



# European Year for Rare Diseases 2019

29 October 2013, CNA Meeting, Paris



# Agenda

1. Update on launch activities by EURORDIS
2. Discussion on the role of National Alliances
3. Discussion on the implication of European Federations

# Why a European Year for Rare Diseases?

- **Raise public awareness** about Rare Diseases to society at large, focusing on the issues that patients, families, doctors and researchers are faced with daily
- Reach out to policy makers to ensure that Rare Diseases are treated as a **health priority**, a **public priority** and a **budget priority**

# Why a European Year for Rare Diseases?

- Launch a new dynamic between 2013 and 2020 to ensure the development and implementation of Rare Disease policies
- Gain momentum to ensure the sustainability of policies beyond 2020
- To build a stronger Pan-European community and enhance our voice at a European Level

# 1. Update on launch activities by EURORDIS

# Timing of the Launch

November –  
December  
2013

Send information  
letter to top  
European  
Commission and  
European  
Parliament Officials

February 2014

Use the  
momentum of  
Rare Disease  
Day to go public  
with the launch  
of the European  
Year for Rare  
Diseases

March 2014

National  
Alliances and  
European  
Federations to  
write letters to  
their own  
national policy  
makers and  
members



# Initiatives already in place

- EURORDIS website
  - <http://www.eurordis.org/european-year-for-rare-diseases-2019>
- Sign up module : one common web counter managed by EURORDIS
- Information Pack

# Information Pack

- Call (translated into website languages: French, Spanish, German, Italian, Portuguese, Russian)
- Q&A (English only)
- Presentation / Prezi with info presented in Dubrovnik (English only)

**QUESTION:** Would it be useful to include a template letter for you to send to your national policy makers, MEP candidates (English only)? If so, what form should it take?



# Funding

- European Years are mostly about creating a momentum and increasing public awareness rather than a means to obtain funding for specific actions organised in the framework of a European Year
- As a consequence, funding of the European Year for Rare Diseases is not expected to be very high
- The timeframe to propose a European Year for Rare Diseases to the European Commission is 3 years in advance: from 2016

## 2. Discussion on the role of National Alliances

# The Role of the National Alliances

- Advocate for the European Year for Rare Diseases at the national level to engage a maximum number of supporters to ensure sign-ups /signatures
- Circulate the official Call and Q&A broadly at national level
- Create and propose “National Road Map” with concrete priorities and initiatives
- Press/ Media contacts at national level
- Write to Head of State, Prime Minister, Health & Social Minister, Research Minister

**QUESTION:** Would National Alliances outside of the European Union like to be involved in this initiative?

# 3. Discussion on the implication of European Federations

# The implication of European Federations

- Organise actions and mobilise your members for the European Year for Rare Diseases to engage a maximum number of supporters / sign-ups
- Engage with doctors, researchers and other health care professionals and social workers to engage a maximum number of supporters / sign-ups
- Circulate the official Call and Q&A broadly
- Enhance and strengthen our voice at European Level

# Task team

## Board of Directors:

Avril Daly, GRDO, Ireland

Rosa Sanchez de Vega, FEDER, Spain

Dorica Dan, Prader Willi Association, Romania

## EURORDIS Staff :

Yann Le Cam, Flaminia Macchia, Paloma Tejada/Lara Chappell, Denis Costello, Anja Helm, Jill Bonjean, Zoe Alahouzou, Sharon Ashton

**We would like to invite 4 members of the CNA to join this task team, and 1 to 2 members from European Federations. Any volunteers?**



# Questions?

We hope you are as excited about the European Year for Rare Diseases as we are!

