Title of the study group: MyoNet study group

Study Group Leader's name: Ingrid Lundberg
Date of annual report submission: 2018-03-28

Summary of last year's activities

We have had one study group meeting, during EULAR 2017, on Thursday June 15, in Madrid. Seventeen participants attended the meeting.

During this meeting we had the following items on the agenda:

All participants were introduced as this was the premier meeting for the EULAR MyoNet study group.

Ingrid Lundberg gave an introduction of the Aims of Study group MyoNet.

Albert Selva O'Callaghan presented two interesting cases within the myositis disease spectrum and the presentation was followed by discussion.

Angelo Ravelli presented the recently published Pediatric minimal data set to use for follow up of Juvenile dermatomyositis (JDM).

Ingrid Lundberg presented the final version of the EULAR/ACR Classification Criteria for Adult and Juvenile Idiopathic Inflammatory Myopathies (IIM) and their Major Subgroups and the webcalculator. The presentation was followed by a discussion on the need for validation in an external cohort and how we can proceed with this process. We also discussed the need to test the performance of other items e.g. some more myositis specific autoantibodies that are now available for commercial testing. For this we need to identify collaborators with cohorts of patients with IIM as well as comparator cases where we have results of the whole spectrum of myositis specific autoantibodies. Ingrid will bring these issues to the Steering committee of the myositis criteria.

Jiri Vencovsky gave an update on the web based Euromyositis registry: organization, steering committee, how to apply to join, how to apply to use data for collaborative projects and some news: The EULAR/ACR classification criteria in Euromyositis and a new module for JDM.

Hector Chinoy gave a summary of the new project approved by FOREUM, **IMPROVEMENT (i**mproving the outco**m**e in myositis s**p**ect**r**um diseases: c**o**re set **v**ariabl**e**s harmoniz**a**tion and use fro**m** child**r**en to adul**t**hood) **project**. In this project we will, among other things, develop tools to facilitate collection of longitudinal outcome data by harmonization of national registers and data from electronic hospital records by technical integration and develop tools to capture clinical data from patients into the Euromyositis registry by developing SmartApps. We will also focus on the transition phase between childhood and adults with myositis. This is a collaboration between Euromyositis registry network and the AENEAS network.

New projects: Ingrid Lundberg presented a new project based on the Euromyositis registry: A project on prognostic biomarkers, an application has been submitted to FOREUM.

Next meeting will take place during EULAR in Amsterdam.

Ingrid Lundberg

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