

## ABSTRACT

On July 22, 2016 Law 85 was approved by the Government of Puerto Rico (PR). This law states that every physician authorized to practice medicine in PR has to register all their patients, with the patient's consent, to the PRMS Registry (Article 2, Law 85). This pioneering law demands neurological clinics, hospitals, and physicians to provide demographic and clinical information to the registry. This law facilitates the progress of clinical studies in hopes of better understanding the manifestations of MS in PR Hispanics. Law 85 could act as a model to other countries for the implementation of similar laws that reinforce long term registries. After informed consent is obtained, a self-report questionnaire consisting of clinical and demographic information is collected from each patient. The data collected by the self-report questionnaires allows one to monitor the manifestation of MS in PR. Law 85 is the first law reported that enforces an MS registry. The development of similar laws will promote more efficient epidemiological surveillance of MS in other countries. This will foster more clinical and demographical research that will allow the medical and scientific community to better characterize MS patients. The information gathered from these studies may also influence the government's approach to MS patient care.

## OBJECTIVE

Law 85 could act as a model to other countries for the implementation of similar laws that reinforce long term registries

## METHODS

The PRMS Registry collects data from all diagnosed Puerto Rican MS patients living on the island. Data is obtained from neurological clinics, hospitals, and physicians who are required to submit the information. A self-report questionnaire consisting of clinical and demographic information is collected from each patient (Fig 1). An informed consent is obtained before collecting any information.

## RESULTS

The data collected by the self-report questionnaires provided by the PRMS Registry allows one to monitor the manifestation of MS in PR and analyze the disease epidemiological disparities compared to other ethnic groups.

## CONCLUSION

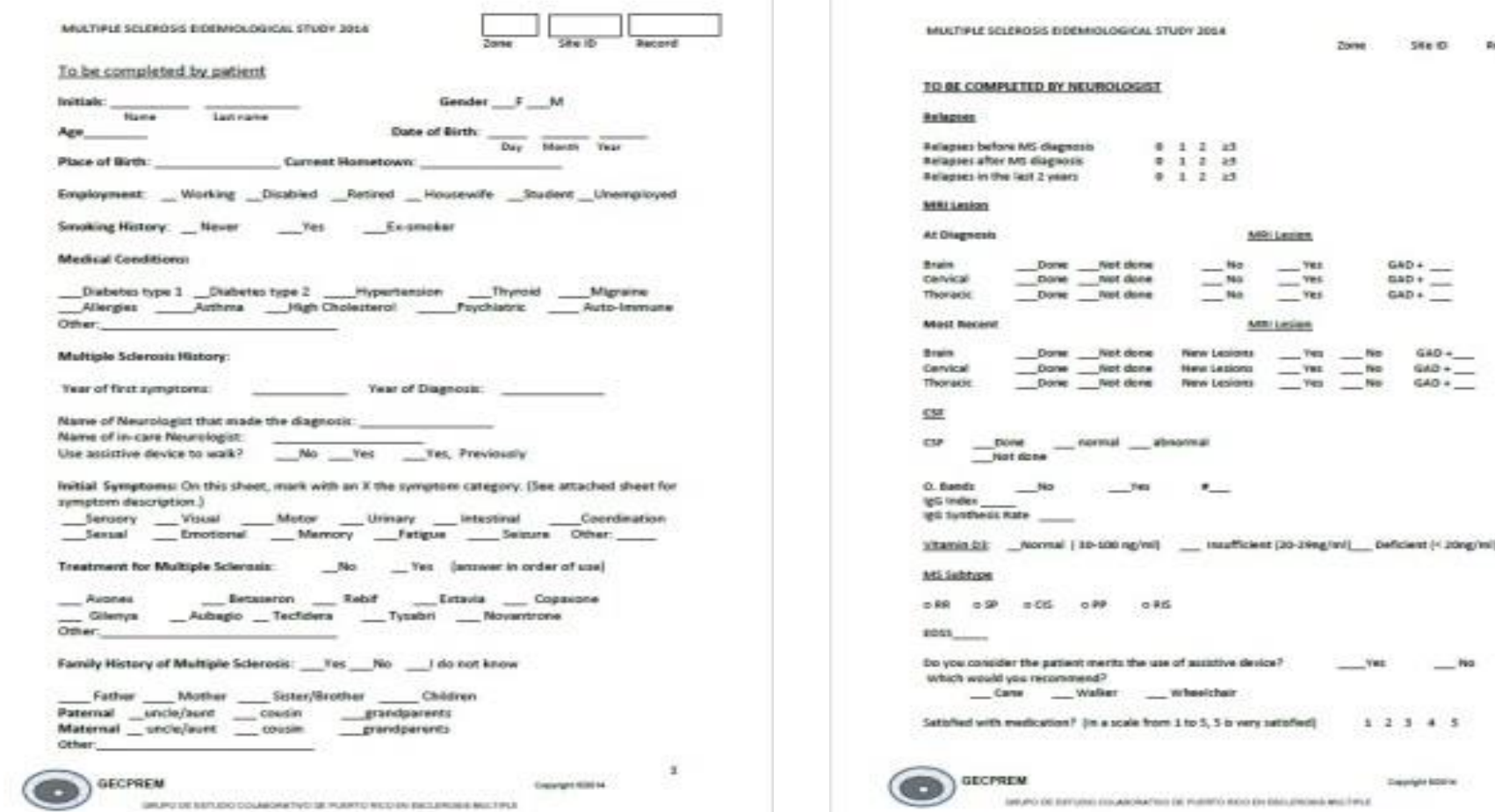
Law 85 is the first law reported, upon our review, that enforces an MS registry. The development of more laws, like Law 85, will promote more efficient epidemiological surveillance of MS, and possibly other chronic ailments, in other countries. This will foster more clinical and demographical research that will allow the medical and scientific community to better characterize MS patients. Furthermore, it will provide greater insight into the genetic and environmental factors associated with MS. The information gathered from these studies may not only affect the medical field but may also influence the government's approach to MS patient care, since it could shed light on disability and working status trends. The benefits of an enforced registry are seemingly endless for both the government and the medical field. This registry will soon become a longitudinal registry.

## BIBLIOGRAPHY

- 1 Bronnum-Hansen H, Koch-Henriksen N, Stenager E. The Danish Multiple Sclerosis Registry. *Scandinavian journal of public health.* 2011;39(7 Suppl):62-4. doi: 10.1177/1403494810390729
- 2 Flachenecker P, Buckow K, Pugliatti M, Kes VB, Battaglia MA, Boyko A, Confavreux C, Ellenberger D, Eskic D, Ford D, et al. Multiple sclerosis registries in Europe - results of a systematic survey. *Mult Scler.* 2014;20:1523-32. doi: 10.1177/1352458514528760.
- 3 Flachenecker P, Stuke K. National MS registries. *Journal of neurology.* 2008;255(6):102-8.
- 4 Trojano M, Russo P, Fuiani A, Paolicelli D, Di ME, Granieri E, Rosati G, Savettieri G, Comi G, Livrea P (2006) The Italian Multiple Sclerosis Database Network (MSDN): the risk of worsening according to IFNbeta exposure in multiple sclerosis. *Mult Scler* 12:578-58.
- 5 Chinae, A., C. F. Ríos-Bedoya, C. Rubi, I. Vicente, E. R. Estades, and Y. G. Hernandez-Silvestrini. "Incidence of Multiple Sclerosis in Puerto Rico, 2014: A Population-Based Study." *Neuroepidemiology.* U.S. National Library of Medicine, 24 Mar. 2017. Web. 09 May 2017.
- 6 Kingwell, Elaine et al. "Incidence and Prevalence of Multiple Sclerosis in Europe: A Systematic Review." *BMC Neurology* 13 (2013): 128. *PMC.* Web. 9 May 2017.

**Disclosure:** Dr. Chinae is a speaker for Novartis, Biogen, Teva, and Genzyme. None of the authors of this research received any grants or monetary compensation.

**Acknowledgements:** We would like to thank the PRMS Foundation and the collaborative group GECPREM for their aid in this investigation.



**Figure 1:** The questionnaires which are completed by the patient (page 1) and the neurologist (page 2).