integriertes Myasthenie Zentrum

BQS
INSTITUT FÜR QUALITÄT & PATIENTENSICHERHEIT

German Myasthenia Registry

Contact:

Deutsche Myasthenie Gesellschaft e. V.
Westerstr. 93, D-28199 Bremen
Telefon: +49 421 59 20 60
E-Mail: mg-register@dmg.online
Internet: www.dmg.online

German Myasthenia Registry

Initial data entry

German Myasthenia Registry

Patients with myasthenic syndromes including LEMS and congenital myasthenic syndromes

Longitudinal design

Baseline Visit Data

- Demographics (age, sex, social status)
- Diagnosis (ocular/generalized MG, LEMS, CMS)
- Current and worst MGFA
- Antibody status: AChR, MuSK, LRP4, Titin, VGCC, SOX-1, seronegative
- Diagnostics (electrophysiological, pharmacological and antibody testing, chest imaging)
- Concomitant diseases
- Thymectomy status (including thymus pathology, postoperative complications)
- Treatment history and current treatment with dose and duration, including exacerbation therapy
- Therapy associated side effects
- Clinical outcome parameters (QMG) and patient reported outcome (MG-ADL; MG-QoL; chronic fatigue score, HADS-D)

Yearly follow - up visit →

Follow-Up Visit Data

- Demographics (social status)
- Antibody status: AChR, MuSK, LRP4, Titin, VGCC, SOX-1, seronegative
- Current MGFA
- Diagnostics (electrophysiological, pharmacological and antibody testing, chest imaging)
- Concomitant diseases
- Thymectomy status (including thymus pathology, postoperative complications)
- Treatment history and current treatment with dose and duration, including exacerbation therapy
- Therapy associated side effects
- Clinical outcome parameters (QMG) and patient reported outcomes (MG-ADL; MG-QoL; chronic fatigue score, HADS-D)
- SARS-CoV-2 infection, hospitalisation and outcome

German Myasthenia Registry

Research on the Treatment of Patients with Myasthenic Syndromes in Clinical Practice

Deutsche Myasthenie Gesellschaft e.V.

Introduction

German Myasthenia gravis registry (**MyaReg**) is assessing and evaluating clinical routine data from patients suffering from myasthenic syndroms, including Myasthenia Gravis (MG), Lambert-Eaton Myasthenic Syndromes (LEMS) as well as Congenital Myasthenic Syndromes (CMS). The primary goal of **MyaReg** is to improve the quality of patients care. Besides assessing clinical routine data the register will also collect patient reported outcome measures (see flow chart).

MyaReg was initiated and established by the medical advisory board in cooperation with “German Masthenia gravis Foundation” (DMG) supported by the “German Institute of Quality and Patients Safety" (BQS).

MyaReg is based on a defined set of quality indicators and using a web based database (ASTHESIS®).

German Myasthenia Registry

Organization

iMZ integriertes Myasthenie Zentrum

All certified integrated Myasthenia gravis Centres (“iMZ“) in Germany providing care for more than 3000 MG patients are participating in the registry. The certification process is based on the full participation in the registry based on the yearly published quality report. Every patient with a myasthenic syndrome treated in the iMZ will be asked to provide the informed consent for participation in the registry.

MyaReg is managed by the user council (“Nutzerrat”) elected from the medical advisory board of DMG to coordinate requests for data use.

MyaReg thus enables patient-oriented research into the care, diagnosis, therapy and course of myasthenic diseases.

Together with the central Mya-Biobank (host by the University Hospital Münster, germany), **MyaReg** will facilitate biomarker research on the pathophysiology, diagnostics and prognosis of myasthenia gravis to identify modifiable impact factors on natural disease course and outcome parameters.

Moreover it’s planned to affiliate patients to the data entry process of patient reported outcome parameters enabling them to monitor their individual outcome.