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).

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 year 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).

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

- 8353 patients to be analysed 14 centres 10/09/2016
- 7786 patients to be analysed 13 centres 11/12/2015
- 7099 patients to be analysed 13 centres 10/06/2015
- 5639 patients to be analysed 12 centres 12/11/2014
- 4715 patients to be analysed 12 centres 10/06/2014
- 2920 patients to be analysed 7 centres 11/12/2013
- 1501 patients to be analysed 3 centres 30/09/2011

- Sex ratio female / male is 71.5/28.5%. median age 40.4 (min 9.8; max 78.4), 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

- 56 % Full-time employment
- 24 % Does not work
- 13 % Part-time employment
- 4 % Not completed
- 3 % Student

- 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

- Time from disease onset to treatment start (months)
  - 6.6 31/12/2013
  - 5.2 30/06/2014
  - 3.6 31/12/2015

- N = 521

Graph 4 Disease modifying drugs

- % of patients using 1. and 2. line treatment
  - 1. Line treatment
    - 2013 82%
    - 2014 80%
    - 2015 78%
  - 2. Line treatment
    - 2013 18%
    - 2014 20%
    - 2015 22%

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.