

Global initiative to integrate patient input in MS research and care

Today, the European Charcot Foundation together with the MS International Federation and Italian MS Society launch a new global initiative to put the patient experience at the heart of research and healthcare for MS. The Italian MS Society will act as the lead agency for, and on behalf of the Global MSIF Movement.

The Patient Reported Outcomes Initiative for MS (PROMS) will bring together the global MS community, people with and affected by MS, healthcare workers and researchers, healthcare industry and many more- to enable science with and of patient input in research, clinical trials of new therapies, and the design of healthcare systems.

Patient Reported Outcomes (PROs) reflect the experiences that patients have in relation to their treatment or condition. This could include how they feel, their symptoms or what they are able to do.

People with MS are the first experts on what it means to live with this disease, on the impact that a treatment has, on the decisive aspects of their life to which a new drug or rehabilitation intervention must respond. In order for their voice on these issues to have a full meaning that can be shared by all the actors in the field, they have to be scientifically qualified (science of patients input).

Enabling PROMS initiative will ensure an informed and quality participation of people with MS in the decision-making processes of research and healthcare regarding their treatments and performances. The initiative aims to focus on the symptoms and aspects of living with MS that matter most to patients.

Efforts to enable the uptake of existing PRO into clinical practice and regulatory agencies decision-making processes will be greatly enhanced and informed by a commonly held strategic PRO research agenda and roadmap, shared by all relevant stakeholders.

The PROMS initiative, launched today, will take a global approach to tackling this challenge. It will advocate for a set of standardised PROs to be used in therapies development and health care and promote research to develop new PROs to meet the needs of all relevant stakeholders.

Engaging people with direct experience of MS in governance is crucial in achieving the initiative's overall mission, as is measuring the impact of the initiative against what matters most to patients.

The programme of work will be led and coordinated jointly by the European Charcot Foundation and the MS International Federation. It will build on the experience and expertise of the Italian MS Society, who will act as the lead agency on behalf of the global MSIF movement.

Professor Giancarlo Comi, President of the European Charcot Foundation said:

“This global initiative aims to give value to the “patient voice” with a multistakeholder approach. We need shared and validated PROs to be used both in experimental medicine and in clinical care.”

Peer Baneke, Chief Executive Officer of the MS International Federation said:

‘This exciting initiative will transform the future of research and clinical care. It gives the global MSIF movement a unique opportunity to ensure the voices of people living with MS right around the world are placed at the forefront of MS research, trials and healthcare design.’

Professor Mario Battaglia, President of the Italian MS Society Foundation said:

‘The global MS movement will play a pivotal role to implement a global master framework for systematic engagement of people with MS in health research and care. The international experience in applying framework for Multistakeholder Initiatives and on PROs for MS research and healthcare positioned Italian MS Society as lead agency of PROMS initiative.’

Notes to editors

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About the European Charcot Foundation

The European Charcot Foundation is an independent non-profit organization for advancing Multiple Sclerosis research in Europe.

The European Charcot Foundation establishes an interface between pharmaceutical companies and the clinical world. Its collaborative base consists of 500 MS research institutes and 1500 MS researchers.

At its Annual Meetings, the Foundation is directive in indicating new lines in MS research. Having identified these lines, the Foundation is then active in finding the funds needed to achieve them.

The European Charcot Foundation is a ‘learned society’ governed by a co-opted Board of recognized active MS researchers in Europe, Asia and the Americas.

Its main activities are:

- the organization of an Annual Meeting and Symposia in Europe, the Americas, the Middle East and Asia
- the coordination of European MS research projects and clinical trials
- an extensive eLearning platform including webinars by key opinion leaders on relevant topics, critical reviews of data presented , Annual Meeting lectures.

- the exchange of MS researchers, clinical practitioners and MS nurses.
More info: www.charcot-ms.org

About the MS International Federation

The MS International Federation (MSIF) is a unique movement made up of 48 MS organisations with links to many others around the world. MSIF and its members campaign for increased awareness of MS, support scientific developments and improve access to treatments and healthcare. Apart from Italy, MSIF's member organisations in Australia, Denmark, Germany, the UK and the USA are also involved in the global PRO initiative. Through capacity building, campaigning and information resources, MSIF supports and collaborates with organisations in countries where there is limited provision for people with MS. The global MSIF movement works together to improve the quality of life of everybody affected by MS. Find out more: www.msif.org

About the Italian MS Society

The Italian Multiple Sclerosis Society (AISM), is the only organization in Italy that addresses every aspect of multiple sclerosis (MS), through advocating for the rights of people with MS, promoting and providing services and, through its Foundation (FISM), orienting, promoting, and financing scientific research. AISM has substantial experience in promoting and financing MS Research internationally, in applying framework for Multistakeholder Initiatives (coordinator of EU H2020 Responsible Research Innovation MULTI-ACT project) and on PROs for MS research and healthcare. AISM is already working on a pilot project to standardize and harmonize PROs between their own PROMOPRO-MS database and iConquerMS (Accelerate Cure Project) network.