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

• 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.
...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.
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
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

MEDIA COVERAGE

THE PARLIAMENT MAGAZINE

FT FINANCIAL TIMES

THE LANCET Neurology

RARE REVOLUTION MAGAZINE

Rare Diseases

Le Parisien

Doctissimo

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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
#30millionreasons for European action on rare diseases

Over 2000 stories from across Europe
7 in 10 patients or carers reduce or stop their professional activity due to their rare disease or to care for their family.

#30millionreasons for European action on rare diseases

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ATTENDANCE OF MINISTERS

European Parliament

New Policy Framework

National Plans

Better care, treatment, QoL and outcomes for PLWRD

Soft/ political pressure

Legislative process

Political pressure / agenda setting

Legislative process

Grasstops

Advocacy and Internal influencing

Grassroots

European Commission

EU Council (Member States)

National Authorities/KOLs/Patient advocates

Business as Usual: Advocacy and Operations by EURORDIS and its Partners

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Timeline
Working Proposal for Europe’s Action Plan for Rare Diseases

2021
Portugal
31 May 2021
Rare 2030 Final Recommendations

31 May 2021
Rare 2030 Final Recommendations

June 2021 – November 2021
#30millionreasons campaign to EC President, Commissioners and DGs

2022
Slovenia
28 Feb 2022
EU Council Presidency HLC on RDs

28 Feb 2022
EU Council Presidency HLC on RDs

June 2022
EC Work programme 2023

June 2022
EC Work programme 2023

France
Nov 2021
Debate in Parliament

Nov 2021
Debate in Parliament

Czech Republic
Oct - Nov 2022
Technical Meeting on Europe’s Action Plan

Oct - Nov 2022
Technical Meeting on Europe’s Action Plan

Sweden
Dec 2023
EC Adoption of Action Plan

Dec 2023
EC Adoption of Action Plan

Spain
Dec 2023
EC Adoption of Action Plan

Dec 2023
EC Adoption of Action Plan

31 May 2021
Rare 2030 Final Recommendations

2023
Spain
Dec 2023
EC Adoption of Action Plan

Dec 2023
EC Adoption of Action Plan

No event

June 2022
ECRD 2022 as official PFUE event

June 2022
ECRD 2022 as official PFUE event

April - Sept 2023
Consultations

April - Sept 2023
Consultations

Note: The timeline is an estimate and may be subject to change.

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NEXT STEPS

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