

## Keep Patients Voting: Campaign Toolkit

***Keep Patients Voting*** is a joint campaign for patient organisations led by EURORDIS–Rare Diseases Europe and the European Patients’ Forum (EPF).

Together, we are calling on EU policymakers to protect and enshrine patient involvement and their voting rights for patient representatives, especially on two of the European Medicines Agency’s most influential committees: the Committee for Medicinal Products for Human Use (CHMP) and the Pharmacovigilance and Risk Assessment Committee (PRAC)

In a [joint statement](#) published on 10 March, EURORDIS and EPF raised the alarm. Since then, over 70 additional patient organisations from across Europe have joined the call to uphold patients’ rightful place at the decision-making table.

### Why now?

The guarantee of these rights, originally proposed by the European Commission, are now in jeopardy, and the coming weeks may determine the future of patient involvement in EU medicines regulation.

On 4 June, the Council [adopted its position](#) on the revision of the EU pharmaceutical legislation. However, patient organisations are deeply concerned about several major shortcomings in the Council’s position, particularly regarding patient involvement.


We regret that key provisions have been significantly weakened compared to the original proposal from the European Commission and the position of the European Parliament adopted in April 2024. In particular, we are particularly alarmed by the Council’s decision to remove voting rights for patient representatives in the Committee for Medicinal Products for Human Use (CHMP) and to reduce the number of patient representatives in the Pharmacovigilance Risk Assessment Committee (PRAC).

Trilogue negotiations between the Council, the Parliament and the Commission are set to begin on 17 June. This final phase will shape the future of EU medicines regulation – and with it, patient representation within the EMA.

This is the last and most consequential opportunity to secure meaningful patient representation. Our communities cannot be passive while others debate our role. Now is the time to raise our voices.

### What’s in our campaign toolkit?

This toolkit equips you to take action and make an impact:

-  **Email templates** – Reach out to your national ministry or MEPs and call on them to defend patient voting rights.

- 📣 **Social media visuals and captions** – Share the message across your platforms: LinkedIn, Facebook, X (Twitter), Instagram, Bluesky.
- 🔑 **Messaging materials** – Stay aligned with the joint EURORDIS–EPF campaign and help amplify a unified voice.

Use these tools to put pressure where it counts.

Together, we can stop this rollback before it happens, and protect the progress patients have fought for.

*[\[BUTTON: Google Drive link – Access the full campaign toolkit here\]](#)*

If you have questions about the campaign, contact **Julien Poulain**, EURORDIS Communications Manager, at [Julien.Poulain@eurordis.org](mailto:Julien.Poulain@eurordis.org) and/or **Dalila Lopes**, EPF Communications Officer, at [Dalila.Lopes@eu-patient.eu](mailto:Dalila.Lopes@eu-patient.eu).