

EVOLUTION OF THE CZECH NATIONAL REGISTRY REMUS — 3 YEARS EXPERIENCE.

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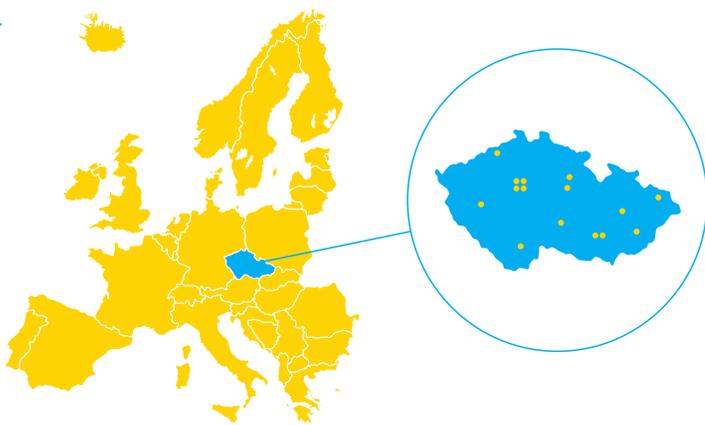
BACKGROUND

There is an unmet need for reliable long term data depicting different aspects of multiple sclerosis (MS) patients in a real life. One of the most important source of this data are well organized registries.

OBJECTIVES

To report an evolution and results from the Czech national registry ReMuS (Fig. 1).

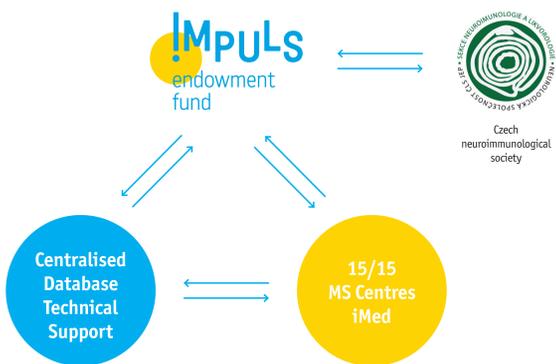
Fig. 1



METHODS

The ReMuS was established in 2013 and is operated by the endowment fund Impuls (www.multiplesclerosis.cz) in collaboration with the Czech neuroimmunological society. Data is collected directly in MS centers via software iMed. There is twice yearly data export from particular center into a centralized database, where data are cleaned (via querying local centers), compile and final report is created. The report is publicly available on www.multiplesclerosis.cz. (Fig. 2).

Fig. 2 ReMuS – project organization



The first stratum to be added to this database was patients treated by disease modifying drugs (DMD). In first two years, only data from this demographic were collected and added to the database. Since the third year, data of all patients followed in the MS centers has been collected and sent. Here we report only data of patients treated by DMD. The registry is completely funded by the fund IMPULS, approx. 70 % of budget is invested directly in centers to support data collection, the rest is spend on datamanagement and analysis of data.

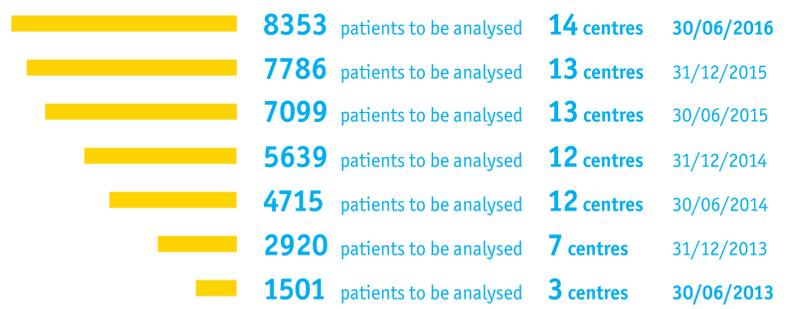
CONCLUSION

ReMuS, the Czech national registry, has already collected comprehensive data of more than 8000 patients, the first 3 centers have participated almost 3 years. The aim is to enroll a majority of MS patients in the Czech Republic (estimated number is 15–17000 patients) within the next 2 years. The registry is already preparing important longitudinal data.

RESULTS

- All 15 Czech MS centers have already joined the registry. The number of DMD treated patient records has increased gradually from 1501 in 2013 to 8353 in the last export in June 2016. (Graph 1.)

Graph 1 Number of patients in the ReMuS registry — development



- Sex ratio female / male is 71.5/28.5%, median age 40.4 (min 9.8; max78.4), EDSS 2.5 (0;8), mean annual relapse rate 0.232. Among all DMDs, the leading preparations are interferons (47.8%) and glatiramer acetate (22.3%), the escalation therapy represents 24.0 % of all DMDs.

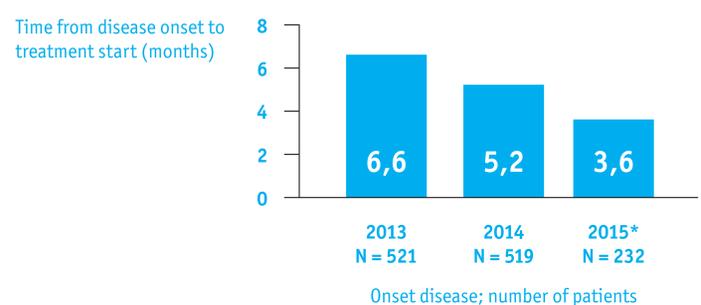
- The registry provides further data about pregnancy, distribution of patients in particular regions, health insurance assignment, and important data about employment and disability pension (71.9% of patients are employed and working full or part time, or are students. (Graph 2).

Graph 2 Patient distribution by employment type



- The registry begins to provide important longitudinal data that can be used as quality of care indicators, e.g. time from disease onset to treatment start (Graph 3) or development of percentage of patients that have been escalated to a second line treatment (Graph 4).

Graph 3 Mean time from disease onset to treatment start



Graph 4 Disease modifying drugs

