The Italian MS Society ongoing advocacy activity includes:

- the statement of the rights as agreed by persons with MS and related disorders, and their caregivers;
- the Agenda 2025, as established in 2021 after consultation process involving all internal and external stakeholders, including government, parliament and other institutions. The Agenda 2025 includes priorities and detailed actions gathered under the four Mission Pathways;
- an annual MS Barometer collecting all the data (produced by observatory and surveys of Italian MS Society and other data publicly available from other sources). The Barometer is supporting the advocacy: where we are and where we have to go regarding the priorities and actions planned in the Agenda 2025.

 $https://agenda.aism.it/2022/download/Agenda_2025.pdf$



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MISSION

Interdisciplinary, person-centered, integrated care

- 1.1 Timely and person-centered diagnosis
- .2 Accreditation by the regional health authorities of the network of MS Clinical Centers and other health and social services providing full resources towards and higher services quality
- 1.3 Full and effective access to disease-modifying drugs and symptomatic treatments through the National Health Service
- 1.4 Specialized and proper rehabilitation for the different MS disability conditions, covered by the National Health Service
- 1.5 Psychological treatment at all stages of illness, disability, life covered by the National Health Service
- 1.6 Full and effective access to social care and other health services
- 1.7 Personalized and integrated healthcare pathways for comprehensive disease management

MISSION

2 Full inclusion and social participation

- 2.1 Comprehensive personalized life and care plan, stated as a fundamental right according to the law
- 2.2 Timely assessment and multidimensional evaluation of disability
- 2.3 Certain and appropriate access to benefits to overcome social exclusion
- 2.4 Overcoming discrimination, including multiple ones
- 2.5 Full accessibility of public and private spaces and services
- 2.6 Inclusive education and training
- 2.7 Ensure adequate employment and personal fulfilment at all stages of illness

MISSION

3 Research on Multiple Sclerosis

- 3.1 Discover the causes and risk factors of MS and other related disorders (primary prevention)
- 3.2 Stop MS and other related disorders in the early phase (secondary prevention)
- 3.3 Reverse or slow down the progression and symptoms of MS and other related disorders, and promote well-being and quality of life (tertiary prevention)
- 3.4 Direct, promote and finance multi-stakeholder and multidisciplinary research agendas in the priority areas of mission-oriented research, in a participatory governance
- 3.5 Direct, promote and finance digital platforms sharing clinical, magnetic resonance, genomic and patient reported data, also promoting the continuous updating of the Italian Multiple Sclerosis Register towards personalized treatments
- 3.6 Finalize a common global agenda on MS research and other related disorders
- 3.7 Promote the multidimensional measurement of the of mission-oriented research impact: excellence, economic, social and person reported
- 3.8 Guarantee adequate resources dedicated to research and to training and career paths of researchers in strategic areas, with the involvement of the noprofit MS organizations, in the definition of strategies and in the development of implementation plans
- 3.9 Promote a unique ecosystem between research and care through the adoption of the approach and principles of Responsible Research Innovation (RRI) with particular attention to the active participation of the persons with MS in the research process
- 3.10 Promote the right to scientific citizenship

MISSION

STRATEGIC PRIORITIES

4 Information and communication, skills, empowerment

- 4.1 Widespread awareness and understanding of the disease in the whole of society
- 4.2 Trustworthy information and timely communication
- 4.3 Skills, knowledge, and awareness of MS and related diseases by health and social services professionals, decision-makers, and other care system providers
- 4.4 Empowerment, engagement, and enablement of persons living with MS and related diseases

STRATEGIC PRIORITIES