## **ECFS Exercise Working Group**

## Report for the ECFS meeting in Sevilla 2017

Activities of the Exercise Working Group and achieved milestones 5/2016 - 05/2017:

## **Meetings of the Exercise Working Group**

- 1) A meeting of the group took place at the ECFS conference in Basel/Switzerland on June 8, 2016 with 13 attendees from around the world. During that meeting, the group discussed the latest information on the documents on exercise testing, on physical activity assessment and on exercise counselling / advice in CF. In addition, the group was updated on the collaborative research projects initiated by the group (ACTIVATE-CF, prognostic value of exercise testing in addition to known predictors of survival, association between genotype and exercise capacity). The meeting ended with a discussion of future topics relevant to the group and the draft of a application for extension of the exercise group. The application was then submitted with the following aims and objectives for the Exercise Working Group:
  - a) Further standardize exercise testing. Specifically, we plan to establish an equation to predict optimal work rate increments during cycle ergometry to complete a maximal test (deliverable: publication). Furthermore, we plan a pre-conference course on exercise testing, data interpretation and clinical utilization.
  - b) Utilizing patients to better understand barriers to exercise and exercise testing across countries (survey, publication).
  - c) Survey the clinical approach to exercise in different case scenarios from centers across Europe and beyond to establish current practice and informed development of consensus (publication) in order to advance knowledge on physical activity/exercise advice in comorbidities and medical complications.
  - d) Develop educational material on exercise testing and physical activity advice adapted to a variety of media platforms
  - e) Establish a mentoring program for CF centers across Europe who are interested in establishing exercise testing and counselling.
  - f) Support protocol development for studies in the area of CF and exercise including studies with exercise as an outcome measure (single-center or multi-center trials).
  - g) Further establish and extend European collaboration by supporting activities of the ERN-LUNG and possibly an ERS Task Force on Standardization of Exercise Testing in Chronic Lung Diseases (application submitted).
- 2) At the North American CF conference in Orlando, a 2-hour meeting was held with 13 participants to discuss future projects in the field of exercise in cystic fibrosis.

## Activities of the Exercise Working Group at the ECFS conference 2016

 For the ECFS conference in Basel, the Exercise Working Group suggested a symposium which took place on 10 June 2016 (Exercise for everybody). Members of the group were involved in an additional symposium (Taking life to extremes with cystic fibrosis on 09 June 2016) and an exercise-related workshop.

#### **ACTIVATE-CF**

 Recruitment into the study has continued in Austria, France, Germany, Switzerland, the United Kingdom and the United States. Centers in The Netherlands and Canada have started recruitment

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

3) To determine the value of exercise testing in predicting survival in addition to established indicators such as FEV1, BMI, or Pseudomonas status, a data base with valid information from 433 patients has been established. The data have been analysed and will be presented at the ECFS meeting in Seville. Briefly, exercise testing does yield prognostic information in addition to age, gender, FEV1, BMI, Pseudomonas-status, and CFRD status.

## Association between genotype and exercise capacity in cystic fibrosis

4) Data on genotype, exercise capacity and potential confounders of the relationship between the two have been collected from centers around the world. A first manuscript was drafted but the group felt that additional data was required. Thus, more data from additional centers were requested and an extend analysis was done. The data will be presented at the ECFS meeting in Seville.

# Objectives of the extended period of the ECFS Exercise Working Group (see above)

- 5) Objective a) Frank Cerny and Helge Hebestreit as members of the Exercise Working Group largely contribute to a pre conference course at the ECFS meeting in Sevilla
- 6) Objective d) Don Urquhart will represent the Exercise Working group in an ECFS group preparing educational material
- 7) Objective g) Several members of the Exercise Working Group (Don Urquhart, Thomas Radtke, Helge Hebestreit) are part of an ERS Task Force on Standardization of Exercise Testing in Lung Diseases which is chaired by Helge Hebestreit. Members of the group are also actively involved in the European Reference Network Rare Lung Diseases (ERN-LUNG), both in the CF-Core Network and the Guidelines and Best Practice of Care Functional Committee.

## **Budget plan for 2017**

The budget plan for 2017 would include the following:

1) Room for a 5-hour meeting at the ECFS conference in Seville (June 7, 2017)