



#ACTRARE2024

CHAMPIONING THE RARE

> Building the Engine of an Inclusive European Health Union <

“RARE IS NOT RARE IF YOU SEE HOW MANY WE ARE.
NO ONE DESERVES TO WALK THIS ROAD ALONE.”

ALEKSANDRA, THE NETHERLANDS



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EURORDIS - Rare Diseases Europe and its over 1,000 rare disease patient organisations, are calling for rare diseases to be a priority of the candidates to the European Parliament, the future European Commission, and other relevant policymakers.

As we approach the European Parliament elections, 30 million people living with a rare disease in Europe call for a world where they can have longer and better lives and achieve their full potential, in a society that values their well-being and leaves no one behind.

We believe that the following recommendations are key to building an inclusive European Health Union that leaves no-one behind:

**EUROPEAN POLICY
FRAMEWORK ON RARE
DISEASES**

01

**EARLIER, FASTER,
AND MORE ACCURATE
DIAGNOSIS**

02

**INTEGRATED NATIONAL
AND EUROPEAN
HEALTHCARE PATHWAYS**

03

**TIMELY ACCESS TO
AFFORDABLE AND INNOVATIVE
TREATMENTS**

04

**INTEGRATED, PERSON-
CENTRED, AND LIFELONG
HOLISTIC CARE**

05

**INNOVATIVE AND
NEEDS-LED RESEARCH
AND DEVELOPMENT**

06

**OPTIMISED DATA FOR
PATIENT AND SOCIETAL
BENEFIT**

07

**SUSTAINABLE AND
RESILIENT TREATMENT
DEVELOPMENT**

08



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Rare diseases affect over 30 million people in Europe, impacting their families and caregivers. These conditions are often chronic, progressive, degenerative, and life-threatening, significantly affecting daily life. While the collective number is substantial, individuals with each of the 6,000 rare diseases are few and dispersed across countries.

1 IN 2,000

is the EU's threshold for classifying a rare disease, affecting that number or less of citizens

30 MILLION

people live with a rare disease in 48 countries in Europe

6,000+

is the estimated number of distinct rare diseases

72%

of rare diseases are of genetic origin

To improve the lives of EU citizens with rare diseases, effective strategies must be cross-border and EU-wide. Currently, unmet needs persist for people with rare diseases in various areas globally and in Europe. Much work remains to ensure equitable access to diagnosis, treatment, healthcare, and social support while promoting the full inclusion of people with rare diseases in society.

We need renewed European action for rare diseases to rebuild the momentum around national plans and strategies, and everything within them. Nobody can do it alone for rare diseases.

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VICTORIA
PATIENT ADVOCATE



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EURORDIS - Rare Diseases Europe is a unique, non-profit alliance of over 1,000 rare disease patient organisations from 74 countries that work together to improve the lives of over 300 million people living with a rare disease globally.

Scan the QR-code to read the detailed version of our priorities or visit our website: www.eurordis.org

