

"UNITED FOR MYELOFIBROSIS": PATIENT ADVOCACY INITIATIVE FOR INSTITUTIONAL AWARENESS

AIL, A.I.P.A.M.M. OdV, A.PRO.T.I.ON, F.A.V.O., Fondazione Renata Quattropani ETS, La Lampada di Aladino ETS



INTRODUCTION & AIMS

Background: Myelofibrosis poses complex challenges to Italian Healthcare System.

Aims: Raise institutional awareness, highlight patient needs, propose new management models, ensure implementation.

METHODOLOGY

Target: Italian institutions, healthcare decision-makers, GPs

Tools: White Paper, Manifesto, patient testimonials, official presentation

Resources: 6 patient associations, clinical experts, GSK support

RESULTS

Five Priority Areas:

1. Research & Equitable Treatment Access
2. Personalized Patient-Centered Care
3. Continuous Psychological Support
4. Caregiver Support
5. Information & Training

Outcomes: Institutional Manifesto endorsement, evidence-based proposals, replicable model

CONCLUSIONS

Key Learnings: Integrated care essential, hospital-community integration beneficial, proactive medicine improves access

Recommendations: Regional model extension, national guideline implementation

Take Home: Institutions can transform vision into reality through shared commitment

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