



European Year for Rare Diseases 2019



CNA, Paris, 14 October 2014

TABLE OF CONTENTS

1. Launch of the campaign

2. How to get involved

1. Launch of the campaign

Timing of the Launch

November –
December
2013

EURORDIS sent information letters to top European Commission and European Parliament Officials

April 2014

National Alliances and European Federations encouraged to write letters to candidate MEPs and their own national policy makers

September
2014

Widespread launch of the campaign by EURORDIS and its CNA, CEF and members

Webinar

- **When:** Thursday, 23 October from 15.00 to 16.00 (Central European Time)
- **Why:** Learn more about:
 - the principle objectives of the campaign
 - value of the campaign at national level
 - Value of the campaign at European level
 - How to get involved

2. How to get involved

Act now!

- Sign-up in support of the campaign here:

www.eurordis.org/eyrd2019

Dedicated webpage

- One common sign-up module and web counter



EURORDIS
Rare Diseases Europe

The Voice of Rare Disease Patients in Europe

Home Languages EN | FR | DE | ES | IT | PT | RU

About EURORDIS About Rare Diseases Rare Disease Policy Orphan Drugs & Treatments Living with a Rare Disease Services to Patients Training Resources News & Events

Campaign for European Year for Rare Diseases 2019

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.



Join the campaign to make 2019 the European Year for Rare Diseases. Sign-up now!

Rare Diseases: we are 30 million in Europe. Ea...



23 October Webinar: European Year for Rare Diseases

When: Join us on Thursday, 23 October at 15.00 (Central European Time) for an hour long interactive webinar.

Why: Learn more about the principle objectives of the campaign for a European Year for Rare Diseases in 2019, its content and European policy and how you can get involved.

Sign-up to join the campaign!

First name *
Last name *
E-mail *
Country *
Organisation/Institution/company

Yes, keep me informed about EURORDIS and the campaign for the European Year for rare diseases

Spam checking: please type 33 in this box:

Send!

Spread the word by email, facebook or twitter!

  

Follow EURORDIS on Facebook & Twitter and subscribe to our Newsletter to stay tuned to the latest rare disease news.

 Like (19)  Follow @eurordis (6,519 followers)

 **MAKE A DONATION**



Accessible via EURORDIS homepage

EURORDIS TV Contact Us Donate

 **EURORDIS**
Rare Diseases Europe

The Voice of Rare Disease Patients in Europe

About EURORDIS About Rare Diseases Rare Disease Policy Orphan Drugs & Treatments Living with a Rare Disease Services to Patients Training Resources News & Events

Home Languages EN | FR | DE | ES | IT | PT | RU

Who we are

EURORDIS is a non-governmental patient-driven alliance of patient organisations representing 633 rare disease patient organisations in 59 countries covering over 4000 diseases.

- Our members
- Our mission statement

What are you looking for:

Sign-up now!

Patients and services

EB House in Austria improves quality of life for people with Epidermolysis Bullosa via outpatient, research and academy units

Featured Event

Find great tips for communicating about Rare Disease Day in the informative webinar: The Spirit of Rare Disease Day

Member's Corner

French Angelman Syndrome Association (AFSA) National Meeting: 18-19 October, Paris

CAMPAIGN for EUROPEAN YEAR FOR RARE DISEASES 2019

Join the campaign to make 2019 the European Year for Rare Diseases. Sign up now!

EURORDIS Initiatives  EURORDIS Rare Diseases Europe  RareConnect  Rare Disease Day 



Act now!

- Add the campaign logo to your websites:



Act now!

- Spread the word via your social media networks
- Tweet using #EYRD2019
- Generate support from your community:
 - Community at large: family, friends, colleagues, association members, schools, gym club, etc.
 - National policy makers
 - Research institutions, academics, scientists, healthcare professionals, centres of expertise
 - Pharmaceutical, biotech, medical device manufacturers, investment firms
 - Media

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

Campaign Task Team

EURORDIS Board of Directors

Avril Daly, GRDO, Ireland

Dorica Dan, Prader Willi Association, Romania

John Dart, DEBRA International, UK

EURORDIS Staff

Yann Le Cam, Flaminia Macchia, Lara Chappell, Denis Costello,

Anja Helm, Jill Bonjean, Zoe Alahouzou, Sharon Ashton

CNA - CEF

Pisana Ferrari, PHA Europe

Alain Fontaine, Alliance Maladies Rares, France

Mirjam Mann, ACHSE, Germany

Maria Tomé, FEDER, Spain



Help us make 2019 the EYRD2019!

eurordis.org/eyrd2019



Questions:
eyrd2019@eurordis.org