

ECFS Exercise Working Group

Report for the ECFS meeting in Brussels 2015

Activities of the Exercise Working Group and achieved milestones 6/2014 - 04/2015:

Meetings of the Exercise Working Group

- 1) A 5-hour meeting of the group took place at the ECFS conference in Gothenburg/Sweden on June 11, 2014 with 16 attendees from around the world. During that meeting, the group discussed briefly the documents on exercise testing in and on physical activity assessment in CF. An in depth discussion took place with respect to the document on exercise counselling /recommendations.
- 2) At the North American CF conference in Atlanta/Georgia, a 2-hour meeting was held with 13 participants to discuss progress with the different documents and to agree on the next steps.

Statement on Exercise Testing (formerly Clinical Practice Guideline on Exercise Testing)

- 3) In June 2014, the document was sent to the European Respiratory Society and – after change of the title to “Statement” rather than “Clinical Practice Guideline” and minor adjustments the document was endorsed by the ERS in September 2014.
- 4) The publication of the Statement on Exercise Testing was first discussed with Dr. Scott Bell and then also with Stuart Elborn. The statement was submitted to the JCF as summary of the statement for publication as online paper plus the full statement as online supplement. The editors of the JCF requested a revision which was done. The revised summary is currently under review.

In the process of negotiations, the Exercise Working Group was informed that a statement cannot be endorsed by the ECFS. Thus, all references to the endorsement granted by the ECFS in February 2014 were deleted from the revised summary and the full statement. We will still need to determine with the ERS, whether the endorsement by the ERS still stands.

Position Stand on Physical Activity Assessment

- 5) The Position Stand on Physical Activity Assessment has been reviewed by the ECFS and was changed based on the recommendations.
- 6) The revised and updated document was submitted and subsequently revised according to the editors comments.

Document on Physical Activity and Exercise Counselling and Prescription

- 7) Based on the intense discussion at the Exercise Working Group meeting in Gothenburg/Sweden, the document was majorly revised and focussed. After further

discussions in Atlanta/Georgia, a newly revised version will be discussed at the meeting in Brussels.

ACTIVATE-CF

- 8) After funding for the international multi-centre ACTIVATE-CF study has now been secured for international coordination, data base management, and data collection in Canada, France, Germany/Austria, and Switzerland with single centres receiving funding in the UK (Edinburgh), the Netherlands (Utrecht), and the USA (Pittsburgh/PA & Birmingham/AL), patient recruitment has started in July 2014. Currently, patients are recruited in five countries (Austria, France, Germany, Switzerland, and the UK) with the US centres and Utrecht/Netherlands are expected to start recruiting within the next months. The Canadian centres are expected to enter the study in June or July.

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

- 9) For the 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, ethical approval has been obtained from several ERBs, and data have been sent into the data base. More data are expected, so that more than 500 datasets should become available.