

CHAMPIONING THE RARE

> Building the Engine of an Inclusive
European Health Union

#ACTRARE2024



1. #ActRare2024 LAUNCH on 29 FEB



Successful launch at the European Parliament on Rare Disease Day

Formal exchange of views at the
European Parliament on rare
diseases with MEPs and
European Commission



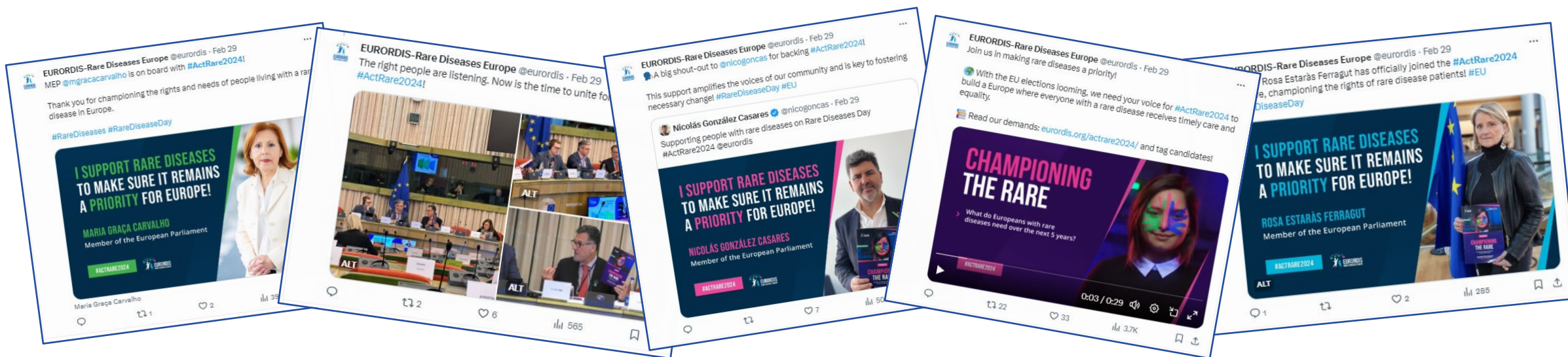
First meetings with MEPs candidates (x15) supporting the Manifesto



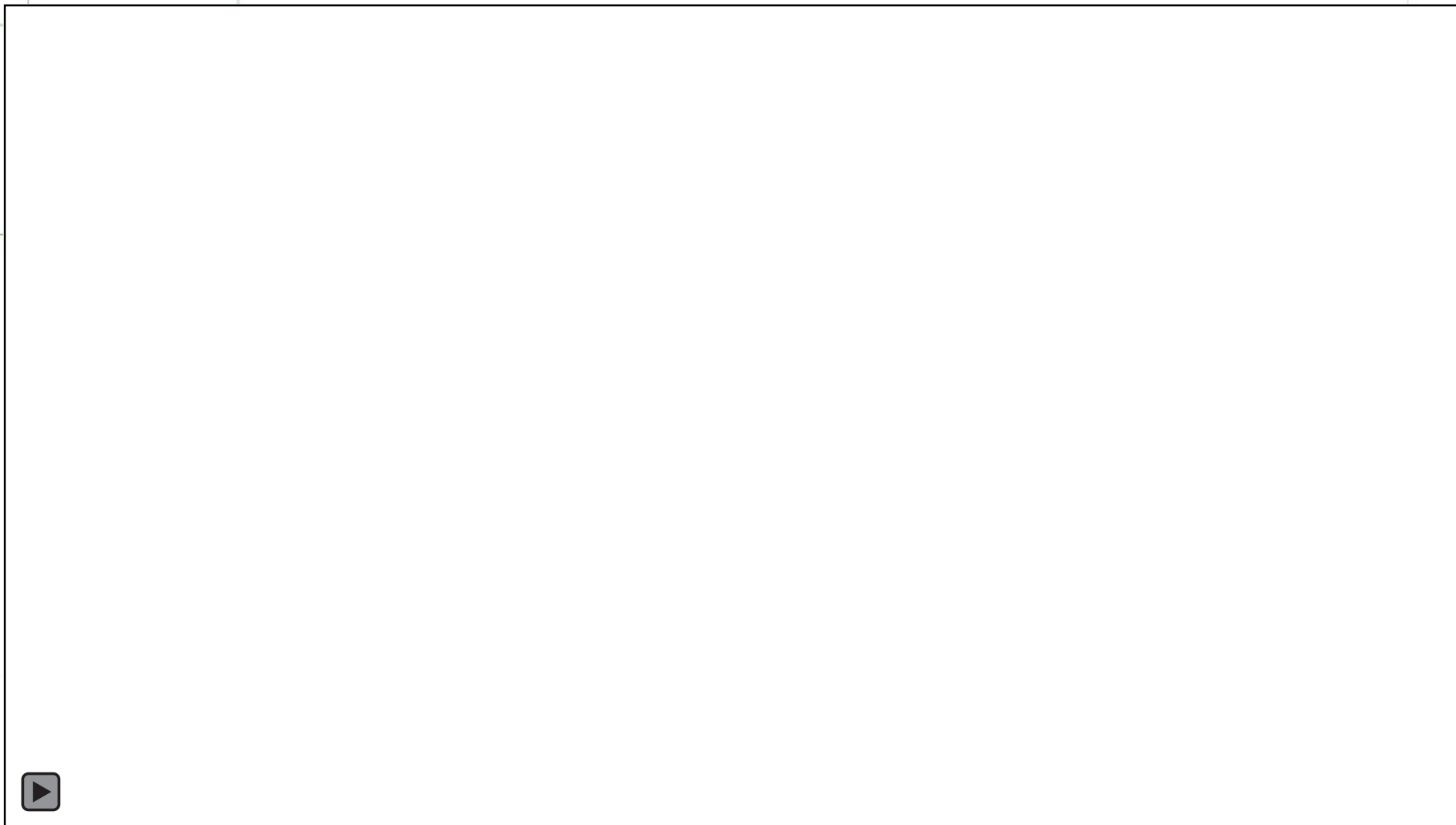
2 Manifestos mentioning Rare diseases

- **PES** : « We will implement fair and transparent medicine pricing to prevent shortages and support timely access and innovation, **including for rare diseases.**”
- **The Greens**: “We will push to eliminate health inequities and guarantee access to affordable medicines and treatment, **including for cancer and rare diseases**, in ways that are inclusive to all parts of society, especially the most vulnerable and racialized communities.”

Communications results from the launch:



Campaign video



2. REACHING OUT TO MEPS CANDIDATES

**Elections: 6-9
JUNE 2024**



Ask candidates to support RD as a policy priority

1. Ask them to sign the Pledge

- A 1 pager summarizing our priorities to EU elections
- QR code and signing form on the pledge
- Goes with the Manifesto
- Send answers to: Julie.Pernet@eurordis.org



CHAMPIONING THE RARE

If elected, I will

EUROPEAN POLICY FRAMEWORK ON RARE DISEASES 01

Promote the creation of a comprehensive and goal-based European Action Plan for Rare Diseases to address the high unmet needs of people living with a rare disease. This will break the silos of different legislative pieces on data, research, treatment, healthcare, social protection, wellbeing, and national and EU initiatives.

EARLIER, FASTER, AND MORE ACCURATE DIAGNOSIS 02

Urge the EU to coordinate a unified approach to diagnosis, promoting collaboration among specialised healthcare providers and sharing best practices among Member States. This guarantees earlier, faster, and more accurate rare disease diagnoses across Europe. Additionally, I will call for EU-wide approaches to newborn screening and support the best research and advanced diagnostic technologies to provide all children with equal opportunities across Europe.

INTEGRATED NATIONAL AND EUROPEAN HEALTHCARE PATHWAYS 03

Ensure timely, equal access to highly specialised healthcare for individuals with rare or complex conditions, e.g. through the integration of the European Reference Networks (ERNs) into both cross-border and national healthcare systems. I will also urge the EU to define and implement specific solutions and provide support for better cooperation and specialised healthcare delivery, particularly for ultra-rare diseases impacting fewer than 500 people in the EU.

TIMELY ACCESS TO AFFORDABLE AND INNOVATIVE TREATMENTS 04

Urge the EU to establish a robust framework focusing on patients' unmet needs, promoting innovation and access to transformative and affordable treatments. This includes early access, compassionate use, early dialogues, and enhanced pricing and reimbursement cooperation, backed by unified European purchasing methods. I will urge the EU to systematically engage with patients and their representatives at all stages of the R&D and regulatory processes.

INTEGRATED, PERSON-CENTRED, AND LIFELONG HOLISTIC CARE 05

Urge the EU to recognise the lifelong care needs of people with rare diseases, including their mental health needs. Assist Member States in developing comprehensive care pathways. Additionally, I will call for the sharing of good practices to improve national disability assessment frameworks and will urge the Commission to recognise the rare disease community as a vulnerable population with specific mental health needs.

INNOVATIVE AND NEEDS-LED RESEARCH AND DEVELOPMENT 06

Continue fostering long-term cross-border collaboration in rare disease research, focusing on regulatory science tailored to rare diseases, leveraging technology, and advanced therapies. Specifically, I will urge the EU to bolster the research capacity of ERNs, support cross-sector partnerships in rare disease research under Horizon Europe, ensure continuity for the European Joint Programme for Rare Diseases, and facilitate patient engagement in research.

OPTIMISED DATA FOR PATIENT AND SOCIETAL BENEFIT 07

Urge the EU to balance data security with enabling data access for new therapies. I will support harmonising and optimising electronic health records for secure cross-border data exchange, along with establishing a trusted governance framework that involves ERNs for ethical data utilisation. Collaborating with patient representatives will be crucial at all stages.

SUSTAINABLE AND RESILIENT TREATMENT DEVELOPMENT 08

Call for a more integrated and resilient approach that balances and optimises the health and wellbeing of individuals, animals, and the environment across the entire research, development, and access lifecycle of treatments and care. I will also facilitate the development of digital tools, telemedicine, and mobile healthcare to enhance accessibility and convenience for clinical trial participants.

2. Ask them to send a picture for the social media card



⇒ EURORDIS will make the card

⇒ The picture will feed the virtual wall of RD champions

⇒ You can send back the card to candidates for their own social media

**I SUPPORT RARE DISEASES
TO MAKE SURE IT REMAINS
A PRIORITY FOR EUROPE!**

JOÃO ALBUQUERQUE

Member of the European Parliament

#ACTRARE2024



**I SUPPORT RARE DISEASES
TO MAKE SURE IT REMAINS
A PRIORITY FOR EUROPE!**

BRANDO BENIFEI

Member of the European Parliament

#ACTRARE2024



**I SUPPORT RARE DISEASES
TO MAKE SURE IT REMAINS
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TOMISLAV SOKOL

Member of the European Parliament

#ACTRARE2024



**I SUPPORT RARE DISEASES
TO MAKE SURE IT REMAINS
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LAURA BALLARÍN CEREZA

Member of the European Parliament

#ACTRARE2024



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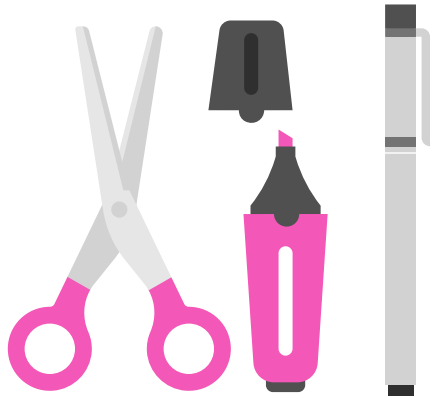
MARIA GRAÇA CARVALHO

Member of the European Parliament

#ACTRARE2024



The Toolkit #ActRare2024



- **EU Manifestos** – translation possible
- **A Pledge card for candidates**
- **Social media cards for candidates and patient organisations**
- **A template email** to reach out to candidate
- **A customisable PPT presentation of our priorities**
- **A dedicated web page**

To keep in mind...

1. Send answers and coordinate with me 😊
2. Always use **#ActRare2024** on social media
3. Feel free to ask for help to identify candidates

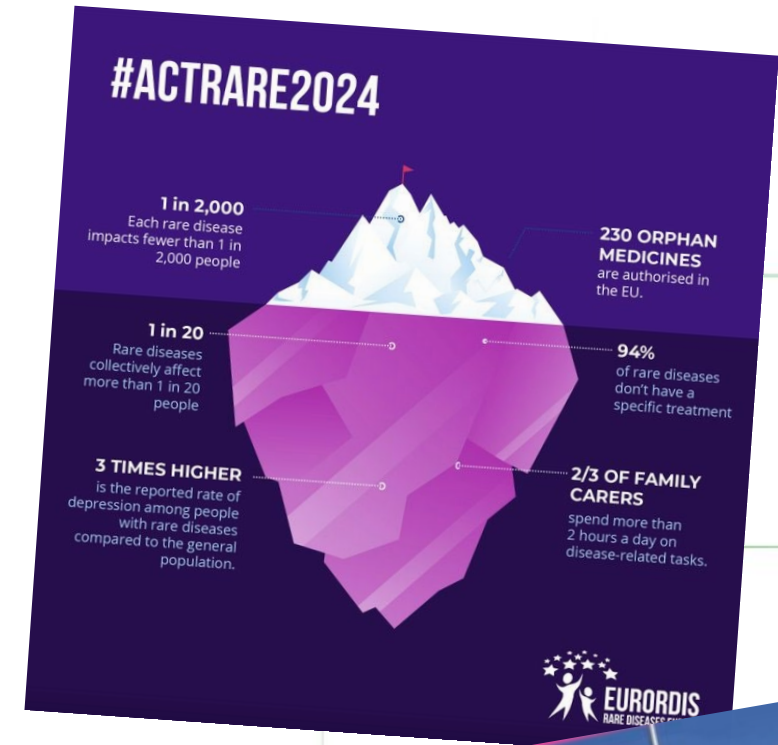
4. Alternative ways to become a RD champion:
 - *Positive answer via email*
 - *A candidate using our #*

3.SUPPORTING ActRare2024 COMMUNICATION



Like and share!

- Keep an eye on social media and the #ActRare2024 hashtag!
- EURORDIS outputs over the coming weeks and months:
 - Infographics
 - Ask-specific videos
 - Articles



Thank you !

Any questions ?

