

## 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.rett-databasenetwork.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 Hryniewiecka-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), Aglaia Vignoli (Ospedale San Paolo, Milano, Italy), Giorgio Pini (Versilia Hospital, Viareggio, Italy), Milena Djuric (University of Belgrade, Belgrade, Serbia), Anne-Marie Bisgaard (Glostrup, Denmark), Kirstine Ravn (Glostrup, Denmark), Vlatka Mejaski-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)

# Rett Syndrome Networked Database

[www.rett-databasenetwork.org](http://www.rett-databasenetwork.org)

> Database coordinator

Alessandra Renieri  
University of Siena  
email: [renieri@unisi.it](mailto:renieri@unisi.it)

> Database administrator

Rossano Di Bartolomeo  
3W Net Service S.a.s.  
email: [rossano@3wnet.net](mailto:rossano@3wnet.net)

> Database Europe Manager

Laurent Villard  
Aix Marseille University  
email: [laurent.villard@univmed.fr](mailto:laurent.villard@univmed.fr)



