

Fendlipo

Issue 13 November 2015

Fendlipo means Cleft Lip in Esperanto*

Newsletter of the

 **European
Cleft
Organisation**

Cleft Nursing Workshop Bucharest

ECO has successfully organised the first ever European workshop in cleft nursing. The event, which took place in Bucharest, Romania, 15 – 16 October 2015, was a resounding success with more than 40 participants present from 17 countries including Bulgaria, Estonia, Poland, Romania, Slovenia, Ukraine, – and from Latin America (Brazil and Chile). Feedback has been excellent and there are lots of suggestions for the way forwards in cleft nursing including research studies and mutual support forums/networks.

The event had been possible thanks to generous support from the European Science Foundation through the EUROcleftNet programme.

The workshop provided an opportunity to define the nursing role and focus on specific areas of care including antenatal diagnosis,

feeding, support for the whole family and managing additional anomalies. The backdrop to the workshop was the recently finalised report from the European Committee for Standardisation setting out guidelines on early cleft care. These were summarised at the workshop and their potential as an audit tool for assessing service delivery was highlighted. There was a strong focus on research with papers on Pierre Robin

gates were all asked to present on their role in their own countries and a hands-on feeding equipment session allowed participants to see the wide range of feeding implements used across Europe.

Plans for the future include collaborative audit and potential research topics relating to the range of feeding equipment used, length of hospital stays, pain management and the scope of the 'nurse role' in different countries. The group was keen to remain in touch and a Facebook group for European cleft nurses will be set up, linked to the European Cleft Nurses Special interest Group.



Nurses from all over Europe attended the ECO Nursing Workshop in Bucharest in October

Sequence, infant follow up protocols, breastmilk feeding and growth. There was a good range of free papers including an evaluation of the new Bulgarian nurse network, a study of post-operative feeding and pain relief, the development of an internal appliance to assist with feeding and an overview of another EUROcleftNet funded project, the lip tissue biobank (genetics research). Dele-

Nurse network in Bulgaria: making a difference

The network of Bulgarian cleft nurses—trained and funded by ECO and the national patient group ALA—is changing the face of early cleft care in Bulgaria. In the year to June 2015 the nurses intervened with 28 families who would otherwise not have had early cleft support. Within this num-

* The international language of Esperanto was created by L L Zamenhof in 1887. The goal was to create a politically neutral language that would serve as a universal second language to foster international understanding. ECO goes forward in the same spirit.

ber, six babies had already been sent to orphanages but three of these were subsequently reunited with their families and 2 were successfully adopted. In recent months the focus on training nurses has moved from a centralised model to going out to visit areas where they know there are high numbers of referrals to orphanages. Earlier this year two senior nurse trainers visited Russe and organised training for 34 local nurses and midwives from two hospitals and an orphanage. Feedback was very positive.

Serbia mission

ECO is pleased to announce an exploratory trip to Serbia mid November 2015. The visit, organised by orthodontist Dr Julija Radojic from Niš, will include meetings at cleft centres in Belgrade and Niš as well as a planned meeting with the Minister of Health. We will be introducing the subject of the new European early cleft care guidelines and looking at how these can be implemented in Serbia. We will also look at opportunities for training options and exchanges.

Workshop in Brussels - early cleft care

Following the approval by the European Committee for Standardisation (CEN) of the guidelines in early cleft care, a workshop is scheduled for March 2016 to look at implementation. This will be funded by the European Science Foundation through the EUROcleft-Net programme. The guidelines were an ECO initiative

and we were pleased to have input from Austria, Belgium, Bulgaria, Estonia, Finland, France, Germany, Lithuania, Spain, Romania and the UK. It is hoped representatives from these countries, and others, will join a high profile list of participants including MEPs, lobbyists, and health professionals at the Brussels meeting.

We are in discussion with CEN about free distribution of the guidelines which are currently only available from national standards agencies.



Colleagues from Turkey, UK, Sweden and Italy attend a meeting in (wet) Florence as part of the Erasmus + [When Looks Get in the Way](#) project

New Erasmus+ grant programme

ECO is delighted that it is now a partner in a third *Erasmus* + grant programme which will look at potential issues in school for children with clefts that might affect learning. The project will last for two years and kick off in Malmo, Sweden in December. The other *Erasmus* + projects are now half way through and are on target to deliver the educational materials promised. [Face Value](#) and [When Looks Get in the Way](#) focus on training within health professional and higher

education environments.

International Cleft meetings

The annual [Americian Cleft Palate Association](#) conference will take place in Atlanta, Georgia from 4 - 9 April 2016. [The Craniofacial Society of Great Britain and Ireland](#) will hold its annual congress from 20 - 22 April 2016. The bi-annual [Francophone Cleft Congress \(AFFF\)](#) will be in Lille, France 10 - 12 March 2016. The next European Craniofacial Congress will be in Utrecht, Netherlands in 2019. ECO is offer-

ing its support and proven expertise in the development of a European Cleft/ Craniofacial Association - a membership body of national craniofacial societies. [Please contact ECO if you would like us to publish details of any national and international meetings](#) organised by professional or lay organisations. Our newsletter and website reach a very

wide audience.

New website launch

During November ECO will launch its new website: www.ecoonline.org

Our work is only possible thanks to the generosity of our supporters.

YOU CAN HELP BY MAKING A DONATION using the link below:

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