



GET THE BEST OUT OF EURORDIS' RESOURCES

EURORDIS Membership Meeting 2021

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&

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[EURORDIS.ORG](https://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

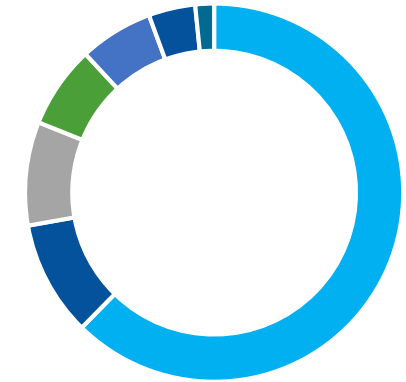
7 languages



Monthly Newsletter



Over 15 000 subscribers



- English
- French
- Spanish
- Italian
- German
- Portugues
- Russian

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



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EU Directive on patients' rights in cross-border health



Member News

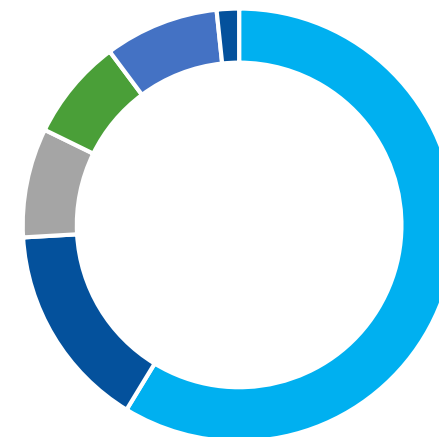
6 languages



Biweekly Newsletter



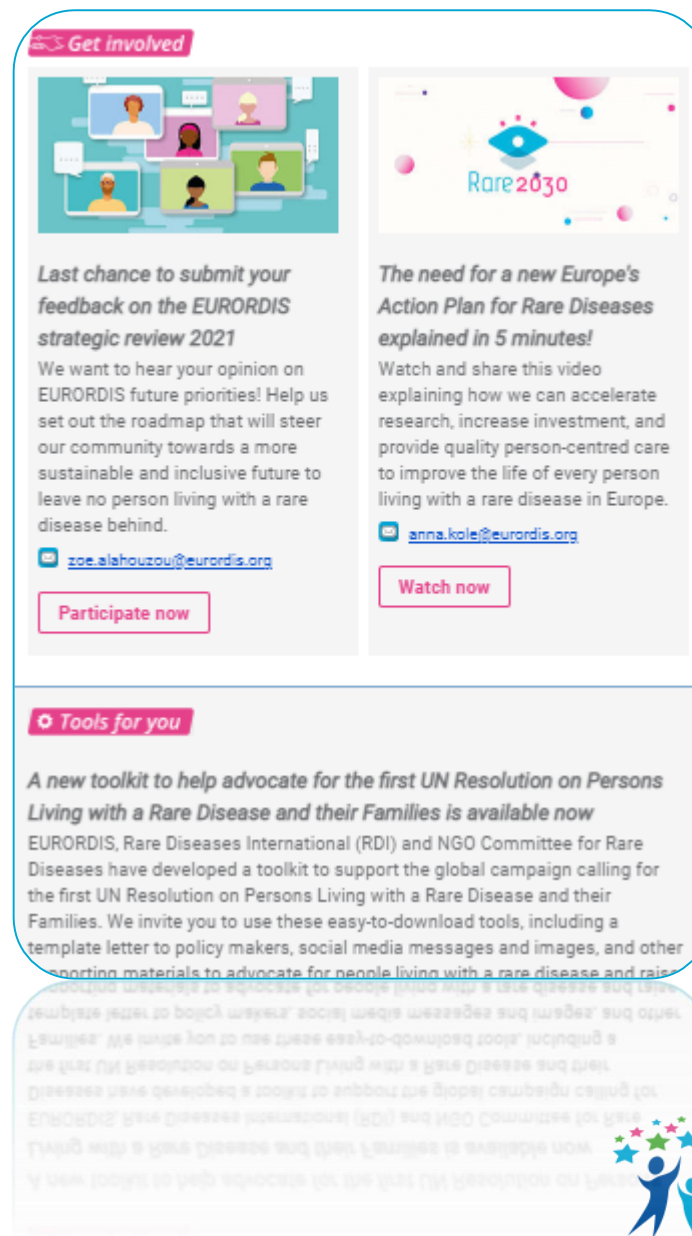
Nearly 2 500 subscribers



- English
- French
- Spanish
- Italian
- German
- Portuguese

Member News

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




Get involved

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.elahouzou@eurordis.org
[Participate now](#)

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 supporting materials to advocate for people living with a rare disease and raise awareness.



EURORDIS
RARE DISEASES EUROPE

EURORDIS TV

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

- News & current issues channel - 52
- Living with a rare disease channel - 172
- Patient groups' channel - 36
- EURORDIS events channel - 78
- Explaining rare diseases channel - 37
- Research channel - 40
- Rare Disease Day channel - 53
- Orphan drugs & treatments channel - 24
- Health policy channel - 27
- Non-English videos channel - 79
- Webinars - 45





Thank you!

Stanislav Ostapenko & Davor Duboka
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