ReMuS

MULTIPLE SCLEROSIS
PATIENT REGISTRY

Regular Output from ReMuS Registry

Data export updated on 31.12.2017

– Basic Information from the Summary Export

In Prague, 7th March 2018

1 Introduction

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 possible risk factors both for the development of MS itself and lack of effectiveness oftreatment 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 includesmultiple 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 includes only patients who attended their appointment within the second half of 2017(or within the last year in case of non-DMD patients). The analysis is presented in two sections.The main part treats DMD/IVIG patients and has identical structure for all centres. The second part summarizes preliminary results for non-DMD patients and is present only for MS centres which enter the non-DMD patients into the registry.

2 Conclusion

On 31. 12. 2017, the tenth data export into ReMuS registry was delivered, followed by regular interim data analysis from the registry focusing on the period from 1. 1. 2017 to 31. 12. 2017.Over the evaluated period datafromfifteen MS treatmentcentres - General University Hospital in Prague (VFN), Hospital in Teplice, Hospital in Jihlava, University Hospital Motol in Prague, University Hospital in Plzeň, Hospitalof Pardubice Region, University Hospital in Ostrava, University Hospital Královské Vinohrady in Prague, Thomayer University Hospital in Prague in Krč, University Hospital in Hradec Králové, University Hospital in Brno in Bohunice, University Hospital in Olomouc, Hospital in České Budějovice, University Hospital St. Anna in Brno and RegionalHospital T. Baťa in Zlín are included.Information about non-DMD patients was provided by 8 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 and Hospital České Budějovice. These MS treatment centres are no more in the 2-year initial phase (they have been entering data for more than 2 years) and were eligible to enter the analysis by providing data on more than 20 non-DMD patients. Allcentres enter data on their patients in the registry on continual basis, and as of the day of export on 31. 12. 2017 data on the treatment of 10666DMD/IVIG patients and 2337 non-DMD patients has been collected. After the exclusion of patients missing recent data, data of the total of 10230 DMD/IVIG and 2019 non-DMD patients from the whole Czech Republic were processedfor the purpose of the present analysis.

The main analysis was performed on the data from DMD/IVIG patients. Patients in the registry are in 71.7% of cases of female gender, mean age at the last visit is 41.8 years and the mean age at the disease onset is31.0 years. 99.7% of patients areover 18 years old at the time of the last visit. The registry includes data of patients from all regions of the Czech Republic. 73.9% of patients are able to work (they work full-time or part-time) and 34.1% receive stage 1-3 disability pensions. The most frequent degree of damage impairment are patients with EDSS between 1.5 and 2. A total of 154 MS patients (2.1 %) delivered children in 2017.

Non-DMD patients were described in terms of demographic, working activity, social benefits, duration of the desease, EDSS, frequency of relapses and pregnancy. Data from 8MScentres which are contributing wereprocessed.Non-DMD patients are elder in average compared to DMD/IVIG patients (54.3 years vs. 41.8 years) and they appear to be elder at the onset of the disease (35.3 years vs. 31.0 years). Significantly smaller portion of non-DMD patients were working compared to DMD/IVIG patients which can be caused by higher age of the first group. 8 non-DMD patients (0.4%) gave birth in 2017.

Progressive engagement of the individual centres needs 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 numberof patients in the registry increased more than eight-foldwhile 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.