

Rethinking Rett Syndrome

Saturday, November the 19th, 2005
Grimaldi Forum, Monaco



This symposium has been possible by the involvement of Rett Syndrome Associations of Parents in European countries.

« Under the Auspices of Rett Syndrome Europe Organised by AFSR (French Rett Syndrome Association) In Partnership with RSAUK (Rett Syndrome United Kingdom) and Rett Syndrome Germany»



SESSION 1

1.00 - 3.00 PM **Towards Better Understanding Of The Disease**

Chair: Marc Tardieu, Gérard Nguyen

Welcome Message

Philippe Evrard, Paris, France

Lessons from 40 years of experience in Rett Syndrome

Bengt Hagberg, Sahlgrenska University, Göteborg, Sweden

Brain immaturity and autonomic dysfunction

Peter Julu, Autonomic Unit, Neurophysiology Department, Central Middlesex Hospital, London, UK

Brain development and Rett disorder

Michael Johnston, Kennedy Krieger Institute, John Hopkins Hospital, Baltimore USA

From early clinical detection to developmental perspective

Alison Kerr, Academic Centre, Dept Psychological Medicine, Gartnavel Royal Hospital, Glasgow, UK

From gene to hope

Laurent Villard, Génétique Médicale et Développement INSERM U 491, La Timone, Marseille, France

DISCUSSANTS

Neuropediatrics point of view

Marc Tardieu

Parent point of view

Yvonne Milne, Rett Syndrome Europe Association

COFFEE BREAK 15.00-15.30

SESSION 2

3.30 - 5.30 PM **From Better Understanding To Better Care**

Chair: Simone Gilgenkrantz, Christiane Roque

Osteoporosis, the hidden burden in Rett syndrome

Agnes Linglart, Boston USA

Epilepsy impact on Quality of life

Nadia Bahi, Neuropédiatrie, Hôpital Necker Enfants Malades, Paris France

Brain development and psychosocial disorders

Paul Casaer, Dept Pediatrics, University Hospital Leuven Belgium

Brain responsiveness to musicotherapy

Marith Bergstrom, Rett Center, Frösö Strand, Frösön Sweden

DISCUSSANTS

Neuropediatrics point of view

Vlatka Bonsjak, Zagreb, Croatia

Parent point of view

Tina Winters, Rett Syndrome Association, Germany