Topics

- Relevance of Rett syndrome and MeCP2 function to the understanding of brain development
- MeCP2 structure, function, regulation and targets
- Role of MeCP2 in synaptic development
- Neuroimmune and neuroinflammatory defects in Rett syndrome
- Opportunities and limitations of mouse models in Rett syndrome
- Pathological basis and clinical implications of respiratory and autonomic abnormalities in Rett syndrome
- Potential therapeutic options for reversing the effects of Rett syndrome
- Clinical variability in Rett syndrome and its genetic basis
- Unusual phenotypes and mechanisms including effects in males
- Ethical implications relating to the genetics of Rett syndrome
- Relationship between Rett syndrome and autism: mechanisms, clinical presentation and diagnostic criteria
- Evidence base and cost-effectiveness of genetic testing for *MECP2* pathology
- Preparing for a new era of clinical trials in Rett syndrome: methodologies and assessment tools
- International databases and biobanks: contribution to collaborative research
- Promotion of rare disorders
- Management of the major clinical problems in Rett syndrome including: seizures ; dystonia ; orthopaedic complications particularly scoliosis ; nutrition and growth ; gastrointestinal problems ; end of life issues
- Role of therapy in Rett syndrome including: physiotherapy ; speech and language ; communication ; music therapy
- Implementation of best practices
- Role of specialised clinics in Rett syndrome
- Comparison of service delivery models across the world in developed and developing nations
- Healthcare systems
- Quality of life for those affected and their families
- The adult woman with Rett syndrome
- Day to day management of child disability
- Resources and child disability
- Rethinking parents' role
- Rethinking Associations' missions

and much more…

General Information

DATES AND VENUE OF THE CONGRESS

The World Rett Syndrome Congress will be held on October 10-13, 2008 at the :
Maison de la Mutualité – 24 rue Saint-Victor – 75250 Paris Cedex 05 - www.congresmutualite.com
Subway stations: Maubert Mutualité, Cardinal Lemoine & Jussieu
RER: ligne B, station Saint-Michel-Notre-Dame

CONGRESS SECRETARIAT

Registration, hotel reservation, abstract submission and exhibition:

AIM FRANCE

AIM FRANCE – AIM Group
Leila Zribi
World Rett Syndrome Congress
29-31, rue de l'Espérance – 75013 Paris – France
Phone: +33 (0)1 40 78 38 00 – Fax: +33 (0)1 40 78 38 10
E.mail: info@worldrettsyndrome2008.com
Abstract submission, exhibition, registration, accomodation and downloading of the forms on the Congress web site: www.worldrettsyndrome2008.org

CONTINUING MEDICAL EDUCATION / EACCME

The World Rett Syndrome Congress will be submitted to the European Union of Medical Specialists for accreditation.

LANGUAGE

Official language of the congress is English. However, some sessions might be presented in French.

EXHIBITION

An exhibition hosting the Industry, Institution and all other partners of World Rett Syndrome Congress, will be held at the Maison de la Mutualité, during the congress.

CALL FOR ABSTRACTS

All participants are invited to submit abstracts.
Abstracts for the conference will be selected for oral or poster presentation. Only electronic submissions will be possible on the congress website.
The opening for electronic submission is February, 1st 2008.
The deadline of submissions is April, 30th 2008.
To submit your abstract, visit the conference web site at www.worldrettsyndrome2008.org and follow the instructions.

Sous le Haut Patronage de
Monsieur Nicolas Sarkozy,
Président de la République Française

Under the Patronage of
Mister Nicolas Sarkozy
President of the French Republic

WORLD RETT SYNDROME CONGRESS

A Hand Link from Gene to Care

October 10-13, 2008

Maison de la Mutualité, Paris – France

First Announcement

www.worldrettsyndrome2008.org

Welcome Addresses

Dear Friends,

We are happy to welcome the 6th World Rett Syndrome Congress to Paris.

We thank you for your tireless efforts on behalf of all the children and adults with Rett syndrome. Remembering Andreas Rett's warm words "Through their eyes they tell us they understand far more than we can imagine."; the choice of Paris, city of lights and love in the country of human rights, is a real resonance for all our actions.
Rett syndrome is a devastating neurodevelopmental disorder. Since the discovery of the genetic nature of the disease with the *MECP2* mutation, we have been facing new challenges and key issues: ethics, clinics, therapeutics, care...
For all clinicians, scientists, healthcare providers, politicians and parents making such huge efforts to increase awareness and understanding; for the progress of research and development of best practices in Rett syndrome and other childhood disabilities, this congress is the gateway to a vision of excellence in disability management.
The key to success in reaching this ambitious goal lies in gathering together all the major players. We are deeply indebted to all contributors, parents' associations, sponsors and friends. We look forward to meeting you in Paris.

Professor Philippe Evrard
President of the Scientific Committee

Doctor Gérard Nguyen
President of the Organisation Committee

Dear Colleagues,

As I write it is almost eight years to the day since "The gene was found" in September 1999.
So much has happened since that time and the acceleration in Rett syndrome research probably exceeds that of any other genetic disorder. The achievements relate to an increased understanding both of the biology of MeCP2 and the genetic determinants of the clinical variation seen in Rett syndrome. The ability to restore neurological function in mice previously lacking in MeCP2 has spurred the research community to search for therapeutic options which may be applicable to humans. Therefore we are entering an extremely exciting era for which researchers, clinicians and families alike all need to be prepared. As a community we need to work together to develop the infrastructures which, when the time comes, will allow us to undertake the scientifically rigorous clinical trials that will be required. This Rett Syndrome World Congress provides the ideal opportunity to foster such a collaborative network and to share our knowledge as we move towards the future.

Clinicians experienced in the care of children and adults with Rett syndrome and prominent international research scientists will join us in Paris to spearhead the Rett Syndrome World Congress last held in Japan in 2000.

The objectives of the Congress are:
- To provide a forum for scientists to present topical research findings in either oral or poster presentations, as well as to foster international collaborations
- To provide medical practitioners and other health care professionals, including physiotherapists, occupational therapists and speech pathologists with an opportunity to update their knowledge and skills in the care of patients with Rett syndrome
- To provide an opportunity for parents, families and carers of those with Rett syndrome to meet other families, as well as experts in the field, who can offer practical insights into the management and care for those with Rett syndrome

We invite you to join us in making the World Rett Syndrome Congress 2008 in Paris a great success.

Clinical Associate Professor Helen Leonard
Coordinator of the Programme Committee

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