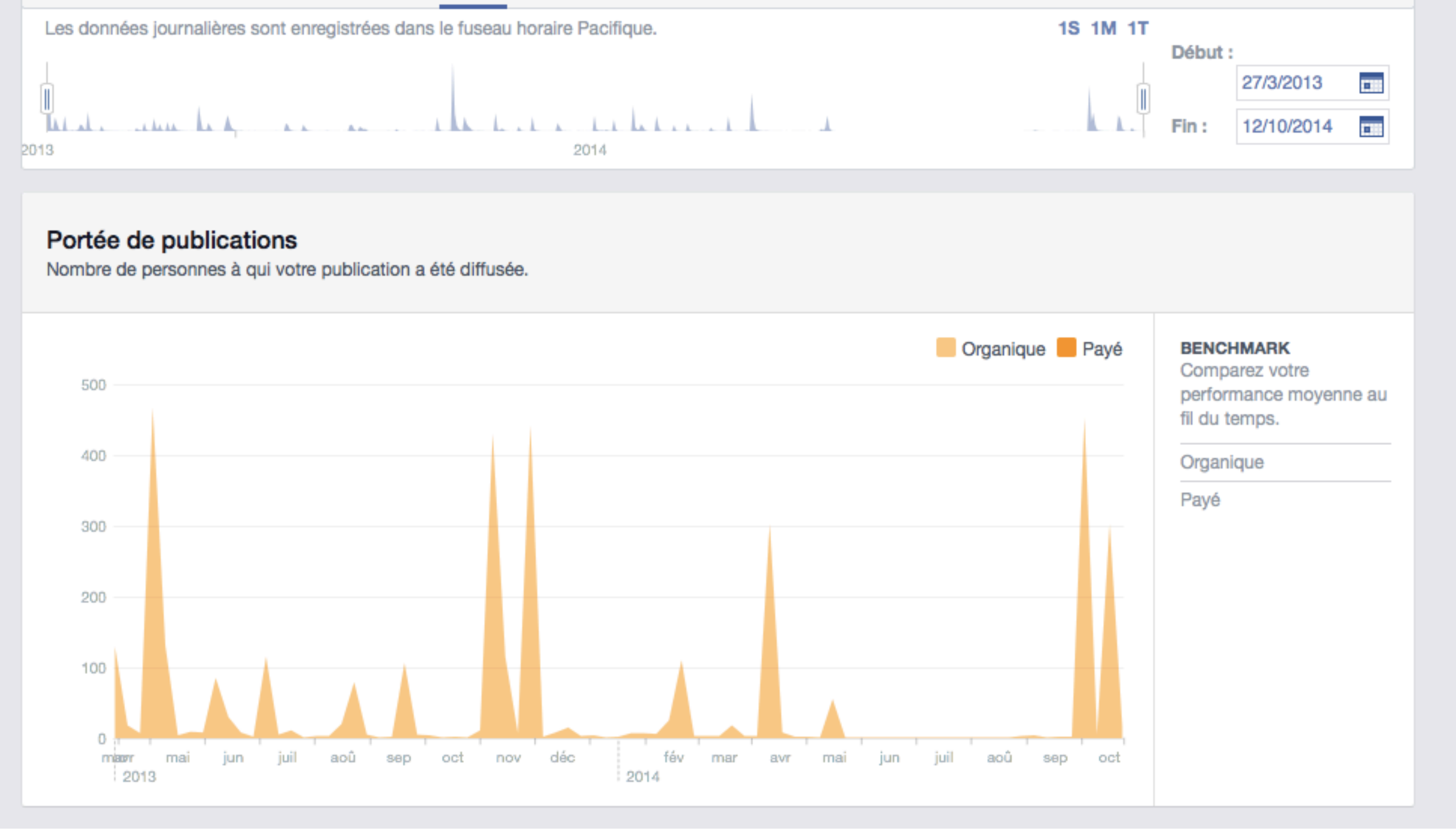
Statins improve symptoms of Rett syndrome in mice
réponse publié il y a 4 jours
Voir la transcription

L'huile de poisson comme "traitement" pour le syndrome de Rett
document publié il y a 22 jours
Voir la transcription

Phase 2 Study of EPI-743 for Treatment of Rett

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

Facebook statistics



Les données journalières sont enregistrées dans le fuseau horaire Pacifique.

Début : 27/3/2013

Fin : 12/10/2014

Portée de publications

Nombre de personnes à qui votre publication a été diffusée.

BENCHMARK

Comparez votre performance moyenne au fil du temps.

Organique

Payé

RareConnect statistics (since October 2013)

RSE Moderators: Danijela Szili, Stella Peckary, Thomas Bertrand

273 members (**84** new members during last year)
3 patient groups featured
24 articles (**8** new articles during last year)
13 documents
12 testimonials (**6** new testimonials during the last year)
88 forum topics (**38** new forum topics during last year)

Data below is since last year (October 2013):

Who has visited the Rett Syndrome Community since October 2013?
11,438 unique visitors **(+62%)**

What do they do when they visit?
These visitors visit **2.22** pages on average

Where are visitors to your community coming from?
Top 10 countries with most visitors

1.	United States	**2,737**
2.	Spain	**1,191**
3.	United Kingdom	**918**
4.	Germany	**696**
5.	Italy	**524**
6.	Mexico	**465**
7.	France	**384**
8.	Australia	**361**
9.	India	**342**
10.	Ireland	**338**

How did visitors find your community?

1.	google	**7,487**
2.	m.facebook.com (mobile)	**1,471**
3.	facebook.com	**1,298**
4.	(direct)	**1,093**
5.	eurordis.org	**290**
6.	rettsyndrome.eu	**228**
7.	rett.cz	**117**
8.	bing	**98**
9.	m.mail.naver.com	**85**
10.	yahoo	**72**

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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 ECRD (European Congress for Rare Diseases), *Danijela and Thomas in Berlin (May 2014)*

→ *RSE was granted funds in EURORDIS "Support Rare Disease Federations" 2014 call for Eastern European countries to be able to attend today's RSE General Assembly*

External Influence and Advocacy

Rare Diseases: an EU Public Health Priority

Improving access to quality care

Improving access to Orphan Drugs

Member of
EURORDIS
Rare Diseases Europe

Deal with ethical issues

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 2014, Barcelona, *Friðrik Friðriksson (Iceland)*
  - *DEADLINE FOR 2015 SUMMER SCHOOL IS DECEMBER, 8*

3. EURORDIS Task Force:

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

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

5. EMA European Medicine Agency (London):

- Training programs for patients and patients advocates: Pharmacovigilance Workshop

6. EUnetHTA European network for Health Technology Assessment:

- Europe HTA2.0 Teaming up for Value, October 2014, Roma, *Danijela (EUnetHTA and Eurordis fellowships)*

7. EUPATI European Patients Academy on Therapeutic Innovation:

- Workshops organised

Our Network

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

1. Macedonia
2. Bulgaria
3. Cyprus
4. Armenia
5. Moldova
6. Albania

→44 contacts

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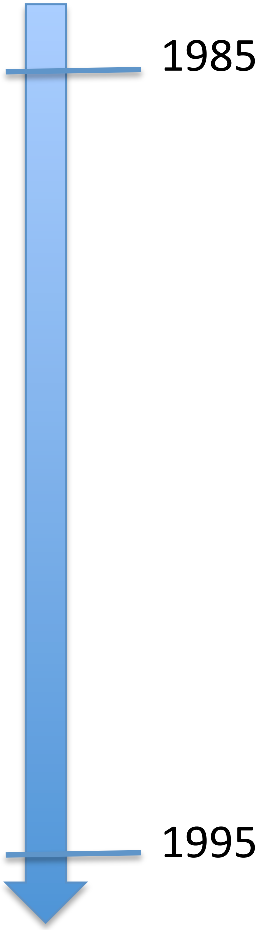

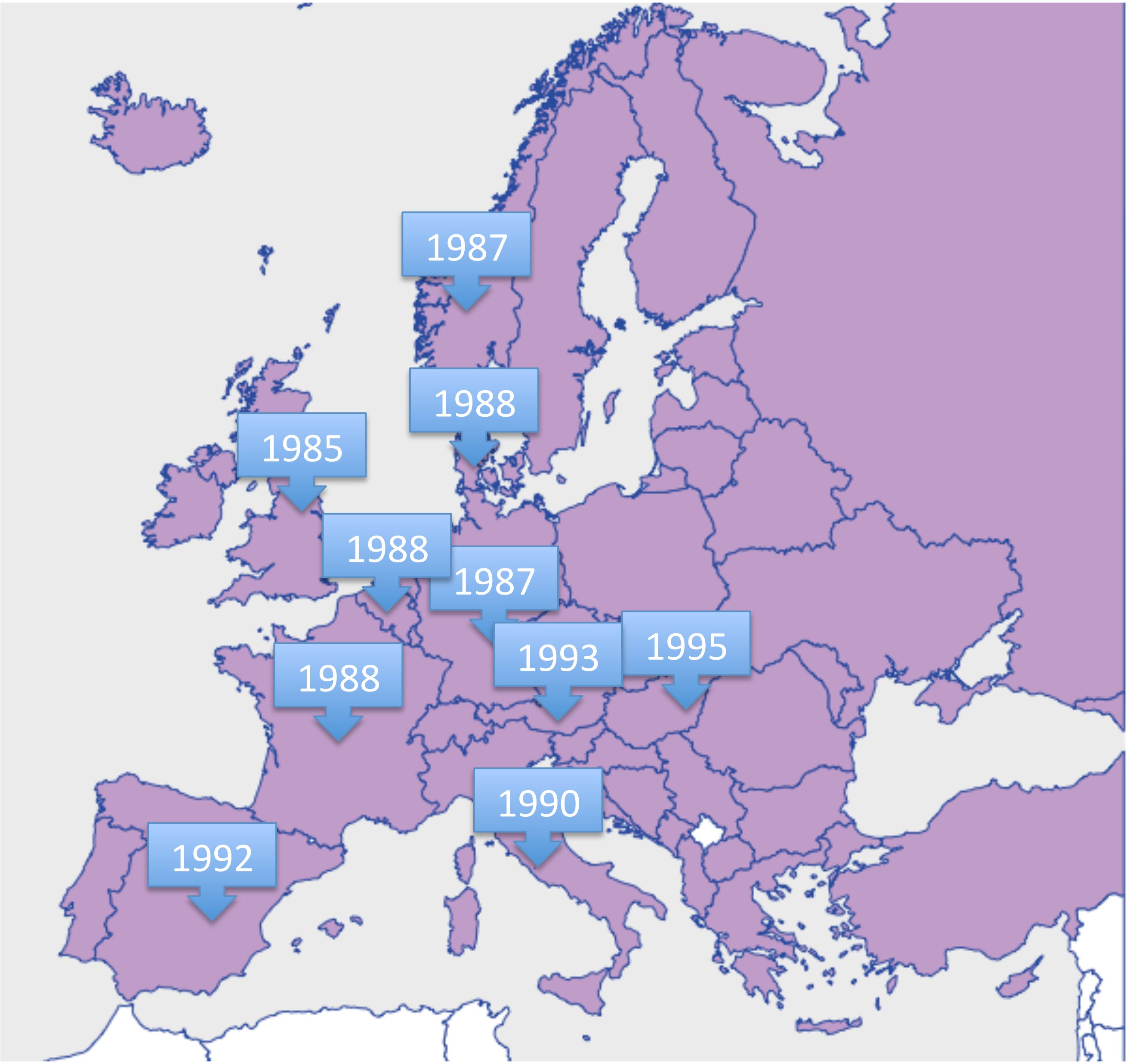

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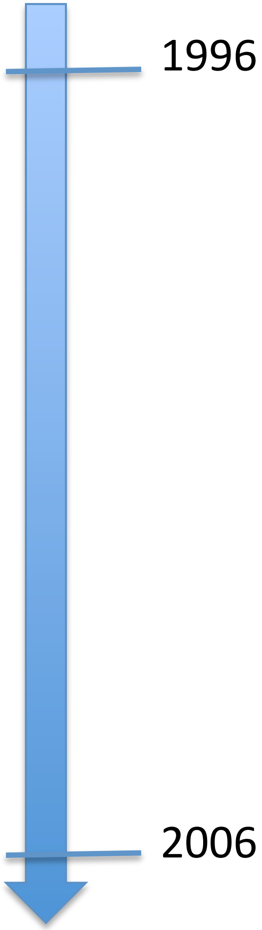
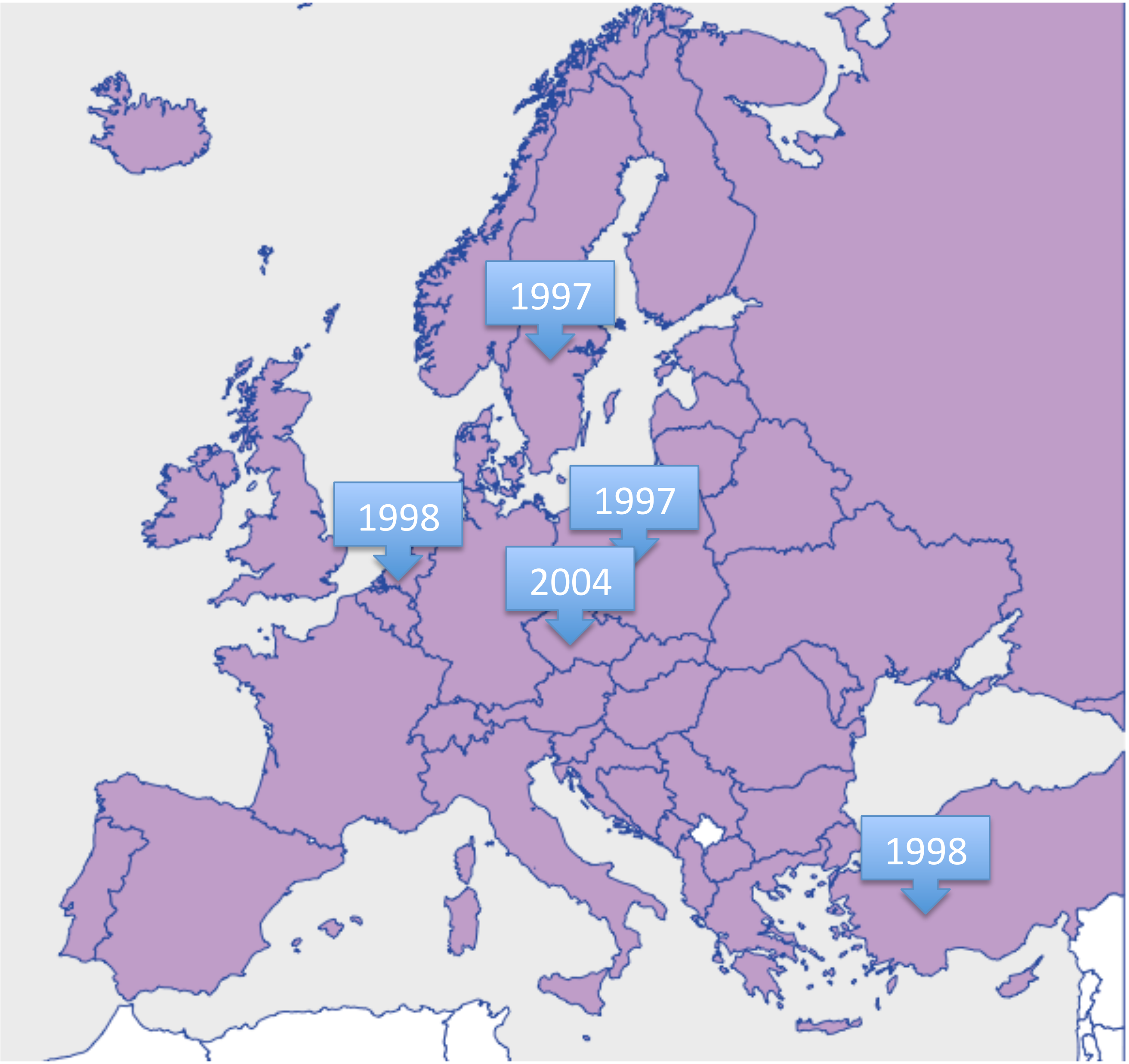
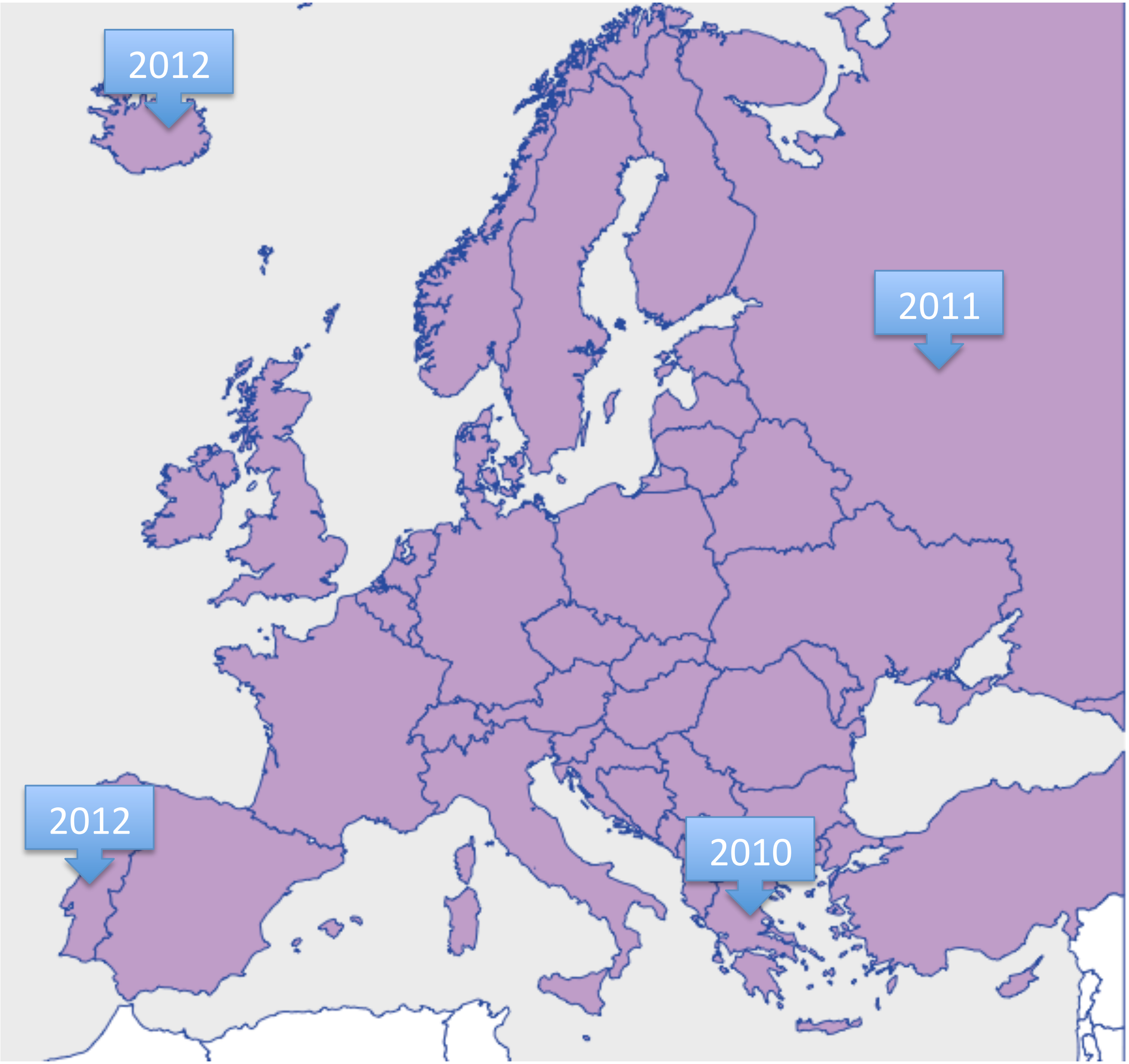

1996
2006


1997
1998
1997
2004
1998

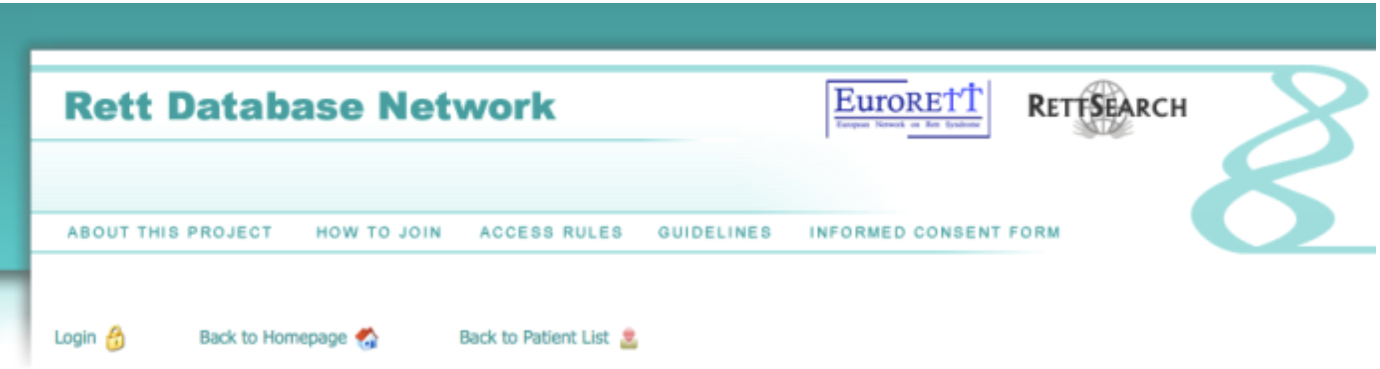
44 European contacts in 2014

2007

2014

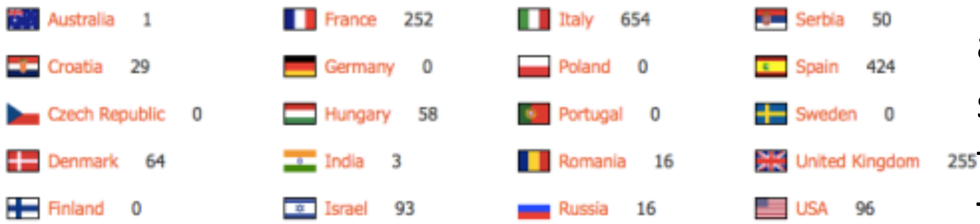


AIM 5: To promote research into Rett syndrome



Rett Database Network

Number of patients in archive: 2012 (+6%)



Australia	1	France	252	Italy	654	Serbia	50
Croatia	29	Germany	0	Poland	0	Spain	424
Czech Republic	0	Hungary	58	Portugal	0	Sweden	0
Denmark	64	India	3	Romania	16	United Kingdom	255
Finland	0	Israel	93	Russia	16	USA	96

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.»

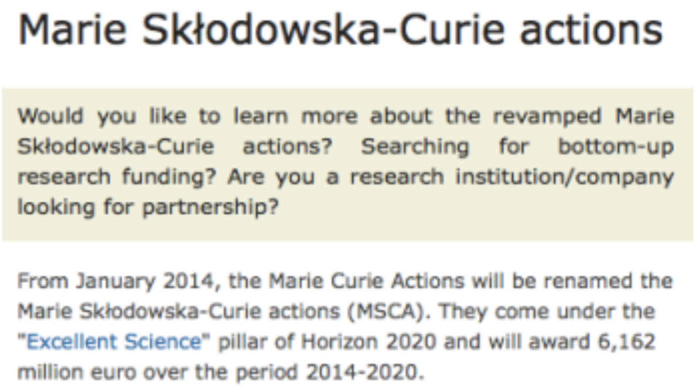
AIM 5: To promote research into Rett syndrome

HORIZON 2020

The EU Framework Programme for Research and Innovation

What is Horizon 2020?

Horizon 2020 is the biggest EU Research and Innovation programme ever with nearly €80 billion of funding available over 7 years (2014 to 2020) – in addition to the private investment that this money will attract. It promises more breakthroughs, discoveries and world-firsts by taking great ideas from the lab to the market.



Marie Skłodowska-Curie actions

Would you like to learn more about the revamped Marie Skłodowska-Curie actions? Searching for bottom-up research funding? Are you a research institution/company looking for partnership?

From January 2014, the Marie Curie Actions will be renamed the Marie Skłodowska-Curie actions (MSCA). They come under the "Excellent Science" pillar of Horizon 2020 and will award 6,162 million euro over the period 2014-2020.

6,162 million euros

Types of MSCA:

Research networks (ITN): support for Innovative Training Networks

ITNs support competitively selected joint research training and/or doctoral programmes, implemented by European partnerships of universities, research institutions, and non-academic organisations. The research training programmes provide experience outside academia, hence developing innovation and employability skills. ITNs will include industrial doctorates, in which non-academic organisations have an equal role to universities in respect of the researcher's time and supervision, and joint doctoral degrees delivered by several universities. Furthermore, non-European organisations can participate as additional partners in ITNs, enabling doctoral-level candidates to gain experience outside Europe during their training.

http://ec.europa.eu/programmes/horizon2020/en/h2020-section/marie-sklodowska-curie-actions

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AIM 5: To promote research into Rett syndrome

Marie Curie ITN (Innovative Training Network): "Networked" for Rett (RETT-net)

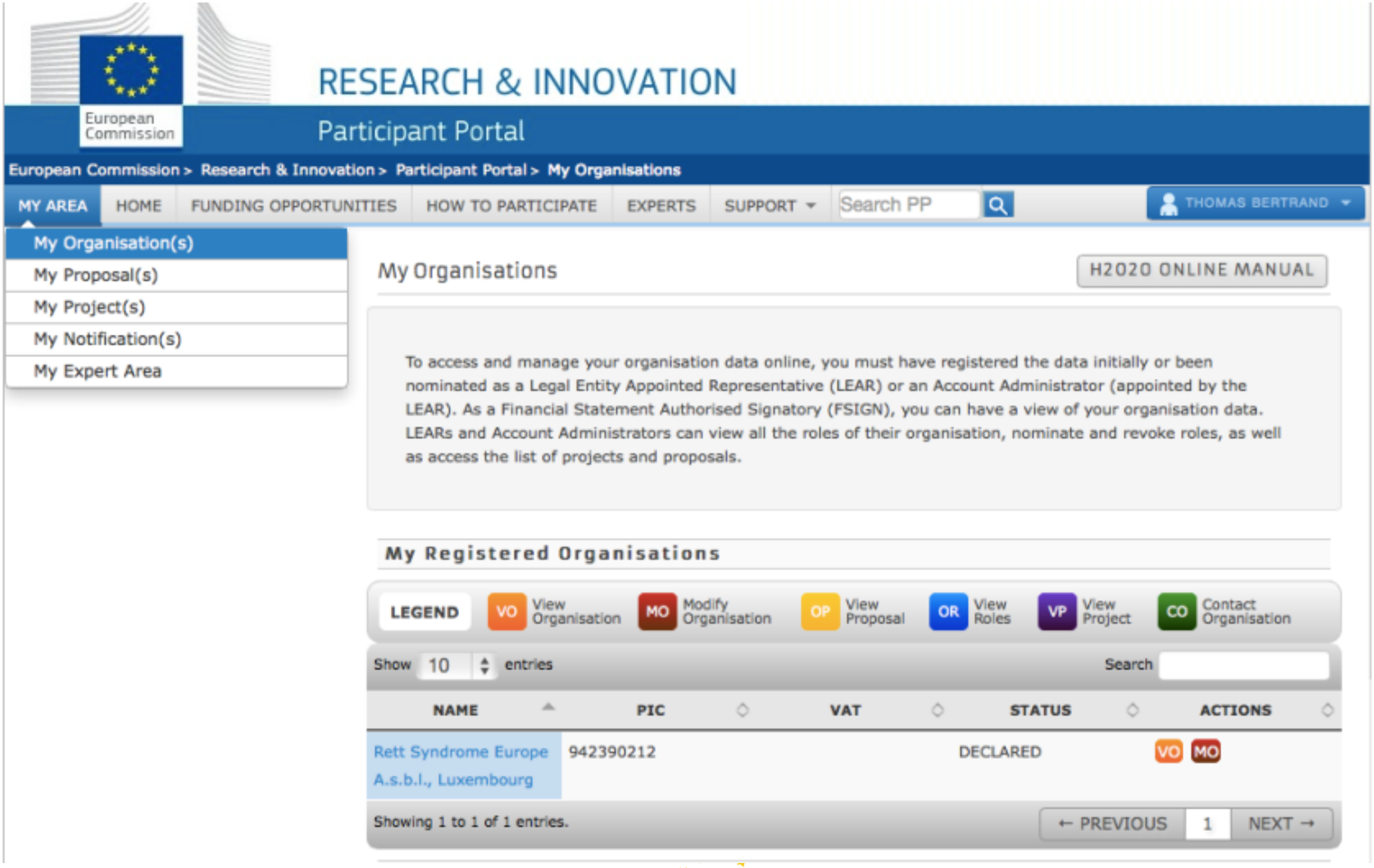
Participants are the major European centers working on Rett syndrome in Italy (Siena), France, UK (Cardiff), Israel, Hungary and Spain.

The aim of the program is the activity in the field of Rett syndrome to foster exchanges of relevant experience, policies and practices between European countries including:

-Enhancing the visibility and recognition of the international registry, Rett Networked Database and improve accuracy of data
-Connecting the Rett Networked Database to biobank resources
-Contributing to the development and dissemination of knowledge on Rett syndrome through to the support of patients' association
-Contributing to improvements in access to quality services from diagnosis to care

The plan is to recruit researchers for filling the Rett networked database, improve the biobanks and offering them a training in Rett (at least 7 for a period of 3 years) in a way that each center has at least 1 MD per year. Each center will have 1800 Euros per month in order to plan formation (the recruitment of researchers to be trained; training and networking costs, organization of joint activities and conferences; management and overheads).

AIM 5: To promote research into Rett syndrome



My Organisations

To access and manage your organisation data online, you must have registered the data initially or been nominated as a Legal Entity Appointed Representative (LEAR) or an Account Administrator (appointed by the LEAR). As a Financial Statement Authorised Signatory (FSIGN), you can have a view of your organisation data. LEARs and Account Administrators can view all the roles of their organisation, nominate and revoke roles, as well as access the list of projects and proposals.

My Registered Organisations

NAME	PIC	VAT	STATUS	ACTIONS
Rett Syndrome Europe A.s.b.l., Luxembourg	942390212		DECLARED	VO MO

Showing 1 to 1 of 1 entries.

THANK YOU!

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