



**Ministero della Salute – Direzione Generale della Ricerca e dell’Innovazione in Sanità**

**Rendiconto 5 per mille ANNO 2023**  
**Contributo percepito € 2.058.872,63 In data 2 ottobre 2024**

**Ente della Ricerca Sanitaria**  
**Denominazione Ente: Fondazione Italiana Sclerosi Multipla ETS**  
**Codice fiscale: 95051730109**  
**Sede legale: Via Operai, 40 - 16149 Genova**  
**Indirizzo di posta elettronica dell'ente: fism@pec.aism.it**  
**Dati del rappresentante legale: Mario Alberto Battaglia, CF**  
**BTTMLB54T29D969Z Domiciliato per la carica presso la sede legale di cui sopra**

**Titolo del progetto: PROMS A Joint Global Initiative**

<b>Data di inizio progetto: 01/10/2024</b>	<b>Data di fine progetto: 30/09/2027</b>
<b>Fondi 5 per mille assegnati al progetto: € 640.000,00</b>	<b>Di cui:</b> <b>Quota sostenuta entro l’anno di rendicontazione: € .....</b> <b>Quota accantonata, da sostenere, per progetti pluriennali (durata massima tre anni): € 640.000,00</b>

<b>VOCI DI SPESA</b>	<b>Quota sostenuta entro l’anno di rendicontazione</b>	<b>Quota accantonata, da sostenere, per progetti pluriennali (durata massima tre anni)</b>
Personale di ricerca (borsista, a contratto e di ruolo in quota parte)		€ 520.000,00

Apparecchiature (ammortamento, canone di locazione/leasing)		
Materiale d'uso destinato alla ricerca (per laboratori di ricerca, acquisto farmaci ecc.)		
Spese di organizzazione (manifestazioni e convegni, viaggi e missioni ecc.)		€ 100.000,00
Elaborazione dati		
Spese amministrative		€ 20.000,00
Altro (indicare quali)		
<b>TOTALE</b>		<b>€ 640.000,00</b>

Data

15 luglio 2025

Il Responsabile del Progetto

Il Legale Rappresentante



Si autorizza al trattamento dei dati ai sensi del d.lgs. 196/2003

Il Legale Rappresentante



## **PROMS A Joint Global Initiative**

The Global PROMS Initiative (PROMS) is a multi-stakeholder collaboration among 60+ stakeholders launched in 2019 at the 35th Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS). This initiative is jointly led and coordinated by the European Charcot Foundation (ECF) and the Multiple Sclerosis International Federation (MSIF) with the Italian MS Society (AISM) as lead agency on behalf of and for the MSIF Movement.

PROMS is built on a well-recognised participatory governance with assigned areas of interests and it has the ambition to (i) maximise impact of science with and of patient input on the health, healthcare and quality of life of people affected by MS (PwMS), and to (ii) represent a unified view on Patient-Reported Outcomes (PROs) for MS to PwMS, healthcare providers, regulatory agencies and Health Technology Assessment (HTA) organisations/bodies. Description on the current achievements is reported in the last PROMS publication .

Deep phenotyping of PwMS experiential knowledge will guide/inform the selection of existing PROMs, where both active and passive measurements are considered, towards clinical trial and practice validation of the selected PROMs in a selected target population. Leveraging on the Industry digital database collection and on the public MS registries is at the core of the PROMS strategy to also develop a cost-effective approach which uniquely reflect the experiences of PwMS and to provide data to policy-makers for their related recommendations. This effort to 'deep phenotype' the experiences of PwMS took a leap forwards with the recent global survey undertaken by the PROMS initiative. Here, over 5,000 people with MS from across the world reported the symptoms they experience the most and the impact they have on daily life. The survey has been designed with PwMS for PwMS and they played an important role in engaging a representative community of PwMS in the survey. Nonetheless, a second survey designed by PwMS addressing the map of digital accessibility reached over 1,500 respondents and is still under analysis. The outcomes of this latest research leverage on the functional domains that prevails most among PwMS and aim to reveal if any of the digital technologies available are of interest and within PwMS's reach.