Czech National Registry of Myotonic Disorders

by Vohanka Stanislav, Parmova Olesja, Mazanec Radim, Strenkova Jana, Ridzon Petr, Ehler Edvard, Forgac Martin, Junkerova Jana, Bozovsky Tomas, Kunc Pavel

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Abstract Details

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 Czech National Registry of Myotonic Disorders was established in 2011 under the supervision of Czech Neuromuscular Society. The technology, the data collection, storage and backup and their analyses are provided by the Institute of Biostatistics and Analyses, Masaryk University, Brno. On-line data collection is based on a TRIALDB system developed on Yale University. For each patient is generated a unique ID; all data transfer is encrypted and the system is designed to prevent their unauthorized use during data transfer. Laws and regulations in Czech Republic require having an informed consent from all patients whose data are used in the registry. All claims for personal data protection were met. Data are stored on the central server in Oracle 9i database.

Up to January 2015 422 patients form 8 centres has been included. The majority (84%) of all records are from centres in Prague and Brno. The average annual recruitment during total 3.5 years period are 121 patients. The mean follow-up time in the registry is 16 months.

The majority consists from patients with DM2 (n=207, 49.1%) and DM1 including congenital form (n=157, 37.2%). Non dystrophic myotonias (chloride and natrium channelopathies) are represented with 26 persons (6.1%). The rest are asymptomatic mutation carriers and files with poor defined or missing data (32 items).

Among patients with DM (1 and 2) there are 219 females (63%) and 129 males (37%). Mean age in the time of the registry entering is 45 years, approximately 10 years after disease manifestation which was in patient with MD1 25 (10- 54) years and in persons with MD2 40 (17-62) years. Nearly all patients

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Author Information

Author: Vohanka Stanislav, Parmova Olesja, Mazanec Radim, Strenkova Jana, Ridzon Petr, Ehler Edvard, Forgac Martin, Junkerova Jana, Bozovsky Tomas, Kunc Pavel

Email: stanislav.vohanka@gmail.com, olesja.parmova@fnbrno.cz, radim.mazanec@email.cz, strenkova@iba.muni.cz, petr.ridzon@ftn.cz, edvard.ehler@nemocnice-pardubice.cz, martin.forgac@vfn.cz, jana.junkerova@seznam.cz, bozovskyt@fnplzen.cz, kunc@fnhk.cz

Affiliation: University Hospital and Medical Faculty Masaryk University Brno, University Hospital and Medical Faculty Masaryk University Brno, University Hospital Prague - Motol, Masaryk University Brno, Thomayer Hospital Prague, Regional Hospital

with MD 1 and MD2 are ambulatory (assisted or unassisted). Only 4 patients are wheelchair bound.

Pardubice, General University Hospital Prague, University Hospital Ostrava, University Hospital Plzen, University Hospital Hradec Kralove

Presenter Information

Presenter: Vohanka Stanislav

Email: stanislav.vohanka@gmail.com

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