

# WORKSHOP 3: MOVING FORWARD: THE RARE 2030 CAMPAIGN

This hands-on workshop is designed to set you up with the tools you need to advocate during the upcoming Rare 2030 campaign at the local and national level.

Moderator: **Anna Arellanesová**, Rare Diseases Czech Republic

## EURORDIS Membership Meeting May 2021

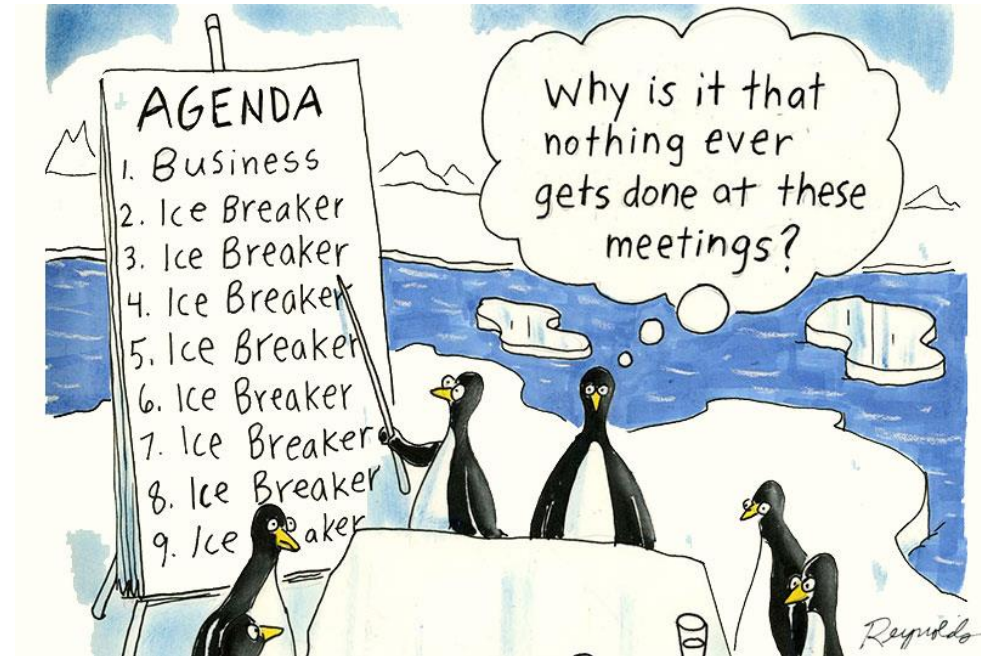


# OBJECTIVES OF THIS WORKSHOP

1. Understand how you can talk about the campaign for Europe's Action Plan on rare diseases in your own contexts
2. Leave with a plan! A target, a message and tactics!
3. Share ideas and experiences



# ICEBREAKER

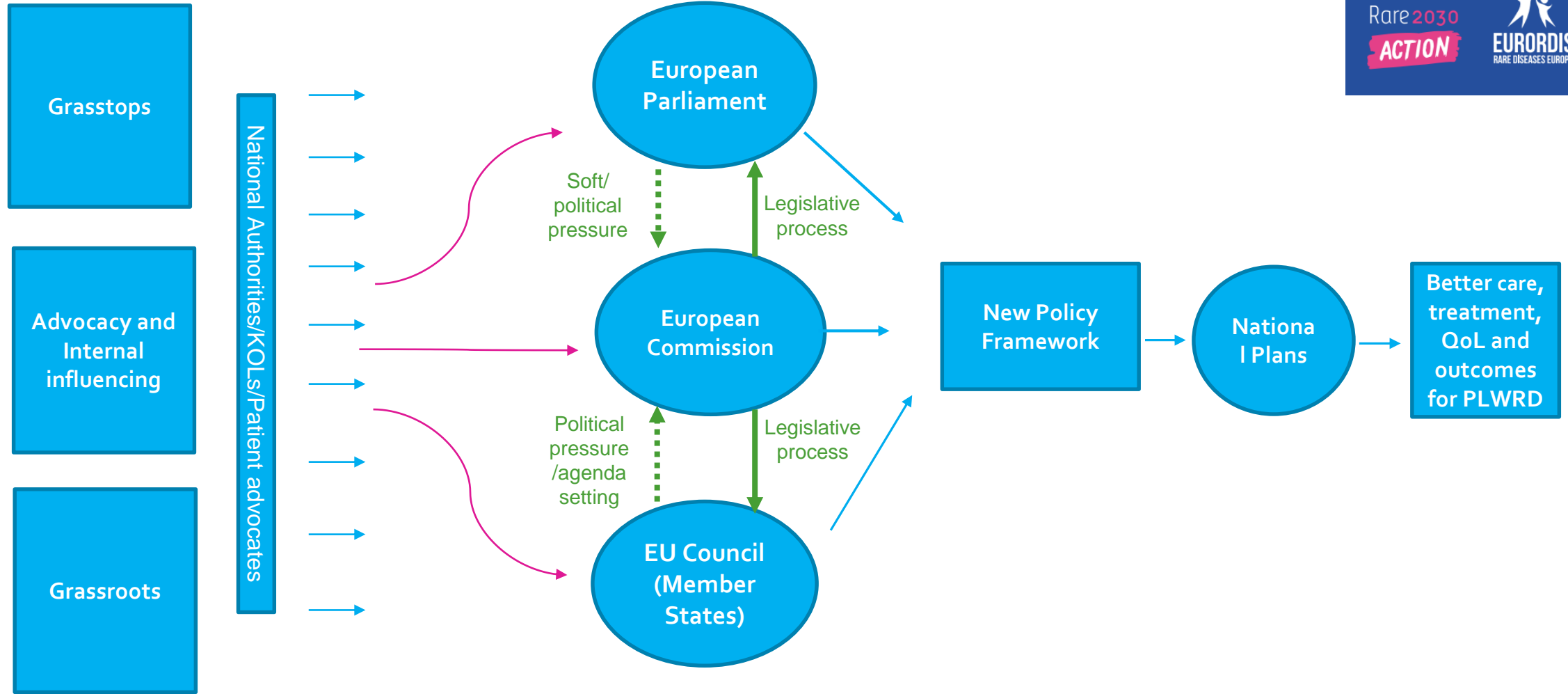




# EUROPE'S ACTION PLAN FOR RARE DISEASES

*LEAVING NO ONE BEHIND*

# A LAYERED STRATEGY



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

1

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

NOW

by  
2030

**6%** of rare diseases have a treatment

**5 YEARS** to diagnosis

**51%** rare disease has a severe impact on daily life

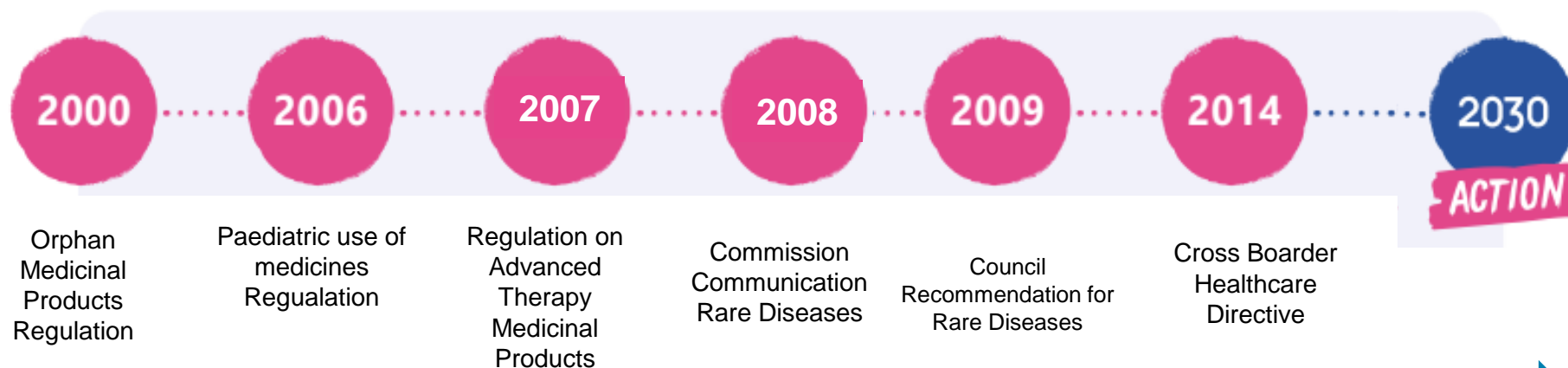
**1000** new therapies

All people living with a rare disease to receive a diagnosis with **6 MONTHS**

Reduce the level of psychological, social and economic vulnerability by **1/3**

2

## CURRENT RARE DISEASE STRATEGIES ARE **OUTDATED**



**12 Trends Rare 2030: New technologies, new values, new expectations**





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

*“A European plan ensures that Europe continues to enable the rare disease community to create the **critical mass** of patients, experts, knowledge, guidelines and resources needed by coordinating and adding value to national efforts”*





## WRITE IN THE CHAT...

Something you are proud of this year... personal or professional!



# **CAMPAIGN TOOLKIT** [eurordis.org/30millionreasons](http://eurordis.org/30millionreasons)

- Rare 2030 Recommendations
- Campaign factsheet
- Letter to MEP template
- Social media templates

*Coming soon*

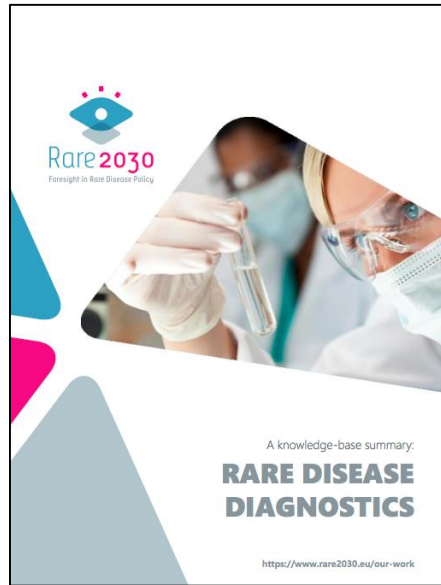
- Platform in 23 languages
- Press release on the Rare 2030 survey
- Slide deck

... Anything else?





Rare 2030 Report



8 Knowledge Base Summaries

Topic-specific documents

Overview of knowledge

| Overarching Trends in RDs   | Specificities for RDs  | Relevant Broader Trends in Health and Healthcare | Type of Trend |
|---|--|--|---------------|
| 1. <a href="#">Rise of pan-European multi-stakeholder networks to advance diagnostics, treatment and care for rare diseases</a> | Europe is now firmly in the age of the European Reference Network (ERNs) - networks of centres of expertise and healthcare providers organised across EU borders whose future depends on continued support. Multi-stakeholder collaboration is also becoming increasingly popular in the research and innovation sectors (e.g. European Joint Programme for Rare Diseases (EP RD)). Stakeholders in the rare disease field are increasingly collaborating with actors from complementary fields including social sciences, health policy, regulatory science, eHealth, big data, -omics approaches, bioinformatics, nanotechnology, etc. | Multi-stakeholders governance                    | Political     |
| 2. <a href="#">Strains on the health care budget and the emergence of new care delivery models</a>                              | As healthcare budgets continue to strain and rare diseases "compete" with more increasingly prevalent non-communicable diseases, health care delivery models for people living with rare diseases become more person-centred and holistic to maximize impact.  | New healthcare delivery models                   | Economic      |
| 3. <a href="#">Greater variation in access to treatments</a>  | High market price of orphan medicinal products allows for return on investment and continued R&D in the sector but   | Access to medical products                       | Economic      |



Trends

Overview of current trends in rare diseases



# WHAT CAN YOU DO AS A EURODIS MEMBER?

TAKE

**ACTION**



**1**

**SHARE YOUR REASON**

**2**

**ASK YOUR NETWORKS TO SHARE THEIR REASON**

**3**

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



# HAVE YOU WRITTEN YOUR REASON YET?



A EURORDIS INITIATIVE

Edit

Email share

Webform

Results

Translate

Widget

English ▼

## 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?

**13** people have given their reason. Will you help us get **487** more?

First name \*

Last name \*

E-mail address \*



# YOUR VOICE COUNTS!

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



# TAKE FIVE MINUTES TO WRITE YOUR REASON



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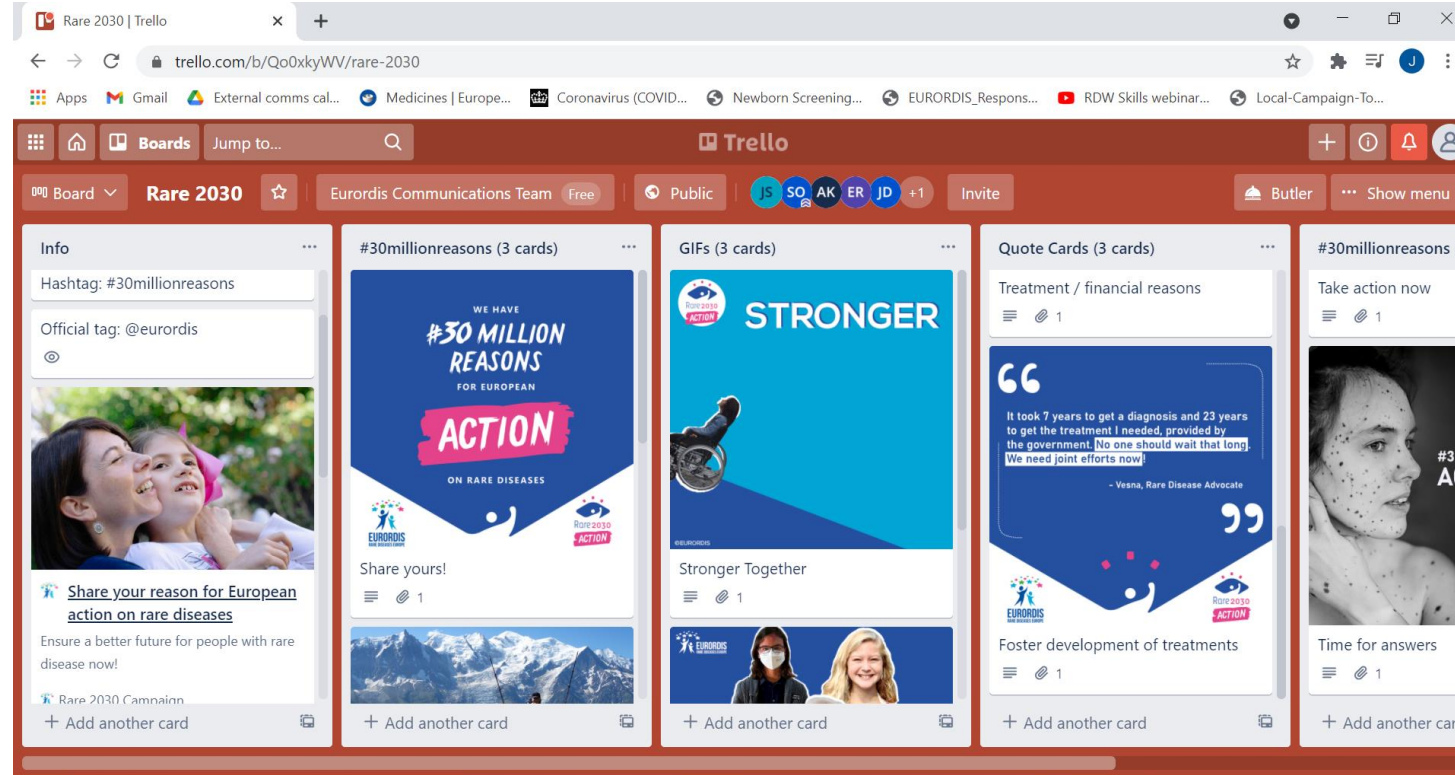
Last name \*

E-mail address \*





# TALKING ABOUT THE CAMPAIGN ON SOCIAL MEDIA



# WRITE TO YOUR MEP TO JOIN OUR NETWORK OF PARLIAMENTARY ADVOCATES FOR RARE DISEASES



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 role 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



# WHAT CAN THE NETWORK OF PARLIAMENTARY ADVOCATES DO?

- Organise events
- Ask questions to the European Commission
- Contribute in debates
- Propose amendments to legislation

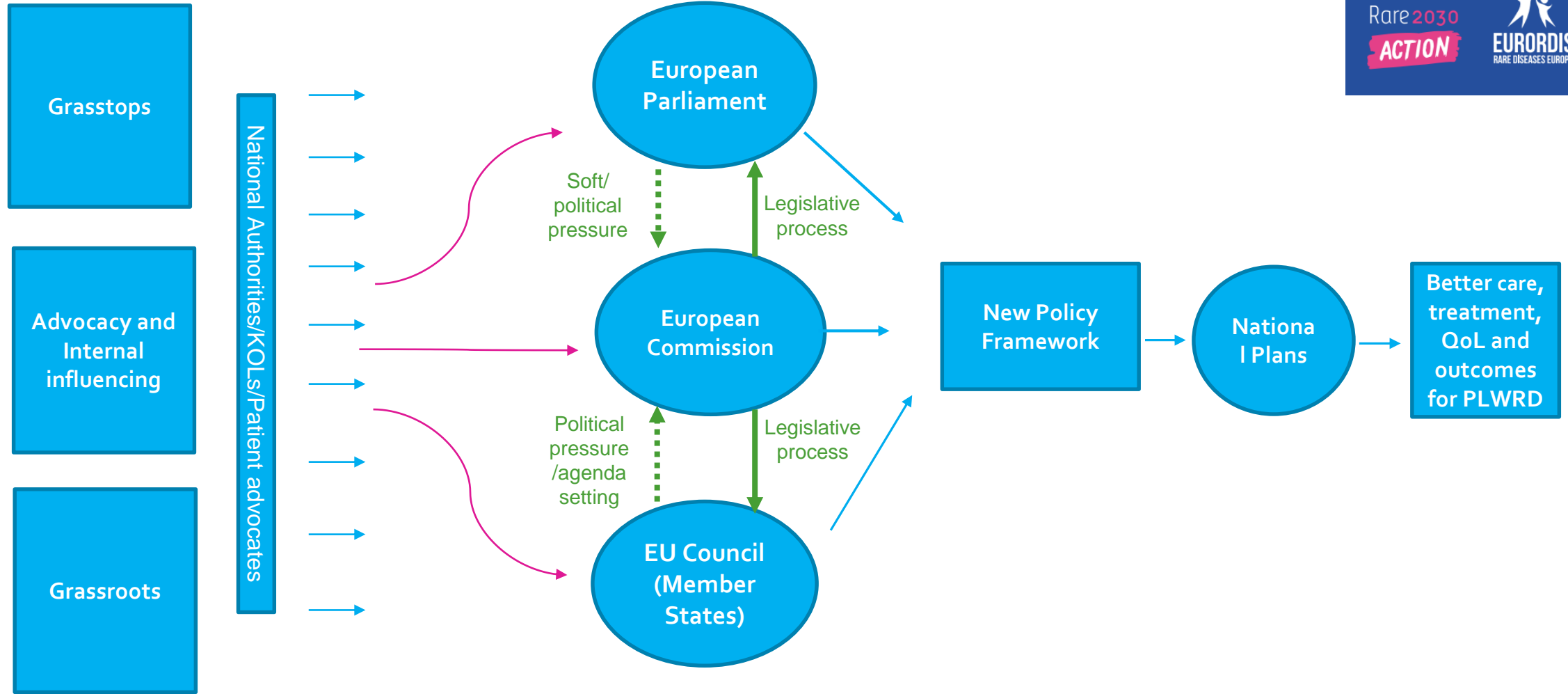


# WHAT ARE THE PRIORITIES FOR THE NETWORK?

1. Join our call for a European Action Plan on rare diseases
2. Ensure the review of Orphan Medicinal Products Regulation increases access to treatments for people with rare diseases
3. Embed European Reference Networks in a European Health Data Space to ensure access to high quality healthcare
4. Support the uptake of harmonised approaches to newborn screening for rare diseases across EU Member States



# A LAYERED STRATEGY

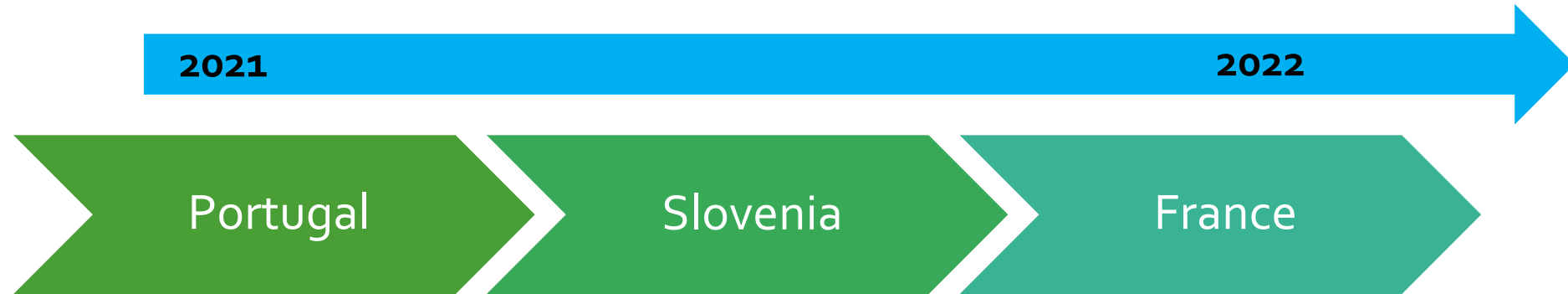


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# THIS IS JUST THE BEGINNING...



# THIS IS JUST THE BEGINNING...



MEP -> Network

Share your reason

Letter to health ministers?

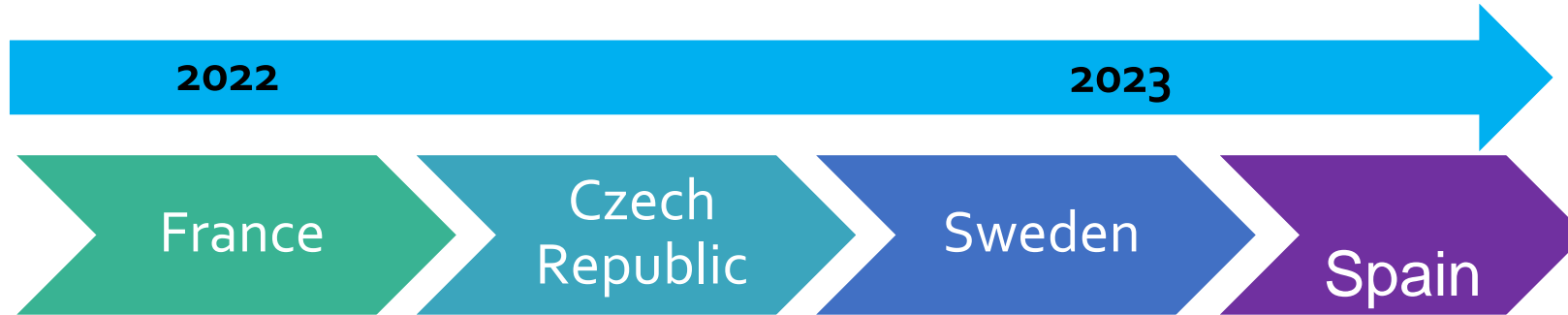


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# WHAT NEXT?



# ANY IDEAS?





# WHAT *ELSE* CAN YOU DO AS A EUORDIS MEMBER?

TAKE **ACTION**



# WHAT *ELSE* CAN YOU DO AS A EUORDIS MEMBER?

- Organise meetings with policy makers



# WHAT *ELSE* CAN YOU DO AS A EUORDIS MEMBER?

- Talk about the need for EU action in the press

## MORNING HEALTH CARE

### RARE DISEASES

**MORE ACTION ON RARE DISEASES:** A dedicated Commission action plan for rare diseases? That's the goal of the upcoming campaign by rare disease umbrella patient group EURORDIS. The official launch of the campaign is June 1 — but the NGO is testing the waters with a soft launch today, which coincides with the beginning of a three-day membership meet.

**Cancer plan inspired:** Public Health Policy Director Anna Kole told [POLITICO](#) the successful launch of Europe's Beating Cancer plan had provided inspiration for the idea of creating a dedicated action plan for rare diseases.

**Institutional support:** Kole explained that during the unveiling of its [Rare2030 policy document](#), which EURORDIS launched in February, the Council, Parliament and Commission had signalled their support for more action on the rare disease front.

**Joining up the dots:** Meanwhile, the Commission is moving on several different fronts to improve rare disease treatment in the EU. An [impact assessment](#) evaluating proposals to change EU regulations for medicines for rare diseases and for children is expected to run until the first quarter of next year. That will open the door to new legislative changes. And creation of a European health data space will allow pooling data from rare disease patients across different member countries.

**EU value add:** Kole said that an action plan would allow better coordination across the disparate fields that the Commission is acting on, as well as the introduction of new flagship initiatives.

"If there's one disease area where EU added value can't be more clearly demonstrated, it's rare diseases," said Kole, who pointed to the benefits of allowing patients to move across borders for specialist treatment, or for facilitating data sharing throughout the bloc, as examples.



# WHAT *ELSE* CAN YOU DO AS A EUORDIS MEMBER?

- Link a local or national event with EU/international policy actions
  - How can you link this with Rare Disease Day?
  - How can you link this to the international campaign for a UN Resolution on Rare Diseases?

