



# Implementation of National Plans or Strategies on RD (« EUROPLAN II »)

## CNA Meeting - 12 May 2011, Amsterdam



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# EUROPLAN PROJECT – March 2008 - 2011

## 1st EUROPLAN PROJECT: A SUCCESS

- 57 partners altogether from 34 countries + EURORDIS
- Production of EUROPLAN recommendations accompanying the Council Recommendation on action in the field of rare diseases to promote and foster the development of national plans or strategies for rare diseases
- Production of Indicators to monitor the implementation of national plans for RDs by areas
- **Work Package 8:** 15 national EUROPLAN Conferences organised with the support of EURORDIS and 6 Advisors
  - bringing together all stakeholders
  - 15 reports for each of the National Conferences
  - A synthesis report of the National Conferences highlighting key outcomes of these Conferences

# CONTINUATION OF EUROPLAN

- **Will become Work Package 4 of the Joint Action on Rare Diseases**
  - **What is a Joint Action?**
    - Funding Mechanism of the EC: 50% comes from the EC, 50% from EU MS
    - EU MS sends their expression of interests to be involved
  - **Joint Action on Rare Diseases (JARD):**
    - Coordinated by DG SanCo, European Commission
    - Involve representatives of the EUCERD -EU Committee of Experts on RDs
    - In progress – Deadline for application: Friday May 27 2011
  - **JARD WP 4: Implementation of Plans or Strategies at MS level**
    - WP leader: Domenica Taruscio, Istituto Superiore di Sanità

# WP4 Implementation of Plans & Strategies

- **OBJECTIVE: Support the process of elaboration of plans or strategies**
  - 1) Where it has to start yet
  - 2) Where it needs to be sustained
- **STRATEGIC APPROACH: Integrated (EU/National), comprehensive, long term, multi-stakeholders**
  - Build on WP8 successful strategy of organising National Conferences
  - Sustain grassroots movement in favour of NPs or strategies for RDs
  - Involve all stakeholders, broadest possible outreach
  - Share values, concepts and policy measures
  - **NEW!** Incorporate future **EUCERD** opinions and recommendations on RD-related themes – assess transferability at national level

# WP4 Implementation of Plans & Strategies

- **ACTIVITIES AND METHODS**

## 1) Identify 20 National Conferences on Rare Diseases

- In countries that **have not** organised a EUROPLAN Conference, and amongst them:
  - EU/EEA Member States (possible applicants: Portugal, Austria, Slovenia, Belgium, Cyprus, Finland, Estonia, Czech Republic);
  - Countries outside the EU, both candidates and potential candidates to the EU (e.g. Turkey, Serbia, Macedonia) and selected neighbouring countries (e.g. Russia, Ukraine)
- In countries that **have organised** a EUROPLAN Conference and need to sustain the process initiated towards the establishment of a national plan or strategy
- **Call for Expressions of Interest to identify EURORDIS partners:**
  - National Alliances (where existing)
  - Potential Partners able to mobilise stakeholders at the national level

# WP4 Implementation of Plans & Strategies

- **ACTIVITIES AND METHODS**

## 2) Support to the organisation of 20 National Conferences on RDs

EURORDIS will coordinate and supervise the organisation of the National Conferences and ensure that during all National Conferences:

- the Commission's Communication on RD, the Council Recommendation on RD, EUROPLAN Recommendations and EUROPLAN Indicators are presented and promoted;
- opinions, recommendations and other measures approved by the EUCERD are presented and promoted;
- the transferability into national context of this whole body of measures relevant to RDs is assessed;
- the development of national plans or strategies on RD is promoted.

**The National Conferences will be organised between 2012 and 2013**

**Expression of interest and identification of countries in 2011**



# WP4 Implementation of Plans & Strategies

- **ACTIVITIES AND METHODS**

### 3) Set of guiding documents “INFO PACK” for organising the National Conferences

EURORDIS will provide a set of guiding tools and documents, including:

- a common Conference layout,
- content guidelines reflecting the thematic structure of the EU main documents (Council Recommendation, EUROPLAN Recommendations and Indicators, etc.),
- guidelines for Chairs and Rapporteurs,
- presentations for the thematic Workshops aligned with the main European documents.

**Organisers will be left enough flexibility to adapt the layout of the Conferences to the most pressing needs of the RD community in their respective countries**

# WP4 Implementation of Plans & Strategies

- **ACTIVITIES AND METHODS**

- 3) **Set of guiding documents “INFO PACK” for organising the National Conferences**

EURORDIS will update its web pages on EUROPLAN:

- Information related to the project
- EU fundamental policy documents
- EURORDIS support documents for National Conferences
- Information on previous National Conferences
- Information on existing national plans
- Additional documents: future measures adopted by the EUCERD

# WP4 Implementation of Plans & Strategies

- **ACTIVITIES AND METHODS**

## 4) Team of 9 Advisors

Ensure a supranational coordination while ensuring a close touch with the national situations:

- Advisors appointed for previous conferences – invited to renew their interest
- Call for Expression of Interest for new Advisors
- Each Advisor is responsible for supervising 2 to 3 National Conferences

# WP4 Implementation of Plans & Strategies

- **ACTIVITIES AND METHODS**

- 5) **Final Reports of the National Conferences**

- Draft a template report (EURORDIS and Advisors)
    - Distribute it to the local Conferences' organisers (EURORDIS' website)
    - Write the final report in local language – applied for dedicated budget for translation in English
    - Collect the 20 reports drafted in English by local organisers (EURORDIS – Advisors)
    - Proof-reading and editing of the reports by an English native speaker

# WP4 Implementation of Plans & Strategies

- **DELIVERABLES**

1. **Info Pack for organisers of National Conferences**
2. **20 National Conferences**
3. **Final Reports in English of the 20 National Conferences**

# WP4 Implementation of Plans & Strategies

**READY FOR IT?**

You can start **today** to express your interest