

# Expanded Newborn Screening Programme

Creating a European common model. The positive example of the Italian system.

**January 30, 2019 - From 9.30 to 12.30**  
Room A1E2, 1° floor Altiero Spinelli Building  
European Parliament - Place du Luxembourg, Bruxelles

## 9:30 • Opening Remarks

**Fabio Massimo Castaldo**, Vice-President of the European Parliament

## 9:45 • Newborn Screening Programmes in Europe

**Dott. Giancarlo la Marca**, Director of U.O. Newborn Screening, Biochemistry and Pharmacology laboratory, Meyer Children's University Hospital, Florence, President of Siemesn (Italian Society for Inborn Errors of Metabolism and Neonatal Screening), member of Coordination centre for the newborn screening (CCSN)

**Dott. Simone Boselli**, Eurordis, Public Affairs Director European and International Advocacy Eurordis

## 10:15 • The example of the Italian system

**Paola Taverna**, Vice-President of the Italian senate

**Leda Volpi**, Member of the Italian Chamber of Deputies

**Dott. Domenica Taruscio**, Director of the National Centre for Rare Diseases, member of the Coordination centre for the newborn screening at the National Institute for Health

**Manuela Vaccarotto**, Vice-President of AISMME, member of the Coordination centre for the newborn screening at the National Institute for Health

**Dott. Carlo Dionisi Vici**, Head of the Unit of Metabolic Disease, Department of Pediatric Medicine at the Bambino Gesù Children's Research Hospital in Rome, member of the Advisory Board "Osservatorio Screening Neonatale"

## 11:30 • Policy Roundtable

**Piernicola Pedicini**, Member of the European Parliament, M5S - EFDD Group

**Peter Liese**, Member of the European Parliament - EPP Group (TBC)

**Michèle Rivasi**, Member of the European Parliament - Group of the Greens/European Free Alliance

## 12:00 • Technical Roundtable

**Dott. Alberto Burlina**, Director of the Reference Centre Expanded Newborn Screening, University Hospital of Padova and member of the Coordination centre for the newborn screening at the National Institute for Health

**Stephan Schreck**, European Commission, Health programme and chronic diseases (TBC)

**Jim Bonham**, Vice-President/Treasurer (UK, European region) - International Society for Neonatal Screening (ISNS)

## 12:30 • Conclusion - Brunch

**Moderator: Ilaria Ciancaleoni Bartoli**, Director of the Rare Diseases Observatory



**HOSTED BY: FABIO MASSIMO CASTALDO**  
Vice-President of the European Parliament • Efd group



**GUEST: PAOLA TAVERNA**  
Vice-President of the Italian Senate

