

Fendlipo

Issue 15 April 2016

*Fendlipo means Cleft Lip in Esperanto**

Newsletter of the

 **European
Cleft
Organisation**

Early cleft care guidelines download available

The early cleft care guidelines approved by the European Committee for Standardisation (CEN) last year are now available as a free download from our website www.eurocleft.org

The document can now really become a blueprint for early cleft care around the world and will also provide ECO with a template for its training activities.

A workshop looking at implementation of the guidelines took place in Brussels in March this year (see below).

Guidelines launched in Brussels

An international workshop funded by the European Science Foundation (ESF) was organised at the European Committee for Standardisation (CEN) in Brussels on 21 March. The delegates comprised those who helped put the guidelines together as well as senior clinicians, academics, NGO leaders and government ministers from 13 coun-

tries. We were especially pleased to welcome Dr Vesna Knjeginjić, Assistant to the Minister (Public Health), Ministry of Health, Republic of Serbia, who spoke about plans to use our guidelines as a reference point in developing a national strategy for cleft care in Serbia. We have recently been working on projects in Serbia (see below) and it was gratifying to know we have the government's full support. Other



Dr Vesna Knjeginjić, Ministry of Health Republic of Serbia, addresses our meeting in Brussels

keynote speakers were Maitane Olabarria from CEN and Nicola Bedlington, Director of the European Patient Forum. The afternoon session focused on implementation and how we can get our guidelines adopted by governments, medical schools and healthcare providers. A full report is on our [website](http://www.eurocleft.org). We are keen to press ahead with an implementation

strategy and we plan to organise further meetings where we will look at practical steps that can be undertaken by delegates present at the Brussels meeting. We were due to take a delegation to the European Parliament the following day but the terrorist attacks prevented this happening. We will press for another date.

Training in Serbia

Further to our successful exploratory trip to Serbia in November 2015, we went ahead with training activities in February 2016. This included a workshop on the psychosocial aspects of cleft care (funded by ESF through the EUROcleftNet programme) as well as a training day for nurses and other 'front line' hospital staff who

are likely to come into contact with a baby born with a cleft. We hope during 2016 to be able to facilitate a round table discussion amongst cleft clinicians from different hospitals in Serbia to look at the adoption of a national strategy for cleft care, developing some common protocols.

** 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.*

Educating parents

A kick off meeting for a third Erasmus + EU funded project took place in Malmö, Sweden in early December and we are again partnering with some of our existing collaborators from projects [Face Value](#) and [When Looks Get in the Way](#). The new project (known as *IHEM—Innovative Health Education Module*) will aim to deliver a course that will enable NGOs and health professionals to help parents identify at an early stage any potential educational problems experienced by children born with clefts. ECO has already produced a report for this project based on survey data collected from health professionals across 14 countries and this will be available on the project website in due course.

Urgent - funding needed for nurse training

In the last newsletter we highlighted the network of Bulgarian cleft nurses—trained and funded by ECO—which is changing the face of early cleft care in Bulgaria. We also carried an article about the first ever meeting of European cleft nurses which we organized in Romania in October. At that meeting it was agreed that ECO must step up its training activities to ensure every baby born with a cleft in Europe receives the very best care. Even using volunteer trainers, training is expensive—a two day programme for 40 participants can cost more than €3000 taking into account travel, accommodation, venue hire and interpreters. We have ap-

plied for EU funding to develop a modular training course that can be rolled out over Europe but it is by no means certain we will be successful and even if we are, not all costs will be met. Please support our training activities in 2016 by making a [donation now!](#) If the link doesn't work log onto our website at www.europecleft.org and click the donate button.



Volunteer nurse trainers Emma Southby and Kostadinka Bojikova at the nurse training event in Nis, Serbia in February this year

Training - making a difference in Bulgaria

A repeat survey recently undertaken by the patient group ALA in Bulgaria has shown that there has been a significant improvement in the establishment of normal feeding of babies with clefts when compared to a survey done for UNICEF Bulgaria in 2009. The percentages of babies either being breastfed or fed

with a regular bottle had increased from 44 % to 64 % during this period. Inability to establish feeding and the consequent automatic insertion of naso-gastric tubes 10 years ago was cited as the main reason for babies ending up in orphanages. Indeed this is reflected in the fact that in 2009 as many as 40% of parents reported they had been advised to abandon their baby whereas in the recent survey this figure had dropped to 28%. Whilst we are pleased things are going in the right direction, much more needs to be done: more training, more information at point of diagnosis and, above all, the need for funding to make this happen.

ECO invited onto Scientific Faculty at Cleft World Congress

We are delighted to have been invited to be part of the Scientific Faculty at the 13 International Congress of Cleft Lip and Palate and Craniofacial Anomalies India in 2017. This prestigious congress takes place once every four years and brings together top clinicians from all over the world. Our Executive Director, Gareth Davies, will be co-chairing a preliminary one day session on the role of NGOs in global cleft care.

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

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

Web: www.europecleft.org

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