

WE HAVE  
**#30 MILLION REASONS**  
FOR EUROPEAN

**ACTION**

ON RARE DISEASES



# MAIN UPDATES:

- Recognition of Rare 2030 Recommendations
- Key messages clearly supported by all stakeholders
- Excellent attendance of Ministers
- Commission response was inadequate
- #30millionreasons grassroots campaign successfully handed in
- Follow up actions to strengthen French launching of a call for an Action Plan
- Subsequent milestones during upcoming Trio Presidencies of Czech Republic, Sweden and Spain



# KEY OUTCOMES

- Support for coordination on rare diseases including Action Plan from:
  - EU Member States (12 Ministries represented in person/recording)
  - European Parliament
  - WHO-Europe
- Lacking support from European Commission who showed no explicit support for Europe's Action Plan
- Concrete steps of commitment from Czech Republic and Spain

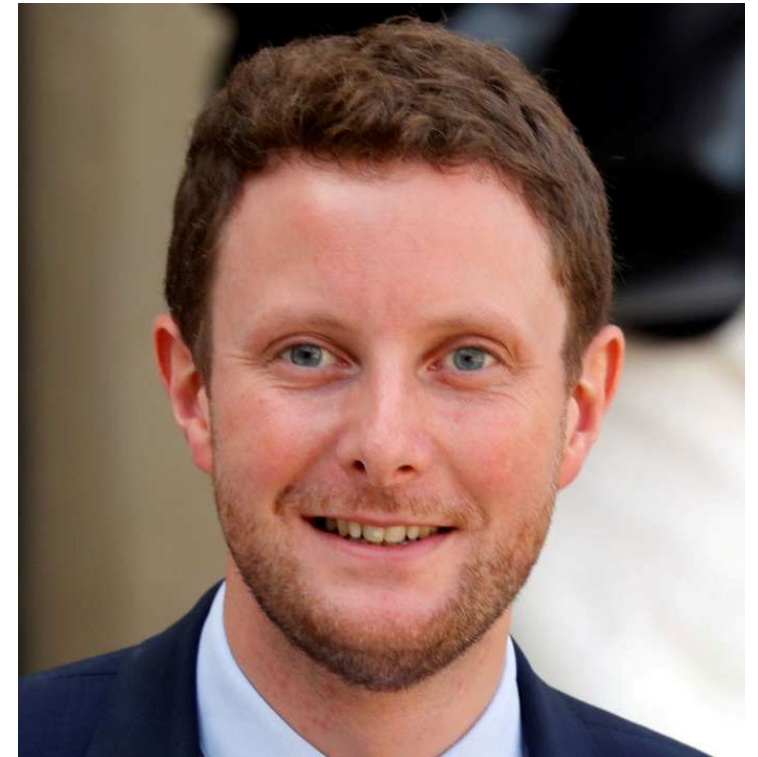


# MESSAGES FROM THE FRENCH

*Clement Beaune, French Secretary of State for European Affairs*

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- *praised significant advances in the area of rare diseases in the past years and emphasised the importance of a **European plan for rare diseases**, similar to Europe's Beating Cancer Plan, to continue serving the best interests of European citizens living with a rare disease.*





# MESSAGES FROM THE FRENCH

*Olivier Veran, Minister of Health*

*...the Europe of health is no longer a supplement to the soul of the European Union. This is evidenced by the call to unite all stakeholders – patients, carers, families, researchers – in advocating for a **European plan for rare diseases**. In 2008, we already had the intuition that the specificities of rare diseases made this an area where the European Union could bring strong added value. If these initiatives prove us right, European action for rare diseases would help Member States become more efficient by optimising the allocation of resources, and by sharing and coordinating expertise and data.*

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



# MESSAGES FROM CZECH REPUBLIC

*need an overarching European Action Plan or similar policy initiatives in order to federate and synergize various initiatives, make them effective and impactful, and avoid working in disparate 'silos'*



# COMMITMENT FROM CZECH REPUBLIC

## *3 CZECH EUROPEAN COUNCIL PRESIDENCY EVENTS ON RARE DISEASES*

1. Early diagnosis (20 July 2022)
2. Road Map for Europe's Action Plan for Rare Diseases (25 Oct 2022) **HLC**
3. Orphan Drug/Paediatric Drug legislations (26 Oct 2022) **HLC**



# SUPPORT FROM MEMBER STATES



Spain



Netherlands



Germany



Cyprus - P



Greece - P



Belgium - p



Latvia



Slovenia



Hungary - p



Sweden - p





# PRESENTING #30MILLION REASONS



*Il Ministero della salute, unitamente alla nostra Rappresentanza permanente a Bruxelles, assicurerà un costante e forte impegno nel supportare il Piano d'azione Europeo.*



# PRESENTING #30MILLION REASONS



# VIDEO AND TRANSCRIPTS

<https://presidence-francaise.consilium.europa.eu/fr/medias/photos-et-videos/>



# MEDIA COVERAGE

**THE PARLIAMENT**  
POLITICS, POLICY AND PEOPLE **MAGAZINE**

**FT**  
FINANCIAL  
TIMES

THE LANCET  
**Neurology**

**RARE**  
REVOLUTION  
MAGAZINE

**MEDIA PLANET**  
**Rare Diseases**

**Le Parisien**

**Doctissimo**



# SOCIAL MEDIA CAMPAIGN

- **Engaged MEPs** - to share on social media
- **Key Commission contacts** - to input decision making
- **French contacts** - ahead of conference
- **HLC speakers** - ahead of conference
- **Rare 2030 partners and advisors**
- **National Alliances**



# WEBSITE



[Why now?](#) [Reasons](#) [Manifesto](#) [Goals](#) [Rare Disease Timeline](#) [A European collective](#) [Contact](#)

## #30millionreasons for European action on rare diseases

Over 2000 stories from across Europe



# VIDEOS



... d'un enfant atteint d'une maladie très rare  
montagne russe émotionnelle.

7 in 10 patients or carers reduce or stop  
their professional activity due to their  
rare disease or to care for their family.

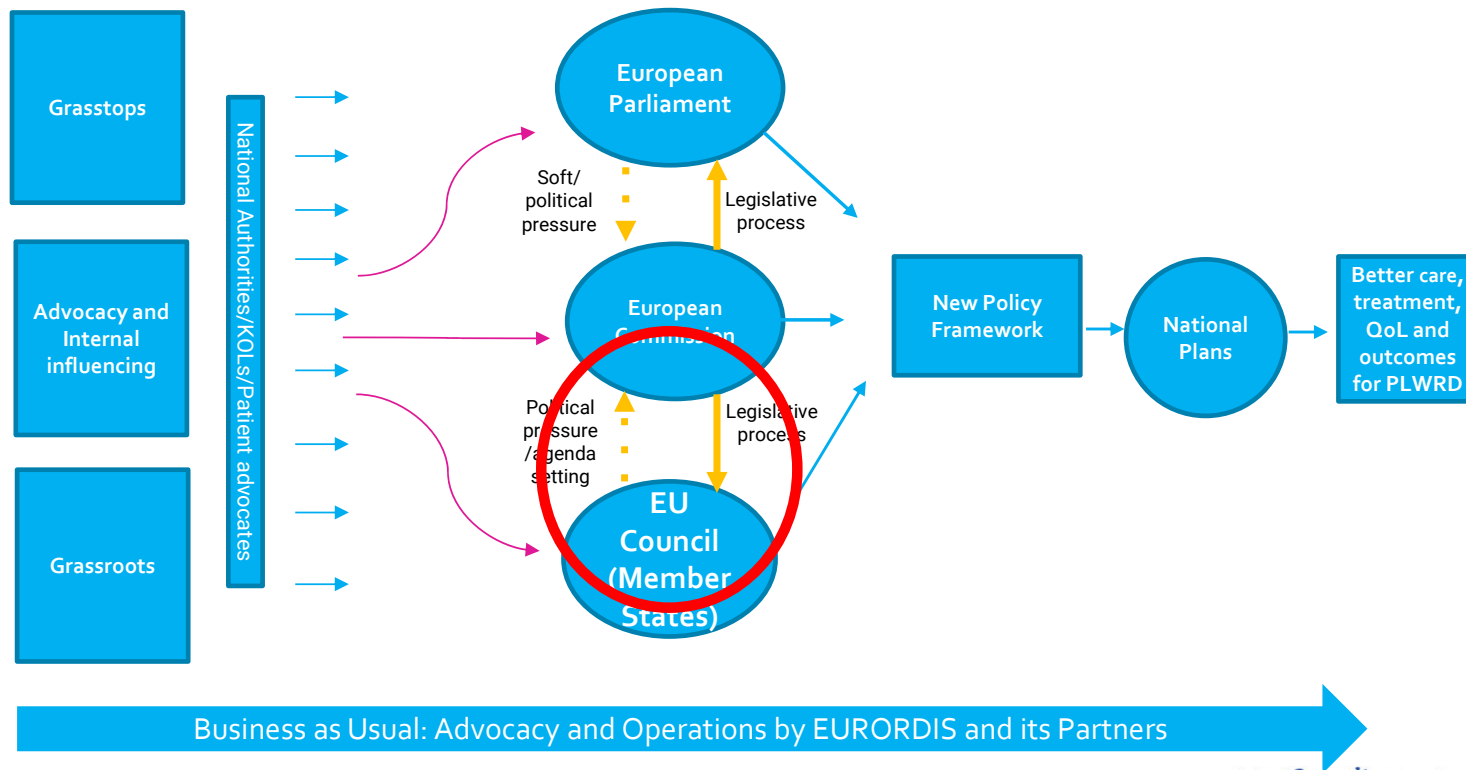
... ou aidants sur 10 réduisent ou arrêtent leur activité professionnelle  
raison de leur maladie rare ou pour s'occuper de leur famille.



#30millionreasons  
for European action on  
rare diseases



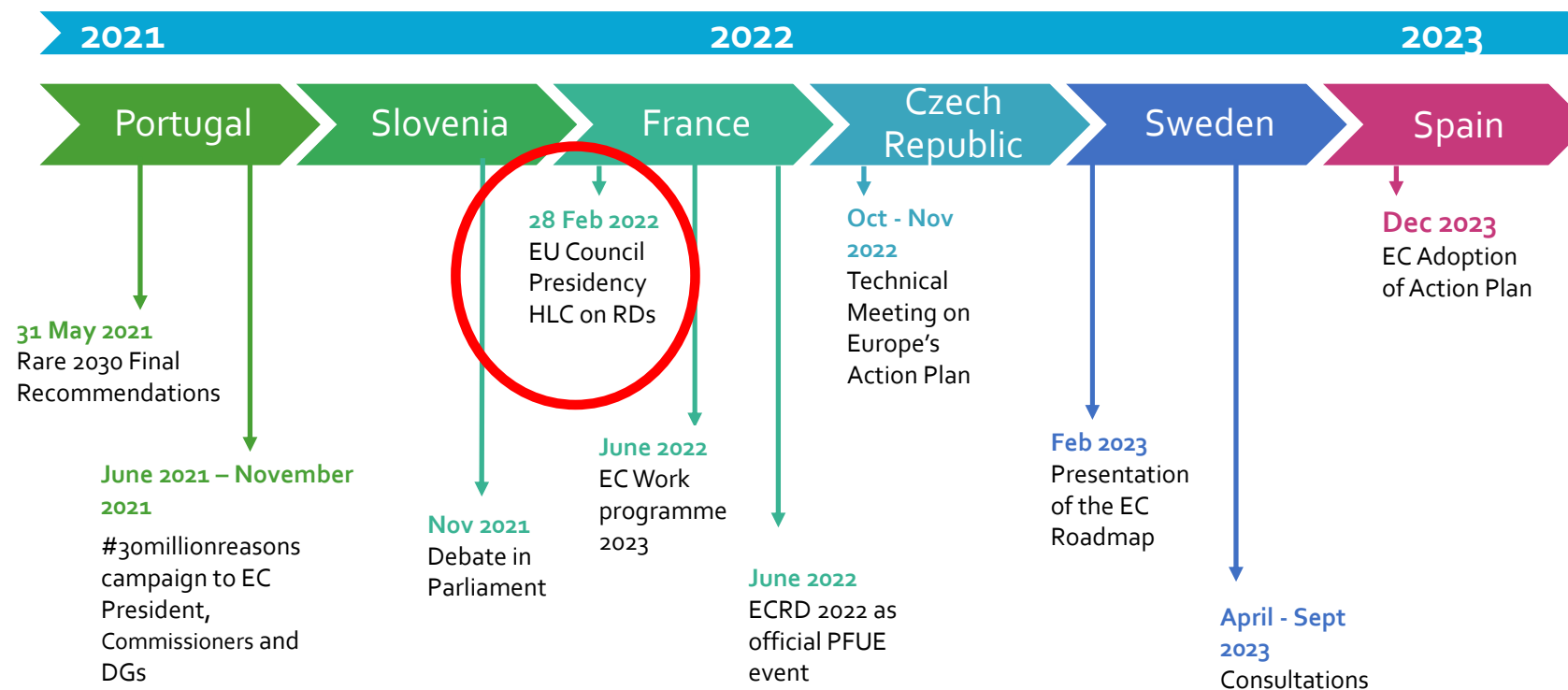
# ATTENDANCE OF MINISTERS





# Timeline

## Working Proposal for Europe's Action Plan for Rare Diseases



# NEXT STEPS

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- Informal consultation of Ministers in support of Action Plan
- Conference conclusions
- Council conclusions
- European Conference on Rare Diseases and Orphan Drugs (PFUE official event)
- Technical meetings during CZ and SE presidencies

