

# 20<sup>th</sup> Scientific Meeting *online*

## CF Registry: Ready for science!? - Value of registry data to improve CF care

- Date** 9<sup>th</sup>-10<sup>th</sup> September 2021
- Chairs** Lutz Nährlich (DE/Gießen) / Carsten Schwarz (DE/Potsdam)
- Registration** You can register on [www.muko.info/sciem](http://www.muko.info/sciem).

### Preliminary schedule

Thursday, September 9 <sup>th</sup>		Friday, September 10 <sup>th</sup>	
12:30 pm	Opening of the meeting	8:00-1:15 pm	Sessions/Discussions
12:45-18:00 pm	Sessions/Discussions	1:30 pm	Closing of the meeting

### Planned topics/speakers

#### Data structure and quality

- > Rebecca Cosgriff (UK/London) - Annual Review or Encounter data in CF Registries – which is best? *confirmed*
- > Ed McKone (IR/Dublin) - Harmonization

#### Analytic strategies

- > Ruth Keogh (UK/London) - Survival analysis *confirmed*
- > Daniela Schlüter (UK/Liverpool) - Longitudinal analysis *confirmed*

#### Lessons learned from other disease areas

- > Friederike Erdmann (DE/Mainz) - German Childhood Cancer Registry *confirmed*
- > Staffan Lindblad (SW/Stockholm) - Swedish Rheumatology Quality Registry *confirmed*

#### Focus on the patient

- > Siobhán Carr (UK/London) - Patient Report Outcome *confirmed*
- > NN - PROM and Real Life data project under CFE involvement

#### Pharmacovigilance

- > Beate Wieseler (DE/Köln) - HTA perspective *confirmed*
- > Xavier Kurz (NL/Amsterdam) - EMA perspective *confirmed*
- > Tim Friede (DE/Göttingen) - Statistical perspective *confirmed*

#### Study design

- > Kevin Southern (UK/Liverpool) - CF-Start a randomized registry study *confirmed*
- > André Schultz (AU/Nedlands) - BEAT-CF - a adaptive platform trial *confirmed*

#### Keynote

- > Bruce Marshall (US/Bethesda) *confirmed*

The Meeting is supported by the DFG (Deutsche Forschungsgemeinschaft) and sponsored by:

