Sous le Haut Patronage de

Monsieur Nicolas Sarkozy,
Président de la République Française
et
S.A.R La Princesse de Hanovre

Under the Patronage of

Mister Nicolas Sarkozy
President of the French Republic
and
HRH the Princess of Hanover

6th WORLD RETT SYNDROME CONGRESS

A Hand Link from Gene to Care

October 10-13, 2008

Maison de la Mutualité, Paris – France

Preliminary Programme

www.worldrettsyndrome2008.org

L'Europe et les maladies rares
un espoir à la mesure des attentes des malades et des familles

Vendredi 10 octobre 2008 - Friday October 10th, 2008

PARIS
Maison de la Mutualité

Organized by / Organisé par :
L'Alliance Maladies Rares
In collaboration with / En collaboration avec :
EURORDIS, AFM
In partnership with / En partenariat avec :
l'AFSR

SYMPOSIUM

Friday 10, October, 2008

8.30 - 9.45	***REGISTRATION***
	European Health Policy: a Tailored Community for Rare Disease Challenges? *Language: French (with simultaneous translation in English)* *Under the High Patronage of Mister Nicolas Sarkozy, President of the French Republic* *Organised by Alliance des Maladies Rares, EURORDIS and AFM* *In partnership with AFSR (French Rett Syndrome Association)*
9.45	INTRODUCTION *Françoise Grossetête, European Parliament*
10.00 - 11.15	**SESSION 1: *Rares Diseases: a Public Health Priority in Europe?*** *Chair: Francis Brunelle, Necker Hospital, APHP (Assistance Publique Hôpitaux de Paris)* The French Experience, a Source of Inspiration for Europe? *Ségolène Aymé, Rare Disease Task Force* Rare Diseases in Europe: Recent Advances and Perspectives *Andrzej Rys, DG SANCO (European Commission)* Orphan Drugs, a Policy Initiative Success *Agnès de Saint Raymond, EMEA (European Medicines Agency)*
11.15 - 12.45	**SESSION 2: *Rare Diseases and Research Policy : Europe a Mandatory Link*** *Chair : Alain Fisher, Necker Hospital, APHP (Assistance Publique Hôpitaux de Paris)* Research Policy on Rare Diseases: Status and Perspectives *Elisabeth Tournier-Lasserve, GIS Rares Diseases Institute* Rares Diseases, a Research Priority for Europe? *Catherine Berens, DG Research (European Commission)* *The European Dimension Interest for Research:* - An added Value for Registries and Data Base Development *Laurent Villard, Inserm* - An Added Value for Clinical Trials *Nicolas Levy, Inserm*
12.45 - 14.30	*Break*
14.30 - 15.45	**SESSION 3: *Rare Disease Management: Needs for an European Level Organisation?*** *Chair: Frédéric Sicard, Health Ministry* Rare Diseases, Excellence and Expertise Centers *Alexandra Fourcade, Health Ministry* An European Network exemple *Hervé Puy, reference centre for porphyrias*

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	Pole of Competitiveness: ORPHEME *Jacquie Berthe, ORPHEME*
15.45 - 17.00	**SESSION 4:** ***Rares Diseases: Patients' Associations, the Cornerstone?*** *Chair: Dominique Donnet Kamel, Inserm*
	A Patients' Organisation: AFM the Leader in the Field of Rare Diseases *Laurence Tiennot-Herment, AFM (French Association against Muscular Dystrophy)*
	A National Alliance Organisation: Alliance des Maladies Rares, a Privileged Interlocutor of Authorities in France *Françoise Antonini, Alliance Maladies Rares*
	An European Umbrella Oragnisation: EURORDIS, a Voice for Patients with Rare Diseases in Europe *Yann Le Cam, EURORDIS*
17.00	CONCLUSION *Chantal Lecerf,* Porte parole de l'Alliance des Maladies Rares
17.15 - 17.30	*Break*

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PROGRAMME COMMITTEE

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Hilary Cass – UK
John Christodoulou – Australia
Jenny Downs – Australia
Carolyn Ellaway – Australia
Susan Fyfe – Australia
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Peter Huppke - Germany
Walter Kaufmann – USA
Janine Lasalle – USA
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Catherine Senez – France
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Xi-Ru Wu - China

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Agnès Linglart – France
Alina Midro – Poland
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Yoshiko Nomura – Japan
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Christian Richelme – France
Eric Smeets - Netherlands
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ORGANISATION COMMITTEE

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Vice-Presidents
Kathy Hunter – IRSF
Yvonne Milne – RSE
Christiane Roque – AFSR

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Lorna Jaffa – UK
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Dirk Mühlmann - Germany
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Lynn Weeks - UK

Local Organisation Committee
Thierry Bienvenu – France
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Elisabeth Celestin – France
Katherine Dessain Gelinet – France
Martine Gaudy – France
Dany Gerlach – France
Pascaline Guerin – France
Etienne Joly – France
Philippe Kostka – France
Jean-Christophe Roux – France

6th WORLD RETT SYNDROME CONGRESS

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Friday 10, October, 2008

17.30 - 20.00	**6th World Rett Syndrome Congress Opening Ceremony** *Language: English (simultaneous translation into French)*
	Under the High Patronage of Mister Nicolas Sarkozy, President of the French Republic and HRH the Prncess of Hanover Organised by AFSR (French Rett Syndrome Association) In partnership with RSE (Rett Syndrome Europe) and IRSF (International Rett Syndrome Foundation)
17.30	Welcome addresses: Rare Diseases, Child Handicap, Towards Citizenship *Didier Gaboriaud, President of FMP (La Mutualité Française)*
17.40	Introduction: Rare Diseases and Child handicap, Rett Syndrome a Hand Link from Gene to Care *Christiane Roque, President of Honour, AFSR*
17.50 - 18.30	**Opening lectures** *Chairs: Philippe Evrard (France), Helen Leonard (Australia)*
	Child Handicap, the French Model Policy *Jean-François Chossy, Député (French Parliament)*
	Rett Syndrome: Parents' Associations Expectations to Rebuild Rituals *Gérard Nguyen, Rett Syndrome Europe, President of the Organisation Committee*
	Welcome message from Bengt Hagberg (video), President of Honour of the Congress
	Opening message from the President of the Congress, Philippe Evrard
	Opening message from the President of the Programme Committee, Helen Leonard
18.30 -20.00	**PLENARY SESSION** *Chairs: Masaya Segawa (Japan), Helen Leonard (Australia)*
	Inaugural Overview of Rett Syndrome, MECP2 and Beyond *Huda Zogbi (USA)*
	MECP2, Structure and Function *Adrian Bird (UK)*
20.30	*CONGRESS ASSOCIATION GALA DINNER* **UNDER REGISTRATION**
	We are pleased to inform you that the Association Gala Dinner will be held on Friday at 20.30 in the reception room of the city hall of Paris. This will be a costume dinner on the theme of «World Fashion». We kindly invite you to come with your costume.

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Saturday 11, October, 2008

	PLENARY SESSION Language: English (simultaneous translation into French)						SATELLITE SYMPOSIUM
8.30 -10.00	Clinical Overview *Alan Percy (USA)* Relationship between Genotype and Phenotype *Helen Leonard (Australia)*						**9.00-17.30** SCATED : Complex Situations: Autism and Devlopmental Disorders: What's New? ***Organised by URAPEI*** *Language: French Audience: Parents and Caregivers*
10.00 - 10.30	**Coffee Break, Visit of the posters and exhibition**						
10.30 - 12.00	**PARENTS WORKSHOP**	**WORKSHOP**	**ORAL COM.**	**ORAL COM.**	**SATELLITE WORKSHOP**	**SATELLITE WORKSHOP**	**SATELLITE SYMPOSIUM**
	Hilary Cass (UK) Getting Older, Living Well	*Susan Fyfe (Australia)* Gastro-intestinal (swallowing, feeding and digestive ability)	*Selected Abstracts*	*Selected Abstracts*	*Evelyne Camaret (France)* *Philippe Kostka (France)* Psychomotricity, understanding and progress ***Organised by CPME AFSR*** *Language: French Audience: Parents and Caregivers*	*Annick Champolion-Puel (France)* *Sophie Laperche (France)* Conductive Education ***Organised by CPME AFSR*** *Language: French Audience: Parents and Caregivers*	***Organised by URAPEI*** *Language: French Audience: Parents and Caregivers*
12.00 - 14.00	**Coffee Break, Visit of the Posters and exhibition**						
12.00 - 13.00	**"BEST OF" THE DAY** ***Organised by the Scientific Committee of the French Association*** *Language: French - Audience: AFSR Members*						
14.00 - 15.30	**WORKSHOP**	**WORKSHOP**	**WORKSHOP**	**ORAL COM.**	**ORAL COM.**	**SATELLITE WORKSHOP**	**SATELLITE SYMPOSIUM**
	Jenny Downs (Australia) Scoliosis	*Janine Lasalle (USA)* Molecular Pathogenesis of Rett Syndrome		*Selected Abstracts*	*Selected Abstracts*	*Dany Gerlach (France)* *Therese Musitelli (Germany)* Basal Stimulation: Issue of Daily Life ***Organised by CPME AFSR*** *Language: French and German Audience: Parents and Caregivers*	***Organised by URAPEI*** *Language: French Audience: Parents and Caregivers*
15.30 - 16.00	**Coffee Break, Visit of the Posters and exhibition**						

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Sunday 12, October, 2008

	PLENARY SESSION Language: English (simultaneous translation into French)					
8.00 -10.00	Other Phenotypes *Chair: Sakkubai Naidu (USA)* *Male Phenotype* *Hilde Van Esch (Belgium)* *Congenital Rett syndrome Variant* *Alessandra Renieri (Italy)* *CDKL5* *John Christodoulou (Australia)* *Rett syndrome and autism: What is the relationship?* *Walter Kaufmann (USA)*					
10.00 - 10.30	**Coffee Break and Visit of the posters and exhibition**					
10.30 - 12.00	**WORKSHOP**	**WORKSHOP**	**ORAL COM.**	**ORAL COM.**	**SATELLITE WORKSHOP**	**SATELLITE WORKSHOP**
	Bruria Ben Zeev (Israel) Epilepsy, Clinical Presentation, Investigation, Management, Medications	*Sarojini S. Budden (USA)* Cognition Communication	*Selected Abstracts*	*Selected Abstracts*	*Catherine Senez (France)* *Irène Benigni (France)* Food and Nutrition: the Recipes! ***Organised by CPME AFSR*** *Language: French* *Audience: Parents and Caregivers*	Shouts and Cries in a Silent World *Language: French* *Audience: Parents and Caregivers*
12.00 - 14.00	**Coffee Break, Visit of the Posters and exhibition**					
12.00 - 13.00	**"BEST OF" THE DAY**			**AFSR Scientific Committee meeting**		
	Organised by the Paramedical Committee of the French Association *Language: French - Audience: AFSR Members*			***Organised by the French Association*** *Language: French* *Audience: AFSR representatives and Scientific Committee members*		
14.00 - 15.30	**WORKSHOP**	**WORKSHOP**	**WORKSHOP**	**ORAL COM.**	**SATELLITE WORKSHOP**	**SATELLITE WORKSHOP**
	Susan Fyfe (Australia) Outcomes for Clinical Trials and how they should be measured?	*Alison Kerr (UK)* Emotional and Behavioural Aspects and Sleep Disorders Management	*Adrian Bird (UK)* Gene Therapy in Mouse Models	*Selected Abstracts*	Pascale Gondebeaud (France) Games and Challenges in Communication *Language: French* *Audience: Parents and Caregivers*	Martine Tollet (France) Disease Story and Narrative Approach *Language: French* *Audience: Parents and Caregivers*
15.30 - 16.00	**Coffee Break and Visit of the Posters**					

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Monday 12, October, 2008

8.30 - 10.00	**PARENTS WORKSHOP**	**WORKSHOP**	**ORAL COM.**	**ORAL COM.**
	Gérard Nguyen (RSE) International Collaboration Association Advocates in Research	*Laurent Villard (France)* Breathing and Autonomic Abnormalities	*Selected Abstracts*	*Selected Abstracts*
10.00 - 10.30	**Coffee Break and Visit of the posters and exhibition**			
10.30 - 12.00	**PLENARY SESSION** Language: English (simultaneous translation into French)			
	Rett Syndrome, View from Emerging Economies *Xi-Ru Wu (China)* Synthesis, Moving from Diagnosis to Therapies *Carolyn Schanen (USA)*			
12.00 - 12.30	6th World Rett Syndrome Congress, Closing Ceremony Philippe Evrard (France), Helen Leonard (Australia), Gérard Nguyen (France)			
14.00 - 18.00	**WORKING MEETING**			
	Organised by EuroRett *Laurent Villard (France)* *Language: English* *Audience: EuroRett members (upon invitation)*			

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
Subway stations : Maubert Mutualité, Cardinal Lemoine & Jussieu
RER : ligne B, station Saint-Michel-Notre-Dame

CONGRESS SECRETARIAT

Registration, abstract submission and exhibition:
AIM FRANCE – AIM Group
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 and down-laoding of the forms on the Congress web site:
www.worldrettsyndrome2008.org

ON-LINE REGISTRATION

To participate to the 6th World Rett Syndrome Congress, participants are kindly requested to register in advance. You can register on-line (www.worldrettsyndrome2008.org) or download and print the registration form. Fill and return the form by fax or regular mail to the congress secretariat.

Registration and payment	Until September 19, 2008	After	On Site
Physicians (MD)	300 €	360 €	400 €
Therapists	120 €	150 €	190 €
Students*	80 €	100 €	120 €
Patients' Association Member*	50 €	60 €	70 €
Registration fees include access to all sessions, exhibition, coffee breaks, documents of the congress.			
Accompanying persons	30 €	30 €	30 €
Registration fees for accompanying persons include, access to the exhibition, coffee breaks.			
* Certificate will be required			
Association Gala Diner on Friday 10th October 2008 : 30 €			

CANCELLATION POLICY

Cancellation of registration must be notified to the Congress Secretariat in writing (by regular mail or fax) according to the following conditions:
Cancellation on/before September 5, 2008: refund of 50 % of the registration.
After September 5, 2008: no refund.

CONTINUING MEDICAL EDUCATION

EACCME
The World Rett Syndrome Congress will be submitted to the European Union of Medical Specialists for accreditation. More information will be available in the congress web site:
www.worldrettsyndrome2008.org

LANGUAGE

Official language of the congress is English. Plenaries sessions will be translated in French. However, some satellite 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 "salle Théâtre" at the Maison de la Mutualité, during the congress.

ASSOCIATION GALA DINNER

The association Gala dinner will be held on Friday October 10, 2008 at 20.30 in the reception room of the city hall of Paris.
This will be a costume dinner on the theme of «Hand in Hand from Diversity to a World Fashion». We kindly invite you to come with you costume.

The participation to the gala dinner is upon registration. You can register to the gala dinner directly on the congress website or by downloading the registration form.

Registration fees for the gala dinner = 30 €

CONGRESS PARTNERS

- French Rett Syndome Association
- Rett Syndome Europe
- InternationalRett Syndome Foundation
- Alliance Maladies Rares
- EURORDIS
- Association Française Contre les Myopathies
- Israeli Rett Centre