



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



Tuesday October 15th:
Projects and Services for Families with Rare Diseases
A Care model for Rare Diseases

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| 8.15 h | Participants should be at the hall of the Hotel Executive. Coaches will leave and take them to destination |
| 9.00 h | Welcome message at the Town Hall of Cartagena |
| 9.30 h | FEDER Help Line SIO Information and Orientation Service on RD: 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. <i>Isabel Motero, Psychologist of FEDER</i> |
| 10.45h | Educative experiences in Rare Diseases 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. <i>John Dart, General Secretary of EURORDIS</i> |
| 12.15h | A model for Rare Diseases Care in Spain, FEDER proposal: Reference Centres (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. <i>Colombia</i> |
| 13.15h | Presentation of the Patients' Ecuadoran Foundation with Lissosomal disease.. FEPEL/DASHA. <i>Ecuador</i> |
| 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. <i>Brasil</i> |
| 14:45h | Conclusion and ideas for action |
| 15.00h | Lunch |



MONDAY October 14th:
Policy Action

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| 8.15 am | Participants should be at the hall of the Hotel Executive. Coaches will leave and take them to destination |
| 9.00h | Registration |
| 9.30h | Welcome message at the Town Hall in Murcia |
| 10.00h | Opening session of the 1st Iberoamerican meeting of Rare Diseases. Goals and expected outcomes. <i>Juan Carrión, President of FEDER, Elizabeth Zabala, Organiser Committee and Naca Eulalia Pérez de Tudela, president of D'Genes</i> |
| 10.15h | What is the situation of the Rare Diseases in Spain? 13 Proposals for the 2013 Rare Diseases Year. Policy Action. <i>Claudia Delgado, Executive Director of FEDER</i> |
| 11.00h | What is the state of the art regarding advocacy on people with RD rights in Europe? <i>Yann Le Cam, Executive Director of EURORDIS</i> |
| 11.45h | Coffee break |
| 12.15h | Presentation of the Colombian Federation of Rare Diseases (FECOER). <i>Colombia</i> |
| 12.45h | Presentation of the Argentinian Federation of Rare Diseases (FADEPOF). <i>Argentina</i> |
| 13.15h | Presentation of the Uruguayan Association of Rare Diseases "Todos Unidos" ATUERU. <i>Uruguay</i> |
| 13.45h | Presentation of SIO Guatemala. Spanish Charity Association. <i>Guatemala</i> |
| 14.15h | Presentation of Patients' Venezuelan Association with Lissosomal Disease. <i>Venezuela</i> |
| 14.45h | Conclusion and ideas for action |
| 15.00h | Lunch |



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

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| 8.15 h | Participants should be at the hall of the Hotel Executive. 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. <i>Maria Tomé, Manager of Comunicación and Fundraising. FEDER</i> |
| 10:00h | Planning the next International Rare Disease Day 2014: "Together we are stronger". <i>Anja Helm, Manager of Relations with Associations. EURORDIS</i> |
| 10.30h | Raising funds strategy. Relations with the industry: Ethical issues, Independence, transparency. <i>Maria Tomé, Manager of Comunicación and Fundraising of FEDER and Claudia Delgado, Executive Director of FEDER</i> |
| 11:00h | Social network 'Rare Connect': 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. <i>Venezuela.</i> |
| 12:00h | Coffee break |
| 12.30h | Presentation of GADAPER Online Community. Argentine Group for the support of Patients with Rare Diseases. <i>Argentina – Spain.</i> |
| 13.00h | The National Registry of Rare Diseases in Spain: Manuel Posada. Director of the National Research Institute for Rare Diseases. IIER. ISCIII |
| 13.30h | Presentation of the Patients' Colombian Association with Lissosomal Disease (ACOPEL). <i>Colombia.</i> |
| 14.00h | Presentation of the Mexican Organization of Rare Diseases OMER. <i>Mexico</i> |
| 14.30h | Conclusions and ideas for action |
| 15.00h | Lunch |