

Morning Session – Optimization of programmes

chaired by Kevin Southern & Silvia Gartner

- 09.30 Teas and coffees served
- 10.00 Welcome & Introduction
Jürg Barben, Chair ECFS NSWG (St. Gallen, Switzerland)
- 10.10 Optimization of performance of the Polish programme using extended gene analysis
Dorota Sands (Warsaw, Poland)
- 10.40 Improving the performance of the Dutch newborn screening programme
Karin de Winter-de-Groot (Utrecht, Netherlands)
- 11.10 Cystic Fibrosis newborn screening in Switzerland – Evaluation and scenarios for improvement
Corina Ruegg & Jürg Barben (Oslo, Norway & St. Gallen Switzerland)
- 11.40 Outcome data from 15 years of CF NBS in a large UK region
Francis Gilchrist (Stoke on Trent, UK)
- 12:00 Lunch (provided)

Afternoon Session – CRMS/CFSPID dilemmas

chaired by Jürg Barben & Olaf Sommerburg

- 13:00 CRMS/CFSPID outcomes up to 9-10 years of age in the US CFF Patient Registry
Clement Ren (Philadelphia, USA)
- 13.30 Children designated with CRMS/CFSPID whose sweat Cl goes ≥ 60 mmol/L have a diagnosis of CF regardless of symptoms
PRO diagnosis of CF: *Kevin Southern (Liverpool, UK)*
CON diagnosis of CF: *Carlo Castellani (Genoa, Italy)*
- 14:00 European CFSPID-Registry – potential for quality improvement
Andreas Jung (Zürich, Switzerland) & Egil Bakkeheim (Oslo, Norway)
- 14:25 For children with a CFSPID designation, can characterisation of CFTR variants help determine the risk for a CFTR related disorder?
Caroline Raynal (Montpellier, France)
- 14.50 Discussion
- 15:00 Finish

Registration for the meeting is required - please contact Jürg Barben at juerg.barben@kispisq.ch