

Information:

Hotel Madrid Norte (Cadena Rafael Hoteles)



Located in Alcobendas city, at 15 km from Madrid throw A1 SALIDA 17, in a business and residencial area with direct connection (10 minutes) with terminal T4 Madrid Barajas Airport by road M12. So close to the hotel you can enjoy the shopping center Plaza Norte 2 o Herón Diversia, José Caballero Sport Center and the residencial complex of La Moraleja.

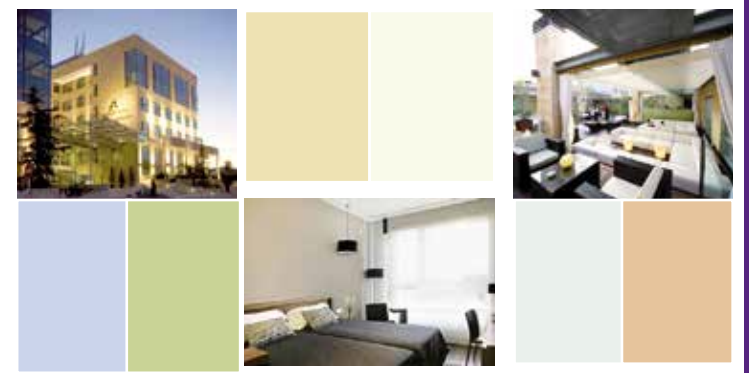
Adress hotel: Avda. de Barajas 22 - Parque Empresarial Omega (A-1, salida 17) 28108, Alcobendas. Madrid

Coordinates: Latitude: 40.534689 / 40 ° 32 '4.8804 " / Lon: -3.621143 / -3 ° 37 '16.1148 "

Access to the hotel:

By car: From Madrid, take M-30 road direction Burgos A-1 exit 17. At the circular square take the third exit direction Alcobendas. Then turn around back the next circular square, from where you are coming and you will find the hotel on your right. The hotel has parking places.

Bus: Number L9, L10 y L11 // From airport 827 y 828 // From Plaza Castilla 159 (Service from monday to friday, except holidays). The nearest bus stations are La Moraleja and Marqués de Valdivia, Bus line 10.



With the collaboration:



The 10th International Scientific-Family Congress Spanish MPS Society 2014 that be held on 3th and 4th october in Madrid has been recognized by Health Interes, according resolution issued June 11th 2014.

Applied for accreditation to the Comission of Continuing Educational Professions by the National Health System.

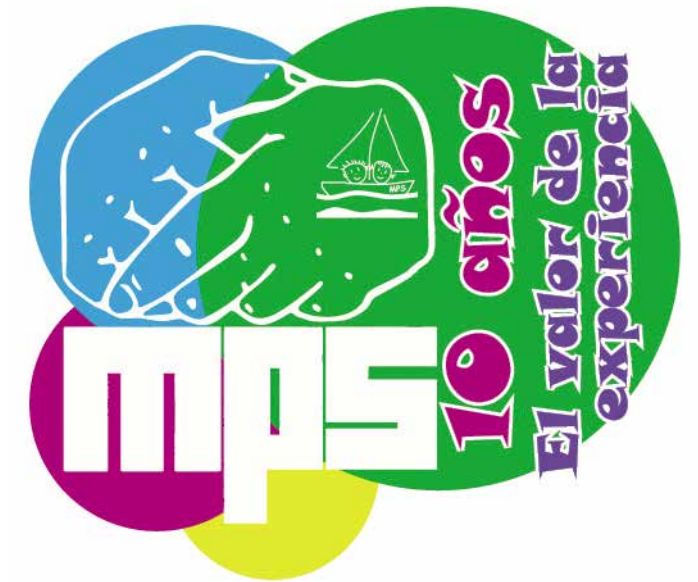
ORGANIZED BY:

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Right of admission reserved on this congress

10th INTERNATIONAL CONGRESS SCIENTIFIC - FAMILY

Madrid 3rd and 4th October 2014



ENTITY DECLARED OF PUBLIC UTILITY

10th INTERNACIONAL CONGRESS SCIENTIFIC - FAMILIAR SPANISH MPS SOCIETY 2014

Welcome from president:

Is a pleasure for me to contact with all you again. Our 10th Internacional Congress Scientific-Familiar MPS Spain 2014 is full of hope, full of work, dedication and struggle, wich in recent years has been spinning hard to have what we have today, and all, thanks to you, the families who are our side, as always. A job that will be reflecting in the intensive day and we will check and analyze.

As always we have the collaboration of volunteers of La Obra Social "La Caixa". Children are going to enjoy with them. This edition is going to have different game spaces.

Let's fill up batteries to keep on going and hope to see all of you.

King regards.

D. Jordi Cruz.

President of Spanish MPS Society.

Member of Directive Board of Feder (Spanish Federation of Rare Diseases).

Responsable of Research at Feder Foundation.



10th INTERNATIONAL CONGRESS

2014



Accommodation and Assistance

PROGRAM

PLACE: Rafaelhoteles Madrid Norte

Avda. de Barajas, 22. Parque Empresarial Omega

(A-1, Exit 17)

28108 Madrid

Friday 3

21.30h **Welcome dinner of families and Committee of**

Scientific Medical Consultant

Saturday 4

8.30h **REGISTRATION**

9.30h **PRESENTATION AND OPENING**

Moderator: Dr. Josep Torrent i Farnell, Foundation

Director Doctor Robert and representative of Spanish Medicines Orphan Committee on the European Medicines Agency (EMA)

Authorities at the event

Doña Mercedes González Gomis, Vice-president of

Official College of Pharmaceutical of Madrid

D. Manuel Posada, Director of Research Institute of

Rare Disease. Inst.of Health Carlos III. Madrid

D. Juan Carrión, President of Feder

D. Jordi Cruz, President of Spanish MPS Society

10.00h. **CONFERENCE**

“Focus at current MPS treatments”

Dr. Gregory Pastores. Consultant, Adult Metabolic Service Department of Medicine. National Centre for Inherited Metabolic Disorder. Ireland

10.30h. **CONFERENCE**

“Research therapies in Related Diseases
Dr. Timothy Cox, Department of Medicine.
University of Cambridge, United Kingdom

11.00h **COFFEE BREAK**

11.30h **CONFERENCIA**

“Gene Therapy for MPS III-B”
Dra. Fátima Bosch, Catedrática of UAB and Director of CBATEG (Center of Biotechnology Animal and Gene Therapy) Bellaterra, Barcelona

12.00h **CONFERENCE**

“Development a new generation of pharmacologic chaperons to treat Gangliosidosis GM1 and Morquio B”
Dr. Marc Martinell, Director General y cofundador de Mynorix Therapeutics. Mataró. Barcelona

12.20h **CONFERENCE**

“ Needs Intrathecal Enzyme Therapy in MPS II”
Dr. Luis González Gutierrez-Solana. Enclosed and Coordinator Dep. Neuropediatrics Hospital Niño Jesús. Multidisciplinary Unit Coordinator of MPS and Neurodegenerative Diseases. Hospital Niño Jesús. Madrid

12.40h **CONFERENCE**

“Intrathecal Therapy in MPS III-A “
Dra. Mireia del Toro. Neuropediatrics Department of Hospital Vall d’Hebrón, Barcelona.

13.00h. **PANEL DISCUSSION**

“Answer your questions with the expert I Part”

13.40h **LUNCH**

15.40h **CONFERENCE**

“Advances in MPS IV-A”
Dra. M^ª Luz Couce Pico, Diagnosis and Treatment Unit of Metabolic Congenital Diseases. Hospital Clínico Univ. de Santiago, Santiago de Compostela

16.00h **CONFERENCE**

“Clinical trial with enzyme replacement therapy in MPS III-B”
Dra. M^ª del Mar O’Callaghan, Neuropediatrics Department of Hospital Sant Joan de Déu, Barcelona

16.20h **CONFERENCE**

“FIND Project. Strategy for the early diagnosis on MPS”
Dr. Cristobal Colón Mejeras. Diagnostic and Treatment Unit of Metabolic and Congenital Diseases. Paediatrics Dept. Complejo Hospitalario Univ. de Santiago de Compostela. Xerencia de Gestión Santiago de Compostela

16.40h **CONFERENCE**

“Physiotherapy Guide of MPS”
Alba Jiménez Angulo. Specialist Neurological Physiotherapist in rare diseases. Madrid

17.00h **CONFERENCE**

“¿Who help me? The caregiver in Rare Diseases role”
Alba Ancochea. Licensed in Psychology and Special Education Subdirector Spanish Federation of Rare Diseases

17.20h **PANEL DISCUSSION**

“Answer your questions with the expert II Part”

18.00h **SPECIAL SESSION FOR MPS III o Sanfilippo Disease**

Moderator: Dra. Mercedes Pineda. Neuropediatrician of Sant Joan de Déu Foundation and Clínica Quirón Teknon, Barcelona
•“Developing gene therapies for rare diseases - a global approach to treating Sanfilippo syndrome”. Timothy J. Miller. Abeona Therapeutics
•“Lysogene gene therapy: current status and future development programme”. Samantha Parker. Lysogene’s Chief Patient Access/Public Affairs Officer

20.30h **“GALA DINNER SPANISH MPS SOCIETY “ Charity raffle for MPS society and prize draw**

	Affected families MPS		Attendees
ADULTS			
Conferences	Free		Free
Dinner friday 3	15		26,95
Lunch saturday 4	15		26,95
Dinner saturday 4	15		26,95
CHILDREN	(Afect. x MPS)	No afect.	
Dinner friday 3	Free	Free	Free
Lunch saturday 4	Free	Free	Free
Dinner saturday 4	Free	Free	Free
HOTEL RAFAEL MADRID NORTE ****			
Single room	30		60,50
Doble room	40		71,50
Triple room	60		82,50
Family room	80		98,00
(Prices include VAT and breakfast room/night)			
** Members: those with 6 months of the day of payment MPS fee			

KIDS PROGRAM

All the children coming to the congress will have a playground place. That space will be organized by Volunteers of La Obra Social “La Caixa”. This service is free for all.

This year will have different groups:

Baby sitting service MPS: For kids 8 years old and kids with neurological affection.

Playground MPS: From 8 years old.

During the day, dogs from “Tanamigos” Society will do different activities with kids. The objective is to promote the improvement of physical, psychosocial and cognitive functions for a better social integration of child.

Technical Secretary:

Phone registration, information and doubts:

Reunions i Ciència S.L.

Pilar Garcia - Olivia Cuadrado

Congress Department

E-mail: congresomps@gruporic.com

Tel. 93.410.86.46 Fax 93.430.32.63

Until 1st September: 9h a 15h

From 2nd September: 9h a 14h - de 15h a 18h.

To be part of this congress is necessary to fill up the attached inscription before 27th September.

Payment to: REUNIONS I CIÈNCIA S.L.

“Bank Sabadell”: ES69-0081-0172-9600-0130-6734

