Advancement of Treatments
FOR RARE DISEASES

Amplifying Patient and Public Involvement in small Rare Disease Ecosystems

June 17, 2026

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Director
Cyprus Alliance for Rare Disorders

C.A.R.D

Organisers: THE CYPRUS INSTITUTE OF NEUROLOGY & GENETICS
DEPUTY MINISTRY OF RESEARCH, INNOVATION AND DIGITAL POLICY
REPUBLIC OF CYPRUS
CY2026.EU
CYPRUS PRESIDENCY OF THE COUNCIL OF THE EU
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The conference is funded by the European Union (project no 101297283)

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

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Our Members

MDA
ΣΥΝΔΕΣΜΟΣ
ΜΥΟΠΑΘΩΝ ΚΥΠΡΟΥ

Παιδιά
με Ηπατικές
Παθήσεις
Γιώργος Ψαράς • Round Table

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Παγκύπριος
Σύνδεσμος
Θαλασσαιμίας

πα.συ.π.φι

ΠΑΓΚΥΠΡΙΟΣ
ΣΥΝΔΕΣΜΟΣ
ΓΙΑ ΤΗΝ
ΚΥΣΤΙΚΗ ΙΝΩΣΗ

ένα
όνειρο
μια
ευχή
ΠΑΓΚΥΠΡΙΟΣ ΣΥΝΔΕΣΜΟΣ
ΓΙΑ ΠΑΙΔΙΑ ΜΕ ΚΑΡΚΙΝΟ ΚΑΙ
ΣΥΝΑΦΕΙΣ ΠΑΘΗΣΕΙΣ

ΠΑΓΚΥΠΡΙΟΣ ΣΥΝΔΕΣΜΟΣ ΔΡΕΠΑΝΟΚΥΤΤΑΡΙΚΗΣ & ΜΙΚΡΟΔΡΕΠΑΝΟΚΥΤΤΑΡΙΚΗΣ ΑΝΑΙΜΙΑΣ
2019

ΣΥΝΔΕΣΜΟΣ ΑΜΥΛΟΕΙΔΩΣΗΣ ΚΥΠΡΟΥ
2015

ΣΩΜΑΤΕΙΟ ΑΣΘΕΝΩΝ ΚΑΙ ΦΙΛΩΝ
ΑΣΠΙΔΑ
ΖΩΗΣ
ΚΛΗΡΟΝΟΜΙΚΩΝ ΜΕΤΑΒΟΛΙΚΩΝ ΝΟΣΗΜΑΤΩΝ

ΟΜΙΛΟΣ ΕΛΠΙΔΟΦΟΡΟΣ
"ενάντια στην προκατάληψη"
Λευκωσία-Κύπρος
2007

Σύνδεσμος γονέων και φίλων ατόμων με αυτισμό.
μαζί

breathingtogether
Primary Ciliary Dyskinesia
Support Group

CBTA
CYPRUS BRAIN
TUMOUR ASSOCIATION
ΚΥΠΡΙΑΚΟΣ ΣΥΝΔΕΣΜΟΣ ΦΙΛΩΝ
ΚΑΙ ΑΤΟΜΩΝ ΜΕ ΟΓΚΟΥΣ ΕΓΚΕΦΑΛΟΥ

ΣΥΝΔΕΣΜΟΣ ΑΤΟΜΩΝ
ΜΕ ΣΥΓΓΕΝΗ
ΑΝΟΣΟΑΝΕΠΑΡΚΕΙΑ
ΚΑΙ ΦΙΛΩΝ

MG
CY
Myasthenia Gravis
Association Cyprus

Κυπριακός Σύνδεσμος
για τη νόσο του Huntington

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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

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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

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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

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Cyprus: A living lab of Patient – Centered Innovation

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

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

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

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Digital Platforms

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

DIEKDIKOCY
ΔΙΑΔΙΚΤΥΑΚΗ ΠΥΛΗ
ΕΝΗΜΕΡΩΣΗΣ ΑΣΘΕΝΩΝ

RARE-e-CONNECT

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Digital Platforms

Technology amplifies patient voice

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

DIEKDIKOCY
ΔΙΑΔΙΚΤΥΑΚΗ ΠΥΛΗ
ΕΝΗΜΕΡΩΣΗΣ ΑΣΘΕΝΩΝ

RARE-e-CONNECT

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Patients as research partners

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

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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

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“Innovation happens when patients become partners.”

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Thank you !

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