



The establishment of the Italian ALS Coalition: Outline of the policy changes needed across Italy to improve the lives of People Living with ALS (PLWALS) and their caregivers

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Introduction

The **Italian Amyotrophic Lateral Sclerosis Coalition** is a multistakeholder group of Italian ALS experts. It was established in 2024 and commemorates the first time in which Italian ALS stakeholders united to address the unmet needs of the ALS community. The Italian Coalition operates in parallel and in alliance with the recently established European ALS Coalition (1).

Objective

Collaborating with existing Italian ALS organizations, clinicians, researchers, and policy-decision makers to convey the needs of people living with ALS (PLWALS), their caregivers, and the scientific community into action via a unified voice.

Methods

- On 25 January 2024, a National Assembly was held in Rome to present the Manifest & EU ALS Coalition policy papers.
- Regular follow-up meetings on key deliverables are organized.



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Members

Results

Italian Manifest of PLWALS Clinical Needs Summary

1. Promote scientific research to identify new tools for diagnosis and therapy.
2. Promoting a multidisciplinary disease approach by implementing a PDTA model and encouraging the implementation of "Hub & Spoke" models regionally.
3. Strengthen tools for home health care by examining the 360° patient and family needs.
4. Creating interactions between public and private assisted living residences/clinical care centers (patient centric approach).
5. Improving information quality and enhancing communication with patients and families.
6. Support and encourage a psychological counseling service for patients and families.
7. Eliminate delays in acquiring support.
8. Simplifying the bureaucratic process to obtain disability status.
9. Increase financial aid for patients and their family caregivers by activating the Italian Law "Unified Text of Rare Diseases."

Conclusion

The Italian ALS Coalition was established to unite all stakeholders to work together to urgently bring beneficial changes to all those impacted by the disease. The produced documents highlighted the urgent needs to be achieved for PLWALS and the entire ALS community in Italy. These papers are intended for all Italian stakeholders and policy-decision makers that can achieve these changes into a nationwide practical reality.

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References

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