

ReMuS – CZECH NATIONAL REGISTRY OF MULTIPLE SCLEROSIS PATIENTS – 2 YEARS EXPERIENCE

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BACKGROUND

Multiple sclerosis is a lifelong disease with a very heterogenous clinical course. Randomised controlled clinical trials bring reliable but only short term data. Long term data from real life conditions are needed.

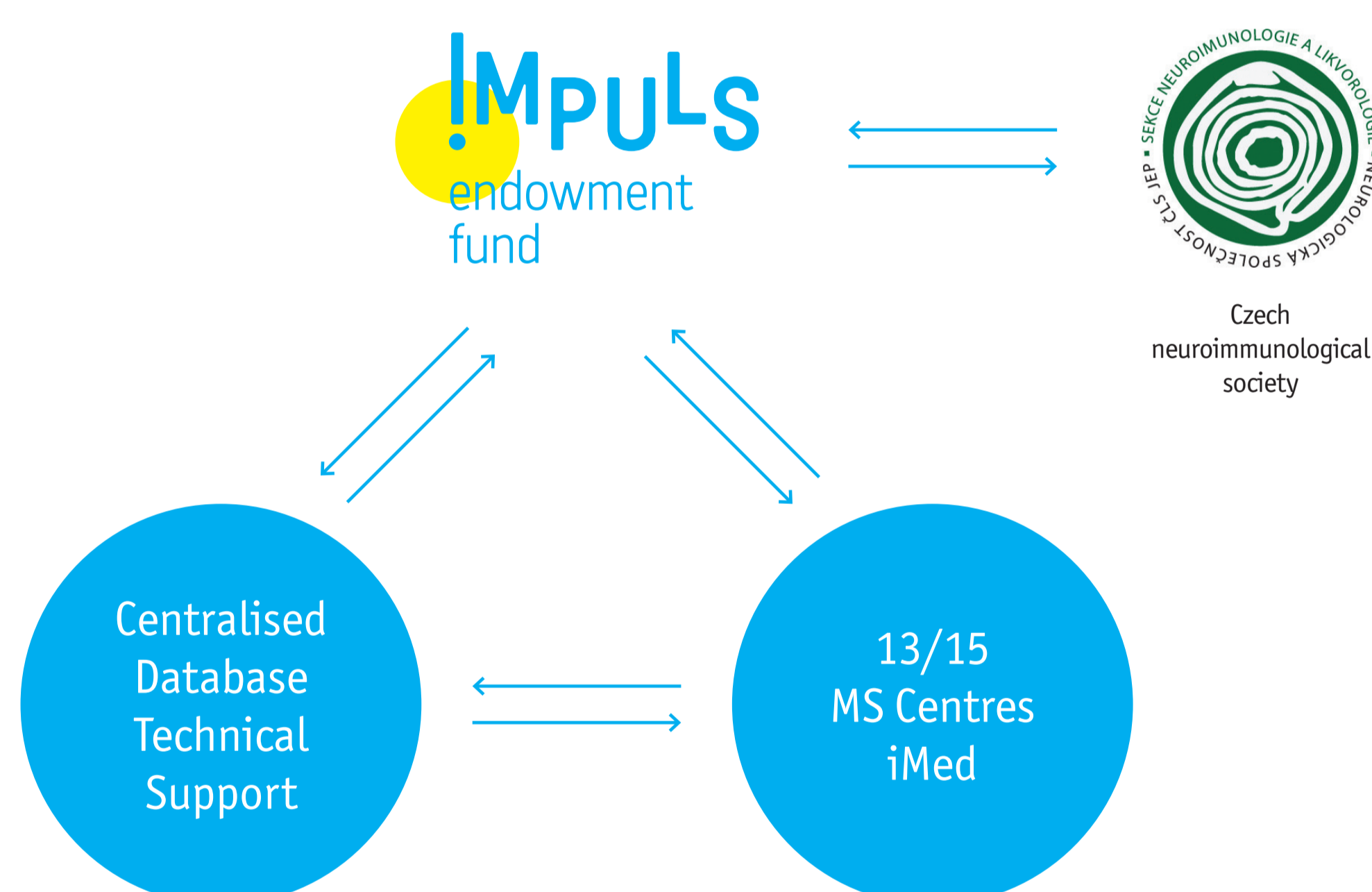
OBJECTIVES

To report a structure, evolution, and first results from the Czech national registry ReMuS.

METHODS

The ReMuS is operated and completely funded by the Endowment Fund IMPULS (www.multiplesclerosis.cz) in collaboration with the Czech neuroimmunological society (Fig. 1). The preparation phase started in 2012 (included all administrative work related to data protection, signing contracts, implementation of software iMed (www.imed.org) in local MS centers). An Operational manual that defines logistics and all items to be collected was created. Demographic and history data are collected retrospectively at the first visit and then prospectively at each visit in local center. Data is exported to a centralised database every 6 months. Final report is created and put on the web twice per year. The first stratum to be added to this database was patients treated by disease modifying drugs. 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.

Figure 1 ReMuS – project organization



RESULTS

13 out of 15 Czech MS centers have already joined the registry. The number of patient records has increased gradually from 1501 to 7099 in the last export in June 2015. Table 1 and Fig. 2.

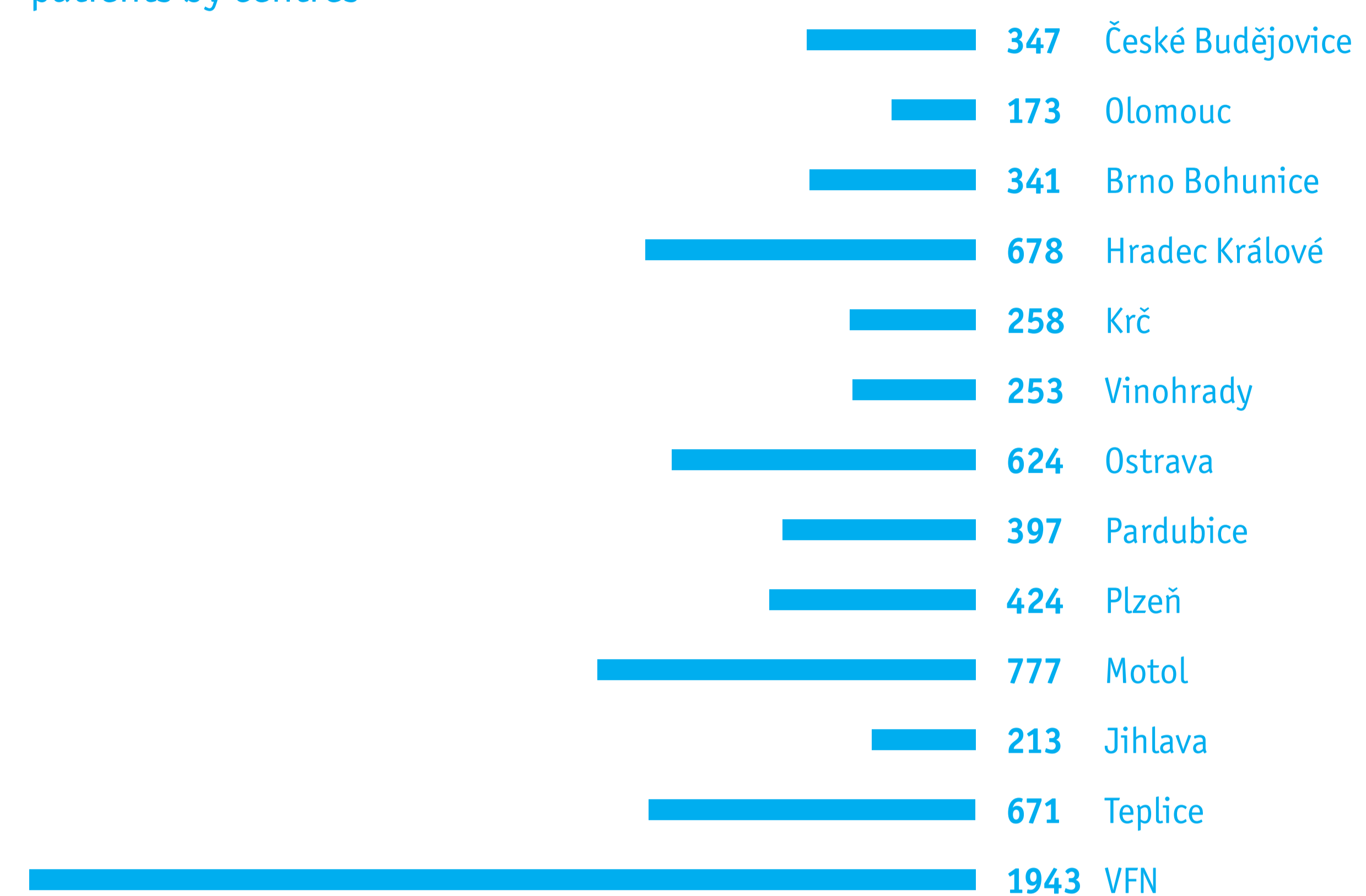
Table 1 Number of patients in the ReMuS registry - development

Data export date	Number of centres	Number of patients to be analysed
30. 6. 2013	3	1501
31. 12. 2013	7	2920
30. 6. 2014	12	4715
31. 12. 2014	12	5639
30. 6. 2015	13	7099

CONCLUSIONS

ReMuS, the Czech national registry, has already collected comprehensive data of more than 7000 patients. The aim is to enroll a majority of MS patients (approx. 13000) in the Czech Republic within the next 2 years. The registry will soon provide not only cross-sectional, but also important longitudinal data. This data will help to better organize care for MS patients in the Czech Republic and also serve as an important scientific platform for future endeavors.

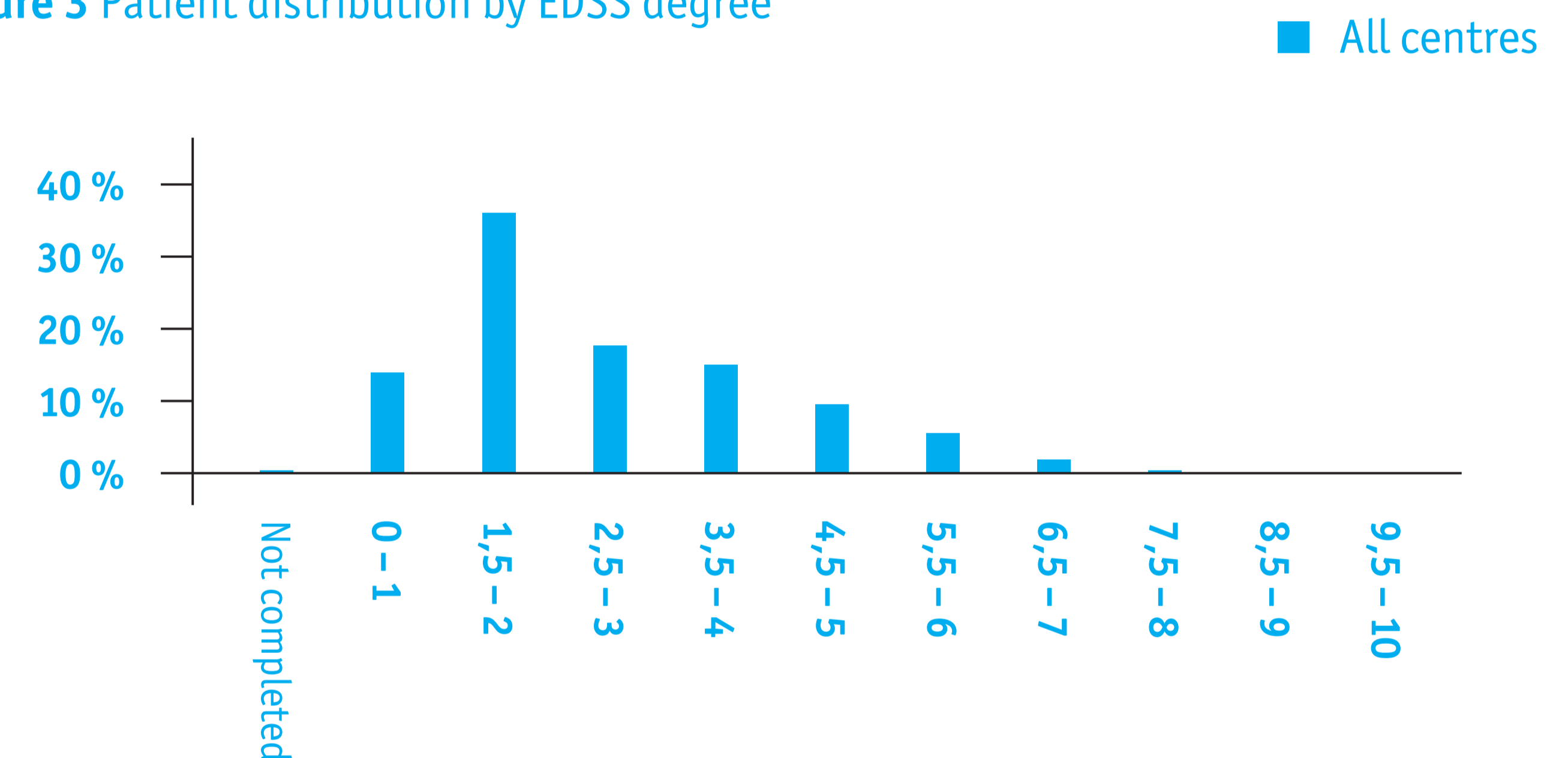
Figure 2 Total number of analysed patients by centres



Sex ratio female / male is 72/28%, average age 40.4 (SD 10.2), age at disease onset 30.3 (SD 9.4).

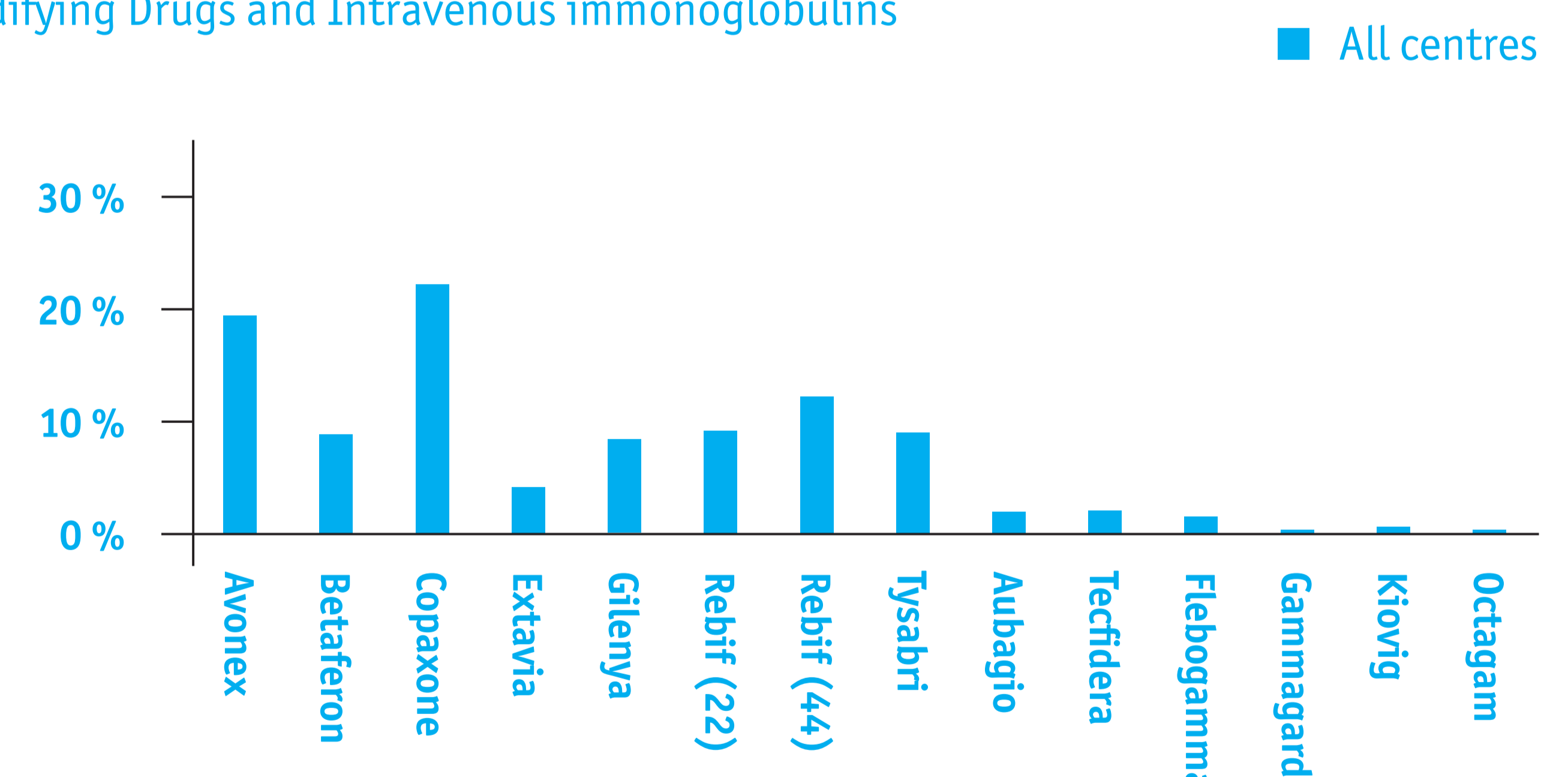
Annual relapse rate was 0.298. Average EDSS at the time of last visit was 2.7 (SD 1.5), distribution of EDSS is in the Fig. 3.

Figure 3 Patient distribution by EDSS degree



Data about treatment show the rate of particular drugs with interferons and glatiramer acetate as leading preparations. Fig. 4.

Figure 4 Medicinal preparations used – Disease Modifying Drugs and Intravenous immunoglobulins



The registry provides further data about distribution of patients in particular regions, health insurance assignment, and important data about employment and disability pension (67.8% of patients are employed and working full or part time). Fig. 5.

Figure 5 Patient distribution by employment type

