



ROMANIA CLEFT

EUROPEAN
SCIENCE
FOUNDATION



EuroCleftNet
www.eurocleftnet.org



EUROPEAN CLEFT ORGANISATION
www.econline.org

Workshop on the early care of babies born with clefts
Evidence based nursing care is the key to a successful overall outcome
Bucharest, 15 – 16 October 2015

08.00 **Registration and coffee**

- 08.30 **Welcome and introduction** (10 min) Dr Radu Spataru, Surgeon, Children's Hospital, Bucharest
Housekeeping, countries represented, aim of day
- 08.40 **Introduction to European guidelines for the early management and care** (20 min)
Explore principles, different approaches, impact of guidelines on provision of services and use as research tool for comparing levels of care across countries. Gareth Davies, Executive Director, European Cleft Organisation
- 09.00 **What is the best care for parents whose children are diagnosed prenatally with a cleft lip and palate?** Nina Lindberg (15 min)
- 09.15 **Feeding a child with cleft lip and / or palate** (2 hours 30 minutes)
- *Normal Feeding – how babies feed and importance of feeding to mother and baby* Trisha Bannister (20 min)
 - *How different types of cleft affect feeding* Emma Southby (20 min) *Feeding assessment* Kostadinka Bojikova (20 min)

10.15 **Coffee**

- 10.30 **Feeding a child with cleft lip and / or palate** (continued)
- *Breast feeding and breast milk expression – Introduction and round table discussion of practices.* Nina Lindberg (20 min)
 - *Assisted Feeding.* Lisa Smedegaard (20 min)
 - *Feeding Equipment – discussion of different equipment used.* Emma Southby (20 min)
 - *Questions and discussion on feeding* (30 min)

(Panel: Emma Southby, Kostadinka Bojikova, Trisha Bannister, Lisa Smedegaard, Nina Lindberg)

12.00 **Impact of additional anomalies and life limiting conditions** (1 hour)

Pierre Robin Sequence (PRS) and other medical associated anomalies. Working with other specialties, where, who and how nursed. Trisha Bannister

13.00	Lunch
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Please reflect on topics brought up during morning session for interactive discussion during the afternoon

14.00 **Focus on research**

Importance of research, cultural perspectives, holistic care and support of the infant and the family

- *PRS and parental support. Karine Latter, Cleft Nurse Specialist Nottingham (30 min)*
- *Protocol - follow-up of parents with infants with cleft lip and palate. Nina Lindberg, Cleft Nurse Specialist, Oslo (15 min)*
- *Hospitalization, breast-milk feeding, and growth in infants with cleft palate and cleft lip and palate born in Denmark. Lisa Smedegaard, Cleft Nurse Specialist, Aarhus (15 min)*

15.00 **Role of the nurse in different countries** (1hour 30 minutes) Leader Emma Southby

Ideas for discussion: - hospital / Community / both, outline of key responsibilities, level of autonomy, part played in multi-disciplinary team, impact on treatment, development of service, difficulties encountered. Led by Emma Southby (Each country to present their model)

16.30	Coffee
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16.50 **Free papers** (8 x 7.5 minutes each – depending on number submitted)

- Kostadinka Bojikova *Development of Bulgarian Nurse Network*
- Karin Jeppesen *Post-operative nutrition/feeding and pain relief*
- *Others papers to follow*

17. 50 **Discussion and selection of topics for raising in open forum the following morning**

18.15 **Close**

FRIDAY 16th OCTOBER

8.30**Delivering cleft nursing care Europe-wide discussion: Panel Discussion (2.5 hours)**

- *Being heard, being noticed – having an impact in differing medical hierarchies*
- *Working within a wider model of cleft care, government strategies, preventative model*
- *Using patient and user groups to influence health care provision*
- *Research opportunities*
- *Facilitated discussion and setting of strategic milestones for next 3 years*

11.30/12.00 **Closing comments**