ReMuS® MULTIPLE SCLEROSIS PATIENT REGISTRY

Regular Output from the ReMuS Registry

Data export updated on 31. 12. 2019

– Summary of Output from Analysis

In Prague, 30th March 2020

Endowment fund IMPULS
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Description of the ReMuS Registry

Czech National Registry of Multiple Sclerosis (ReMuS) was mainly created to obtain data on the prevalence, incidence, severity at the time of diagnosis and clinical course of multiple sclerosis (MS), its clinical symptoms, relapses, progression, MS treatment, disability development, comorbidities and causes of death. The objective is to provide outputs for cost and effectiveness monitoring of health care and medicinal products, assessment of information to be provided to health care payers, other public institutions and manufacturers of medicinal products, to assess the seriousness of MS and its socioeconomic impacts from the scientific, epidemiologic and statistical perspective.

Based on acquired data, it will be possible to look for potential risk factors both for the development of MS itself and lack of effectiveness of treatment or more rapid progression of the disease. Information on course of MS will enable health care payers to plan better the allocation of financial means necessary for the treatment of this disease. Information on treatment effectiveness is instrumental in the selection of the therapy and implementation of changes or modifications when relevant.

The ReMuS registry does not distinguish whether patients are in a study or not. The registry now includes multiple sclerosis patients who:

- undergo treatment in one of the participating MS treatment centres
- have signed informed consent with processing their personal and clinical data in the ReMuS registry.

The detailed analysis includes patients who attended their appointment within the second half of 2019 (or within the last year in case of non- DMD patients) only. The analysis is presented in two sections. The main part covers DMD/IVIG patients and has an identical structure for all centres. The second part summarizes preliminary results for non- DMD patients and is present for MS centres which entered the non- DMD patients into the registry only.

Warning

In this export, the numbers of DMD and non- DMD patients were adjusted to the new definition. Therefore, the ratio of DMD and non- DMD patients has changed abruptly, which may result in a decrease in the mean age, distribution of EDSS or distribution of social benefits, compared to the previous export as of 31. 12. 2018.

Summary of Output from Analysis – 31. 12. 2019

On 31. 12. 2019, the fourteenth data export into ReMuS registry was delivered, followed by regular interim data analysis from the registry focusing on the year 2019. Over the evaluated period data of DMD/IVIG patients from fifteen MS treatment centres - General University Hospital in Prague (VFN), Hospital Teplice (TP), Hospital Jihlava (JI), Motol University Hospital in Prague (FNM), University Hospital Plzeň (FNP), Hospital of Pardubice Region (PA), University Hospital Ostrava (OV), University Hospital Královské Vinohrady in Prague (FNKV), Thomayer Hospital in Prague in Krč (FTN), University Hospital Hradec Králové (HK), University Hospital in Brno Bohunice (FNB), University Hospital Olomouc (OL), České Budějovice Hospital (CB), St. Anne´s University Hospital in Brno (USA) and Regional Hospital T. Baťa in Zlín (ZL) are included. Information about non- DMD patients was provided by 13 MS centres - 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, Thomayer Hospital in Prague in Krč, University Hospital Hradec Králové, University Hospital Olomouc, České Budějovice Hospital, and Regional Hospital T. Baťa in Zlín. These MS treatment centres provided data on more than 20 non- DMD patients. All centres enter data on their patients in the registry on continual basis, and as of the day of export on 31. 12. 2019 data on the treatment of 12 419 DMD/IVIG patients and 3 881 non- DMD patients has been collected. After the exclusion of patients missing recent data, data of the total of 11 778 DMD/IVIG and 3 045 non- DMD patients from the whole Czech Republic were processed for the purpose of the present analysis.

For the main analysis, data of patients with current data available and treated in the last year with one of the DMD or IVIG medication were included. DMDs: Aubagio, Avonex, Betaferon, Copaxone, Copaxone [40], Extavia, Generics of Mabthera (Rixathon, Truxima), Gilenya, Lemtrada, Mabthera, Mavenclad, Ocrevus, Plegridy, Rebif [22], Rebif [44], Tecfidera, Tysabri. IVIGs: Endobulin, Flebogamma, Gammagard, Kiovig, Octagam, Privigen.

DMD/IVIG patients in the registry are in 71.5% of cases of female gender, mean age at the last visit is 42.9 years and the mean age at the disease onset is 31.5 years. A total of 99.7% patients are over 18 years old at the time of the last visit. The registry includes data of patients from all regions of the Czech Republic. A total of 77.5% patients up to 65 years of age are able to work (they work full-time or part-time) and 33.1% receive stage 1-3 disability pensions. In 2019 a total of 192 MS female patients (2.3%) delivered children.

Patients classified as “non- DMD” are also included into the present analysis for centres with such data available. These patients had been treated with DMD or IVIG in the last year or haven´t used these products at all. Non- DMD patients were described in terms of demography, working activity, social benefits, duration of the treatment, EDSS, frequency of relapses and pregnancy. Data from 13 MS centres which are contributing were processed. The mean age of non- DMD patients is higher than in DMD/IVIG patients (53.8 years vs. 42.9 years) and they appear to be elder at the onset of the disease (34.9 years vs. 31.5 years). Notably smaller portion of non-DMD patients up to 65 years were working. Non- DMD patients in the registry have higher mean EDSS compared to DMD/IVIG patients (4.8 vs. 2.7) whilst the most frequent non- DMD patients are those with EDSS stage 6.5 (18.2%). A total of 6.3% non- DMD patients experienced relapses in 2019. In the last year a total of 20 non- DMD female patients (0.9%) delivered children.

Progressive engagement of the individual centres and gradual increase in the number of patients needs to be considered for interpretation of the outcomes. The records are continuously corrected and amended based on the deviation reports in all participating centres. Compared to the first data export in June 2013, the number of missing data has now decreased and with participation of new centres the variability of patients and their treatment in the Czech Republic increased.

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