

The European position on patient associations as key players in health, one of the central themes of the "7th Encuentro Nacional de Pacientes. Keys to Health".

Patients' associations call for a greater role and regulation in healthcare decision making

- *A clear legal framework is demanded, regulating patient involvement in health policies; according to the president of the European Patients' Forum **"patients are valuable partners in the political process"**.*
- *This meeting, to be held in Madrid on April 18 (in person and online), coincides with the **European Day of Patients' Rights**.*
- *The situation of the National Health System will be analyzed, with contributions and proposals from the highest representatives of Health and Politics.*

The **Spanish Patients' Forum (FEP)**, which brings together **more than 75 patient organizations**, warns about the **critical moment the healthcare system** is going through in **our country** and demands a **greater role for patients in the design and implementation of healthcare policies**, aimed at maintaining the sustainability of our healthcare system, its equity and minimum levels of quality. The **demand** is not only confined to Spain, but **extends to the whole of Europe**.

This will be highlighted at the **"7th Encuentro Nacional de Pacientes. Keys in health"**, which will take place **on April 18** at the Gregorio Marañón Hospital in **Madrid and will be transmitted via streaming**. This meeting, which is organized by the **FEP**, and which is annually the most important and largest gathering of patients' associations in Spain, will be held on this occasion to coincide with **European Patients' Rights Day**. Many of the deficits and demands made by Spanish patients' associations are common to those made at the European level.

A European problem

Although the participation of patient organizations in the design, implementation and evaluation of health policies varies from country to country, the *European Patients' Forum (EPF)*, of which the EFF has been a member since its inception, is concerned that in many EU countries **patient organizations are not fully recognized as equal partners** alongside other types of experts, such as scientists, industry representatives and healthcare professionals.

The EPF currently comprises 78 organizations from 19 countries, representing some 150 million patients across Europe. As indicated by the president of this organization, **Marco Greco**, who will participate in this meeting, **"patients are valuable partners in the policy process, both in helping decision-makers understand the experience of living with a disease and in bringing the end-user perspective to promote patients' interests at all stages of policy-making and in various institutional settings."**

The president of the Spanish Patients' Forum, **Andoni Lorenzo Garmendia**, is of the same opinion, calling for a **regulation on the participation of patients in decision-making bodies**, stressing that **"patients' associations have become professional organizations with a very high degree of knowledge of health policies"**.

An unfinished business, an unfulfilled promise

Currently, **the representation of patient organizations is not always integrated into the various European legal systems**. In fact, as will become clear on this day, the patient community is disappointed to see that the legal commitments to patient participation, and society in general, have been almost completely disregarded during the **COVID-19** crisis.

*"Despite the rhetoric of politicians, **the patient-centered approach is still not fully integrated into healthcare and is still seen as an ornament and not as one of the essential elements of quality care,**" denounces the president of the European Patients' Forum, who demands that **"patient involvement be structurally integrated into a clear legal framework, to prevent a new pandemic from wiping out ongoing collaborations."***

In this sense, the president of the Spanish Patients' Forum demands **"a comprehensive reform of our National Health System, in which all healthcare agents must participate, including, of course, the patients"**. From the FEP, which defends the health interests of patients, volunteers, caregivers and all citizens, *"we are trying to contribute to improving a healthcare system that is increasingly in need of everyone's collaboration"*, stresses Andoni Lorenzo.

Common European position

To try to make progress in resolving these deficits, European collaboration is essential and, as an example, he highlights the good harmony and cooperation between the Spanish Patients' Forum and the European Patients' Forum (of which he is a member of its board of directors). As Andoni Lorenzo points out, **"in the EU common strategic lines are now being established in health matters, and the patients' organizations are working to achieve quality healthcare for the whole of Europe"**. Although many health policies, including pricing and reimbursement, are the responsibility of national countries, **strong European cooperation** on health is seen as an opportunity to move towards quality-oriented, person-centered, equitable, resilient and sustainable health systems.

"European healthcare legislation, such as the European Health Data Space or the revision of EU pharmaceutical legislation, can contribute to providing better care and ultimately to improving patients' lives," assures Marco Greco. However, as the president of the European Patients' Forum makes clear, **"this will only be possible with the participation of patients and their representatives in the design, governance, implementation and evaluation of EU healthcare policies"**. As the EFF and EPF presidents agree, **"meaningful patient involvement has a real potential to improve the effectiveness, efficiency and long-term sustainability of healthcare systems"**.

*All these aspects will be addressed at the "7th Encuentro Nacional de Pacientes", which will reflect the **position of more than a hundred patients' associations on the proposals and changes that must be made in the National Health System to meet the new needs of society.***

Meeting website: encuentro.forodepacientes.org

For more information:

Paco Romero. pacoromeroperiodista@gmail.com. Tel. 639 64 55 70

Mónica de Elío. gerente@forodepacientes.org. Tel. 660 801 878.