

## PURPOSE AND BACKGROUND

Myasthenia gravis belongs to orphan disease with prevalence varying from 15-200 per million depending on country [1]. The patient registries belong to the core activities which can help us in planning of the effective health care, assessing standards of diagnosis and care, and answer the questions concerning on epidemiologic data. The new Czech registry (MyReg) for patients suffering from myasthenia gravis should gather and pool data from neuromuscular centres in Czech Republic.

## METHODS

The technology, the data collection, storage, backup and their analyses are provided by the Institute of Biostatistics and Analyses. On-line data collection is based on a TRIALDB system developed on Yale University, Connecticut, USA [2]. Data are stored on the central server on Masaryk University in Brno.

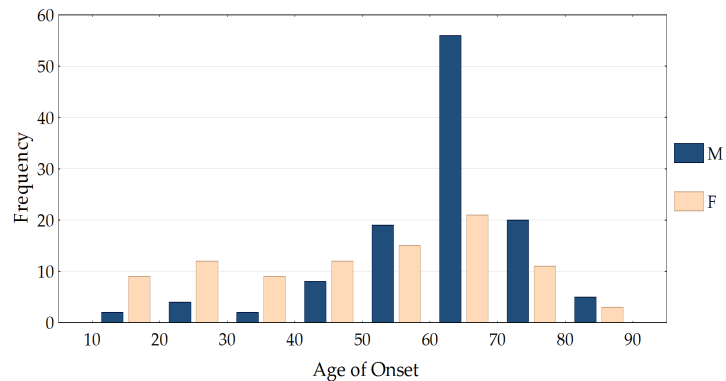
MG Composite Score (MGC) and MG-QOL 15 were chosen as outcome measures. Both classifications are easy to administer in routine clinical practice.

## GROUP OF PATIENTS

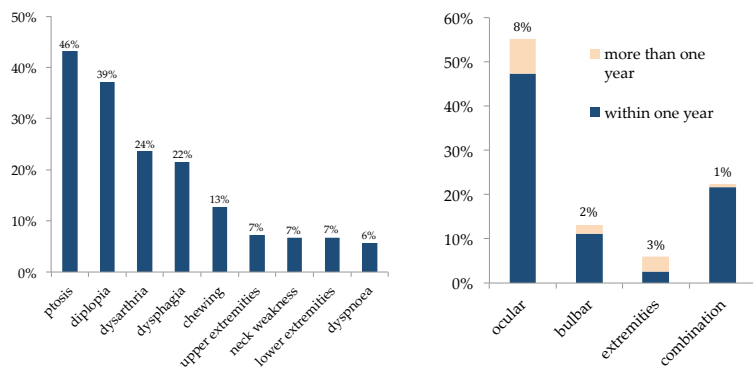
Pilot data for MyReg were collected from patients of Neuromuscular Centre of University Hospital Brno. Total number of 208 patients were gathered and selected characteristics were analysed.

The sex ratio M : F was 1.3 : 1. There were 116 men (56 %) and 92 women (44%). The mean age of patients at data entry to registry was 66 years. The mean age of onset was 57 years. In detail, the mean age of onset for women and men was 50.1 and 62.5 years respectively. Early onset myasthenia gravis was defined as beginning before the age of 50. Generalized form was found in 75 % patients.

## AGE OF ONSET



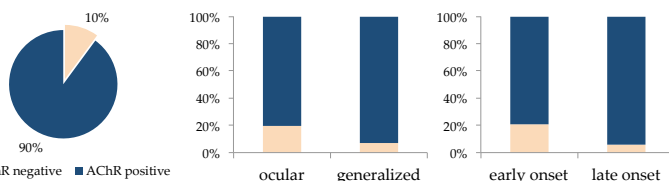
## FIRST SYMPTOMS AND TIME TO DIAGNOSIS



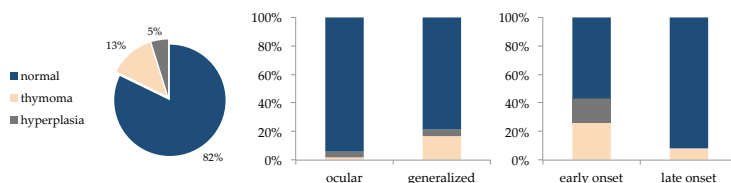
Most frequent first symptoms were ocular (ptosis or diplopia or both in 68 %). The diagnosis was made within six months in 74 % and

within a year in 86 % patients. Time required to make the diagnosis differed depending on first symptoms.

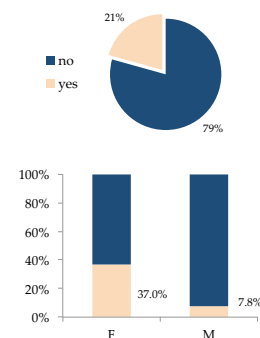
## AChR ANTIBODY



## THYMOMA



## THYMECTOMY



This marked difference between frequency of thymectomy in men and women is caused by higher occurrence of thymoma in women. In our group 16 % of women had thymoma (in contrast to 8 % of men). Another reason is thymectomy of normal thymus in younger patients.

## CONCLUSION

Patient registry MyReg has proved to be simple, clearly organized and able to gather important data. According to raw data from all Neuromuscular centres in Czech Republic, there are approximately 2 500 patients suffering from myasthenia gravis. It indicates the prevalence 240 per million which is higher than expected [1].

Overall, our data are in agreement with other studies apart from two exceptions [3]. Higher percentage of males was found in our sample. Furthermore, thymomas were more frequent in early onset myasthenia.

The registry is opened for international cooperation. It will serve as a source of data for improvement of therapy strategies and better understanding of subtypes of myasthenia in the future.

## REFERENCES

- [1] Carr AS, Cardwell CR, McCarron PO, McConville J. A systematic review of population based epidemiological studies in Myasthenia Gravis. BMC neurology. 2010;10(1):1.
- [2] Nadkarni P, Brandt C, Marengo L. TrialDB: a clinical studies data management system, 2010. UR L <http://ycmi.med.yale.edu/trialdb/> Archived at <http://www.webcitation.org/5mm4G1K1S>.
- [3] Berris-Akinn S, Frenkian-Cuveiler M, Eymard B. Diagnostic and clinical classification of autoimmune myasthenia gravis. Journal of autoimmunity. 2014;48:143-148.

