Thursday October 17 <sup>th</sup> : Patients 'groups Empowerment		
8.15	Participants should be at the hall of the Hotel Execuive. Coaches will leave and take them to destination	
9.00h	Welcome message at the Town Hall in Lorca	
9.30h	Keys and evolution of the associative community in Spain. Tomás Castillo, Treasurer of FEDER and Luján Echandi, Manaager of Relations with members. FEDER.	
10.00h	<b>Evaluation of the disability degree: an international perspective.</b> Tomás Castillo, Treasurer of FEDER. Consultant of WHO on the International Disability and Health Function Classification (IDFC). Project "making disability visible to the world"	
10.30h	What is the cost of Rare Diseases? Study on the financial burden and quality of life of people with rare diseases and their carers. Based in 10 rare diseases in 8 European countries. (BURQOL-RD). Pedro Serrano, FUNCIS	
11.00h	Observatory of the Rare Diseases. Studies of social Research ENSERio increasing the knowledge of the ER. Antonio Bañón, Responsible for OBSER of FEDER	
11.30h	Advances in the Social Services in Rare Diseases in Spain: National Centre of Reference for People with Rare Diseases and their Families CREER in Burgos, Aitor Aparicio, Director of CREER	
12.00h	Coffee break	
12.30h	Translational research, from biomedical research to the clinical care in rare diseases.  Francesc Palau, Scientific Director of The Biomedical Research Centre for Rae Diseases (CIBERER).  Valencia.	
13.00h	<b>Experiences of the Spanish Case-Control Registry on Congenital Anomalies (ECEMC) and its outcomes.</b> María Luisa Martínez-Frías, Director of Research Centre on Congenital Anomalies (CIAC) at the Health Institute Carlos III	
13.30h	Presentation of the Association Paolista de Mucopolisacaridosis and Rare Diseases APMPS E RARÍSSIMAS. <i>Brazil</i>	
14.00h	Presentation of the Rare Diseases Federation Portugal (FEDRA). Portugal	
14:30	Presentation of the Augusto Turenne Foundation. Uruguay	
15:00	Conclusions and ideas for action	

### I ENCUENTRO IBEROAMERICANO DE ENFERMEDADES RARAS

DIRIGIDO A PROFESIONALES Y REPRESENTANTES DE ASOCIACIONES DE ENFERMEDADES RARAS

14 A 18 OCTUBRE 2013



9.00h Photographic exhibition "Patient 123". Artistic sample that inspires thoughts about the disease, pain, treatment and hope to find the simplest things reasons to live every day

> Artist: Carlos Mauricio Bernal (Pacient 123) with Melorreostosis. Colombia



EXHIBITION: "Entre bordados y barro" is a traveling exhibition that takes six months in various cities. This consists of two craftsmen from the region of Murcia. "Trajes regionals Justa" and "Alfar Tudela", recent winner of Murcia regional crafts prize in

creative crafts category

Lunch

Conclusions of the 1st Iberoamerican meeting 9.30h

Signature of the Latin-American Alliance of Rare Diseases 10.30h

Meeting with the Spanish Authorities 11.00h

OPENING SESSION 1st PART: 12.00h

ROUND TABLE: LIFE STORIES OF PEOPLE WITH RARE DISEASES

OPENING SESSION 2nd PART.

START OF 6th NATIONAL CONGRESS ON ER.





**FEDER** 

movat

### Program of the Congress



**MONDAY October 14h:** 

Advocacy and Lobby for people with RD rights. Policy Action

Sightseeing: Murcia 's cathedral and old city



**TUESDAY October 15th:** 

**Projects and Services for Families with Rare Diseases Care model for Rare Diseases** 

Sightseeing: Roman Theatre in Cartagena and old city



**WEDNESDAY October 16th:** 

Visibility and Awareness Rare Diseases Day 2014
Sightseeing: La Santa Sanctuary and Aledo Medieval
City



THURSDAY October 17th:

Support Groups Empowerment

Sightseeing: Lorca Castle and old city



FRIDAY October 18th:

Key partnership lines for the Iberoamerican Alliance of Rare Diseases

Start of the VI National Congress of Families with Rare Diseases









## MONDAY October 14th: Policy Action

**8.15 am** Participants should be at the hall of the Hotel Execuive. Coaches will leave and take them to destination

9.00h Registration

Welcome message at the Town Hall in Murcia

9.30h Welcome message at the Town Hall in Murci

10.00h Opening session of the 1st Iberoamerican meeting of Rare Diseases. Goals and expected outcomes. Juan Carrión, President of FEDER, Elizabeth Zabala, Organiser Committee and Naca Eulalia Pérez de Tudela, president of D´Genes

10.15h What is the situation of the Rare Diseases in Spain? 13 Proposals for the 2013 Rare Diseases Year. Policy Action. Claudia Delgado, Executive Director of FEDER

11.00h What is the state of the art regarding advocacy on people with RD rights in Europe? Yann Le Cam, Executive Director of EURORDIS

11.45h Coffee break

12.15h Presentation of the Colombian Federation of Rare Diseases (FECOER). Colombia

12.45h Presentation of the Argentinian Federation of Rare Diseases (FADEPOF). Argentina

13.15h Presentation of the Uruguayan Association of Rare Diseases "Todos Unidos"

13.45h Presentation of SIO Guatemala. Spanish Charity Association. Guatemala

14.15h Presentation of Patients' Venezuelan Association with Lisosomal Disease.

Venezuela

14.45h Conclusion and ideas for action

ATUERU. Uruguay

15.00h Lunch



#### **Tuesday October 15th:**

Projects and Services for Families with Rare Diseases

A Care model for Rare Diseases

8.15 h	Participants should be at the hall of the Hotel Execuive. Coaches will leave and take them to destination	
9.00 h	Welcome message at the Town Hall of Cartagena	
9.30 h	<b>FEDER Help Line SIO Information and Orientation Service on RD</b> : a holistic approach to support families with RD. <i>Estrella Mayoral, SIO Coordinator. FEDER</i>	
9.45h	European Help Lines Network for RD in Europe. The relevance of joint action. Rosa Sánchez de Vega, EURORDIS & FEDER Board member	
10.15h	Innovative experiences in psychological support for Rare Diseases. Isabel Motero, Psychologist of FEDER	
10.45h	<b>Educative experiences in Rare Diseases</b> to promote children 's inclusion at school. <i>Alba Ancochea, Psychologist of FEDER</i>	
11.15h	Coffee break	
11.45h	A model for Rare Diseases Care in Europe European Reference Networks. John Dart, General Secretary of EURORDIS	
12.15h	A model for Rare Diseases Care in Spain, FEDER proposal: Reference Centrea (national level) and Clinical Expertise Units for RD (regional level). ENSERio2 Study. <i>Justo Herranz, Board member of FEDER</i>	
12.45h	Presentation of Cronicare Foundation. Colombia	
13.15h	Presentation of the Patients' Ecuadoran Foundation with Lisosomal disease  FEPEL/DASHA. Ecuador	
13.45h	Presentation of Mexican Federation of Rare Diseases. FEMEXER / Project Ask for a wish. <i>Mexico</i>	
14.15h	Presentation of Rare Diseases Study Group GEDR. Brasil	
14:45h	Conclusion and ideas for action	



Lunch

15.00h

12.30h

13.00h

13.30h

14.00h

14.30h

15.00h









# WEDNESDAY October 16th: Visibility and Awareness. International Day in 2014

8.15 h	Participants should be at the hall of the Hotel Execuive. Coaches will leave and take them to destination	
9:00h	Welcome message at the Town Hall in Totana. Murcia	
9:30h	How to become visible in society?: Practical ideas to achieve a social change. Maria Tomé, Manager of Comunicación and Fundraising. FEDER	
10:00h	Planning the next International Rare Disease Day 2014: "Together we are stronger".  Anja Helm, Manager of Relations with Associations. EURORDIS	
10.30h	Raising funds strategy. Relations with the industry: Ethical issues, Independence, transparency. María Tomé, Manager of Comunicación and Fundraising of FEDER and Claudia Delgado, Executive Director of FEDER	
11:00h	<b>Social network 'Rare Connect':</b> Building a Rare Diseases community around the world. <i>Denis Costello, Rare Connect project. EURORDIS.</i>	
11:30h	Presentation of the Spanish-speaking Community Latin Marfan Community.  Venezuela.	
12:00h	Coffee break	

Presentation of GADAPER Online Community. Argentine Group for the support of

The National Registry of Rare Diseases in Spain: Manuel Posada. Director of the

Presentation of the Patients' Colombian Association with Lisosomal Disease

Presentation of the Mexican Organization of Rare Diseases OMER. Mexico

Patients with Rare Diseases. Argentina - Spain.

(ACOPEL). Colombia.

Lunch

Conclusions and ideas for action

National Research Institute for Rare Diseases. IIER. ISCIII