

ECFS Exercise Working Group

Report for the ECFS meeting in Gothenburg 2014

Activities of the Exercise Working Group and achieved milestones 6/2013- 5/2014:

Meetings of the Exercise Working Group

- 1) A 5-hour meeting of the group took place at the ECFS conference in Lisbon/Portugal on June 12, 2013 with 17 attendees from around the world. During that meeting, the group discussed in depth the comments from the ECFS board with respect to the Clinical Practice Guideline on Exercise Testing and consented on revisions of the guideline / wording of controversial parts. Furthermore, the group discussed the next steps in preparing the documents on physical activity assessment and exercise counselling.
- 2) At the North American CF conference in Salt Lake City/Utah a 2-hour meeting was held with 13 participants to discuss progress with the different documents and to agree on the next steps.
- 3) A 5-hour meeting of the ECFS Working Group with 15 expected participants will take place in conjunction with the ECFS annual meeting in Gothenburg on June 11, 2014. At that meeting, the progress in all projects of the Exercise Working Group will be presented and discussed.
- 4) A symposium on the results of the work of the Exercise Working Group will be held on June 12, 2014 during the ECFS conference in Gothenburg.

Clinical Practice Guideline on Exercise Testing

- 5) During June and July 2013, the document on exercise testing was revised based on the discussions at the ECFS meeting in Lisbon, and circulated several times within the writing group. The revised document was then submitted to the ECFS board for evaluation and endorsement on 12 July 2013. A slightly revised document was endorsed by the ECFS on February 17, 2014.
- 6) The CF Foundation Guidelines Steering Committee has reviewed the document endorsed by the ECFS but felt unable to endorse the document "at this time" and suggested additions to the document (email from Bruce Marshall dated April 25, 2014). The next steps will be discussed among the group but there is agreement not to wait for CFF endorsement before publication.
- 7) The Exercise Testing Guideline will now be submitted to the ERS for review.
- 8) A first contact with the editor of the Journal of Cystic Fibrosis was made to discuss options for open access publication of the document.

Position Stand on Physical Activity Assessment

- 9) The group in Belfast headed by Judy Bradley (and with significant contributions from Lisa Kent and Brenda O'Neill) along with the group in Utrecht headed by Erik

Hulzebos circulated the Position Stand on Physical Activity Assessment several times during 2013 within the writing group and also to the whole Exercise Working Group. The document was revised and updated and finally submitted to the ECFS board for review and endorsement on March 5, 2014.

Document on Physical Activity and Exercise Counselling and Prescription

10) The writing group headed by Anne Swisher (Morgantown/West Virginia) has presented a draft document to all members of the Exercise Working Group on March 26, 2014 and asked for feedback. The text will now be revised and further discussed at the Exercise Working Group meeting in Gothenburg.

ACTIVATE-CF

11) Funding for the international multi-centre ACTIVATE-CF study has now been secured for Canada, France, Germany/Austria, and Switzerland with single centres receiving local funding in the UK (Edinburgh) and the Netherlands (Utrecht) and a sufficient number of centres have agreed to recruit patients. The study protocol which was improved based on suggestions of the ECFS-CTN review has been approved by the ethics committees in Würzburg/Germany and Zurich/Switzerland. The study will start to recruit patients in June or July 2014.

Retrospective study on additional prognostic information from cardiopulmonary exercise testing in cystic fibrosis

12) During the meeting at the North American CF conference, a study protocol was consented for a collaborative retrospective study to determine the value of exercise testing in predicting survival in addition to established indicators such as FEV1, BMI, or Pseudomonas status in a large cohort of patients from several centres. The protocol has received ethical approval in Würzburg/Germany and data collection has started.

ECFS Exercise Working Group will continue to work on the above projects

13) An application for the continuation of the ECFS Exercise Working group was submitted in August 2013 and approved by the ECFS for another 3-year period in November 2013.