



European Cystic Fibrosis Society Diagnostic Network Working Group

http://www.ecfs.eu/ecfs_dnwg



22nd Annual ECFS DNWG Meeting Brussels, Belgium 6-8 February 2025

Organizing Committee:

Elke De Wachter, ECFS-DNWG Coordinator, UZ Brussel, VUB, Brussels, Belgium
Nicholas Simmonds, ECFS-DNWG Vice-coordinator, Royal Brompton, London, UK
Marlies Destoop, ECFS-DNWG Assistant, UZ Brussel, Brussels, Belgium
Caroline Raynal, CHU de Montpellier, Montpellier, France
Simon Gräber, Charité, Berlin, Germany
Sophie Gohy, UCL, Brussels, Belgium
Isabelle Sermet-Gaudelus, Necker, Paris, France

Part 1. Hands-on session: beta-adrenergic sweat test - Evaporimetry

Isabelle Sermet (Paris, FR) - Sophie Gohy (Brussels, BE)

- Thursday 6 Feb: 11.30-13.30
- Max 12 participants
- Registration is required
- **Venue location:** Vrije Universiteit Brussel, Brussels Health Campus, **meeting room A045** (Laarbeeklaan 103, 1090 Brussels)

Part 2. Scientific Program

- **Venue location:** Vrije Universiteit Brussel, Brussels Health Campus (Laarbeeklaan 103, 1090 Brussels)
- **Meeting room:** Auditorium Brouwer

14.00 Arrival and coffee

14.30 Welcome - Elke De Wachter (Brussels, BE) & Nicholas Simmonds (London, UK)

Session 1: Let's start with world's best beer and cheese

Chairs: Elke De Wachter (Brussels, BE) – Caroline Raynal (Montpellier, FR)

14.40 The journey of men with CBAVD in UZ Brussels
Veerle Vloebergs and Stefanie Vincken (Brussels, BE)

15.10 Progress on work regarding intestinal organoids as a tool for personalized medicine
Marlies Destoop (Utrecht, NL & Brussels, BE)

15.30 Evaporimetry in Europe
Sophie Gohy (Brussels, BE)

16.00 – Coffee break –

Session 2: What else is happening in the Low Countries?

Chairs: Nicholas Simmonds (London, UK) – Simon Gräber (Berlin, DE)

16.30 The use of rectal organoids for diagnosis and personalized medicine in CF
Senne Cuyx (Leuven, BE)

17.00 ROMA and other CFTR-functional tests as diagnostic tools in practice: a joint effort
François Vermeulen (Leuven, BE) and Inez Bronsveld (Utrecht, NL)

17.30 Wrap-up of Day 1

- Wrap-up by Nicholas Simmonds (London, UK)
- Plans for the evening shared by Elke De Wachter (Brussels, BE)

17.35 – End of Day 1 –

Evening program day 1

19.15: Let's gather in the hotel lobby to walk together to the restaurant.

19.30: Dinner in "*Restaurant De l'Ogenblik*" (Galerie des Princes 1, 1000 Brussel).

Session 3: Neonatal screening session

Chairs: Jürg Barben (St Gallen, CH) – Olaf Sommerburg (Heidelberg, DE)

- 09.00 Overview of the NSWG activities and plans
Jürg Barben (St-Gallen, CH)
- 9.10 Diagnostic and management challenges in the CFTR-modulator therapy exposed fetus/infant
Jane Davies (London, UK) and Idan Bokobza (London, UK)
- 9.30 Neonatal screening in Belgium
Marijke Proesmans (Leuven, BE)
- 9.50 YI: Report from the MODUL-CF study: First real-world study of fetal therapy in CF
Anaïs Le (Paris, FR)
- 10.05 Case 1: Can we rely on sweat chloride measurement?
Andrea Párniczky (Budapest, HU)
- 10.25 Case 2: Pseudo-Bartter with CF, or not?
Alexandra Kowalik (Stockholm, SE)
- 10.45 – Coffee break –**

Session 4: CFTR biomarkers - Does age matter?

Chairs: Kevin Southern (Liverpool, UK) – Natalia Cirilli (Ancona, IT)

- 11.15 Sweat testing in adults at the Brompton hospital
Nicholas Simmonds (London, UK)
- 11.35 NPD in the infant: ready for implementation?
Michael Wilschanski (Jerusalem, IL)
- 11.55 Age-dependency of CFTR function in the rectal tissue
Simon Gräber (Berlin, DE)
- 12.15 The joint efforts of DNWG and ECFS-Education committee
Chris Smith (Brighton, UK)
- 12.40 New DNWG-project: sharing plans and ideas
Sweat test project (led by the moderators)
- 13.00 – Lunch break & group picture –**

Session 5: CFTR-genetic session part 1

Chairs: Karen Raraigh (Baltimore, US) – Emmanuelle Girodon (Paris, FR)

- 14.00 Leaving no one behind: International CFTR-genotyping
Milan Macek (Prague, CZ)
- 14.30 ECFS-DNWG-diagnostic forum: How?
Elke De Wachter (Brussels, BE)
- 14.50 Case 3: Whole genome sequencing can be full of surprises
Caroline Raynal (Montpellier, FR)
- 15.10 Case 4: Positive sweat test: it may not be CF
Emmanuelle Girodon (Paris, FR)
- 15.30 Case 5: CFTR-RD - not always a mild disease: follow-up
Peter Middleton (Sidney, AU)
- 15.50 – Coffee break –**

Session 6: Key Note Lecture (CFTR-genetic session part 2)

Chairs: Milan Macek (Prague, CZ) – Caroline Raynal (Montpellier, FR)

- 16.20 Key note lecture: Expanding CFTR2: Why? How? What's next?
Karen Raraigh (Baltimore, US)
- 17.20 Wrap-up of Day 2**
- Wrap-up and plans for the evening by Elke De Wachter (Brussels, Belgium)
- 17.30 – End of Day 2 –**

Evening program day 2

18.00: Bus pick-up at the meeting venue (in front of Basic-Fit fitness, next to the university)
18.30: Social evening program; afterward, transport is arranged to the restaurant: *Restaurant La Taverne de Passage* (Galerie de la Reine 30, 1000 Brussels)

Session 7: Exploring theratyping from different perspectives

Chairs: Isabelle Sermet-Gaudelus (Paris, FR) – François Vermeulen (Leuven, BE)

- 09.00 The Italy Theratyping program using nasal epithelial cells
Nicoletta Pedemonte (Genoa, IT)
- 09.30 The Berlin Theratyping program
Mirjam Stalh (Berlin, DE)
- 10.00 Theratyping with the use of intestinal organoids: the Utrecht experience
Sacha Spelier (Utrecht, NL)
- 10.30 The French Theratyping program: from compassionate use to new therapeutics
Isabelle Sermet-Gaudelus (Paris, FR)
- 11.00 – Coffee break –**

Session 8: CFTR- biomarkers with/without CFTR-modulator therapy

Chairs: Jane Davies (London, UK) – Peter Middleton (Sydney, AU)

- 11.30 The impact of CFTR-modulator therapy on the new sweat test report form
Natalia Cirilli (Ancona, IT)
- 11.50 Effects of CFTR-modulator therapy in young children (2-6) on sweat chloride, ICM and NPD
Jasmin Berger (Berlin, DE)
- 12.10 Differences in NPD in two children, homozygous for p.Leu467Phe-p.Phe508del and reduced response to ETI
Katharina Schütz (Hannover, DE)
- 12.30 Enhancing the measurement of CFTR activity using artificial intelligence: introduction
Claudio Sorio (Verona, IT)
- 12.40 How to measure CFTR activity with the use of artificial intelligence?
Bogdan Mihai Maris (Verona, IT)
- 13.00 Wrap-up of the meeting**
Nicholas Simmonds (London, UK) and Elke De Wachter (Brussels, BE)
- 13.10 – End of meeting –**

The meeting is kindly supported by:

