



# European Year for Rare Diseases 2019



CNA-CEF, Paris, 28 October 2015

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# 1. Recap: why a European Year?

# Why a European Year for Rare Diseases?

## A reason for celebration

- 20 Years of the EU Regulation on Orphan Medicinal Products
- 10 Years of the Council Recommendation on an Action on Rare Diseases
- 10 Years of the Commission Communication on Rare Diseases
- End of the 3rd EU Public Health Programme “Health for Growth”
- End of Horizon 2020



# 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

# 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**

# 2. Progress so far

# Dedicated webpage

- One common sign-up module and web counter

The screenshot displays the EURORDIS website interface. At the top, the EURORDIS logo is on the left, and the tagline "The Voice of Rare Disease Patients in Europe" is in the center. A navigation menu includes links for "About EURORDIS", "About Rare Diseases", "Rare Disease Policy", "Orphan Drugs & Treatments", "Living with a Rare Disease", "Services to Patients", "Training Resources", and "News & Events". A language selector shows "EN | FR | DE | ES | IT | PT | RU".

The main content area features a campaign announcement for the "European Year for Rare Diseases 2019". The text states: "In 2019, we will celebrate the 20 year anniversary of the adoption of the EU Regulation on Orphan Medicinal Products and the 10 year anniversary of the Commission Communication and Council Recommendation on rare diseases. The European Year will send a strong public and political message on behalf of the 30 million Europeans who suffer from a rare disease and will raise awareness and encourage researchers to focus on these rare, mostly unknown, seriously debilitating and often life-threatening diseases." A graphic of four hands in different colors (pink, blue, green, yellow) is shown with the text "Campaign for EUROPEAN YEAR FOR RARE DISEASES 2019".

Below the text is a video player with the title "Rare Diseases: we are 30 million in Europe. Ea...". The video shows a man with his hands raised in front of his face.

To the right of the main content is a sign-up form titled "Sign-up to join the campaign!". The form includes fields for "First name \*", "Last name \*", "E-mail \*", "Country \*", and "Organisation/Institution/company". There is a checkbox for "Yes, keep me informed about EURORDIS and the campaign for the European Year for rare diseases" and a "Spam checking" field with the instruction "please type 33 in this box". A "Send!" button is at the bottom of the form.

Below the sign-up form are social media sharing options for email, Facebook, and Twitter, followed by a call to action: "Follow EURORDIS on Facebook & Twitter and subscribe to our Newsletter to stay tuned to the latest rare disease news." There are also social media counters for "Like" (19) and "Follow @eurordis" (6,519 followers).

At the bottom of the page, there is a "23 October Webinar: European Year for Rare Diseases" section. It includes the text: "When: Join us on Thursday, 23 October at 15.00 (Central European Time) for an hour long interactive webinar." and "Why: Learn more about the principle objectives of the campaign for a European Year for Rare Diseases in 2019. Its content and European video and how you can get involved."

The EURORDIS logo and the text "MAKE A DONATION" are visible at the bottom of the page.



# Information tools at your disposal

- EURORDIS Call for a European Year for Rare Diseases
- Q&A Document
- Information leaflet
- Campaign logo (horizontal and vertical)
- Template letter to national policy makers
- Video by Yann Le Cam
- Webinar recording

Number of signatures

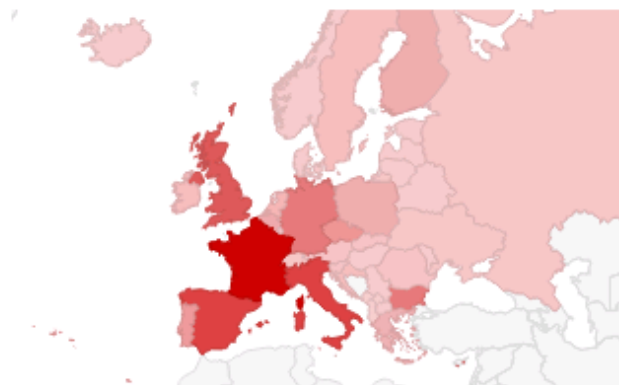
3467

Latest signatures

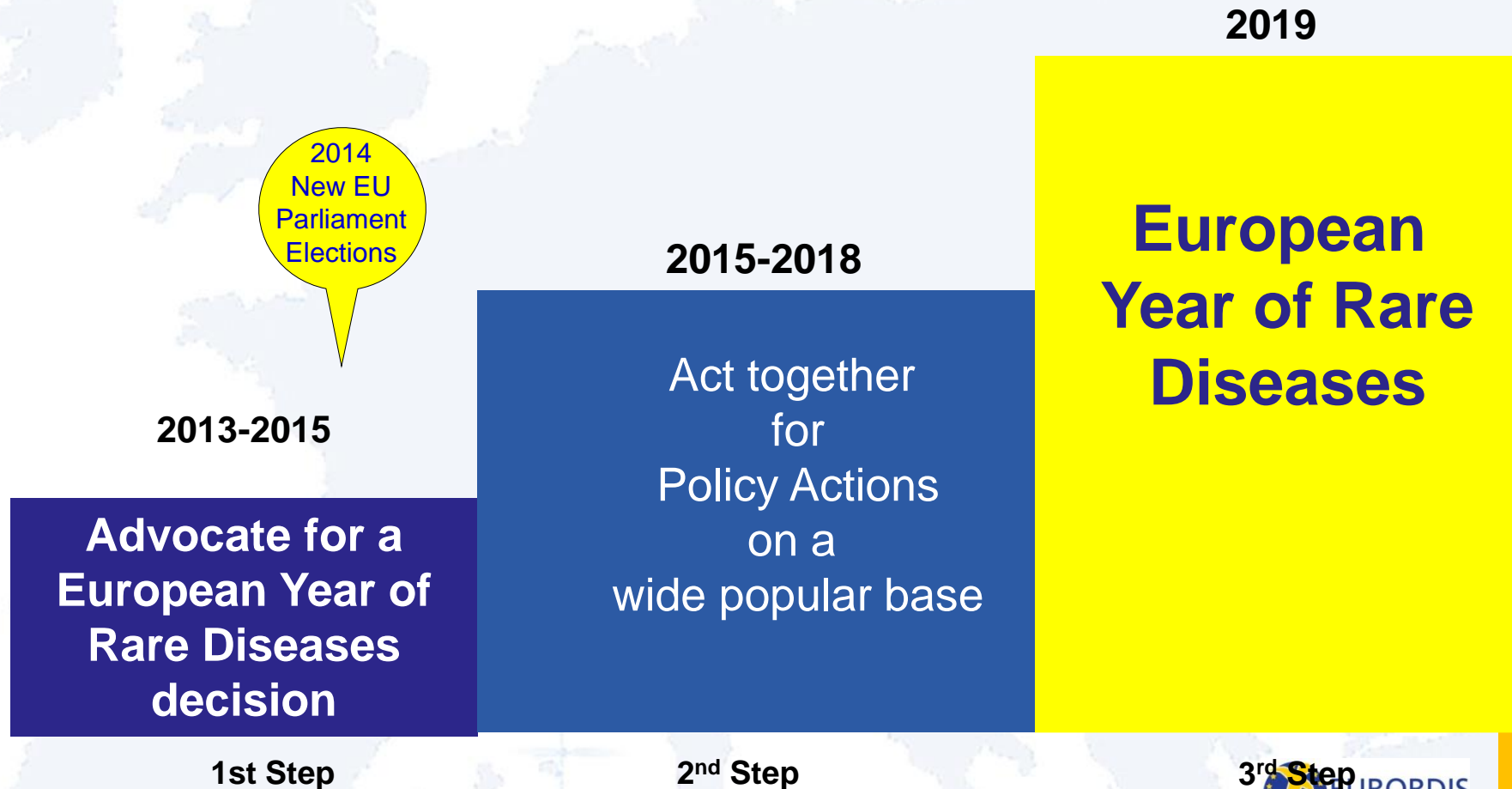
Date ▼	First name	Country ▲
10/20/2015 18:12:00	Alfonso	Spain
10/20/2015 14:23:18	Hanna	Poland
10/20/2015 14:23:19	Hanna	Poland
10/20/2015 12:35:21	Aurelio	Spain

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Thank you!



# Three-step public awareness campaign towards a European Year for Rare Diseases



2015-2018

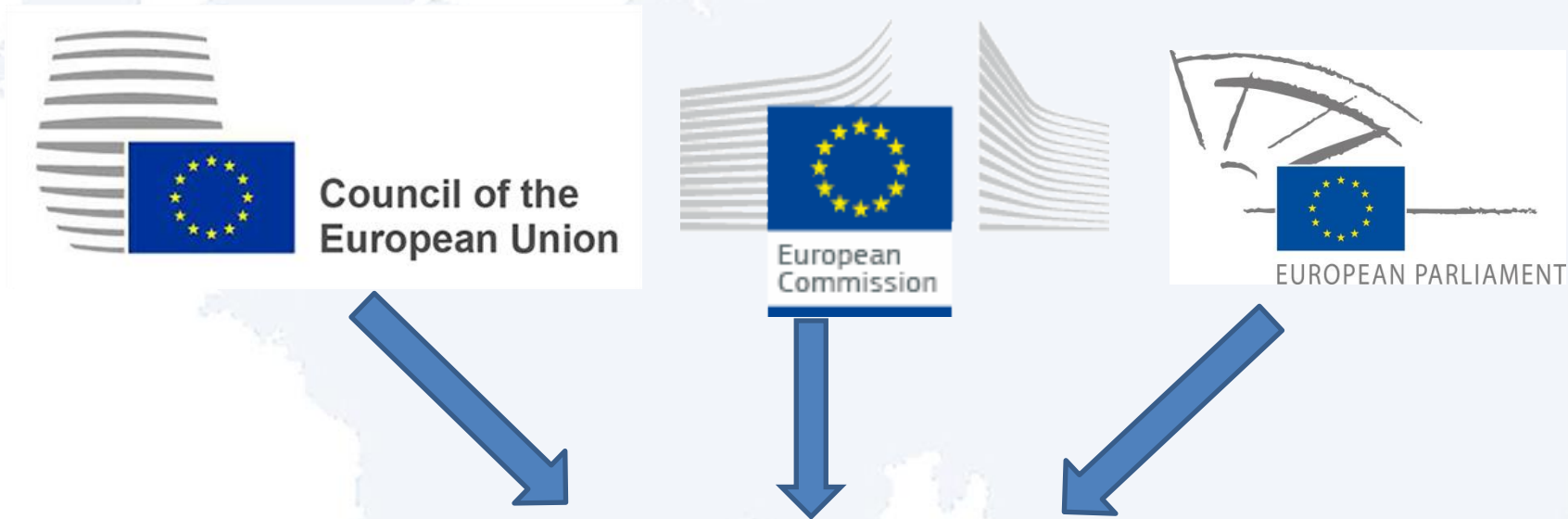
Act together  
for  
Policy Actions  
on a  
wide popular base

# Progress made: Benchmarking



# Progress made:

## Detailed Advocacy plan and timeline

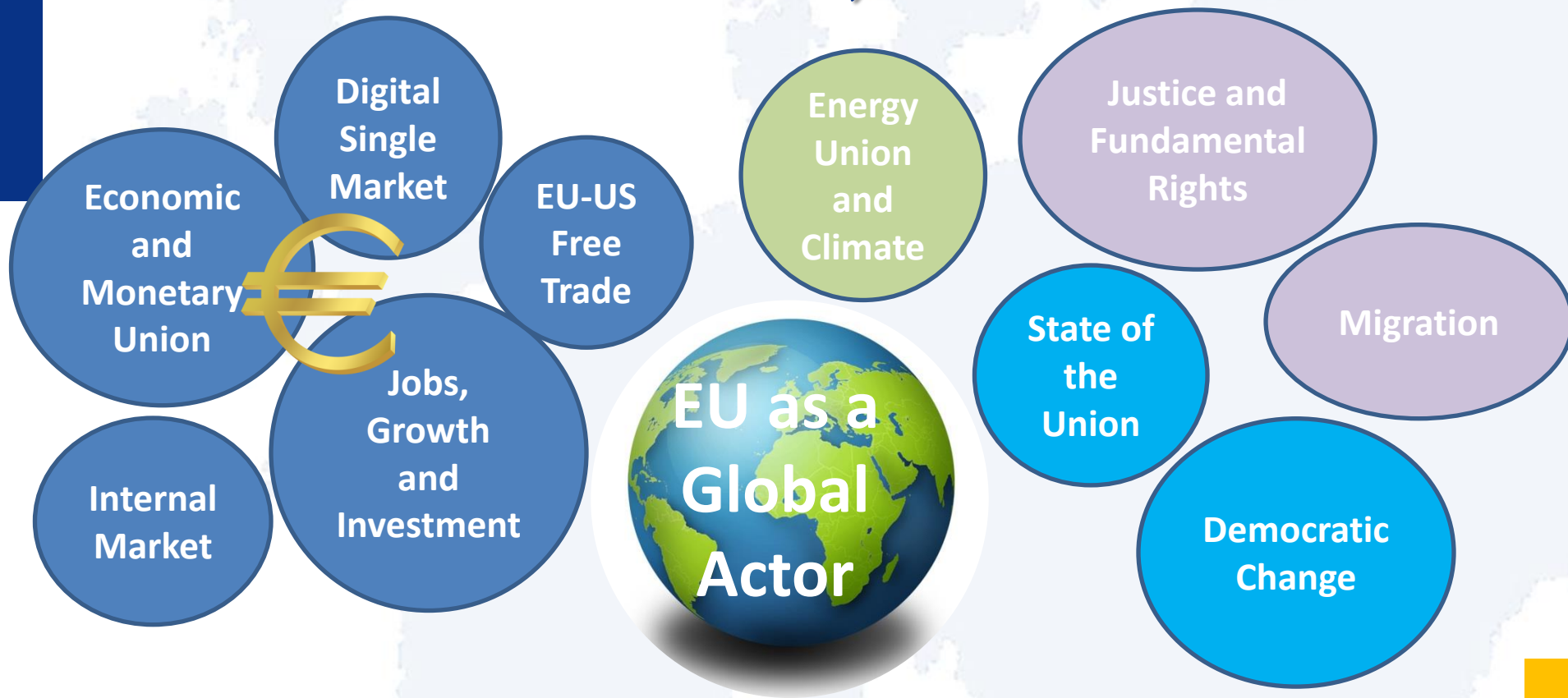


# Progress made:

## Building relationships with MEPs to gain support

- Sending letters
- Engaging on Twitter
- Organising personal meetings

# New Commission, New Priorities



**Where do rare diseases fit in?**



The campaign continues...

YEAR OF THE BRAIN

2015

EUROPE



# The campaign continues...

- Celebratory events
- Foresight study
- Citizens' Conference
- Conferences on National and European level
- Surveys
- Communication campaign
- Build a coalition
- Ambassadors

# The campaign continues...

## Next Steps:

- Adapting strategy
- Mapping activities and stakeholders
  - Consultation with CNA and CEF

# The campaign continues...

In groups:

Any feedback on this adapted approach?



Help us make 2019 the EYRD2019!

[eurordis.org/eyrd2019](http://eurordis.org/eyrd2019)



Questions:  
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