ReMuS MULTIPLE SCLEROSIS PATIENT REGISTRY

Regular Output from ReMuS Registry

Data export updated on 30. 6. 2018

– Summary of Output from Analysis

In Prague, 4th September 2018

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 preparations, 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 possible 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 better plan 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 registry now includes only 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 ReMuS registry.

The detailed analysis contains only patients who attended their appointment within the first half of 2018 (or within the last year in case of non-DMD patients).

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Summary of Output from Analysis – 30. 6. 2018

On 30. 6. 2018, the eleventh data export into ReMuS registry was delivered, followed by regular interim data analysis from the registry focusing on the period from 1. 1. 2018 to 30. 6. 2018. Over the evaluated period data of DMD/IVIG patients from fifteen MS treatment centres - General University Hospital in Prague (VFN), 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 in Brno Bohunice, University Hospital Olomouc, České Budějovice Hospital, St. Anne´s University Hospital in Brno and Regional Hospital T. Baťa in Zlín are included. Information about non-DMD patients was provided by 9 MS centres - General University Hospital in Prague (VFN), Hospital Teplice, Hospital Jihlava, University Hospital Plzeň, University Hospital Ostrava, Thomayer Hospital in Prague in Krč, University Hospital Hradec Králové, České Budějovice Hospital and Regional Hospital T. Baťa in Zlín. These MS treatment centres provided data on more than 20 non-DMD patients. All MS centres enter data on their patients in the registry on continual basis, and as of the day of export on 30. 6. 2018 data on the treatment of 11252 DMD/IVIG patients and 2598 non-DMD patients has been collected. After the exclusion of patients missing recent data, data of the total of 10633 DMD/IVIG and 2082 non-DMD patients from the whole Czech Republic were processed for the purpose of the present analysis.

For the main analysis, we included data of patients for whom current data were available and who were treated in the period from 1. 1. 2013 with one of the DMD or IVIG preparations (DMDs – Aubagio, Avonex, Betaferon, Copaxone[20], Copaxone[40], Extavia, 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 42.1 years and the mean age at the disease onset is 31.1 years. 99.7% of 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. 74.7% of patients up to 65 years are able to work (they work full-time or part-time) and 33.9% of all DMD/IVIG patients receive degree 1-3 disability pensions. The most frequent degree of damage impairment are patients with EDSS between 1.5 and 2. A total of 56 MS female patients (0.7%) delivered children during last 6 months.

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 only before 1. 1. 2013 or haven´t used these products at all. Non-DMD patients were described in terms of demographic, working activity, social benefits, duration of the treatment, EDSS, frequency of relapses and pregnancy. Data from 9 MS centres which are contributing were processed and the results were compared with the results of DMD/IVIG patients from all 15 MS centres in the ReMuS Registry. The mean age of non-DMD patients is higher than in DMD/IVIG patients (54.6 years vs. 42.1 years) and they appear to be elder at the onset of the disease (35.3 years vs. 31.1 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 are those with EDSS stage 6.5–7 (24.8%). Non-DMD female patients did not gave birth in last 6 months.

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 patients in the registry increased manifold while the number of missing data was reduced and with participation of new centres the variability of patients and their treatment in the Czech Republic increased.

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