



EuroCareCF



## **Cystic Fibrosis Neonatal Screening in Europe: Management, Development, Research**

### Partners

European Cystic Fibrosis Society

EuroCareCF

International Society for Neonatal Screening

EuroGenTest

European Molecular Genetics Quality Network

### Location

Garda lake, Italy ([www.poiano.com](http://www.poiano.com))

### Time

28-29 March 2008

### Aim

Production of European Best Practice Guidelines for CF Neonatal Screening

## **STRUCTURE** (*Confirmed participants* **Group leaders**)

- A. The rationale for CF Neonatal Screening
- Effects of early diagnosis on the clinical outcome
  - Pros and Cons of CF Neonatal Screening
  - Costs

**Jeanette Dankert Roelse** NL

**Anil Mehta** UK

Frank Accurso USA

Isabelle de Monestrol SW

Kevin Gaskin AUS

P Rizzotti I

Olaf Sommerburg GER

- B. Technical issues: IRT, mutation analysis, protocols
- IRT: sampling, testing, resampling
  - Optimization of IRT cut off levels
  - Pancreatitis Associated Protein (PAP)
  - Mutation analysis: testing on Guthrie cards, which mutations to test, which mutations not to test
  - Description of protocols and results
  - Is harmonization of protocols desirable and possible?

**Rodney Pollitt** UK

**Bridget Wilcken** AUS

Carlo Corbetta I

Claude Ferec F

Milan Macek CZECH REP

Marci Sontag USA

Georges Travert F

Toni Torresani CH

C. Diagnosis through CF Neonatal Screening

- Sweat test
- Diagnostic criteria for CF and CFTR-related disorders
- Management of carriers
- Follow-up of infants with CF

**Kevin Southern** UK

**Isabelle Sermet** F

Manfred Ballmann GER

Philip Farrell USA

Jutta Hammermann GER

Dorota Sands PL

Annette Vernooij NED

D. Information to families before, during and after CF Neonatal Screening

- General information on CF Neonatal Screening to couples during pregnancy and at birth
- Information at call for resampling and/or sweat test
- Information at diagnosis
- Information for carriers

**Anne Munck** F

**Keith Brownlee** UK

Michael Farrell USA

Maria Feilcke GER

Silvia Gartner SP

Nataliya Kashirskaya RUS

Alec Sammon F

E. Challenges ahead

- Update on current practice
- Establishing a European CF neonatal screening network
- Trials in screened infants

**Carlo Castellani** I

**David Sheppard** UK

*Gerard Loeber NED*

Stuart Elborn UK

Andreas Reimann GER

Gita Mehta UK

Alan Smyth UK

## **PRELIMINARY PROGRAMME**

*Friday March 28th*

13.00-14.30 Welcome lunch

14.30-14.45 Introduction - *Carlo Castellani*

14.30-16.30 Single groups discuss and finalize their work

16.30-17.00 Coffee break

17.00-18.30 Single groups prepare reports for Saturday

20.00-23.00 Dinner

*Saturday March 29th*

07.30-09.00 Breakfast

09.00-13.00 Morning session

09.00-09.30 Group A report - *Jeanette Dankert Roelse, Anil Mehta*

09.30-10.15 Discussion on group A report

10.15-10.45 Group B report - *Rodney Pollitt, Bridget Wilcken*

10.45-11.30 Discussion on group B report

11.30-11.45 Coffee break

11.45-12.15 Group C report - *Kevin Southern, Isabelle Sermet*

12.15-13.00 Discussion on group C report

13.00-14.30 Lunch

14.30-17.30 Afternoon session

14.30-15.00 Group D report - *Anne Munck, Keith Brownlee*

15.00-15.45 Discussion on group D report

15.45-16.00 Coffee break

16.00-16.30 Group E report - *Carlo Castellani, David Sheppard*

16.30-17.15 Discussion on group E report

17.15-17.30 Final remarks, conclusion of meeting – *Carlo Castellani*

18.00-24.00 Transfer to Verona, sightseeing walk, aperitive, dinner in a local restaurant, transfer to the hotel.

## **Participants**

|                            |                                       |
|----------------------------|---------------------------------------|
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We thank for their support:

