SPAIN

EUROPLAN NATIONAL CONFERENCE

In the framework of the EU Joint Action RD-ACTION

Madrid, 3/November/2017

FINAL REPORT

Co-funded by
the Health Programme
of the European Union

FOREWORD

The EUROPLAN national conferences or workshops are organised in many European countries as part of a coordinated and joint European effort to foster the development of comprehensive National Plans or Strategies for Rare Diseases addressing the unmet needs of patients living with a rare disease in Europe.

These National Plans and Strategies are intended to implement concrete national measures in key areas from research to codification of rare diseases, diagnosis, care and treatments as well as adapted social services for rare disease patients while integrating EU policies.

The EUROPLAN national conferences/ workshops are jointly organised in each country by a National Alliance of rare disease patients' organisations and EURORDIS–Rare Diseases Europe. **Rare Disease National Alliances and Patient Organisations have a crucial role to shape the national policies for rare diseases.**

The strength of EUROPLAN national conference/ workshop lies in its shared philosophy and format:

- **Patient-led**: National Alliances are in the best position to address patients' needs;
- **Multi-stakeholders**: National Alliances ensure to invite all stakeholders involved for a broad debate;
- **Integrating both the national and European approach to rare disease policy;**
- **Being part of an overarching European action** (project or Joint Action) that provides the legitimacy and the framework for the organisation of EUROPLAN national conferences/workshops;
- **Helping national authorities adhere to the obligations stemming from the Council Recommendation of 8 June 2009 on an action in the field of rare diseases.**

Since 2008, National Alliances and EURORDIS have been involved in promoting the adoption and implementation of National Plans and Strategies for rare diseases. Altogether, 30 EUROPLAN national conferences took place in the framework of the first EUROPLAN project (2008-2011) and the EU Joint Action of the European Committee of Experts on Rare Diseases – EUCERD - (2012-2015).

Within RD-ACTION (2015-2018), the second EU Joint Action for rare diseases, National Alliances and EURORDIS continue to get involved in a coordinated European effort to advocate for and promote integrated national policy measures that have an impact on the lives of people living with rare diseases.

The EUROPLAN national conferences or workshops taking place within RD-ACTION focus on specific themes identified by the National Alliances as the most pressing priorities to tackle with national authorities. These thematic priorities are addressed in sessions where all the stakeholders discuss relevant measures to be taken or ways to sustain the full implementation of already approved measures.

Each National Alliance prepares a final report on the national workshop, based on a common format such as the one that follows.

GENERAL INFORMATION

Country	Spain
National Alliance (Organiser)	Federación Española de Enfermedades Raras - FEDER
Date & place of the national workshop/conference	Madrid, 3/November/2017
Website	www.enfermedades-raras.org
Members of the Steering Committee	

FEDER y su Fundación
D. JUAN CARRIÓN TUDELA (Presidente de FEDER y su Fundación)
D. JUSTO HERRANZ (Tesorero de FEDER y su Fundación)
D. JOSÉ LUIS PLAZA (Miembro de la Junta Directiva de FEDER)
Dª ALBA ANCOCHEA (Directora de FEDER y su Fundación)

Ministerio de Sanidad, Servicios Sociales e Igualdad: D.G. de Salud Pública, Calidad e Innovación
Dª PALOMA CASADO (Subdirectora General de Calidad y Cohesión)
Dª PILAR SOLER (Subdirección General de Calidad y Cohesión)

Ministerio de Sanidad, Servicios Sociales e Igualdad: D.G. de Cartera Básica de Servicios del SNS y Farmacia
Dª MARAVILLAS IZQUIERDO (Subdirectora de Cartera Básica de Servicios y Fondos de Cohesión)
Dª LAURA MARÍN (Subdirección de Cartera Básica de Servicios y Fondos de Cohesión)

Ministerio de Educación, Cultura y Deporte
Dª VIOLETA MIGUEL PÉREZ (Directora del Centro Nacional de Innovación e Investigación Educativa)

Ministerio de Economía, Industria y Competitividad
D. JESÚS FERNÁNDEZ CRESPO (Director del ISCIII)

Consejería de Sanidad de la Xunta de Galicia
D. ALFONSO ALONSO FACHADO (Subdirector general de Planificación y Programación Asistencial de la Dirección General de Asistencia Sanitaria del Servizo Galego de Saúde)

Consejería de Sanidad de Asturias
D.MARIO MARGOLLES MARTINS (Representante de la estrategia en ER de la CA)

Consejería de Sanidad y Servicios Sociales de Cantabria
D. JOSE FRANCISCO DIAZ RUIZ (Representante de la estrategia en ER de la CA)

Consejería de Sanidad de Navarra
D. MARIA JOSÉ LASANTA SÁEZ (Representante de la estrategia en ER de la CA)

Consejería de Sanidad de La Rioja
D. ENRIQUE RAMALLE GOMARA (Jefe de Sección de Información Sanitaria)

Consejería de Sanidad de País Vasco
D. GUILLERMO VIÑEGRA (Asesor de programas Sanitarios y Relaciones Ciudadanas del departamento de Salud del Gobierno vasco)

Consejería de Sanidad de la Comunidad Valenciana
D. PABLO RODRÍGUEZ MARTÍNEZ (Jefe de Servicio de Planificación de Programas y Servicios Sanitarios)

Consejería de Sanidad de Aragón
DR JAVIER LÓPEZ TISÓN (Neurólogo del Hospital Miguel Servet)

Consejería de Sanidad de Andalucía
Dª CARMEN Mª. LAMA HERRERA (Subdirectora de Promoción, Participación y Planes de Salud)
D. RAFAEL CAMINO LEÓN (Director del Plan de Atención a Personas Afectadas por Enfermedades Raras)

Consejería de Salud de Murcia
Dª ENCARNA GUILLÉN NAVARRO (Representante de la Estrategia en ER de la Comunidad Autónoma)

Consejería de Sanidad y Políticas Sociales de Extremadura
D. TOMÁS ZARALLO BARBOSA (Jefe de Servicio de Participación Comunitaria en Salud)

Consejería de Sanidad de Castilla La Mancha
Dª MARÍA TERESA MARÍN RUBIO (Directora General de Planificación, ordenación e Inspección Sanitaria)
Dª EMMA CATALÁN RUEDA (Jefa de Servicio de Planificación)

Consejería de Sanidad de Castilla y León
Dª MARÍA ROSA DE LOS RÍOS MARTÍN

Consejería de Sanidad de Madrid
Dª VICTORIA BENAVIDES SIERRA (Responsable del Plan de Enfermedades Poco Frecuentes de la Consejería de Sanidad)

Consejería de Sanidad de Islas Baleares

Dª ISABEL ZALDÍVAR LAGUIA (Subdirectora de Cartera de Servicios del Servicio de Salud) **Instituto de Salud Carlos III** D. JESÚS FERNÁNDEZ CRESPO (Director del ISCIII) **Instituto de Investigación de Enfermedades Raras** D. MANUEL POSADA (Director IIER) **Centro de Investigación Biomédica en Red – Enfermedades Raras** DR. JULIÁN NEVADO (Responsable Área de Genómica Estructural y Funcional - Hospital Universitario La Paz) **Profesionales sanitarios y sociedades científicas** DR. ANTONIO PÉREZ AYTÉS (Miembro del Comité Asesor de FEDER) **Industria** Dª MARGARITA INIESTA (Directora Ejecutiva de AELMHU) **FEDER** Dª ISABEL MOTERO (Área de Formación) Dª PATRICIA ARIAS (Área de Investigación) Dª REBECA SIMÓN (Área de Comunicación) Dª LARA ALBACETE (Área de Investigación)	
List of Themes addressed	Research Centres, Services and Units of Reference (CSUR) and European Reference Networks (ERNs) Access to diagnostics and treatment
Annexes :	I. Programme in English II. List of Participants III. Photographs

FINAL REPORT

Plenary Session

On 3rd June 2009 the Spanish Department of Health and Social Policy announced the launch of a National Strategy for RD (rare diseases) within the National Health System with the objective of understanding and analysing the situation in Spain with regard to RD. Within the European Directives noted in the Council's Recommendation Document in relation to a European action on rare diseases, the first EUROPLAN conference was held in 2010.

Four years later, following the same methodology, the Spanish Federation of Rare Diseases (Federación Española de Enfermedades Raras, FEDER) organised a second EUROPLAN conference in Spain to review the current situation for RDs, what advances have been made and identify challenges and needs which require a response. The second EUROPLAN Conference in Spain was held on 20 and 21 November 2014 at the Department of Health, Social Services and Equalities (Ministerio de Sanidad, Servicios Sociales e Igualdad, MSSSI).

In 2017 a conference is planned with the objective of addressing the most relevant questions for each country. The issues defined for Spain are:

1.- Research

2.- Centres, Services and Units of Reference (CSUR) and European Reference Networks (ERNs)

3.- Access to Diagnostics and Treatment

This edition commenced in May with the consolidation of the Development Committee. Since then, work has been ongoing with **more than 70 representatives involved** in the strategy towards rare diseases. It is important to point out that autonomous participation has increased four-fold since the last EUROPLAN: 16 Implicated Autonomous Communities conference. **Central administration** has also been involved in the same way as in the previous two editions, **experts from the health and scientific sector** have also taken part and, of course, **the patients**.

The inauguration of the Conference was organised by Paloma Casado, Deputy Director General for Quality and Cohesion at the MSSSI and Juan Carrión, the President of FEDER and its Foundation.

The closing ceremony of the conference was the responsibility of Simona Bellagambi, the EURORDIS EUROPLAN Advisor.

Themes

1. Working Group: Research

Indicators:

1.- Monetary funds (euros) destined específically for projects researching rare diseases within the medical field, per 100.000 inhabitants per year.

Verification Sources:

ISCIII(Institute of Health Carlos III): the specific commission for RD and others
MINECO(Ministry of Economy, Industry and Competitiveness)
Private and others (associations, foundations, private companies…)

Rationale: Finance for research is fundamental. For this reason, it is necessary to understand the existing resources at a public and private level, including those obtained through patient organisations.

The information obtained should be broken down according to funding sources. When referring to a multi-centre study, this will be assigned to the Autonomous Community in which the lead researcher is based.

The criteria for the definition of funds destined for research should be standardised, and include only those funds destined specifically for research projects.

Proposal

- To request from MINECO and the ISCIII the identification of RD research projects financed by the Action for Strategic Health (Acción Estratégica en Salud) beyond those identified by the specific commission for evaluating projects on rare diseases.
- Launch a centralised Register for social and biomedical RD projects which allows a similar gathering of information for both types of projects.

2.- Amount of published biomedical or social research published, by year, on rare diseases in Spain.

Verification Source: MeSH from OrphaData

Rationale: Publishing studies and research allows the sharing of information and provides an understanding of the information that is being shared. The publications collected should be from journals containing at least an ISSN. This information can be gathered via MeSH at OrphaData, and it is important that the information is gathered by quartile of the impact factor in order to have a better understanding of the relevance of these publications. Currently, there is insufficient specific resource allocation for gathering and analysing the data extracted from this source.

Proposal
To acquire specific resources for collecting the necessary information to calculate this indicator.

3.- Number of research groups carrying out biomedical or social research into RD in Spain per year.

Verification sources: MAPER from CIBERER and Orphanet

Rationale: MAPER from CIBERER is available to provide information on how many working groups there are in Rare Disease research. MAPER includes information on competitive and active RD projects in Spain, compiled through the initiative and with the resources of CIBERER. One can also make use of the Research Groups Register on Orphanet, but currently, this register is voluntarily compiled, monitored and updated by the groups.

Proposal:
Request that in the calls for financing, the projects put forward include an identification code for the research group allocated by Orphanet. This identification code could be managed by Orphanet and updated annually by the research group. The purpose is that an external body with a national remit maintains a register of research groups working on RD.

4.- Number of clinical trials on RD for Phases (I-IV) per 100.000 inhabitants per year.

Verification Sources: AEPMS (Spanish Agency for Medicines and Health Products) and EMA (European Medicines Agency)

Justification: An important part of the research into RD is the clinical trials for the development of treatments. The information should be gathered according to added value as well as by Phases (I-IV).

Proposal
To also include ClinicalTrials.gov and EudraCT as verification sources, if the REec of AEMPS does not gather the research developed by the lead researcher in Spain.

5.- Number of Autonomous Communities which contain established autonomous calls for financing research projects in which rare diseases are within the priority themes, by year.

Verification Sources: Those responsible for the RD Strategy in each Autonomous Community.

Rationale: This indicator is a temporary one and responds to the need for gathering the feelings of the public administration relating to RD.

Proposal

Once this indicator has reached 100% it should be substituted for an analysis of the specific allocations from each Autonomous Community for financing RD research projects, per 100.000 inhabitants.

Issues to Emphasise

It is difficult to gather information on research in Spain: where the research is being carried out, what is being researched and what finance has been allocated to this research.

Providing general information about this sector is complex and it is very fragmented, there is no systematic gathering and the criteria for gathering this information is not standardised.

Nonetheless, the need to possess this information is patently obvious, in order to optimise resources, to share the information and for it to reach the patients and society at large.

The selected indicators are those defined as priorities. It is also important to point out that there are other questions which could be incorporated into future phases.

Conclusions

Given that the proposed information on indicators is not available immediately, it is necessary to create a search, development and monitoring process, as well as to establish uniform criteria and objectives, a work timetable and the allocation of resources. It is necessary to create a specific structure to carry this task forward. This could be similar to the model already cited in the Strategy (the National Transplant Organisation model).

This would lead to the creation of an entity with specific resources which is responsible for the gathering of information, monitoring and tracking of research indicators.

Through the work carried out by this body we will be able to obtain these indicators and evaluate if the proposed objectives have been achieved. It will also be necessary to explore new indicators that take patient participation in research into account.

2. Working Group: CSUR and ERNs

Indicators

1.- Number of Department of Health web pages that include easy to access information on the CSUR and ERN Project, such as the patient referral process.

Verification Sources: Websites of the Departments of Health within the Autonomous Communities.

2.- Existence of finance specifically allocated to the CSUR and ERN project.

Verification Sources: Information on the General State Budgets.

3.- Percentage of ERN with the participation of at least one CSUR.

Verification Sources: Data provided by MSSSI and the European Commission.

4.- Number of CSUR that have established collaboration agreements with patient organisations.

Verification Sources: CSUR and patient organisations.

5.- Existence of autonomous units or coordination centres that coordinate referrals to CSUR for patients with rare diseases.

Verification Sources: The Autonomous Communities.

Issues to Emphasise:

- The need for Spain to be represented within all ERNs.
- Improve the participation process in ERNs and the visualisation of criteria for participation in ERNs.
- The need to standardise criteria in order to provide "endorsements" for participating in ERNs.
- Address the re-designation of CSUR.
- The need to increase the identification of new susceptible pathologies to be dealt with in CSUR.
- Increase the resource and finance allocations of the CSUR Project and of CSUR itself.
- The need to increase the integration of care and coordination at all levels.
- Support non face-to-face consultations.
- Promote the concentration of experience in the Autonomous Communities.

Recommendations:

1- Actively implicate all actors (MSSSI, CCAA, Scientific Societies and Patients Associations) in the promotion of the CSUR Project and the referral of patients with rare diseases both to the general population and to health professionals.

2- Incorporate clear information on the Autonomous Communities' websites, Help Centres, Scientific Societies and Patients Associations.

3- Create information leaflets.

4- Inform - train professionals and patient associations on the CSUR referral process.

5- Improve resources and financial allocations both for the CSUR Project and for CSUR itself: Provide a Budget for the Cohesion Fund.

6- Provide TIC tools for coordinating the different levels of assistance which will allow for the optimal use of resources.

7- Identify new pathologies for the CSUR designation.

8- Encourage CSUR representatives to participate in the ERNs.

9- Facilitate the dissemination of the ERNs access criteria.

10- Encourage CSUR participation in the ERNs so that it becomes a link for mutual assistance and for the dissemination of knowledge on the National Healthcare System.

11- Encourage CSUR to establish collaboration agreements with patient organisations with a national remit as well as those agreements which exist at the autonomous region level.

12- Carry out a satisfaction survey for patients at CSUR.

13- Encourage the creation of coordination units or centres at the autonomous level to facilitate the referral of patients with rare diseases.

14- Encourage CSUR to act as advisors to clinical units which regularly care for patients.

15- Develop a cycle which allows the patient access to a second opinion within the corresponding CSUR.

16- Encourage the study of covering costs within each Autonomous Community: an analysis of the differences between Autonomous Communities relating to the following costs:

- Housing and maintenance expenses
- Transfers
- Companion costs

17- Improve the efficiency of the CSUR annual monitoring system.

3. Working Group: Access to Diagnostics and Treatment

Indicators:

ACCESS TO DIAGNOSTICS:

1.- PRE-NATAL: Number of pregnancies included in the diagnostics for pre-natal/total pregnancies (referred to each health centre and later added by the Autonomous Community) per year.

Verification Source: The Autonomous Communities, at the hospital obstetrics centres/services level. The data could be gathered at the point of service and the hospital could report this to the community as a further management indicator and aggregate all of this data annually and present it by year and by Autonomous Community.

Recommendation:

The establishment of standardised protocols for the referral of pregnant women at risk to pre-natal diagnostic Units in each Autonomous Community.

2.- NEO-NATAL: Number of diseases included in neonatal screening within each Autonomous Community. Number of cases diagnosed through the neonatal screening programme by total births per year, gender, Autonomous Community and for each disease.

Verification Sources:

- *The information system for the SNS neo-natal screening programme*
- *The Autonomous Communities health services possess this information*
- *The AECN could provide this data although, due to their data gathering system, it is obvious that the information should refer to previous years.*

Recommendation:

Make advances in broadening the definition of diseases detected through neonatal screening based on scientific evidence and agreement on quality criteria as defined by the Department for Health, Social Services and Equality Framework Document on population screening.

3.- DIAGNOSTIC RESOURCES: Number of centres with Genetic Units which are recognised as Services/Units divided by number of health centres (hospitals) in the stated Autonomous Community.

Verification Sources: Health services within the Autonomous Communities.

Recommendation:

Guarantee access to genetic diagnostics in all the Autonomous Communities, either through their own centres or by referral to specialist centres.

4.- DIAGNOSTIC RESOURCES: Number of persons included in Case Programmes without a diagnosis. Number of Autonomous Communities that include the CGH Array and Exoma tests in their service portfolio.

Verification Sources: The Health Departments within the Autonomous Community.

Recommendation:

Standardise Protocols for studying non-diagnosed cases and for the range of genetic studies Portfolios within the Autonomous Communities.

5.- EFFICIENT USE OF DIAGNOSTIC RESOURCES: NUMBER OF Primary Care professionals that have received accredited training on rare diseases from the Autonomous Communities.

Verification Sources:

- *Health Services within the Autonomous Communities*
- *Sub-Directorate General for the Health Departments within the Autonomous Communities. AP Management.*

Recommendation:

Increase the offer of rare diseases training for professionals in Primary Care from the Teaching Units and the Health Services within the Autonomous Communities.

ACCESS TO TREATMENT

6.1- Number of Orphan Drugs (OD) financed in Spain / number of OD authorised by the AEMPS.
6.2- Number of OD authorised in Spain / OD authorised by the EMA.
6.3- Time elapsed between the request for finance, cost and resolution (ranked median).

Verification Sources:

- *MSSSI: DG of Pharmacy should hold this information*
- *AELMHU. Farmaindustria. CIMA. BOTPlus*
- *AEMPS.*

Recommendation:

Optimise authorisation and financing for OD in order to improve access time.

7.- Number of patients treated with OD and/or therapies by disease, Autonomous Community and year.

Verification Sources:

- *Health Services within the Autonomous Communities*
- *AEMPS*

Recommendation:

Improve access to treatments with OD and/or financed therapies.

8.- Number of authorised treatments in compassionate use drug trials (art. 1 letter a) R.D 1015/2009) for the treatment of a rare disease per year/total requests. Number of patients included in the clinical trial for the drug / estimated number of patients according to the State Register for RD.

Verification Sources: State Register for RD and participants in the Clinical Trial.

Recommendation:

Accelerate the access process for clinical trials in order to create contrasting evidence and minimise the use of drugs in particular situations.

9.- Number of patients with RD who have access to functional rehabilitation.

Verification Sources:

- Hospitals y Health Centres (physical medicine and rehabilitation Units)
- Health Services within the Autonomous Communities

Recommendation:

Modify part 8 of the RD 1030/2006 of Anexo III in a way that facilitates access to functional rehabilitation services based on prevention and the promotion of health for a person and their environment (family, employment, education…).

Current Situation

ACCESS TO DIAGNOSTICS:

- Delays in diagnosis and inequalities in access to genetic and clinical diagnostics
- Scarce participation in international forums relating to the most complex diagnostic cases
- 50% of Autonomous Communities have facilitated the creation of Primary Care for RD
- Scarce availability of genetic services and professionals in Third Level hospitals

ACCESS TO TREATMENT:

- Unequal access to treatments including re-evaluation and disparity in the Autonomous Communities' criteria
- Budgetary impacts posed by OD in first and second level hospitals
- Difficulty in accessing non-pharmaceutical therapeutic treatments
- Scarce support for the provision of Rehabilitation services for persons with RD
- In some circumstances, scarce evidence of cost/use which could impede access to services
- No specific funding in existence that guarantees equal access to authorised drugs

ANNEXES

Annex I: Programme

Thursday 2nd November 2017
GROUP WORK SESSIONS

10:00 hrs	**Registration and document collection**
10:30 hrs	Participant Welcome
10:45 hrs	Plenary Meeting "The European Context for Rare Diseases and the EUROPLAN Project" Simona Bellagambi, EUROPLAN Eurordis Advisor (EUROPLAN Assessor at Eurordis)
11:05 hrs	Questions/Debate
11:15 hrs	Break
11:45 hrs	Group work sessions Pooling of group results
14:00 hrs	Lunch
15:30 hrs	Creation of final group reports
18:00 hrs	End of session
18:05 hrs	Group representatives meeting

Friday, 3rd November 2017
GROUP WORK SESSIONS

08:30 hrs	**Accreditation of Work Groups**
09:00 hrs	Group work session - Creation of final group report
11:00 hrs	- Break

PUBLIC SESSION

11:00 hrs	**Accreditation**
11:30 hrs	Opening Ceremony
12:00 hrs	Results of work groups - Group 1: Research into RD - Group 2: CSUR and ERNs - Group 3: Access to diagnostics and treatment
12:50 hrs	Closing Ceremony EUROPLAN III - Simona Bellagambi, EUROPLAN Eurordis Advisor (EUROPLAN Assessor at Eurordis)

DEBRIEF SESSION

13:00 – 14:00 hrs	**DEBRIEF SESSION** **Communication of EUROPLAN III recommendations to relevant authorities for rare diseases.**

Annex II: Participants

Working Group: Research	
D. Jose Luis Plaza	*Miembro JD FEDER*
Dª Lara Albacete (SECRETARIA)	*Técnico de investigación FEDER*
D. Oscar Zurriaga	*Jefe de la Sección de Estudios e Información Epidemiológica en Conselleria de Sanitat de la Comunidad Valenciana*
Dª Pilar Giraldo	*Coordinadora del Grupo de estudio de enfermedad de Gaucher y otras enfermedades lisosomales. EB EL Istituto de Investigación Sanitaria de Aragón. GII Aragón 012. Jefe de grupo de unidad de CIBERER.*
Dª Eva Bermejo	*IIER Presidenta del Centro Internacional de Vigilancia e Investigación de los Defectos Congénitos Coordinadora del ECEMC. Grupo U724-CIBERER*
D. Pablo Lapunzina	*Director científico del CIBERER y en el INGEM M del Hospital La Paz*
Dª. Esther Vicente (MODERADORA)	*Técnico del Registro de Enfermedades Raras del Instituto de Salud Pública y Laboral de Navarra*
D. Enrique Ramalle-Gómara	*Jefe de sección de información sanitaria del gobierno de la Rioja y responsable del Registro de ER de La Rioja.*
D. José María Mato / D. Jorge Dueñas	*Investigador y Director del CICbiogune de PV*
D. Francisco Sánchez Malo	*Jefe de Servicio de Investigación. Consejería de Salud de Andalucía*
Dª Teresa Chavarría Gimenez	*Subdirectora General de Investigación de Madrid*
Dª Naciba Zetchi	*Representante de AELMHU*
D. Manuel Gomez de Cadiñanos	*Representante de AELMHU*
D. Antonio Liras	*Coordinador Grupo de Investigacion UCM de Terapias Avanzadas*
Dª Patricia Arias	*Área de investigación y conocimiento de FEDER y miembro de Secretaría Técnica de EUROPLAN*
Working Group: Centres, Services and Units of Reference (CSUR) and European Reference Networks (ERNs)	
Dª Gema Esteban	*Delegada FEDER*
Dª Irene Rodríguez (SECRETARIA)	*Responsable Delegación Andalucía FEDER*

D. Jordi Pérez López	*Miembros de la SEMI*
D. Ignacio Blanco (MODERADOR)	*Miembro de la Asociación Española de Genética Humana*
Dª Pilar Soler Crespo	*MSSSI Subdirección General de Calidad y Cohesión Dirección General de Salud Pública, Calidad e Innovación*
D. Aitor Aparicio García	*Director-Gerente del Centro de Referencia Estatal de Atención a Personas con Enfermedades raras y sus Familias, CREER, dependiente del IMSERSO.*
Dª Carmen Pérez Mateos	*Consejera Técnica SG de Cartera de Servicios del SNS y Fondos de Compensación*
Dª Laura Marín Calvo	*Jefa de Servicio SG de Cartera de Servicios del SNS y Fondos de Compensación*
D. Mario Margolles	*Representante de la estrategia en ER de su CA de Asturias*
Dª Encarna Guillén Navarro	*Representante de la estrategia en ER de su CA de Murcia*
Dª Rosario Sánchez Martínez	*Responsable de la Unidad Multidisciplinar de Enfermedades de baja prevalencia Hospital General Universitario de Alicante de Valencia*
D. Tomás Zarallo Barbosa	*Jefe de Servicio de Participación Comunitaria en Salud. Dirección General de planificación, formación y calidad sanitarias y sociosanitarias de Extremadura*
Dª Rosell Francisco Bordas	*Área de Atención Sanitaria del servicio Catalán de Salud*
Dª Anna Salazar	*Representante de AELMHU*
Dª Mar Miñano	*Representante de AELMHU*
D. Justo Herranz	*Miembro de la Secretaría Técnica de EUROPLAN*
Working Group: Access to diagnostics and treatment	
Dª Carmen López	*FEGEREC*
D. Manuel Pérez (MODERADOR)	*Miembro de Patronato de Fundación FEDER*
Dª Miriam Torregrosa (SECRETARIA)	*Técnico de Convocatoria de Ayudas FEDER*
D. Fernando Torquemada	*Responsable Asesoría Jurídica FEDER*
D. Carlos Ribot Catala	*Médico de familia en El Centro de salud Jaime vera de Leganés*
D. Miguel García Ribes	*SEMFYC- médico de Atención Primaria*
Dª Paloma Casado	*Subdirectora General de Calidad y Cohesión*
Dª Mercedes Martínez	*Consejera Técnica de la Subdirección General de Calidad de Medicamentos y Productos Sanitarios*
D. Manuel Posada	*Director IIER*

Dª Pilar Díaz de Torres	*Consejera técnica de la S.G. de Cartera de Servicios del SNS y Fondos de compensación*
Dª Belén Pérez González	*Jefe de un grupo del CIBERER*
D. José Francisco Díaz Ruiz	*Representante de la estrategia en ER de su CA de Cantabria*
D. Javier López Pisón	*NEURÓLOGO DPTO. PEDIATRÍA HOSPITAL UNIVERSITARIO MIGUEL SERVET de Aragón*
Dª Emma Corraliza Infanzón	*Responsable de la Unidad Multidisciplinar de Enfermedades de baja prevalencia de Castilla la Mancha*
D. Jordi Rosell Andreo	Coordinador autonómico de la estrategia de enfermedades raras en las Islas Baleares
D. Roberto González	Representante de AELMHU
Dª Elena Molina	Representante de AELMHU
Dª Isabel Motero	*Área de formación y responsable del servicio de atención psicología de FEDER y miembro de Secretaría Técnica de EUROPLAN*

Annex III: Photographs

WORKING GROUPS

Working group: Research

Working group: Centres, Services and Units of Reference (CSUR) and European Reference Networks (ERNs)

Working group: Access to diagnostics and treatment

CONFERENCE

Welcome Speech: Mrs. Paloma Casado, Subdirectora General de Calidad y Cohesión and Mr. Juan Carrión, FEDER and its Foundation President

Exhibition of results: Mr. Enrique Ramalle, Working Group Research spokesperson

Exhibition of results: Mr. Ignacio Blanco; Working Group CSUR and ERN spokesperson

Exhibition of results: Mr. Manuel García Ribes, Working Group Access to diagnostics and treatment spokesperson

Speech of Mrs. Alba Ancochea, FEDER and its Foundation Director

Speech of Mrs. Simoma Bellagambi, EURORDIS Advisor