For Clinicians: How to join the database

This Database is designed primarily for the use of clinical researchers and others with an interest in Rett syndrome. Data is entered only by clinical research teams from each participating country. To protect the confidentiality of patients and families, we need to restrict access to those who agree to comply with our rules for data handling.

If you are a physician or clinical researcher involved in Rett syndrome and if you would be interested to join us in this project on the Rett database network, then please fill in and sign the password request form and send it to the administrator of the database network. Physicians and clinical researchers engaged in work on Rett syndrome will receive a username and password, which will allow them to insert the information about their patients. Each center will be listed under its country flag.

You can find the password request form at:

http://www.rettdatabasenetwork.org/HowToJoin.asp

Scientific Review Board as of December 2011: Alessandra Renieri (Coordinator), Francesca Mari (University of Siena, Siena, Italy), Laurent Villard (Aix Marseille Université and Inserm, Marseille, France), Nadia Bahi-Buisson (University Paris V Descartes, Paris, France), Angus Clarke, Anna Bryniowski-Jaworska (Cardiff University, Wales, U.K.), Mercedes Pineda, Ana Roche Martinez, Judith Armstrong (Fundació Hospital Sant Joan de Déu, Barcelona, Spain; Hospital Sant Joan de Déu, Barcelona, Spain), Bruria Ben-Zeev (Sheba Medical Center, Ramat-Gan, Israel), Members as of December 2011: Edvige Veneselli, Maria Pintaudi (University of Genova, Genova, Italy), Silvia Russo, Francesca Cogliati (Istituto Auxologico Italiano, Milan, Italy), Agaia Vignoli (Ospedale San Paolo, Milano, Italy), Giorgio Pini (Versilia Hospital, Viareggio, Italy), Milena Djuric (University of Belgrade, Belgrade, Serbia), Anna-Marie Blagard (Glostrup, Denmark), Kristine Ravn (Glostrup, Denmark), Vlatka Mejas’si-Bosnjak (University of Zagreb, Zagreb, Croatia), Béla Melegh, Polgar Noémi (University of Pécs, Pécs, Hungary), Dana Craiu (Carol Davila University of Medicine, Bucharest, Romania), Aleksandra Djukic (Montefiore Medical Center, Albert Einstein College of Medicine, New York)
RTT Networked Database

Rett syndrome (RTT) is a neurodevelopmental disorder with one principal phenotype and several distinct, atypical variants (Zappella, early seizure onset and congenital variants). Mutations in MECP2 are found in most cases of classic RTT but at least two additional genes, CDKL5 and FOXG1, can underlie some (usually variant) cases. There is only limited correlation between genotype and phenotype.

The Rett Networked Database has been established to share clinical and genetic information. Through an “adaptor” process of data harmonization, a set of 293 clinical items and 16 genetic items was generated; 62 clinical and 7 genetic items constitute the core dataset; 23 clinical items contain longitudinal information.

The database contains information on 1838 patients from 11 countries (December 2011), with or without mutations in known genes. These numbers can expand indefinitely.

Data are entered by a clinician in each center who supervises accuracy. This network was constructed to make available pooled international data for the study of RTT natural history and genotype-phenotype correlation and to indicate the proportion of patients with specific clinical features and mutations.

We expect that the network will serve for the recruitment of patients into clinical trials and for developing quality measures to drive up standards of medical management.


For Scientists: Database Access Request

Scientists need to provide the following information to access data (a form can be downloaded from the database website or obtained from the coordinator):

- Title of the project
- Applicant details
- Anticipated duration of the project (months)
- Duration of requested access (months)
- Type of project: Basic / Clinical / Epidemiology
- Funding agency

Before sending the application, applicants need to agree to the following terms:

- I understand that the ethical committee of the University of Siena (hosting the database) will review the project before database access can be granted. A negative opinion of the ethical committee will prevent access to the database.
- I understand that any modification to the approved project will necessitate the submission of a new request to the review board.
- I understand that the Rett Syndrome Networked Database must be acknowledged in all publications or communications arising from the project.

A detailed description of the project (including specific aims, design and methods and a list of all personnel involved with affiliations) is attached.

Date  Signature

These statements, together with the project description should be sent to:

Prof. Alessandra Renieri
Rett Networked Database Coordinator
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University of Siena
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