INSA, I.P.
Instituto Nacional de Saúde Dr. Ricardo Jorge

**EJA: EUCERD Joint Action: working for rare diseases**
Glória Isidro

24 de Março de 2014
Introduction

- Joint Action is a co-funded activity between European Commission (EC) and Member States (MS)

Total of 5,504,258€ (five million, five hundred and four thousand and two hundred and fifty-eight Euros) = EC 54.4% (2,994,162€) + 45.6% MS (2,510,096€)

- Project duration: 42 months from March 1st, 2012

- Action supporting the mandate of EUCERD/ expert group
The European Union Commitee of Experts on Rare Diseases was formally established by the European Commission Decision of 30 November 2009 (2009/872/EC) and its first mandate took place between 2010 and 2013. Since 2014 EUCERD was substituted by the European Commission Expert Group on Rare Diseases, established by Decision 2013/C 219/04 with its first meeting in Feb in Luxembourg.

- assisting the Commission in the monitoring, evaluating and disseminating the results of measures taken at Community and national level in the field of rare diseases;
- contributing to the implementation of Community actions in the field, in particular by analyzing the results and suggesting improvements to the measures taken;
- contributing to the preparation of Commission reports on the implementation of the Commission Communication and the Council Recommendation;
- delivering opinions, recommendations or reports to the Commission either at the latter’s request or on its own initiative;
- assisting the Commission in international cooperation on matters relating to rare diseases;
- assisting the Commission in drawing up guidelines, recommendations and any other action defined in the Commission Communication and in the Council Recommendation;
- providing an annual report of its activities to the Commission.

www.eucerd.eu
Areas of Recommendation (aims):

i) Improve the visibility and recognition of RD;

ii) Contribute to the development of the dissemination of knowledge about RD, from specialized research through supporting health care professionals and patient empowerment;

iii) Contribute to improving accessibility to quality services in providing care, from diagnosis through the social support to innovative therapies.
Associated Partners

- Newcastle University (Kate Bushby)
- INSERM Paris (Ségolène Aymé)
- ISS Rome (Domenica Taruscio)
- EURORDIS (Yann Le Cam/Dorica Dan)
- CIBERER (Francesc Palau)
- Finnish Ministry of Social Affairs and Health (FMSAH)(Helena Kääriäinen)
- Goethe University Hospital Frankfurt (GUHF)(Thomas Wagner)
- Portuguese Ministry of Health → INSA (Gloria Isidro)
Collaborating Partners

- All MS and other stakeholder representatives, via EUCERD/ expert group membership
- Collaborating partners are the link between National and EU level activities
- The Expert Group on RD is therefore a key player in EJA activities
  - Needs and opinions of MS (EUCERD meetings, workshops, national conferences, other activities)
  - Dissemination of outputs
- The hope is to retain and cement this two-way relationship
Core Work Packages

WP5
Coding and classification
INSERM

WP6
Specialized social services
EURORDIS

WP7
Quality assurance and the national context (CoE)
CIBERER

WP8
Integration of national and international initiatives (registries, …)
FMSAH & UNEW & GUHF

Promote consistent quality care for RD

Horizontal Work Packages

WP1
Management
UNEW

WP2
Communication
INSERM

WP3
Evaluation
INSA
<table>
<thead>
<tr>
<th>WP</th>
<th>Final objective</th>
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<tr>
<td>WP1</td>
<td>To manage the joint action and to make sure that it is implemented as planned.</td>
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<td>WP2</td>
<td>To ensure that the results and deliverables of the joint action will be made available to the target groups.</td>
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<td>WP3</td>
<td>To verify if the joint action is being implemented as planned and reaches the objectives.</td>
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<td>WP4</td>
<td>Support the process of elaboration and implementation of national plans and strategies for RD. (Continuation of Europlan)</td>
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<td>WP5</td>
<td>Contribute to the ICD11 preparation to ensure an exhaustive coding of RD and an appropriate classification; promote the codes addition for RD in other nomenclatures; promote and facilitate the Orphanet nomenclatures use in health information systems and especially data national repositories on RD patients.</td>
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<td>WP6</td>
<td>Publish recommendations on social services and integration of RD into social policies and services.</td>
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<td>WP7</td>
<td>Identify effective approaches of health care services towards efficient improvement of RD patients quality of life.</td>
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<td>WP8</td>
<td>Develop a model of sustainability for RD initiatives.</td>
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INSA’s Team

Glória Isidro (DGH) – gloria.isidro@insa.min-saude.pt

José Calheiros (CD) – jose.calheiros@insa.min-saude.pt

Dezso David (DGH) – dezso.david@insa.min-saude.pt

Cristina Furtado (DDI) – cristina.furtado@insa.min-saude.pt

Ausenda Machado (DEP) – ausenda.machado@insa.min-saude.pt

Verónica Gomez (DGH) – veronica.gomez@insa.min-saude.pt

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Evaluation's strategy

- Monitoring of process indicators
  - Example: N.º conferences organized

- Monitoring of outputs indicators
  - Example: N.º of good practice guidelines published

- Monitoring of outcome indicators
  - Example: Existing services and best practices in RD social care provision

The overall impact will be evaluated looking at the Joint Action as a whole.
_Future actions_

- May 2014: ECRD workshop: ISS National plans
- 4th Quarter 2014: Eurordis Integration of Social Care for RD

In planning:
- Phase 3 workshop on Indicators/DS (ISS)
- Final conference on NP/NS (ISS)
- Evaluation of EJA with Expert Group (INSA)
- INSA will organize one workshop in **November** where all partners will present their WP
Thanks to:

_Kate Busby and Stephan Lynn from UNEW

_All Project Partners

_WP3 Team: Cristina Furtado, Dezso David, Ausenda Machado, José Calheiros and Verónica Gomez