



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

Medical University of Vienna 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/>

Medical University of Vienna Developmental Cognitive Neuroscience Lab

Währinger Gürtel 18-20, 1090 Vienna

Director: Prof. Dr. Rainer Seidl | rainer.seidl@meduniwien.ac.at

Contact: Dr. Sandy Siegert | sandy.siegert@meduniwien.ac.at

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<https://kinderklinik.meduniwien.ac.at/forschung/developmental-cognitive-neuroscience-lab/>

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/>

CANADA (continued)

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

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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

Göttingen, 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
neuropsichiatria.infantile@polime.it

349 7386079

https://www.polime.it/scheda_uo.php?id_uo=505400

ITALY (continued)

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/>