



1st SCIENTIFIC CONFERENCE LOWE SYNDROME

Date:

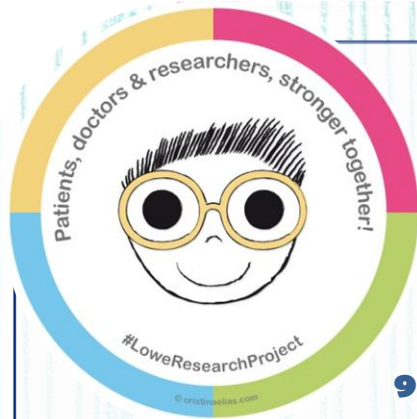
1st December 2012

Place:

Hotel ABBA, Santa Rosa, 33

Close to Hospital Sant Joan de Déu

Esplugues de Llobregat, Barcelona



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9:00- 10:00 Hand in documentation to assistants

10:00-10:30 Introduction to the Conference

Dr. Emili Bargalló, Director de la Fundació Sant Joan de Déu

* **Sra. P Magrinyà** Técnico CatSalut, Comisión Asesora de Enfermedades Minoritarias

* **Sr. J Torrent-Farnell** Director General. Fundació Dr. Robert

* **Sr. A Montserrat Moliner** Policy Officer for Rare and Neurodevelopmental Diseases. Comisión Europea

10:30- 11:30 First Field: Medical Information

Moderator: Dr. MA Vilaseca

- i. Biological Basis of Lowe Syndrome: Dr. M. Serrano
- ii. Nephrological disorders and its treatments: Dr. J.A. Camacho
- iii. Eye disorders and their treatment: Dr. E. Arrondo

11:30-12:00 Coffee Break

12:00-12:30 GH therapy, attendees' experience: Dr. L. Suárez and all the assistants. Interactive session

12:30-13:30 The potential partnerships and web 2.0 for the ECM. Dr. M. Armayones and Mrs. J. Cutillas Moderator: A. Suárez.

13:30-15:00 Luck Break

15:00-16:30 Second field: medical information.

Moderators: Dr. B. Gómez-Zúñiga and Dr. M. Pousada

- iv. Neurological disorders and treatment: Dr. B. Pérez-Dueñas
- v. Exploring behavioural features in Lowe Syndrome: Interactive session. Dr. B. Pérez-Dueñas and all assistants

16:30-17:00 Coffee Break.

17:30-18:00 Rare Connect for Lowe Syndrome. D. Costello

18:00-18:30 e-PaCIBARD. Dr. M. Serrano

18:30 Summary of the Day, and closing group photo.

Closing Speech by Mrs. Roser Vallès, Departament de Salut de la Generalitat de Catalunya



Place: Hotel ABBA, Calle Sant Rosa 33, 08950, Esplugues de Llobregat. Close to Hospital Sant Joan de Déu
Passeig Sant Joan de Déu, 2. 08950 Esplugues de Llobregat

How to get: http://www.hsjdbcn.org/portal/es/web/com_arribar

Enrollment: needed on www.sindromelowe.es

Rates of the enrollment: Free for the families who have enrolled in ASLE. For the other assistants 20 euros. You can pay on the same day of the conference or preferably by bank transfer to the number IBAN (International Bank Account Number) ES44 2038-1079-0660-0050-7222 (Provide your name on the concept).

It includes: documentation, coffees and lunch.

There will be a kindergarden for children over 3. For other needs, please contact us.

Accommodation: Special rates Hotel Husa Via Barcelona (Tel. 93 477 46 89) and Hotel ABBA Garden Hotel Esplugues (Tel: 93 503 54 54)

More information: loweresearch@gmail.com



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(asle)

Ponentes:

M.A. Vilaseca (HSJD)
L. Carranza (ASLE)
J. Armstrong (HSJD)
M. Serrano (CIBERER, HSJD)
J.A. Camacho (HSJD)
E. Arrondo (IMO)
L. Suárez (HSJD)
A. Suárez (ASLE)
J. Cutillas (HSJD)
M. Armayones
(ASLE/UOC)
B. Gómez-Zúñiga (UOC)
M. Pousada (UOC)
B. Pérez-Dueñas (HSJD)
D. Costello (Web Communications Manager of EURORDIS)

Colaboradores:



HUSA
HOTELES



**Our sincere thanks to the volunteers
of the HSJD and many other people
who work with your help in
journalism, photography,
translation, graphic design, etc..
who have made this meeting possible**

Logo #LoweResearch designed by:

<http://www.cristinaelias.com/>

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e-PaCIBARD Project have the support from:

Fundació Doctor Robert
UAB

