

## ECFS Non Tuberculosis Mycobacteria Working Group Report May 2012

The working party has three main aims:

- a. Develop NTM management guidelines.
- b. Develop NTM-specific fields for the ECFS patient registry.
- c. Facilitate in the development of a greater evidence base for the management of NTM infection in CF.

### a) Development of Management Guidelines

Following discussions between Stuart Elborn and Bruce Marshall, it was agreed to develop joint ECFS / NACFF Management Guidelines. The guidelines committee is co-chaired by Charles Haworth (Papworth Hospital, Cambridge, UK) and Andres Floto (Cambridge University, Cambridge, UK). The working party is split into five sub groups which are outlined below:

Epidemiology and Risk Factors

Screening

Microbiology

Treatment

Transplantation

Experts from Europe and North America (Ken Olivier, Kevin Winthrop, Isabelle Sermet, Jerry Nick, Ron Gibson, Karsten Kotz, Jean-Louis Herrmann, Richard Wallace, Jakko Van Ingen, Andres Floto, Charles Daly, Lisa Saiman, Alan Smyth, Charles Haworth, Diana Bilton, Peadar Noone and Paul Corris) are collaborating on the project.

Thus far, we have participated in a series of telephone conferences to establish methodology and agree specific questions to be addressed in the guidelines and are due to have our first face to face guidelines meeting on 18 May 2012 in San Francisco (immediately prior to the ATS).

### b) NTM Specific Registry Fields for the ECFS database

We have developed NTM specific registry fields in collaboration with Hanne Olesen. Through incorporating these fields into the ECFS Registry (and possibly some national registries), we will:

- a) Gain important novel information about the epidemiology of NTM infection in CF
- b) Evaluate clinical outcomes of new clinical management guidelines and compare them to historical best practice.
- c) Establish a database of NTM-infected patients that may be willing to be enrolled in pan-European clinical trials of novel therapeutic agents

We are also collaborating with Laura Viviani to interrogate the current ECFS registry data set on NTM and we hope to get the initial analysis later this year.

### c) Clinical Trials

We anticipate that the systematic search performed as part of the clinical management guideline development process will highlight the paucity of trial data to direct management of CF patients with new / chronic NTM infection.

The development of the ECFS NTM interest group and NTM registry fields will facilitate the initiation of clinical trials across CF centres in Europe.

Charles Haworth | Andres Floto, Coordinators

