Observatoire français de la sclérose en plaques (French MS Registry) - OFSEP

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Network

Network identification

Network ID

1000000862

Network countries

🇫🇷 France

Network website

https://www.ofsep.org/en/

ENCePP partner

No

Network description

OFSEP aims to provide a major epidemiological tool on MS for the scientific community in France and abroad. This tool must help to answer a large number of questions concerning the causes and mechanisms of MS, the prognostic factors of disease progression, the effectiveness and safety of therapeutic drugs, the impact of the disease on patients and society, etc.

To achieve this goal, OFSEP's missions include:

OPERATION

To maintain and develop the national cohort of patients suffering from MS or related diseases and syndromes. This means collecting standardized socio-demographic and clinical data as part of the routine medical follow-up of patients already in the cohort and recruitment of new patients.

To supplement the existing clinical data with biological samples and MRI scans, which must also comply with standardization and quality criteria.

To improve the previous data with medical/administrative data from the health insurance fund databases in particular, in order to get more information on comorbidity, treatment protocols and the medico-economic aspects of this disease.

To use OFSEP infrastructures to facilitate the implementation of specific studies requiring the collection of additional data or specific patient monitoring processes.

To ensure the availability of these data and samples to researchers, health care authorities and industrial players to enable analysis and thus provide answers to research questions or public health issues.

SCIENCE

To provide regular descriptions of the patient population in the cohort to offer statistics, targets and up-to-date information on this disease and thus enable a better approach to the personal, professional and social impacts of the illness, the effects of basic treatments and the requirements related to the follow-up of this disease in France.

To conduct specific research on the entire population of patients in the cohort (parent cohort) or on patient sub-groups with specific characteristics (nested cohorts).

Network details

Network primary therapeutic area:

- Disorders of the central nervous system

Network funding:

- - National competent authority (NCAs)
- - Non-for-profit organisation (e.g. charity)
- - Other public funding (e.g. hospital or university)
- - Pharmaceutical company and other private sector

Contact

Sandra Vukusic sandra.vukusic@chu-lyon.fr

Main

sandra.vukusic@chu-lyon.fr

Lucie Bellon-Tabart ext-lucie.bellon-tabart@chu-lyon.fr

Alternate

ext-lucie.bellon-tabart@chu-lyon.fr