



European Cystic Fibrosis Society Diagnostic Network Working Group

Coordinator: Nico Derichs
http://www.ecfs.eu/ecfs_dnwg



15th Annual Meeting, St. Gallen, Switzerland

8th – 10th February 2018

Organizing committee:

Jürg Barben, Children's Hospital of Eastern Switzerland, St. Gallen, Switzerland

Valerie Mühlbacher, ECFS DNWG Assistant, Charité University Berlin, Germany

Nico Derichs, ECFS DNWG Coordinator, Charité University Berlin, Germany

Scientific Program

Thursday 8 February 2018

13.30 Arrival and coffee

14.00 Welcome – Jürg Barben (St. Gallen, Switzerland)

Session 1: Newborn screening – looking over the precipice (Chairs: Kevin Southern, Karin De Winter)

14.10 Issues around IRT - Ralph Fingerhut (Zürich, Switzerland)

14.35 The Californian experience of newborn screening - Danieli B. Salinas (Los Angeles, California, USA)

15.00 The recognition of CFSPID is beneficial for families
PRO: Danieli B. Salinas (Los Angeles, California, USA)
CON: Sarah Mayell (Liverpool, UK)

15:30 Unclear/unresolved cases after newborn screening – Andreas Jung (Zürich, Switzerland)

15:50 Monitoring long-term outcomes for CFSPID: working together across Europe – Anne Munck (Paris, France)

16:15 - Coffee break -

Session 2: Current practice and challenges of diagnosing CF in ... (Chairs: Kris De Boeck, Valerie Mühlbacher)

16:45 Morocco – Amal Hassani (Rabat, Morocco)

17:00 Georgia – Tsitsino Parulava (Tbilisi, Georgia)

17:15 Macedonia – Dijana Plaseska-Karanfilska (Skopje, Macedonia)

17:30 Iceland – Olafur Thorvaldsson (Reykjavik, Iceland) **TBC**

18:00 - Evening programme -

Friday 9 February 2018

Session 3: Taking sweat testing to the next level

(Chairs: Nico Derichs, François Vermeulen)

9.00 The new CLSI sweat test guidelines – Vicky LeGrys (Chapel Hill, North Carolina, USA)

9:45 Sweat collection from two sites is essential to reduce QNS samples
PRO: Vicky LeGrys (Chapel Hill, North Carolina, USA)
CON: Kevin Southern (Liverpool, UK)

10.15 Is it time to unwrap the Nanoduct? – Jürg Barben (St. Gallen, Switzerland)

10.40 Learning to optimize structures after newborn screening: information pathways, sweat test, tracking - Olaf Sommerburg (Heidelberg, Germany)

11.00 - Coffee break -

11:30 Improving sweat test performance in Europe: development of new ECFS DNWG training resources - Natalia Cirilli (Ancona, Italy)

12:00 Discussion forum: Defining the DNWG Top 3 priorities for sweat testing in Europe (all)

12:30 Young Investigator 1 (NN)

12:45 Young Investigator 2 (NN)

13.00 - Lunch break & Group picture -

Session 4: Current and future CF diagnostic markers

(Chairs: Nick Simmonds, Silvia Gartner)

14:00 Update from the International (Global) CF Registry Group: designing future documentation of CF diagnosis and related phenotypes – Lutz Nährlich (Giessen, Germany)

14:25 Evaporimetry in atypical and Lumacaftor/Ivacaftor treated patients with CF - Thao Nguyen-Khoa (Paris, France)

14:50 ICM responsiveness to oral Lumacaftor/Ivacaftor treatment - Valerie Mühlbacher (Berlin, Germany)

15:10 Revisiting the diagnosis of CF-related diabetes: lessons from a multicentre study - Manfred Ballmann (Rostock, Germany)

15:30 Young Investigator 3 (NN)

15:45 Young Investigator 4 (NN)

16:00 - Coffee break -

**Session 5: *CFTR* genotyping – options for the next generation
(Chairs: Carlo Castellani, Emmanuelle Girodon)**

16.30 How do you assess the historical and current *CFTR* genetic identity in your population? - Sabina Gallati (Berne, Switzerland)

16:55 The multi-faceted nature of *CFTR* mutations: impact on their functional classification - Caroline Raynal (Montpellier, France)

17:20 How do we get improved quality for genetic results? – Elke De Wachter (Brussels, Belgium)

17.45 - Evening programme -

Saturday 10 February 2018

Session 6: Intestinal organoids as (diagnostic) markers of CFTR function

(Chairs: Inez Bronsveld, Hugo De Jonge)

- 9:00 Are organoids an additional helpful technique for diagnosing CF? – Kris De Boeck (Leuven, Belgium)
- 9:30 Do organoids correlate with sweat tests and ICM? - Jeffrey Beekman (Utrecht, Netherlands)
- 10:00 Relation between intestinal organoids and respiratory CFTR function (NPD) - Paola Melotti (Verona, Italy)
- 10:30 Rescue of CFTR-dependent bicarbonate transport in CF organoids – Hugu De Jonge (Rotterdam, Netherlands)

11:00 - Coffee break -

Session 7: Functional and structural markers of CF lung disease

(Chairs: Jürg Barben, Jane Davies)

- 11:30 Multiple breath washout: ready for inclusion into registries? – Florian Singer (Zürich, Switzerland)
- 11:55 Airway mucus properties as a biomarker in lung disease – Kathryn Ramsey (Berne, Switzerland)
- 12:25 Respiratory rate and functional MRI in early CF lung disease – Philipp Latzin (Berne, Switzerland)
- 12:50 Discussion panel

13:00 - End of meeting -

The meeting is kindly supported by:



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