

Fendlipo

Issue 6 December 2013

Fendlipo means Cleft Lip in Esperanto*

Newsletter of the

European
Cleft
Organisation

East meets West— major cleft research conference in Bulgaria

A major research conference was held in Plovdiv, Bulgaria from 25 – 27 September. ECO was instrumental in planning the conference which was funded by the European Science Foundation through the EUROcleftNet programme.

The event was a great success and was very well received by the delegates from both Eastern and Western Europe. There were nearly 100 participants with a total of 25 countries represented, 12 from Eastern Europe. There were also delegates from Israel and the US.

This was a unique opportunity for scientists and clinicians from Central and Eastern Europe to exchange ideas with some of the best scientists and clinicians from Western Europe and beyond.

** 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.*

Meeting with parliament

The conference received wide publicity in Bulgaria and provided an opportunity for ECO and the cleft team in Plovdiv to meet with the Chairperson of the healthcare committee of the Bulgarian Parliament. The purpose of the meeting was to explain some of the difficulties around cleft care



Training nurses to feed babies with clefts in Spain

and research in Bulgaria and to try to push for the creation of 'expert centre/s' that would facilitate best practice cleft care, treatment and research. The proposal has been taken seriously and the next meeting will be with the Ministry of Health.

Appearance Matters

ECO is pleased to be represented on the Management Committee of a pan-European programme tackling dissatisfaction with ap-

pearance. More details here: COST1210

European guidelines in early cleft care

ECO has finally got the go ahead from the European Standards Agency (CEN) to develop a set of guidelines on the early care of babies born with clefts. The pro-

cess is being coordinated by the Austrian Standards Institute and the kick off meeting took place in Vienna in September. A first draft of the guidelines will be ready early in the new year and will be circulated for wide consultation. The aim is to provide an agreed blueprint for early cleft care for those

countries that currently have no national guidelines.

Training in Spain

Following an information meeting with the newly-established federation of Spanish patient support groups, we ran a pilot 'front-line' nurse/midwife training course in Bilbao in January 2013. The cleft team were keen to support this and have a long history of international collaboration. The two day course was run

by cleft nurse specialists from the UK and Bulgaria. In May ECO also participated in a family weekend in Burgos, run by the parent support group ASPANIF.

European Cleft Gateway www.gateway.ecoonline.org

The Gateway, funded by the European Science Foundation and hosted by ECO, is now online. We are continuing to build a directory of all the cleft services and cleft research projects in Europe which will be invaluable for patients and clinicians alike. If you know of a cleft centre not yet listed please let us know and we will ask them to complete the questionnaire on the home page of the site. In time we plan to create interactive forums for families and clinicians and develop a comprehensive online digital library.

New cleft nurse network launched going in Bulgaria

ECO has been involved in 'front line' nurse/midwife training in Bulgaria since 2008 and has developed and supported four courses which together have reached about 100 nurses/midwives. Last year we began to think in terms of creating a nurse network that would be available nationally, supervised and supported by a core group of three trained cleft nurses.

We are delighted that this new network is now up and running and being highly effective. There have already been two direct interventions preventing

abandonment of babies in orphanages - one of the primary aims of this project. The cost of the network is being met by ECO and the parent support group ALA. Evaluation of the service is important for future fundraising.



Orthodontist Radost Velikova in Bulgaria

Romania-Norway exchange awarded funding

Long standing links between the cleft teams in Bucharest and Oslo have resulted in some funding being awarded to enhance cleft care in Romania. The funds will be used for a teaching seminar in March which will include visitors from other countries in the region. There are also plans for a larger scale conference in the autumn. ECO hope to be represented at these events.

EUROcleftNet grants for short visits

Grants of up to €85 per day, and including travel costs, are now being considered by EUROcleftNet. Applicants should be working in the field of cleft

lip and palate and be affiliated to a hospital or research institute. The visit must involve a significant research element and take place at least two months ahead of the application. For further details send an email via the contact pages on the ECO website.

Photo project

Two professional photographers from Paris, Clément Reisky and Stéphane Simon, are working with us to document our work and raise awareness of the difficulties faced by children and clinicians working with cleft lip and palate in Eastern Europe. They

plan to publish a book and put on an exhibition, the proceeds of which will come to ECO. We are very grateful for their support. Watch this space!

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

PERHAPS YOU CAN HELP BY [MAKING A DONATION!](#)

Web: www.ECOonline.org
Tel: +31 (0) 1747875649

Marijndijk 43
2675 SX Honselerdijk
Netherlands