

Amplifying Patient and Public Involvement in small Rare Disease Ecosystems

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Organisers:



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Who we are

Founded: 2010 | Non-profit umbrella organization

Represents: ~60,000 people living with rare diseases in Cyprus

Members: 18 patient associations & 400+ individual patients

Key Roles:

- Patient support & advocacy
- Policy collaboration with Ministry of Health and other stakeholders
- National representative to EURORDIS & RDI

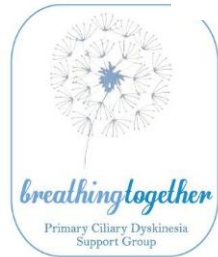
Key Initiatives:

- Folia Centre – patient information & support hub
- digital platforms



Advancement of Treatments FOR RARE DISEASES

Our Members



Advancement of Treatments FOR RARE DISEASES

Why Patients & Public Involvement matter in Rare Diseases

- 300+ million people globally affected
- 95% of rare diseases have no approved treatment
 - Patients often become disease experts



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Patients are not passive recipients — they are essential partners



The reality of Rare Diseases

- Diagnostic Delays (5-7 years)
- Fragmented Care Pathways
- Limited Expertise
- Psychosocial & Economic Burden



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Complexity Requires Collaboration



The Cyprus Context

Challenges

- Small population
- Limited and scarce disease specific expertise
- Limited trial access

Opportunities

- Fast Policy Implementation
- Strong Patient Networks
- Digital Health Readiness



Cyprus: A living lab of Patient – Centered Innovation

- ✓ Agile healthcare ecosystem
- ✓ Direct collaboration between patients, clinicians, policymakers
- ✓ Rapid piloting of innovative solutions



Cyprus Alliance for Rare Disorders – C.A.R.D.

- ❖ National Patient Umbrella Association
 - ❖ Advocacy & Policy Influence
- ❖ Patient Education & Empowerment
- ❖ National & European representation



Advancement of Treatments FOR RARE DISEASES

Digital Platforms

- Digital Patient Support
- Tele-expertise
- Professional education
- Cross – border collaboration



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Technology amplifies
patient voice



Patients as research partners

- Protocol feedback
- Outcome measure design
- Recruitment optimization
- Patient – friendly trial models
- Research co - design
- Priority setting
- Ethical review participation
- Dissemination



Strategic Recommendations

For Cyprus

- ✓ National Patient & Public Involvement
- ✓ Rare disease registry
- ✓ Patient advisory boards

For Europe

- ✓ Mandatory patient involvement
- ✓ Harmonised Patient & Public involvement standards



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Call to action

- ❖ Include patients early
- ❖ Invest in patient capacity building
- ❖ Design systems with patients and not for patients



Advancement of Treatments FOR RARE DISEASES

“Innovation happens when patients become partners.”



Advancement of Treatments FOR RARE DISEASES

Thank you !

