



# RETT SYNDROME CLINICS INTERNATIONAL

## AUSTRALIA

### **The Children's Hospital at Westmead The Genetic Metabolic Disorders Service**

Hainsworth Street, Locked Bag 4001 Westmead NSW 2145 Australia

**Director:** Dr. Kaustuv Bhattacharya

Contact: Prof. Carolyn Ellaway

02.9845.3654

<https://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/metabolic-genetic-disorders/chw>

### **Queensland Children's Hospital Child Development Program**

Level 6, 501 Stanley Street, South Brisbane, Queensland 4101

CDPAccessService@health.qld.gov.au

1300 366 039

<https://www.childrens.health.qld.gov.au/service-child-development-program/>

### **Royal Children's Hospital, Melbourne**

50 Flemington Road, Parkville Victoria, Australia 3052

neurodev@rch.org.au

61 3 9345 5898

<https://www.rch.org.au/neurodevelopment-and-disability/>

## AUSTRIA

### **Vienna Medical University Vienna Center for Rare and Undiagnosed Diseases**

Lazarettgasse 14, AKH BT 25.3, 1090 Vienna

**Director:** Dr. Kaan Boztug | kboztug@cemm.oeaw.ac.at

cerud@meduniwien.ac.at

<https://cerud.meduniwien.ac.at/>

## CANADA

### **Complex Care Rett Syndrome Pathway Clinic Holland Bloorview Kids Rehabilitation Hospital**

150 Kilgour Road, Toronto, ON M4G 1R8

**Director:** Dr. Laura McAdam

416.425.6220, Ext. 3210

<https://www.rett.ca/for-families/clinics/complex-care-rs-pathway-clinic/>

### **Children's Hospital of Eastern Ontario Rett Syndrome Clinic**

Dr. Peter Humphreys Rett Syndrome Clinic

401 Smyth Road Ottawa, ON K1H 8L1

**Director:** Dr. Melissa Carter

613.737.7600, Ext. 3227

<https://www.cheo.on.ca/en/clinics-services-programs/rett-syndrome-clinic.aspx>

### **Thames Valley Children's Centre**

779 Base Line Rd East, London, ON N6C 5Y6

**Director:** Dr. Victoria Siu

519.685.8700, Ext. 53406

<https://www.tvcc.on.ca/service/specialty-clinics>

### **BC Children's Hospital The Neurological Care Centre**

4480 Oak Street, Vancouver, BC V6H 3V4

**Director:** Dr. Anita Datta

604.875.2121

<http://www.bcchildrens.ca/our-services/clinics/neurology#About>

## DENMARK

### Kennedy Centret, Rigshospitalet Clinical Genetic Clinic – Kennedy Center

Gamle Landevej 7, Glostrup 2600, Denmark  
**Director:** Anne-Marie Bisgaard Pedersen, MD PhD  
anne-marie.bisgaard.pedersen@regionh.dk  
43 26 01 00

## FRANCE

### Necker-Enfants Malades University Hospital

149 Rue de Sèvres, 75015 Paris, France  
**Director:** Pr Nadia Bahi-Buisson  
01 42 19 26 61  
<http://www.maladiesrares-necker.aphp.fr/defisciences-rett/>

### APHM Hôpitaux Universitaires de Marseille

278 Rue Saint-Pierre, 13005 Marseille  
**Director:** Pr Mathieu Milh  
04 91 38 55 80  
<http://fr.ap-hm.fr/centre-referance-maladies-rares/deficience-intellectuelle-de-cause-rare-et-polyhandicap>

## GERMANY

### Klinikum Kassel

Mönchebergstr. 41-43, 34125 Kassel, Germany  
**Director:** Pr Bernd Wilken  
info@klinikum-kassel.de  
49 0 561 980 3096

### Georg August University

Gottingen, Germany  
**Director:** Dr. Peter Huppke  
phuppke@med.uni-goettingen.de

## ISRAEL

### Sheba Medical Center Pediatric Neurology Institute – The Rett Syndrome Center

Derech Sheba 2, Ramat Gan, Israel  
**Director:** Prof. Bruria Gidoni-Ben-Zeev  
972 77 996 6905  
<https://www.shebaonline.org/department/pediatric-neurology-care/>

## ITALY

### Istituto Giannina Gaslini

Via Gerolamo Gaslini, 5, 16147 Genoa, Italy  
**Director:** Prof. Edvige Veneselli  
339 2712005  
<https://www.gaslini.org/cas/22-centro-per-la-diagnosi-e-la-cura-delle-epilessie-delle-ta-evolutiva/>

### Ospedale San Paolo

Via Antonio di Rudini, 8, 20142 Milano MI, Italy  
**Director:** Prof. Maria Paola Canevini  
366 2909186

### Policlinico Universitario Via Consolare

Valeria, 1, 98124 Messina ME, Italy  
**Directors:** Prof. De Luca Filippo and Gabriella Di Rosa, gdirosa@unime.it  
neuropsychiatria.infantile@polime.it  
349 7386079  
[https://www.polime.it/scheda\\_uo.php?id\\_uo=505400](https://www.polime.it/scheda_uo.php?id_uo=505400)

### Bambino Gesù Hospital Pediatrico

Piazza di Sant'Onofrio, 4, 00165 Roma RM, Italy  
**Directors:** Dr. Federico Vigeveno and Dr. Michelina Armando,  
michelina.armando@opbg.net  
psp.neurologia@opbg.net  
06 6859 2232  
<http://www.ospedalebambinogesu.it/neurologia>

### Policlinico Le Scotte

Viale Mario Bracci, 16, 53100 Siena SI, Italy  
**Director:** Dr. Joussef Hayek, j.hayek@ao-siena.toscana.it  
accogl@ao-siena.toscana.it  
333 5616090  
<http://www.ao-siena.toscana.it/index.php/scienze-neurologiche-e-motorie>

## JAPAN

### Yoshiko Nomura Neurological Clinic for Children (NNCC)

Ochanomizu-Myojn Building 3rd Floor, 1-2-13 Yushima Bunkyo-ku  
Tokyo 113-0034 Japan  
ynomura@wind.ocn.ne.jp  
81 3 3258 5563  
Cell phone: 090 1732 8868  
<https://www.rch.org.au/neurodevelopment-and-disability/>

## NETHERLANDS

### Maastricht University Medical Centre Rett Expertise Centre

PO Box 5800, 6202 AZ Maastricht

**Directors:** Professor Leopold M G Curfs, Ph.D.

Eric E J Smeets, M.D. Ph.D.

polikliniek.klinischegenetica@mumc.nl

043 3875855

<https://klinischegenetica.mumc.nl/rett-syndroom>

## NORWAY

### Frambu kompetansesenter for sjeldne diagnoser

Sandbakkveien 18, 1404 Siggerud, Norway

**Director:** Kristian E. Kristoffersen

info@frambu.no

64 85 60 00

<https://frambu.no/>

## SPAIN

### Hospital Sant Joan de Déu

Institut d'Investigació i recerca Biomèdica de Bellvitge

Avinguda de la Granvia de l'Hospitalet, 199, 08908

L'Hospitalet de Llobregat, Barcelona, Spain

**Director:** Dr. Mercedes Pineda

34 93 600 97 83

<https://www.sjdhospitalbarcelona.org/es>

## SWEDEN

### Nationellt Center för Rett syndrom och närliggande diagnoser

PO Box 601, SE-832 23 Frösön, Sweden

**Contact:** Marianne Olsson

46 63 15 48 10

<https://www.nationelltcenter.se/diagnoser/rett-syndrom/>

## UNITED KINGDOM

### Centre for Personalised Medicine in Rett Syndrome (CPMRS) King's College

**Director:** Dr. Paramala Santosh

cpmrs@slam.nhs.uk

### Evelina London Children's Hospital

St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH

PaediatricAppointmentsNeurology@gstt.nhs.uk

020 7188 4003

<https://www.evelinalondon.nhs.uk/our-services/hospital/rett-clinic/overview.aspx>

### Manchester Centre for Genomic Medicine

6th Saint Mary's Hospital, Oxford Rd, Manchester M13 9WL

**Director:** Dr Catherine Breen

0161 276 6206

<https://www.mangen.co.uk/specialist-clinics/developmental-disorders/rett-syndrome/>

### Royal Hospital for Children

Glasgow, Scotland

**Director:** Dr. Sameer Zuberi

<https://www.nhsggc.org.uk/patients-and-visitors/main-hospital-sites/royal-hospital-for-children-glasgow/>