

# GET THE BEST OUT OF EURORDIS' RESOURCES

## **EURORDIS Membership Meeting 2021**

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& Davor Duboka, Web Technology Manager

**EURORDIS.ORG** 

## **EURORDIS External Communication Channels**

**Social Media** 

Over 80 000 followers

eNews & Member News

Nearly 18 000 subscribers



Webinars & Events

Thousands of participants annually

Website & EURORDIS TV

40 000

# **Monthly visitors**



## eNews



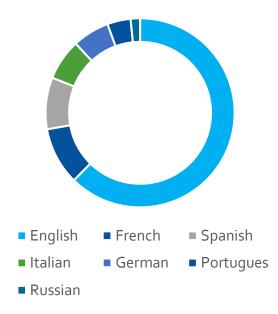
## Monthly Newsletter



Revision of the EU pharmaceutical framework to ensure equitable access to rare disease therapies



## Over 15 000 subscribers





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## eNews

- RareConnect
- Living with a rare disease
- Rare Disease Day, Black Pearl Awards, European Conference on Rare Diseases, EURORDIS Round Table of Companies, Rare 2030, European Conference on Rare Diseases
- Rare Diseases International (RDI), International
- Rare Barometer Voices, Open Academy
- Get involved, What's new at EURORDIS, EURORDIS events
- Patients advancing research , Members' corner

#### RARECONNECT

There are 4 new online communities this month! Join the Familial Hypomagnesemia community to connect with others and share experiences around the world!



RARE 2030: FORESIGHT IN RARE DISEASE POLICY

We're about to launch Rare 2030 Action - our campaign for European action on rare diseases. Watch this video on the conclusions of the Rare 2030 Foresight Study that will be the basis of our work!



#### OPEN ACADEMY

Register now for the next EURORDIS Digital School's webinar on Community Engagement on May 25, 2021 04:00 PM CET. Learn how to initiate and sustain discussions, create and curate content and host engaging events and activities on your rare disease online community.



#### GET INVOLVED

• EU Directive on patients' rights in cross-border health

#### GET INVOLVED

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## **Member News**

6 languages



Biweekly Newsletter



Dear Member,

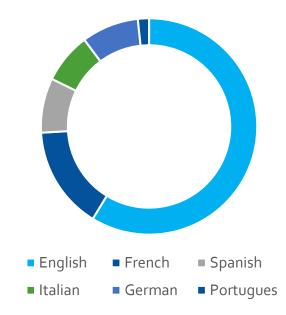
Next week we will meet again to strengthen coordination and cooperation among our members, address the most pressing issues facing the rare disease community and contribute towards the adoption of the first <u>Europe's</u> <u>Action Plan for Rare Diseases</u>. Learn more about how EURORDIS can help you amplify the voice of people living with a rare disease and how you can bring about change at the annual <u>EURORDIS Membership Meeting 2021</u> on 12-14 May. <u>Participate and spread the word</u>!

Highlight of this week's newsletter: Read and share Yann Le Cam's, Chief Executive Officer of EURORDIS-Rare Diseases Europe, <u>editorial on the Key</u> <u>Principles for Newborn Screening to reduce the diagnostic odyssey of children</u> <u>living with a rare disease</u>.



Anja Helm Senior Manager of Relations with Patient Organisations Add me to your contact list

# Nearly 2 500 subscribers







## **Member News**

- Get Involved
- Tools for you
- Take part in events, training, webinars
- Policy update
- New at EURORDIS



Last chance to submit your feedback on the EURORDIS strategic review 2021

We want to hear your opinion on EURORDIS future priorities! Help us set out the roadmap that will steer our community towards a more sustainable and inclusive future to leave no person living with a rare disease behind.

#### zoe.alahouzou@eurordis.org

Participate now

Rare 2030

The need for a new Europe's Action Plan for Rare Diseases explained in 5 minutes! Watch and share this video explaining how we can accelerate research, increase investment, and provide quality person-centred care to improve the life of every person living with a rare disease in Europe.

#### anna.kole@eurordis.org

Watch now

Tools for you

A new toolkit to help advocate for the first UN Resolution on Persons Living with a Rare Disease and their Families is available now EURORDIS, Rare Diseases International (RDI) and NGO Committee for Rare Diseases have developed a toolkit to support the global campaign calling for the first UN Resolution on Persons Living with a Rare Disease and their Families. We invite you to use these easy-to-download tools, including a template letter to policy makers, social media messages and images, and other social meterials to advocate for people living with a rare disease and rais

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## **EURORDIS TV**

### EURORDIS TV is the largest collection of video materials on rare diseases.

5.03.2021

643 videos

- News & current is events channel 52
- Living with a rare disease char
- Patient groups' channel
- EURORDIS events cachan nel provitis 8 pear European framework for rare diseases solidarity for rare diseases
- Explaining rare diseases channel -33732021
- Research channel
- Rare Disease 
  Disease
- Orphan drugs & treatments channel
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## Thank you!

Stanislav Ostapenko & Davor Duboka EURORDIS Membership Meeting 2021

