

WE HAVE  
**#30 MILLION REASONS**

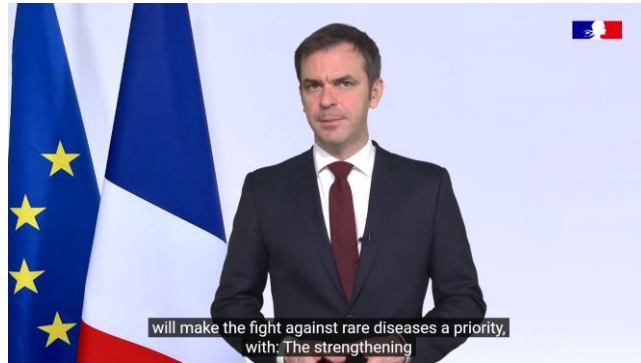
FOR EUROPEAN

**ACTION**

ON RARE DISEASES

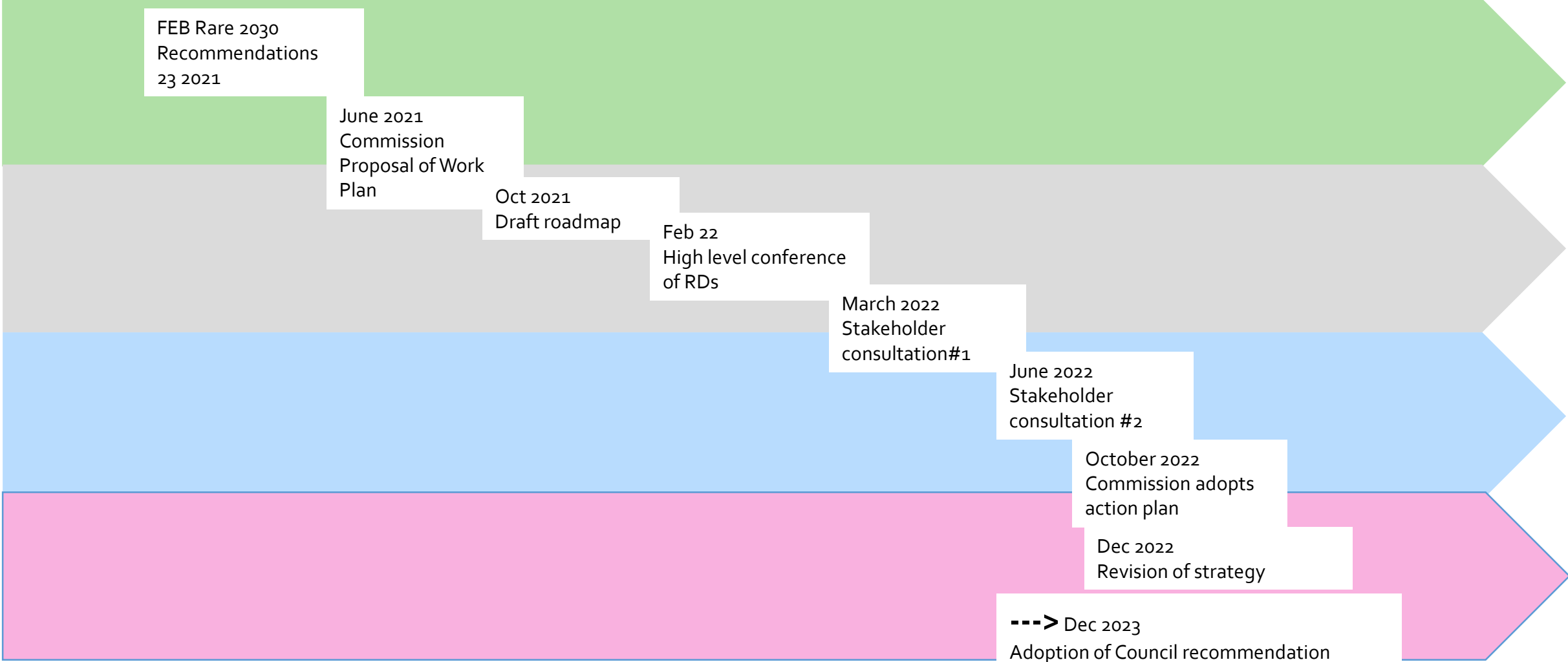


# BUILDING MOMENTUM...



# WHAT ARE WE HOPING TO ACHIEVE?





# #30MILLIONREASONS

**There are 30 million people living with a rare disease in Europe.**

Every person living with a rare disease is a reason for Europe to have an action plan on rare diseases that leaves no one behind by 2030.



# WE HAVE #30MILLIONREASONS FOR EUROPE TO TAKE ACTION



**Stop people  
losing their lives  
too young from  
rare diseases**

**Improve the  
quality of life  
of people living  
with a rare  
disease**

**Ensure Europe  
is a global leader  
in rare disease  
innovation**



**3 MORE REASONS**

FOR **ACTION** NOW

1

**PEOPLE LIVING WITH A RARE  
DISEASE HAVE A HIGH LEVEL  
OF *UNMET NEEDS***





2

**CURRENT RARE DISEASE  
STRATEGIES ARE *OUTDATED***



3

**RARE DISEASES DO  
NOT WORK *IN SILOS***



# CAMPAIGN FACTSHEET

## **THE FUTURE OF 30 MILLION PEOPLE LIVING WITH A RARE DISEASE IN EUROPE DEPENDS ON POLICY MAKERS TAKING ACTION, NOW.**

While great progress has been made thanks to scientific advances and efforts at EU and national levels, too many people living with a rare disease face unmet needs and inequities in accessing a diagnosis, treatments and care, leaving them marginalised in society.

There is currently no overarching action for rare diseases at European level, and policies have not kept pace with new technologies.

**Join EURORDIS and the rare disease community in the #30millionreasons campaign for a new EU Action Plan on rare diseases, that will leave no one behind by 2030.**

There are 30 million people living with a rare disease in Europe. Every person living with a rare disease is a reason for Europe to have an action plan for rare diseases that leaves no one behind by 2030.

 **WE ARE LIVING AN  
EVERYDAY EMERGENCY**

Terkel Anderson,  
President of EURORDIS, living with a rare disease

# WHAT CAN YOU DO AS A EURODIS MEMBER?

TAKE **ACTION**



1

**SHARE YOUR REASON**

TAKE **ACTION**



# SHARE YOUR REASON



**Tell Ursula von der Leyen, the President of the European Commission, the reason why Europe needs to take action now for a better future for people living with a rare disease by 2030.**



“

We need better coordination to **reduce waiting times** and **clarify care pathways** for patients and families.

- Simona, Rare Disease Advocate

”

“

It took 7 years to get a diagnosis and 23 years to get the treatment I needed, provided by the government. **No one should wait that long. We need joint efforts now!**

- Vesna, Rare Disease Advocate

”

“

“To ensure that all people living with **a rare disease** get the opportunity to live their lives in the **best possible way.**”

- Stephanie, Sweden

# SHARE YOUR REASON FOR ACTION ON RARE DISEASES!



**EVERY REASON BRINGS US CLOSER TO A EUROPEAN ACTION PLAN ON RARE DISEASES.**

**Share yours with Ursula von der Leyen, President of the European Commission.**

Can you help us get **500** reasons to hand over to Ursula van der Leyen?

**0** people have given their reason. Will you help us get 500 more?

**First name \***

**Last name \***



# 23 LANGUAGES...coming 1 June

- Bulgarian
- Croatian
- Czech
- Danish
- Dutch
- English
- Estonian
- Finnish
- French
- German
- Greek
- Hungarian
- Italian
- Latvian
- Lithuanian
- Polish
- Portuguese
- Romanian
- Russian
- Slovak
- Slovenian
- Spanish
- Swedish



# YOUR VOICE COUNTS!

We will collect all the reasons from across Europe and share them with Ursula von der Leyen and the European institutions.



# YOUR VOICE COUNTS!

- E-book – page per country including quotes and case study
- Event
- A resource to be used continually



2

# ASK YOUR NETWORKS TO SHARE THEIR REASON

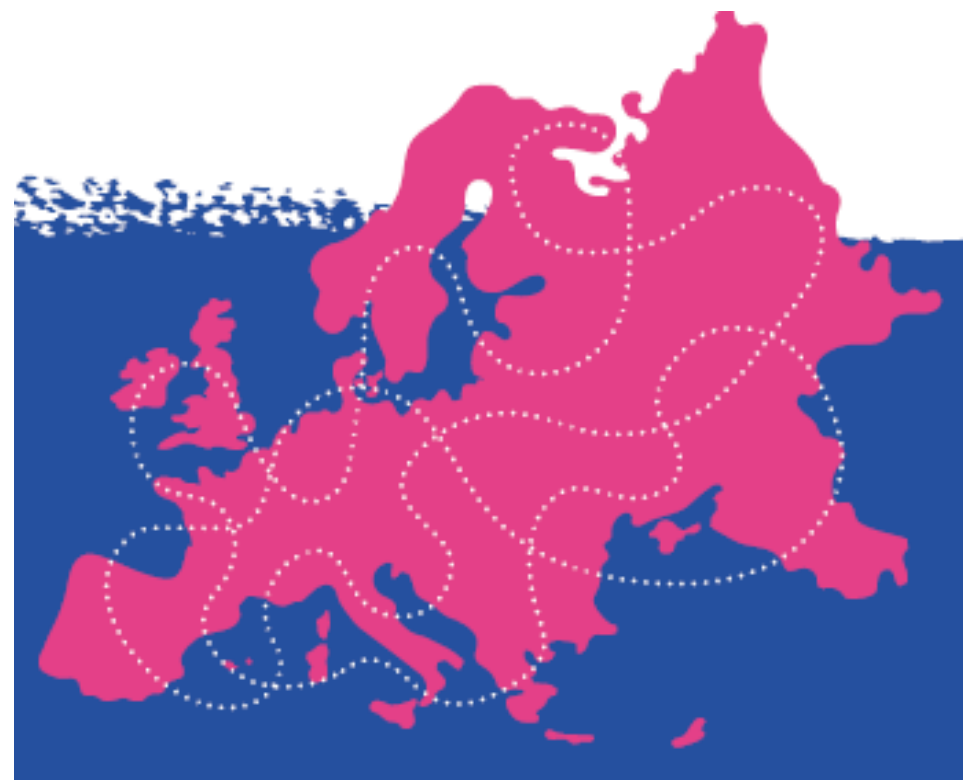
TAKE **ACTION**



# ASK YOUR NETWORKS TO SHARE THEIR REASON

- Social media
- Emails


...At any opportunity!



**Info**

Hashtag: #30millionreasons

Official tag: @eurordis



**Share your reason for European action on rare diseases**

Ensure a better future for people with rare disease now!

Rare 2030 Campaign

+ Add another card

**#30millionreasons (3 cards)**




Share yours!




+ Add another card

**GIFs (3 cards)**




Stronger Together



+ Add another card

**Quote Cards (3 cards)**

Treatment / financial reasons



Foster development of treatments

+ Add another card

**#30million**

Take action



Time for an

+ Add another card

3

**ASK YOUR MEP TO JOIN THE  
NETWORK OF PARLIAMENTARY  
ADVOCATES FOR RARE  
DISEASES**

TAKE **ACTION**



# WRITE TO YOUR MEP TO ASK THEM TO JOIN OUR PARLIAMENTARY NETWORK OF RARE DISEASE ADVOCATES



Dear [MEP NAME]

I am writing to you [as your constituent/on behalf of my patient organisation, {insert name}], to ask you to become a member of the Parliamentary Network of Advocates on rare diseases.

There are 30 million people living with a rare disease in Europe. Yet no country can tackle the challenges of rare diseases alone. Their future depends on policy makers taking European action now.

The network of Parliamentary Advocates for Rare Diseases will help tackle challenges faced by the rare disease community by fostering cross-border EU collaboration.

Through the network of Parliamentary Advocates for Rare Diseases, EURORDIS-Rare Diseases Europe aims to bring together members of the European and national parliaments to ensure strong international and local action, shape political input for current and future legislation and integrate rare diseases into all relevant policies at all levels. There are several [current and upcoming opportunities](#) where we can continue to raise our points.

In particular, the Parliamentary Advocates will play a crucial in the [#30millionreasons campaign](#), calling for an EU Action Plan on rare diseases to improve the lives of the 30 million people living with a rare disease in





# CAMPAIGN TOOLKIT

- Campaign factsheet
- Letter to MEP
- Rare 2030 Recommendations
- Social media trello board & templates

*Coming soon*

- Platform in 23 languages
- Press release on the Rare 2030 survey

... Anything else?



# THIS IS JUST THE BEGINNING...

- Member News
- Social media
- Case studies



**EURORDIS Member News**

News for EURORDIS Members,  
direct to your inbox twice a month

5 May 2021

[View this email in your browser](#)

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



facebook



# QUESTIONS? IDEAS? SUGGESTIONS?

[eurordis.org/30millionreasons](https://eurordis.org/30millionreasons)

[action.eurordis.org](https://action.eurordis.org)

[Jenny.steele@eurordis.org](mailto:Jenny.steele@eurordis.org)



# SHARE YOUR REASON FOR ACTION ON RARE DISEASES!



# THANK YOU!

## EVERY REASON BRINGS US CLOSER TO A EUROPEAN ACTION PLAN ON RARE DISEASES

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