



ECFS Diagnostic Network Working Group Meeting Report

16th Annual Meeting Tunis, Tunisia - February, 14th - 16th 2019
Hotel Africa Tunis, Tunisia

Thursday, 14th February 2019
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At 13:30 all participants of the 16th Annual ECFS DNWG Meeting arrived at Hotel Africa, Tunis, Tunisia. At 14:00 the meeting started with Samia Hamouda's and Nico Derichs' welcome words to all members of the ECFS Diagnostic Network Working Group and participants of the 16th annual ECFS DNWG meeting.

Session 1: Focus on CF in Tunisia

(Chair: Samia Hamouda)

The first presentation on the first meeting day was held by the host herself, Samia Hamouda (Tunis, Tunisia), about evolution of CF features in Tunisia in the first decades of this millenium. She reported that there had been improvements of CF care in regard of diagnosis and therapy, but in Tunisia there was definitely the need for CF care guidelines. Afterwards Sondess Hadj Frej (Tunis, Tunisia) talked about the implication of modifier genes in clinical variability of CF. She gave an insight into the situation in Tunisia, where CF prevalence is not really known and where is a wide spectrum of CF genetics. Samia Hamouda followed with her talk about improvements in CF care that could be made within the next years, which included the establishment of national CF registry, annual patient check ups/follow-up booklets, inventing CF care guidelines.

Session 2: Current practice and challenges of diagnosing CF in ...

(Chair: Valerie Mühlbacher)

The second session was opened by Warda Drali (Algier, Algeria) who gave an overview about the situation of CF diagnosing and the difficulties in CF care in Algeria. Walaa Shahin (Cairo, Egypt) discussed the CF patients population in Egypt as well as the aspect of clinical care and the variation of CFTR genotypes in CF patients. Following Atqah Abdul Wahab (Doha, Qatar) spoke about CFTR mutations in Qatar, as well as clinical care and CF centers in Doha. Samia Hamouda closed the last session on this meeting day.

Friday, 15th February 2019
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Session 3: Revisiting the diagnostic features of CF – clinical opportunities and pitfalls

(Chair: Elke De Wachter)

The second meeting day started with a presentation about a basic topic in CF care: CF symptoms by Nico Derichs (Hannover, Germany). Followed by the presentation about CF Family history by Jane Davies (London, UK). Anne Munck continued with a talk about CF newborn screening.

The discussion was very intense and fruitful as the participants considered this subject as very important to rethink regularly. The discussion led the group “back to the roots” of CF diagnosis and care.

Session 4: What have we learned from functional CFTR assays?

(Chair: Nick Simmonds)

George Marty Solomon (Birmingham, USA) started the 4th session of this year’s meeting with his talk about CFTR function in the respiratory epithelium: nasal PD and nasal epithelial cells. Isabelle Sermet-Gaudelus (Paris, France) followed with a presentation on variability on nasal PD measurements. Hugo De Jonge (Rotterdam, Netherlands) talked about CFTR assay in intestinal organoids and biopsies and what lessons we learned from comparative measurements.

Session 5: ECFS DNWG position papers on CFTR function

(Chair: Nico Derichs)

Session 5 started with a short overview about improving the sweat test performance in Europe by Nico Derichs (Hannover, Germany) in representation of Natalia Cirilli (Ancona, Italy).

Afterwards Inez Bronsveld (Utrecht, Netherlands) presented nasal potential difference measurement (NPD) as a diagnostic marker of CFTR function, cut-off values and results of an European NPD survey. Nico Derichs (Hannover, Germany) talked about intestinal current measurements (ICM) as a marker of CFTR function and presented the results of the European ICM multicenter validation study.

Session 6: The future of ECFS: young blood and sweat for the Society

(Chair: Paola Melotti)

Following, the first of this year's five Young Investigators presented his work: Pavol Ďurč (Brno, Czech Republic) presented his work on skin wipe sweat sampling and analysis as a new method of modern sweat test. In his talk, he gave new insights into the method's development. The second Young Investigator Audrey Reynaerts (Brussels, Belgium) informed about non-invasive image-controlled β -adrenergic sweat test by iontophoresis. Afterwards Karina Kleinfelder (Verona, Italy) as the meeting's third Young Investigator discussed the preliminary evaluation of CFTR Corrector/Potentiator in Phe508del homozygous CF patients by Ratiometric sweat secretion optical (RSSO) test. Talking about the development of the rectal organoid morphology analysis (ROMA) as a diagnostic test for CF, Senne Cuyx (Leuven, Belgium) - fourth Young Investigator - provided an insight into the big research field of organoids in CF research. The fifth Young Investigator, Magdalena Postek (Warsaw, Poland), talked about, differentiation in the Lung Clearance Index connected with the microbiological status in children with CF.

After the talks, Nico Derichs congratulated all Young Investigators in a Young Investigator ceremony.

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Session 7: Celebrating 30 years of CFTR genotyping

(Chair: Caroline Raynal)

The last meeting day started with the presentation of Emmanuelle Girodon (Paris, France), who discussed the penetrance as a parameter for assessing the disease liability of variants from a critical point of view. Following Caroline Raynal (Montpellier, France) presented the phenotypic spectrum and functional characterization of recurrent deep intronic disease-causing variants in the CFTR gene. As the last presentation of session 7, Emmanuelle Girodon gave an insight into the survey on genetic counselling practices in France.

Session 8: Interaction between ECFS DNWG and other ECFS Projects and Groups

(Chair: Nico Derichs)

Daniel Peckham (Leeds, UK) talked about devices, toolkits and homepage links which can be reached through the ECFS homepage and about possibilities to access CF education easily.

Following, Anne Munck (Paris, France) gave a talk about the ECFS newborn screening working group, its work and aims.

Finally, Nico Derichs (Hannover, Germany) summarized the meeting and gave an overview about the current and future DNWG projects and collaborations. He as well informed about the upcoming handover of the ECFS DNWG to a new working group coordinator at the ECFS conference in Liverpool.

He thanked the host – Samia Hamouda - for the great organisation of this meeting and closed the ECFS DNWG Meeting 2019.

We thank all speakers and participants for their fantastic contribution to make the 16th Annual ECFS Diagnostic Network Working Group Meeting a great success!

We are looking forward to meeting you at our next ECFS DNWG Meeting in 2020.

26st March, 2019

Valerie Mühlbacher – ECFS DNWG Assistant

Nico Derichs – ECFS DNWG Coordinator



ECFS DNWG Young Investigators 2019

left to right: Pavol Ďurč (Brno, Czech Republic), Senne Cuyx (Leuven, Belgium), Magdalena Postek (Warsaw, Poland), Audrey Reynaerts (Brussels, Belgium), Karina Kleinfelder (Verona, Italy).

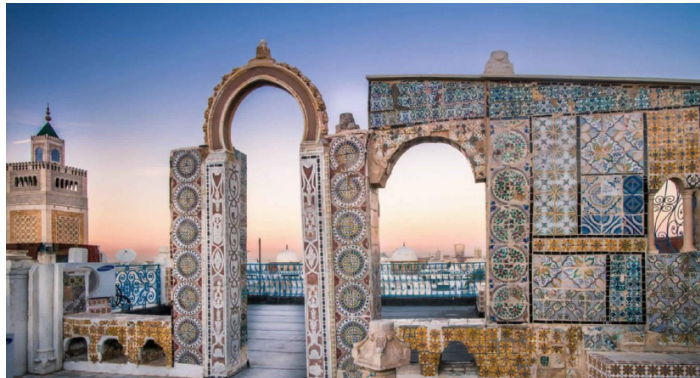


ECFS Diagnostic Network Working Group, Tunis 2019



European Cystic Fibrosis Society Diagnostic Network Working Group

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



16th Annual Meeting, Tunis, Tunisia

14-16 February 2019

Organizing committee:

Samia Hamouda, Bechir Hamza Children's Hospital of Tunis, Tunisia
Valerie Mühlbacher, ECFS DNWG Assistant, Berlin, Germany
Nico Derichs, ECFS DNWG Coordinator, Hannover, Germany

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