

Strengthening Spanish Patient Advocacy: Insights from the 1st National Meeting of Oncohaematological Associations.



AUDIO EXPLANATION

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INTRODUCTION

6-7 November 2024, Madrid, Spain. AELCLÉS aimed to **unite patient associations** from across Spain to address critical issues faced by individuals with **haematological cancers and amyloidosis**, including disparities in resource distribution and delays in accessing innovative treatments. The initiative sought to foster **collaboration** among entities, share **knowledge** and **advocate** for equitable healthcare **access for all patients**.



METHODOLOGY

- **Target:** Patient associations members of AELCLÉS, patients, patient advocates, HCPs, policymakers and stakeholders.
- **Strategy:** **Two-day conference** featuring expert presentations, panel discussions, workshops and collaborative sessions. Key topics: **advancements** in haematology, **socio-economic impact** of blood diseases and strategies to enhance **communication** within patient associations. **Networking** opportunities to strengthen inter-association relationships.
- **Resources:** Financial investment for logistics. Human resources included AELCLÉS board and staff, volunteers, speakers and facilitators. **Collaborations** with the Sociedad Española de Hematología y Hemoterapia (**SEHH**), Myeloma Patients Europe (**MPE**) and Lymphoma Coalition (**LC**) providing additional support and expertise.

RESULTS

**3 MAIN TOPICS:
INEQUITY – UNMET NEEDS –
DELAYS IN TREATMENT APPROVALS**

**OVER 60 ATTENDEES
10 PATIENT ORGANISATIONS**

**4 HEADS OF HAEMATOLOGY
DEPARTMENT HOSPITAL
1 RESPONSIBLE FOR THE NATIONAL BONE
MARROW DONATION PLAN FROM SPAIN'S
MINISTRY OF HEALTH**

**2 WORKSHOPS:
1 RUN BY MPE HEAD OF COMMUNICATION ON
SHARED DECISION-MAKING IN MYELOMA**

**+15 PUBLICATIONS IN NATIONAL
SPECIALISED HEALTH AND
GENERALIST MEDIA**

**19 VIDEOS:
RECORDED SESSIONS AND INTERVIEWS.
OVER 13.300 VIEWS ON YOUTUBE**

CONCLUSIONS

- This initiative underscored the urgent need for **equitable distribution of healthcare resources** and **expedited approval of innovative therapies** for haematological conditions.
- Key takeaways: the importance of **unified advocacy to address regional disparities**, the necessity for **systemic support of comprehensive patient care**, including psychological services.
- Moving forward, AELCLÉS and its members are committed to **ensure all patients have timely access to essential treatments and comprehensive care**, regardless of their geographic location.



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