

Keep Patients Voting

Patient organisations call for guarantee of voting rights and meaningful involvement at the European Medicines Agency

As the EU's general pharmaceutical legislation enters a decisive phase, 72 additional patient organisations have joined EURORDIS–Rare Diseases Europe and the European Patients' Forum (EPF) in calling on EU policymakers to safeguard strong and meaningful patient involvement at the European Medicines Agency (EMA) – including the retention of patient voting rights in the Committee for Medicinal Products for Human Use (CHMP).

In a [joint statement](#) first published on 10 March 2025, EURORDIS and EPF warned that ongoing Council negotiations risk reducing the number of patient representatives and stripping their voting rights in the CHMP and the Pharmacovigilance and Risk Assessment Committee (PRAC) – the two EMA bodies central to approving and monitoring medicines in Europe.

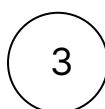
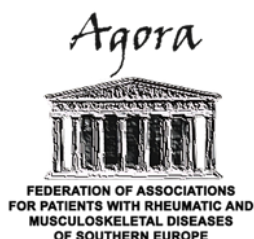
We are therefore proud to announce that our joint statement has now received widespread endorsement from a growing number of patient organisations, members of EPF and EURORDIS. This momentum reflects a shared concern across the community: the current direction of the pharmaceutical legislation risks undermining meaningful patient involvement.

Together, we are raising our voices to ensure the final legislation can fully reflect patients' lived experiences, expertise, and priorities, and does not diminish their role. This strong display of unity reinforces our collective commitment to ensuring that the future EU pharmaceutical framework truly serves the needs of patients by placing them at the heart of every decision.

Joint Statement Co-Signatories

- Acanthamoeba Keratitis (AK) Eye Foundation
- Agora – Federation of Associations for Patients with Rheumatic and Musculoskeletal Diseases of Southern Europe
- AICCA ETS – Associazione Italiana dei Cardiopatici Congeniti Bambini e Adulti
- Alex, The Leukodystrophy Charity (Alex TLC)
- Alliance for Pulmonary Hypertension (AfPH)
- Alpha1 Deutschland e.V.
- Alpha-1 Europe Alliance
- Alpha-1 UK Support Group
- Alzheimer Europe
- ARVC-Selbsthilfe e.V.
- Asociación Alicantina de Pacientes Asmáticos (ASAPA)
- Asociación de Sarcomas Grupo Asistencial (ASARGA)
- Asociación Española de Esclerodermia (AEE)
- Asociación para la Lucha contra los Síndromes Arrítmicos Relacionados con la Muerte Súbita (SAMS)
- Association Ollier Maffucci Europe
- Association Pour Nos Enfants H2
- APN - Associação Portuguesa de Neuromusculares
- BAG SELBSTHILFE
- Borys the Hero Foundation (Fundacja Bohatera Borysa)
- Cure ADOA Foundation
- Cutis Laxa Internationale
- Cystic Fibrosis Europe (CF Europe)
- DEBRA International
- Digestive Cancers Europe (DiCE)
- EPOC España – Asociación Española de Pacientes y Cuidadores de EPOC
- Europa Donna – The European Breast Cancer Coalition
- Europa Uomo
- European Haemophilia Consortium
- European Kidney Patients' Federation
- European Liver Patients' Association (ELPA)
- European Huntington Association
- Federación Española de Asociaciones de Pacientes Alérgicos y con Enfermedades Respiratorias (FENAER)
- FH Europe Foundation
- Fundación contra la Hipertensión Pulmonar
- GBS-CIDP Foundation International
- GlobalSkin – International Alliance of Dermatology Patient Organizations
- HHT Onlus Italia
- Hipertensión Pulmonar España (HPE-ORG)
- International Diabetes Federation Europe (IDF Europe)
- International Mito Patients (IMP)
- Latvian Network of Patient Organizations
- Limb Girdle Muscular Dystrophy Community Advisory Board (LGMD CAB)
- LMNA Cardiac
- Lovexair Foundation
- Lung Cancer Europe (LuCE)
- Malta Health Network
- MNT Mon Poumon Mon Air
- Myeloma Patients Europe (MPE)
- National Association of Patient Organizations (NAPO)
- NF Kinder, Austria
- Osteogenesis Imperfecta Federation Europe (OIFE)
- Parkinson's Europe
- Plataforma de Organizaciones de Pacientes
- Rare Diseases Ireland
- Retina International
- Riksförbundet Sällsynta diagnoser (Rare Diseases Sweden)
- RONARD
- Sevilla Respira
- Sjogren Europe
- Somerville Heart Foundation
- Stichting SpierKracht (the Netherlands)
- Sydänlapset ja -aikuiset ry (Finnish Association for Heart Children and Adults)
- SZÍVSN Országos Betegegyesület
- The European Federation of Homeopathic Patients' Associations
- The European Heart and Lung Transplant Federation
- International Patient Organisation for Primary Immunodeficiencies (IPOPI)
- The Panhellenic Heart Disease Association
- The Swedish Disability Rights Federation
- The World Federation of Incontinence and Pelvic Problems
- Vivre sans Thyroïde (France)
- World Bladder Cancer Patient Coalition
- World Duchenne Organization (WDO)

Received by EPF



Received by EURORDIS



**Acanthamoeba Keratitis
(AK) Eye Foundation**
YOUR EYES MATTER
www.akeyefoundation.com



AICCA
Italian ACHD Association



Alpha 1
Deutschland e.V.



Síndromes Arrítmicos
Relacionados
con la Muerte Súbita



EPOC España
Asociación Española de Pacientes
y Cuidadores de EPOC



Federación Española de Asociaciones de Pacientes
Alérgicos y con Enfermedades Respiratorias



Fundación Contra la
Hipertensión Pulmonar



Received by EURORDIS

