

ICODIMS



CUBARMS, A COMPUTERIZED REGISTER IN MULTIPLE SCLEROSIS AND DEMYELINATING DISEASES. REPORT OF THE FIRST 292 CASES.

In Cuba, Multiple Sclerosis (MS) and demyelinating diseases are one of the most commonly diagnosed neurological disorders of both young and middle-aged adults, and one of the leading causes of significant disability in Cuba. Estimates illustrate there are today 3,500 patients with demyelinating disorders. The need for a functional and accurate means of gathering, storing and working with data was all too relevant. A new data base for MS and demyelinating diseases (CUBARMS) has been designed and implemented in Cuba.

OBJECTIVES: Our objective is to evaluate a new data base system for the current national project on clinical, epidemiological and immunogenetic studies in 292 Cuban patients.

METHODS: A data base system was designed and implemented for the study of the MS and other demyelinating diseases. This system includes the patient's demographic data, genealogical history, family history, initial symptoms, current symptoms, neurological examination, evaluative scales [Scripps Rating Neurological Scale, EDSS Kurtzke, Disease Steps (DS), Ambulatory Index (AI) and 9 Hole-peg test (9 HPT)], complementary tests (evoked potentials, neuropsychological tests, CSF studies, urodynamic and ultrasound tests for bladder dysfunction) and clinical evolutive forms (Lublin & Reingold). A follow-up evolution survey will monitor variation in patients' neurological examination, evaluative scales [Scripps Rating Neurological Scale, EDSS Kurtzke, Disease Steps (DS), Ambulatory Index (AI) and 9 Hole-peg test (9 HPT)], complementary tests (evoked potentials, neuropsychological tests, CSF studies, and urodynamic and ultrasound tests for bladder dysfunction). An additional MRI data base system was done according to the recommendations of the International MRI Committee of the CMSC meeting that was held in Vancouver.

RESULTS: *Demographic data of the 292 MS Cuban patients Clinical-Laboratory Supported definite (Poser et al) before 2002 or Multiple Sclerosis (McDonald et al) after 2002 were:* female 74.32%; married 57.88%; higher educational level 59.93%; white 73.97%. *Genetic data:* With family history of MS 9.25%; European ancestry 54.79%; with family history of psychiatric disorder 34.25%; with family history of collagen diseases 22.60%; allergy to medications in 40.07% and coffee intake 60.62%. *Initial symptoms:* Weakness, numbness, paresthesias, ataxia and blurred vision. *Trigger factors:* Viral diseases (20.54%), stress (12.32%), puerperium (6.51%), optic neuritis (3.42%) and trauma (3.76%), were observed in 66.44% cases. The diagnosis of MS was confirmed in the first three years (50.76%) from the initial symptoms. *Pyramidal and cerebellar systems* indicated higher levels of impairment in the functional systems; EDSS in 3 - 3.5 was observed in 23.97% and 6.0 - 6.5 in 18.49%; Scripps Scale, DS, AI and 9 HPT showed lesser levels of impairment; MRI (84.44%), motor evoked potentials (62.63%) and CSF with higher IgG index or oligoclonal bands (77.92%) were the most sensitive complementary tests. *Cognitive disorders* were observed in 65.75%. Relapsing remitting was observed in 53.08% [1-a (12.67%) / 1-b (40.41%)]; Secondary Progressive in 20.20% [3-a (8.22%) / 3-b (11.99%)]; Primary Progressive in 18.49% [2-a (10.96%) / 2-b (7.53%)]; Progressive with exacerbations was only seen in 0.68%. A new clinical evolutive form was observed in 3.77% of the cases.

CONCLUSION: The Cuban Data Base System is an accurate and useful tool for the register of the Cuban MS patients. It is applicable for similar registers in other countries. In addition, this is the first MRI Data Base Register with the current recommendations for the MRI studies in MS.

Gonzalez-Valdes Nelson, EE; Cabrera-Gomez, JA, MD, PhD
Multiple Sclerosis Clinic, University Hospital Cienfuegos, Cuba

