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Multiple Sclerosis on behalf SFSEP

Organization of care for multiple sclerosis in France

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ABSTRACT

Multiple sclerosis (MS) is a disease with a number of aspects involving cooperation among many caregivers. In France, the organization of care for patients with MS has changed over the past 10 years with the development of specific structures, such as regional networks and expert centers. Their aims are to help improve MS patient care and quality of life. Multiple domains are involved, ranging from MS diagnosis to treatment, and including rehabilitation and the psychological and social impact of the disease. Thus, a personalized plan of care service is set up for each MS patient under the guidance of MS healthcare professionals.

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Introduction

Multiple sclerosis [MS, or SEP (la sclérose en plaques)] is one of the diseases for which healthcare has advanced the most over time. In addition, the development of knowledge of MS and its specific treatment has certainly helped to change society's view of the disease. However, taking on an MS patient requires management of a number of aspects of the disease, such as its diagnostic criteria, treatment and symptoms, including those that are imperceptible yet with social consequences. For this reason, the referring physician should be supported by a neurologist and a team of MS experts, made up of medical and non-medical partners. From the new millennium onwards, health networks have been created all over France to provide a global high-quality approach to MS patients. In 2016, an official circular disseminated by the Ministry of Social Affairs and

Health (DGS; Direction Générale de la Santé) formalized competence and resource centers for MS (CRC SEP) within the developmental framework of the implementation of the 2014–2019 neurodegenerative disease program [1].

2. The French SEP network

Health networks were created to develop complementarity between urban healthcare quality and specific hospital competencies. This was the purpose of Article L6321-1 of the French Code of Public Health wherein a single legal definition of a health network was integrated under law no. 2002-303 (dated 4 March 2002) on patients' rights and quality of the healthcare system [2]. Its features aimed to promote public access to adequate healthcare, with coordinated, continuous and interdisciplinary healthcare especially for specific popu-

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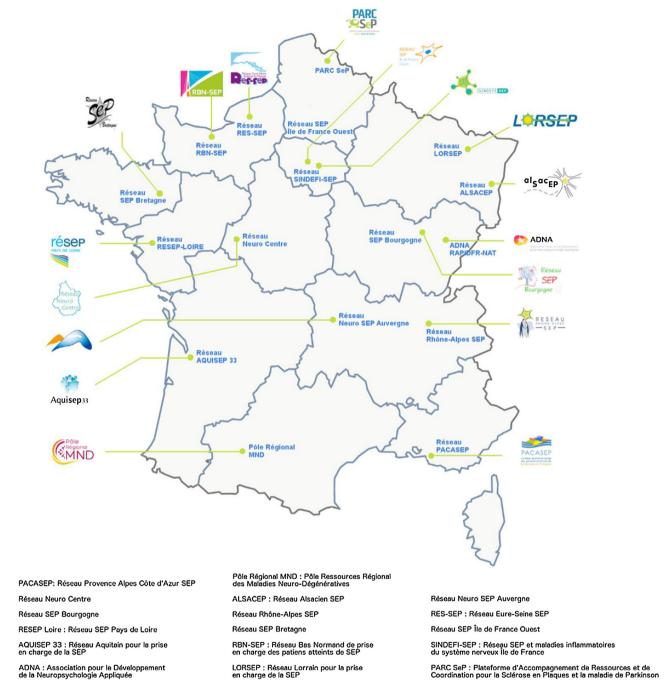


Fig. 1 - The multiple sclerosis (MS) network covering the whole of French territory.

lations, diseases and/or health practices. Such activities include: (i) specific healthcare adapted to the needs of people as regards therapeutic education, prevention, diagnosis and care; (ii) the participation of public-health initiatives; and (iii) evaluation of the quality of the given services and their performance.

These networks are managed by committees composed of different healthcare players, including private and occupational physicians, and representatives of care facilities and medico-social institutions, as well as users' representatives. The networks are designed to: (i) coordinate patients' care close to home; (ii) enhance medical

training based on mutual agreement over diagnosis and treatment; (iii) coordinate the interfaces across all involved health professionals and their synergy; and (iv) conform to regional and national healthcare dynamics. Today, there are 17 regional MS networks established across the entire French territory (Fig. 1).

3. MS competence and resource centers

In the context of the development of the neurodegenerative diseases program [1], the CRC SEP were established to improve

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