

Fendlipo

Issue 16 August 2016

*Fendlipo means Cleft Lip in Esperanto**

Newsletter of the
 European
Cleft
Organisation

Bulgarian government promises support

Our partners in Bulgaria have had a breakthrough in discussions with the health ministry. Deputy Minister of Health, Dr Persensky, has said that he will endorse the national dissemination of our Early Care Cleft Guidelines (see below) and integrate a national craniofacial electronic patient record system developed by our

partner team in Plovdiv into the Ministry's website and promote it as a national register. There has been ongoing dialogue with the Ministry over many years but there has been little evidence of active support on the side of the Government. We are hoping this marks a positive step towards improving resources for

cleft care in Bulgaria. The news comes shortly after ECO facilitated a meeting at the Bulgarian Standards Institute (BDS) in Sofia to discuss implementation of our guidelines in Bulgaria, Greece, Serbia and Spain, which received high profile TV coverage. The

meeting was a follow-up to a larger meeting in Brussels in March at the headquarters of the European Committee for Standardisation (CEN). The Early Care Cleft Guidelines drawn up by ECO were approved by CEN last year. They are available as a free download from our website www.europecleft.org. We hope to be able to organise another meeting in Brussels early next year.



Delegates from Spain, Bulgaria, Greece and Serbia meet to discuss implementation of our Early Care Cleft Guidelines

Gateway cleft directory multi language service

ECO's online directory providing details of cleft teams around Europe is in the process of being updated. The Gateway was funded by a grant from the European Science Foundation EUROcleftNet programme which is shortly winding down. Funds have been set aside within the programme for a final upgrade of

the site which will now be permanently managed by ECO. Among other developments we have an ambitious plan for a multi language search engine 'landing page'. In short this will mean that anyone typing 'cleft' in their own language into Google will arrive at a page (also in their language) providing information about cleft care in their country. We have come across many instances of new parents not

being aware there are good cleft facilities accessible in their area meaning that they sometimes travel hundreds of kilometres to a capital city, or even abroad, in order to search for good cleft care. It is hoped this new service, available in 25 languages, will

ensure families know where they can go in their own countries to get the right care and support.

Online courses available for health professionals and NGOs - Erasmus +

Thanks to two EU Erasmus + grant programmes ECO has been able to partner with other organisations in developing online training material focusing on the psychosocial issues

** 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.*

around disfiguring conditions. These programmes are now coming to an end and the course material is being finalised. You can see progress of both projects and download training material through their respective websites, [Face Value](#) and [When Looks Get in the Way](#). A third project is also underway (known as *IHEM—Innovative Health Education Module*) which aims 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.

Urgent - funding needed for nurse training (update)

It was agreed at the first ever meeting of European cleft nurses in Bucharest last October that ECO must step up its training activities to ensure every baby born with a cleft in Europe receives the very best care. To this end ECO has now appointed a Training Manager, initially on a one year contract, to coordinate and plan training. Emma Southby, cleft nurse specialist for the large South Thames Cleft Service in the UK has 17 years' senior cleft nursing experience and will be taking up post later in the year. We have applied for EU funding to develop a training course and ensure this new training post is sustainable but this has been turned down. We will reapply next spring but in the meantime we urgently need to raise funds. Please support our training activities by making a [donation now](#)! If the link doesn't work log onto

our website at www.eurocleft.org and click the donate button. Thank you!

Chennai 2017

We are delighted to have been invited to be part of the Scientific Faculty at the 13th International Congress of Cleft Lip and Palate and Craniofacial



ECO welcomes cleft nurse specialist Emma Southby, left, who will become ECO's Training Manager later in the year

Anomalies India in 2017. This prestigious congress takes place once every four years and brings together top clinicians from all over the world. Executive Director, Gareth Davies, will be co-chairing a one day session on the role of NGOs in global cleft care. We will be manning a display stall at the Congress which we will share with the Canadian charity Transforming Faces with whom we have worked closely in the past.

EUROcleftNet research conference, Dundee

ECO was pleased to take part in the EUROcleftNet conference in Dundee at the end of June: Genetics, Environment, Prevention. An impressive list of high level researchers from around the world participated in the event which marks the last funded event of the EUROcleftNet programme. It is hoped that collaborations will continue and relationships built over the last five years will lead to successful grant applicants within the European 2020 Horizon funding initiatives. A summary of the conference can be seen on their website

www.eurocleftnet.org.

ECO has been a key contributor to, and beneficiary of, EUROcleftNet. Of specific note has been funding for the Gateway project (see first page) and support for 3 major ECO-driven conferences: Plovdiv, 2013 - building bridges with Eastern Europe; Bucharest 2015-first European cleft nursing workshop; Brussels 2016 -high level meeting of users, ministers and practitioners looking at implementation of Early Cleft Care Guidelines. In addition, a high number of individuals working in our partner

projects have benefited from generous funding for educational trips and exchanges.

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.eurocleft.org

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