



Advocating towards a new European policy framework for rare diseases & How to join forces

26 November 2020
CNA/CEF meeting

EURORDIS.ORG



Some background information

- A complex environment with risks and opportunities
- The why, what and how of a campaign

A complex environment & shifting priorities



Risks resulting from COVID pandemic

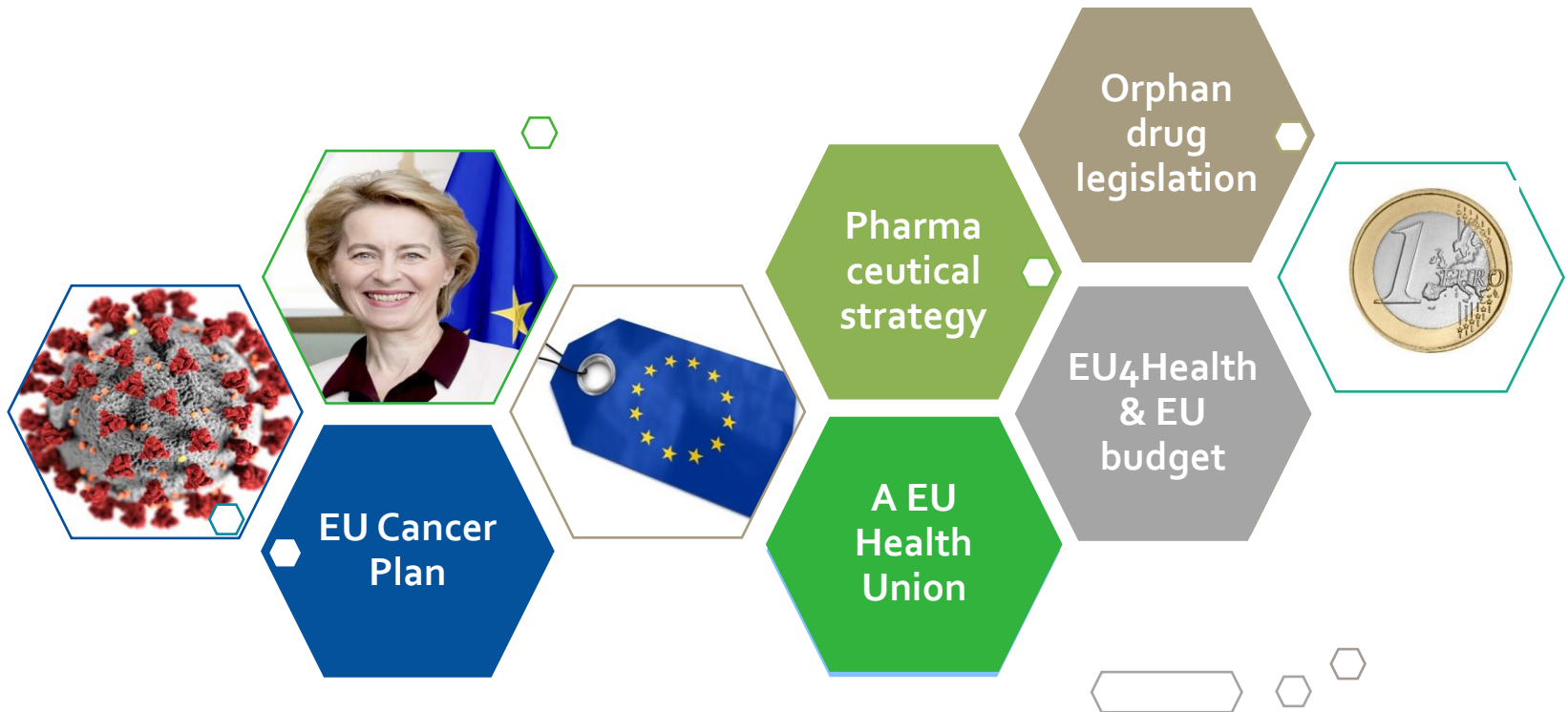
Risks of COVID- pandemic are political, medical/social, organisational

- Political – COVID takes priority in EU and national discourse
- Medical/Social – Rare Barometer Voices survey shows 84% of PLWRD experienced disruption of care, increased isolation
- Operational – availability of volunteers - Face to face exchange – etc.

Backdrop of COVID-19 pandemic :

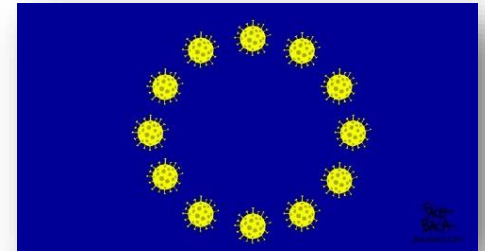
- ✓ The world is now familiar with what the vulnerable PLWRD face everyday
- ✓ Demonstrating - more than ever- the need to prepare for the future

Great news ! Look at how much attention health is getting



With every crisis come opportunities

- A **ten-fold increase of the EU budget for public health**
- The new **Recovery Fund** – a new Marshall plan for Europe?
- A **EU Health Union** to be born from the ashes of the post pandemic Europe?



Opportunity to advocate for:

- ✓ a clear place for rare diseases in **budget allocation and planning**
- ✓ overall **more resilient and shock-resistant healthcare systems** that do not exacerbate the vulnerabilities of people living with a rare disease across Europe
- ✓ **greater collaboration and solidarity** between countries, health systems and all stakeholders & **pooling of resources**
- ✓ A real **European Health Union** <https://europeanhealthunion.eu> **Sign the Manifesto !**

How to avoid that rare diseases get lost?



We need a new policy framework !





Rare 2030

Foresight in Rare Disease Policy

What to put in that frame?

AS A RETURNING MEP OR CANDIDATE
**PLEDGE YOUR SUPPORT
FOR RARE DISEASES**

A RARE OPPORTUNITY TO SHOW THE ADDED VALUE OF EUROPE!

To ensure that the 25 - 30 million people living with a rare disease in Europe and their families are not left behind and achieve their highest potential of health and well-being you can pledge to support a new political framework that:

- 

1. ENABLES ALL PEOPLE LIVING WITH A RARE DISEASE TO RECEIVE AN ACCURATE DIAGNOSIS AND APPROPRIATE CARE WITHIN ONE YEAR OF COMING TO MEDICAL ATTENTION
- 

2. SUPPORTS HOLISTIC CARE AND SOCIAL SYSTEMS THAT ARE INCLUSIVE OF PEOPLE LIVING WITH A RARE DISEASE, THROUGHOUT THEIR LIVES
- 

3. SEIZES OPPORTUNITIES IN SCIENCE AND INNOVATION THAT EMBODY HOPE FOR PEOPLE LIVING WITH RARE DISEASES AND THEIR CAREERS AND CAN CHANGE THEIR LIVES

> Overall vision statement

- *Solidarity – need-led innovation*
- *Importance of maintaining a multistakeholder platform of design and decision making/monitoring*

> Final recommendations

- Diagnosis
- Healthcare coordination and access
- Basic, clinical and translational research
- Drug development and regulation & access
- Patient engagement & partnership
- Social integration and holistic care



Overarching trends that will influence rare disease policy



Trend #5

Threats to solidarity, equity, and the prioritization of rare diseases.



To make it happen ...



... we need you !

Grassroots and Public Affairs Campaign (2021-2022)

Campaigning for a new policy framework in 2022

Objective	A sustainable policy framework for RDs EU and national level to improve lives of people living with RDs
Content and messages	<p>From Rare2030 recommendations to messages for campaign – audience definition, different levels</p> <p>Across all communication</p> 
Members	<p>Drive a meaningful change that has an impact on your lives</p> <p>Embrace & carry the message & engage in the political discourse (grassroot campaign)</p>
Timeline	<p>From RDD 2021 to end 2022 or RDD 2023 & builds upon:</p> <ul style="list-style-type: none"> • Political milestones • EURORDIS / RD community milestones – link events together
Output	<div style="border: 1px dashed black; padding: 10px; text-align: center;"> <p><i>New Council Recommendation – Rare Disease policy: the next 15 years?</i></p> </div> 

What's in a campaign?

- **Grassroots advocacy:** general public or concerned citizens (EURORDIS Membership at large) connect with their local policy makers on an issue they care about.
- **Grasstops advocacy:** focus narrowly on enlisting the help of **individuals who have personal connections with the decision makers** you are targeting.
- **Public Affairs:** EURORDIS continued relations with government, EU, companies and other stakeholders



Campaigning for a new policy framework in 2022

#RD2022

#RDframework2022

#TheFutureStartsToday

#JobNotDone

#BeTheChange



Content and messages



8+ recommendations



3 pillars

- What we want to see in Europe in 2030 ?
- Underlying philosophy
- Why we need to act?

3 or 4 key areas

- Care, Research, xxx
- EU added value
- Leave no one behind
- Holistic approach

My unmet needs

- Stories & Testimonies

HARVEY

Africa

Kenya

Spinal Muscular Atrophy - SMA
(Neuromuscular)

4 years old – Access to treatments

SYAFIQ

Asia

Malaysia

Hypohidrotic Ectodermal Dysplasia - HED (Skin)

32 years old

ANGELINA

Australia

Australia

Calcium/calmodulin dependent serine protein
kinase - CASK (Neurological)

Research, very rare disease (50
worldwide), family isolation

RARE

ES

REGINA

South America

Brazil

Leiomyosarcoma (Adult Solid Tumor)

50 years old – Adult onset, in remission
cancer

RARE IS MANY. RARE IS
STRONG. RARE IS PROUD.

emia (Blood)

visible disease, self-management

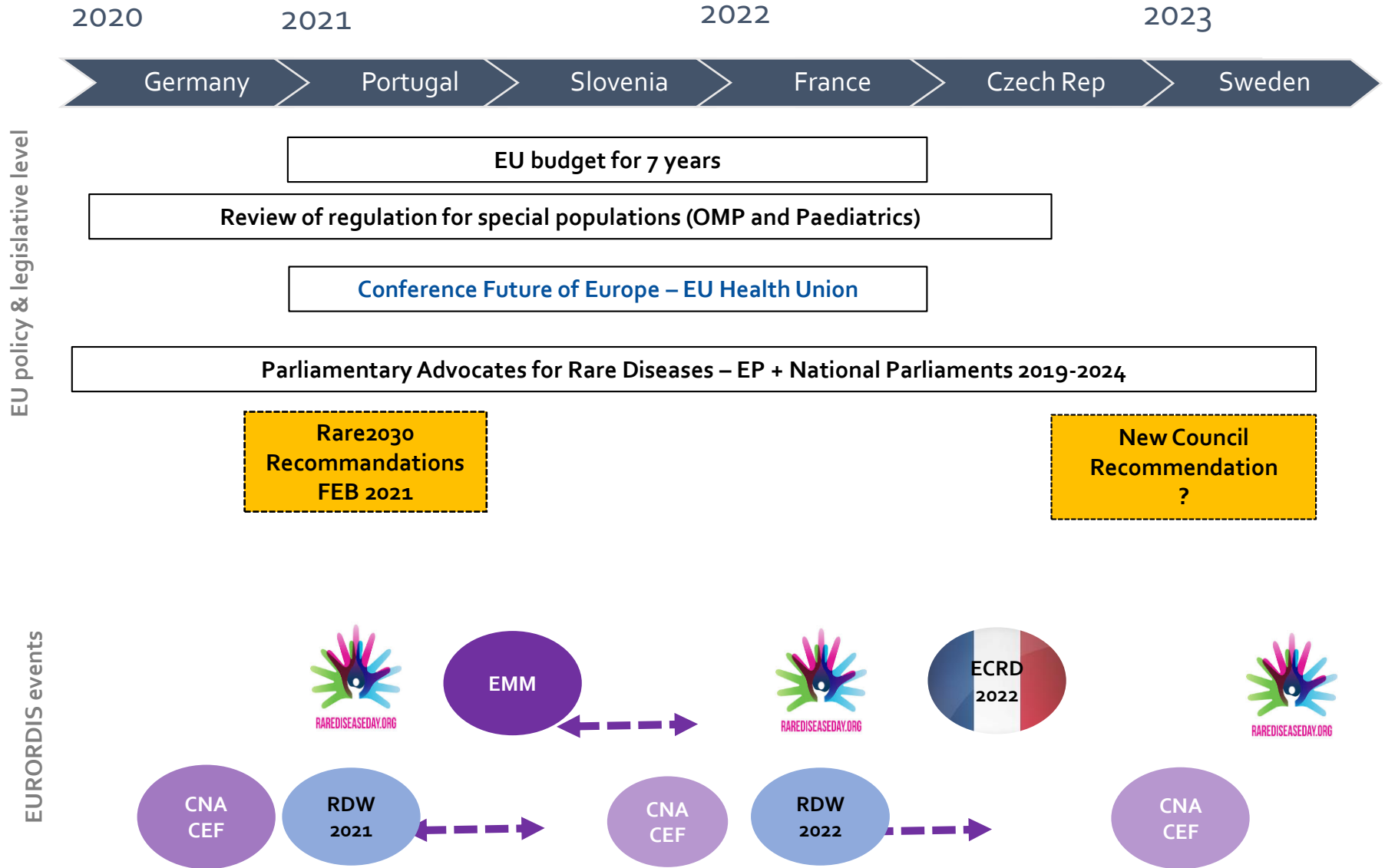
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Content and messages

Level of message	Grassroot	Grasstop
	Clear simple messages, 3 or 4 key asks	More detailed from Rare2030 recos
Main audience	EU & national policymakers	Targeted policymakers e.g. working on RD files
Main carriers	Membership at large ePAGs RDW participants Rare2030 Panel of Experts RD community ...	NAs + EFs RDW participants BoD Rare2030 Young Citizens ...

- Linking events, build the **same narrative**, coherence of messages
- Grassroots campaign approach
- **Bottom-up approach & meaningful for all**

Timeline RDD 2021 – RDD2023



Joining forces

- **Grassroots advocacy:**

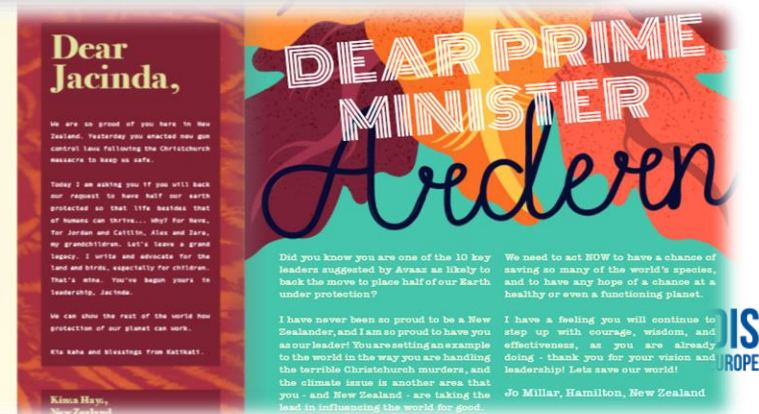
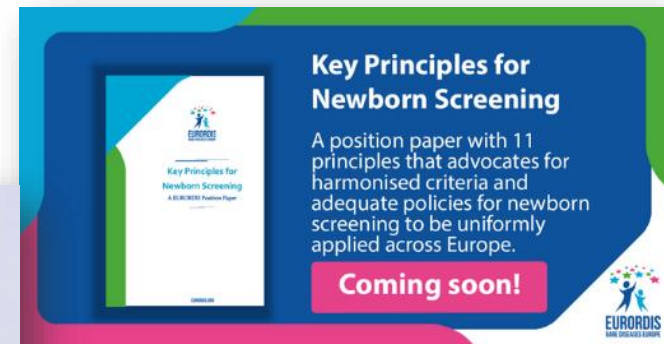
general public or concerned citizens connect with their local policy makers on an issue they care about

→ Online petitions

→ Calls

→ Joint letters

→ Twitter cards etc...



Joining forces

- **Grasstop advocacy:**

focus narrowly on enlisting the help of individuals who have personal connections with the decision makers you are targeting

→ In person meetings

→ Ad hoc letters

→ Scientific reports

- National government
- MPs or MEPs
- Ambassadors ...



M. Terkel ANDERSEN
Président EURORDIS
Mme Nathalie TRICLIN-CONSEIL
Présidente Alliance maladies rares
Mme Laurence TIENNOT-HERMENT
Présidente AFM-Téléthon

M. Olivier VERAN
Ministre des Solidarités et de la Santé
14, avenue Duquesne
75007 Paris France

23 novembre 2020

Objet : Demande de rendez-vous avec EURORDIS-Rare Diseases Europe, alliance européenne des patients atteints de maladies rares, l'Alliance maladies rares, porte-voix des 3 millions de français concernés les maladies rares en France, et l'AFM-Téléthon, pionnier majeur de la lutte contre les maladies rares

Monsieur le Ministre,

Au nom d'EURORDIS, de l'Alliance maladies rares et de l'AFM-Téléthon, qui représentent la communauté de personnes atteints de maladies rares en France et en Europe, nous souhaitons solliciter un entretien avec vous en vue de discuter de la place des maladies rares dans le cadre de la prochaine présidence française du Conseil de l'Union européenne en 2022



Joining forces

→ Are you supportive of this idea?

- Who has created a grassroots campaign?
- Who has worked with “grasstops” contacts to influence policy?



→ Regional meetings to promote a policy framework for RDs

- How was your experience? What would be the next steps?
- For the others: what similar initiatives could be helpful in your country?

Joining forces

→ What tools?

- Can you please give us examples in your **native language** for **#** that you think could work in comparison to the ones listed

#RD2022

#RDframework2022

#TheFutureStartsToday

#JobNotDone

#BeTheChange

- What **tools** do you use to get the attention of policy makers? Letters? Meetings? Videos? Tweets?
- What tools do you use **to mobilise your membership** in supporting your advocacy efforts? Letters? Meetings? Videos? Tweets?
- Are there new tools you are eager to try?

Joining forces

→ Can you help us shape messages from Rare2030 ?

→ Would you join a working group?

Especially if you:

- Come from a country of future EU Council Presidencies
- Can help with defining messages and/or have experience in grassroots campaigns
- Coordinate actions with policymakers...

