

ECFS Diagnostic Network Working Group Meeting Report

DNWG meeting during the 47th ECFS Conference 2024 Glasgow, UK,

June 7th, 2024

Chair: Elke De Wachter (Brussels, Belgium) – **Nick Simmonds** (London, UK)

Elke De Wachter opened the meeting with a warm welcome, providing a brief overview of the group's recent work and outlining future projects.

The first presentation was given by **Daniela Dolce** (Florence, Italy), who introduced her poster titled "*Sweat Test: Different Clinical Questions Require Different Lab Reports.*" Daniela proposed two distinct laboratory reports tailored to specific clinical needs: one optimized for diagnosing CF and the other for monitoring patients receiving CFTR-modulator therapy. The latter report, she suggested, should include additional information relevant to treatment.

Following this, **Nick Simmonds** (London, UK) provided an update on the "*ECFS Standards of Care for CFTR-Related Disorders*" project. He reviewed the progress of the four key papers and outlined future efforts, focusing on expanding awareness of CFTR-related disorders (CFTR-RD) both within the CF community and beyond. **Carlo Castellani** (Genova, Italy) then initiated a discussion about the potential need for an *ECFS CFTR-RD Registry*. This was followed by a talk from **Andreas Jung** (Zurich, Switzerland), who outlined the steps and considerations required to establish such a registry. The session continued with an update from **Mairead Kelly-Aubert** (Paris, France) on biomarkers for diagnosing CFTR-RD, providing valuable insights into advancements in this area.

Afterwards, difficult diagnostic cases were presented and discussed by **Peter Middleton** (Sydney, Australia) and **Inez Bronsveld** (Utrecht, The Netherlands). This started an engaging discussion with the audience, moderated by Elke De Wachter and Nick Simmonds.

Elke De Wachter closed the DNWG session during the ECFS conference and invited all the

participants to the next DNWG meeting (6 - 8th February 2025) which will take place in Brussels, Belgium.

We would like to thank ECFS for this successful meeting. We thank all speakers and participants for their fantastic contribution and for making the meeting such a great success!

We are looking forward to seeing you at our next annual DNWG Meeting in Brussels.

23th October 2024

Elke De Wachter – ECFS DNWG Coordinator

Nicholas Simmonds – ECFS DNWG Vice-coordinator

Marlies Destoop – ECFS DNWG Assistant

The meeting was kindly supported by:



Photos taken during the meeting:



Left to right: Elke De Wachter (Brussels, Belgium), Nick Simmonds (London, UK), Peter Middleton (Sydney, Australia)



