PRESS RELEASE

Multiple sclerosis, Italy: Barcoding MS Initiative ranked first as European best practice for Data Sharing in Personalised Medicine Clinical Research
Today, Italian MS Society and its Foundation, FISM, have received the ICPerMed Best Practice in Personalised Medicine Recognition 2022 with "BARCODING MS" Initiative. A recognition of excellence in collecting and sharing data of people with multiple sclerosis and the ability to promote and build network of excellence.

Today 17 January 2023, in Pamplona, the Italian Multiple Sclerosis Association (AISM) and its Foundation, FISM, have received the ICPerMed Best Practice in Personalised Medicine Recognition 2022 with the BARCODING MS Initiative. The award is a recognition of Italian excellence in research and care of multiple sclerosis, as well as data sharing used as a tool to give patients personalised answers to improve their treatment and consequently their quality of life. It is an acknowledgement of over thirty years commitment of AISM and FISM to Research, including the entire network of centres and researchers who actively collect and share clinical, epidemiological, genetic and MRI data. An essential element of this initiative is the commitment of the people with multiple sclerosis themselves, who have decided - and will decide - to make their data available to develop research capable of improving the quality of life and give an answer to their still unmet needs.

The BARCODING MS Initiative was launched during the last annual scientific congress of FISM. The aim of the Initiative is to develop an integrated database of clinical, genetic, imaging and patient-reported measures capable of producing a "BARCODING" of all new cases diagnosed with MS in Italy. An algorithm will be developed to identify factors responsible for disease progression towards personalized pharmacological and rehabilitative treatments.

BARCODING MS builds on solid experience in good practices in terms of acquiring data about the disease in various areas of expertise. For years AISM and FISM have promoted the development of registers and data bases to study different aspects of MS. This was possible thanks to work carried out by centres and researchers including initiatives such as the Italian Multiple Sclerosis and Related Pathologies Register (RISM), the Italian Network of NeuroImaging – INNI, the PROgnostic GEnetic Factors in Multiple Sclerosis (PROGEMUS), the Sardinian Genomic Data Base (ProgeNIA), and also Patient-Reported Outcome Measures for MS databases, PROMOPRO-MS_PROMS. This network of excellence has also been instrumental to provide answers to People with MS during SARS-CoV-2 pandemic using data collected through the Multiple Sclerosis and COVID-19 (MuSC-19) platform.

The ambition today is to go even further, with a data integration Initiative that pools together robust and quality data thanks to the networking skills of organisations and researchers. However, none of this would have been possible without the driving force of people with MS who are an active part of the research and the first to encourage the circulation of data and get involved.

ICPerMed "Best Practice in Personalised Medicine Recognition 2022" is an initiative by the International Consortium for Personalised Medicine (ICPerMed) financed by the European Union, with Italy being represented by the Ministry of Health. (Members).

AISM. INSIEME, UNA CONQUISTA DOPO L'ALTRA

The President of FISM, Mario Alberto Battaglia was in Pamplona today to receive, on behalf of Barcoding MS network, the award and illustrated the project during the Workshop "Preparing the Future for Personalised Medicine (EP PerMed)".

This important European award is especially an acknowledgement for the network of researchers, Italian MS clinical centres and research organisations which have supported AISM and its Foundation in this challenge. The BARCODING MS Initiative is possible thanks to:

- **Francesco Cucca**, Full Professor of Medical Genetics at the Faculty of Medicine of the University of Sassari and coordinator of numerous studies such as the Sardinia Project, funded since 2001 by the National Institute of Health (NIH, USA) and the Institute for Genetic and Biomedical Research (IRGB) of the CNR which he has directed for 10 years. Francesco Cucca is also Coordinator of the ProgeNIA Consortium.
- **Sandra D'Alfonso,** Full Professor of Medical Genetics at the Department of Health Sciences, A. Avogadro University of Eastern Piedmont and Coordinator of the PROGEMUS Consortium (PROgnostic GEnetic factors in Multiple Sclerosis).
- **Massimo Filippi,** Director of the Neurology Unit, Neurophysiology Service and Neurorehabilitation Unit at the IRCCS San Raffaele Scientific Institute and Full Professor of Neurology at the Vita-Salute San Raffaele University in Milan. Coordinator of the INNI database.
- **Roberto Furlan**, Manager of the Clinical Neuroimmunology Unit and Director of the Institute of Experimental Neurology (INSpe) at the IRCCS San Raffaele Scientific Institute. Chairperson of the Italian Neuroimmunology Association (AINI).
- **Claudio Gasperini,** Director of the Complex Operative Unit of Neurology and Neurophysiotherapy at the "San Camillo-Forlanini" Hospital in Rome as well as Coordinator of the MS Study Group of the Italian Society of Neurology (SIN).
- **Maurizio Lenzerini,** Professor of Computer Engineering, Department of Computer, Control and Management Engineering at the Sapienza University in Rome. Co-Founder and Chairperson of "OBDA Systems", a Sapienza Start-up and part of the Almawave Group (http://obdm.obdasystems.com/).
- **Maurizio Leone,** IRCCS Casa Sollievo della Sofferenza Research Hospital, Opera di Padre Pio San Giovanni Rotondo and Coordinator of the PROGEMUS Consortium.
- **Marco Salvetti**, Professor of Neurology at the Sapienza University in Rome and Director of Neurology at the S. Andrea University Hospital in Rome.
- **Mariapia Sormani,** Professor of Biostatistics at the University of Genova and Coordinator of the MuSC-19 platform.
- **Maria Trojano**, Full Professor of Neurology at the "Aldo Moro" University Hospital in Bari and Chairperson of the Scientific Committee of the Italian Multiple Sclerosis and Related Pathologies Register.
- For AISM and FISM:
    - **Mario Alberto Battaglia**, Professor of Hygiene and Public Health at the University of Siena and President of the of the Italian MS Society Foundation.
    - **Giampaolo Brichetto,** Coordinator of the Italian MS Society Foundation Research in Rehabilitation, Medical Director of the Italian MS Society Rehabilitation Centre in Liguria and President of RIMS.
    - **Paola Zaratin,** Director of Scientific Research of the Italian MS Society Foundation, co-chair of the Scientific Committee of the Global Patient Reported Outcome for MS Initiative.