ReMuS®
THE CZECH REPUBLIC
MULTIPLE SCLEROSIS
PATIENT REGISTRY

Regular Output of the ReMuS Registry

Summary report

analyzed period 1st January – 31st December 2023
Data export as of 31st December 2023

In Prague, 29th May 2024

ReMuS, nadační fond
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www.multiplesclerosis.cz

IMPULS endowment fund

The ReMuS® Registry Description

The nationwide multiple sclerosis patients' registry (ReMuS) was created in 2013 as a project of IMPULS, Endowment Fund mainly in order to obtain data on prevalence, incidence, severity at the time of diagnosis, and the clinical course of multiple sclerosis (MS); its clinical symptoms, relapse occurrence, progression of the disease, MS treatment, disability development, comorbidities, and the causes of death. The objective is to provide output which can help monitor the costs and the effectiveness of healthcare and medicinal products, to assess information addressed to health care payers, to other public institutions and to manufacturers of medicinal products, and to evaluate the seriousness of MS and its socioeconomic impact for scientific, epidemiologic, and statistical purposes. Although the ReMuS Registry is now an independent endowment fund, its mission remains unchanged.

Based on the data acquired, it is possible to look for potential risk factors for not only the development of MS itself, but also for insufficiently effective treatment and for more rapid progression of the disease. Information on the course of MS does enable health care payers to better plan the allocation of financial means necessary for the treatment. Information on treatment effectiveness, then, is instrumental in the selection of therapy and the implementation of changes or modifications when relevant.

The ReMuS registry does not distinguish whether its patients are involved in a study or not. The registry currently includes MS sclerosis patients who undergo treatment in one of the participating specialized MS centers and who have provided an informed consent with the processing of their personal and clinical data in the ReMuS registry.

Detailed analysis involves only patients with at least one MS center visit recorded during 2023, whose data can therefore be considered up to date. This analysis focuses on patients undergoing biological treatment (DMT), as well as patients receiving a different form of treatment (nonDMT). Both of these groups are analyzed both collectively and separately.

The drugs included in the ReMuS registry as a part of DMT (disease-modifying treatment) are the following: Aubagio, Avonex, Betaferon, Copaxone [20], Copaxone [40], Extavia, Gilenya* (and its generics), Kesimpta*, Lemtrada*, Mabthera* (and its generics), Mavenclad*, Mayzent*, Ocrevus*, Plegridy, Ponvory*, Rebif [22], Rebif [44], Tecfidera, Tysabri*, and Zeposia*.

* Drugs marked with asterisk are classified as high-efficacy DMTs.

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Summary report – 31st December 2023

This report describes the state of the ReMuS Registry as of 31st December 2023, focusing on the year 2023 in all the 15 Czech MS centers: General University Hospital in Prague, Hospital Teplice, Hospital Jihlava, Motol University Hospital in Prague, University Hospital Plzeň, Hospital of Pardubice Region, University Hospital Ostrava, University Hospital Královské Vinohrady in Prague, University Thomayer Hospital in Prague, University Hospital Hradec Králové, University Hospital in Brno Bohunice, University Hospital Olomouc, České Budějovice Hospital, St. Anne's University Hospital in Brno and Regional Hospital T. Baťa in Zlín. MS centers enter their patients' data into the registry on an ongoing basis, at each visit of a patient. As of 31st December 2023 – the date of the export, data from 21 537 MS patients were available, out of whom 16 047 belonged to the DMT group and 5 490 to the nonDMT group. After the data from patients without a recorded visit in 2023 were excluded, data of 19 304 patients (15 915 DMT and 3 389 nonDMT) entered the analysis in total.

In the DMT group, the patients' average age was 45.21 years. At the time of the onset of the disease, DMT patients were 32.19 years old on average. There were 70.67 % of women in this group. Out of all the DMT patients analyzed, 53 patients (0.27 %) were younger than 18 years by the end of the analyzed period. DMT patients are mostly (56.12 %) clients of the General Health Insurance Company of the Czech Republic (VZP). The registry covers data from DMT patients coming from all the 14 regions of the Czech Republic, most frequently from Prague (16.90 %) and Central Bohemia (14.13 %). 79.3 % of patients below 65 years of age were capable of working (i.e. they worked full-time or part-time), whereas 31.98% were granted invalidity pension of grade 1 to 3. The largest group in terms of degree of disability were DMT patients with EDSS of 1.5 (18.07 %). Less than one percent of DMT patients (0.50 %) had EDSS value higher than 6.5. In 2023, 49.03 % of DMT patients' relapses were assessed as mild, 47.02 % as moderately severe; majority (85.76 %) of these relapses was treated by means of ambulatory care. The most commonly used DMT was Ocrevus (15.47 %). During 2023, 4.22 % of the patients started their first DMT treatment; 0.83 % resumed using the same DMT after an intermission; a change of the DMT used was recorded in 11.62 % of the patients, and DMT was discontinued last year by 2.39 % of the patients. In 2023, IVIG drugs were used in case of 0.3 % of the patients. During the same year, 203 DMT-treated female patients gave birth. Furthermore, 4 instances of suspected serious or unexpected side effected related to MS-specific treatment were recorded.

In the group of nonDMT patients, the average age was 56.88 – these patients are therefore older on average than DMT patients. At the time of the onset of the disease, nonDMT patients were 35.48 years old. There were 73.18 % of women in this group. Seven (0.04 %) of the nonDMT patients analyzed were younger than 18 by the end of the monitored period. NonDMT patients, too, are mostly (57.86 %) clients of the General Health Insurance Company of the Czech Republic (VZP). The degree of disability is generally higher in nonDMT than in DMT patients, with 17.94 % of nonDMT patients having an EDSS value higher than 6.5 (i.e. indispensable both-sided walking aid). The most frequent degree of disability in nonDMT patients is EDSS of 6.5 (19.00 % of the patients). 8 nonDMT female patients gave birth during 2023. 234 (6.90 %) of nonDMT patients in total received IVIG treatment.

The long-term increasing trend of using high-efficacy DMTs is confirmed by the ReMuS registry data; by the end of 2023, these DMTs were used in 53.3% of DMT patients (as opposed to 43.8 % at the end of 2022).

Special attention is paid to data quality check, which takes place in all the participating MS centers and subsequently also at the level of the ReMuS registry. Based on regular data exports, the data are further supplemented and corrected by the respective MS centers. In comparison with initial data exports, it is apparent that the amount of missing data has been significantly lowered.

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