

Fendlipo

Issue 11 April 2015

*Fendlipo means Cleft Lip in Esperanto**

Newsletter of the

European
Cleft
Organisation

New early cleft care guidelines approved

ECO is pleased to announce that its initiative to develop a set of guidelines on early cleft care has been successfully accomplished. The report, published by the European Committee for Standardisation (CEN) in March was approved by an overwhelming majority of voting countries. This has been a long process, beginning in 2011 and along the way we have had input from Austria, Belgium, Bulgaria, Estonia, Finland, France, Germany, Lithuania, Spain, Romania and the UK. Gareth Davies, Executive Director of ECO and Chairman of CEN/TC 424 said:

"I am delighted we now have a set of guidelines on early cleft care, agreed at a European level."

** 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.*

These will be enormously helpful to those countries that do not have national guidelines in cleft care and we will be bringing this document to the attention of health ministries throughout Europe. It is in the interest of early cleft care that these guidelines are implemented."



Participants at the ECO training workshop in Vilnius receiving certificates

This document is available from the National Members (standards offices) of CEN in 33 European countries.

There is also a proposal to organise a European workshop looking at how these guidelines can be implemented. More details to follow.

Early cleft care workshop Bucharest October 15

This workshop, originally planned for June in Gothenburg, has now been rescheduled for October in Romania. The workshop will be aimed at health professionals responsible for the planning and coordination of early cleft care, in-

cluding feeding assessments, development of feeding plans and providing support to the family. The event is funded by the European Science Foundation through the EUROcleftNet programme and will be organised in collaboration with the Roman-

nian Cleft Association. Full details will be circulated shortly and updates will be posted on our [website](#).

Training in Latvia

Following successful training in Vilnius, Lithuania, in January (see photo) three members of the ECO board will be running a training programme in Riga, Latvia, mid-May. One of the days

will focus specifically on psychosocial issues around “looking different” and is funded by the European [COST 1210](#) programme. The second day will focus on early cleft care and nursing, with an emphasis on feeding and the role of the specialist cleft nurse. We are delighted to be joined by one of our trained nursing specialists from Bulgaria who will provide an overview of how a successful national cleft nurse network has been established in Bulgaria.

We also hope to meet with parents keen to set up their own support network and will be offering some guidance on how to get started.

Photo reportage project: update

We are pleased to report that the photo project aimed at raising our profile and generating funds is attracting interest.

Two professional photographers, Clément Reisky and Stéphane Simone from France and Switzerland, respectively, spent a week with our project partners in Bulgaria last October doing a photo and video reportage. They have now secured their first exhibition and are guests of honour at the Ingré photo festival, Orléans, beginning in November. All costs will be covered by the organisers. They will be publishing a photo

book which they plan to sell during the exhibition which should attract around 2000 visitors. We wish them luck and hope this will propel their work further - they have already caught the interest of the editor of one of France’s top professional photography magazines, *Competence Photo*.

EU project updates

The two Erasmus+ funded projects developing training programmes aimed at health pro-

the returns we got through the [European Cleft Gateway](#).

ECO presents at international congresses

ECO was pleased to have abstracts accepted at both the annual meeting of the Craniofacial Society of Great Britain and Ireland in London in April and also the upcoming European Cleft Congress to be held in Gothenburg in June. The latter will be a unique Europe-wide networking event.

Clefts: discrimination?

The European Patient Forum ([EPF](#)) is putting together a positioning paper on discrimination on the basis of health issues. ECO has been invited to provide a response to the paper and specifically we

would like to hear from anyone who feels they may have faced

discrimination at work or in education on account of having a cleft. Please contact Gareth Davies at gareth.davies@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:

Web: www.ECOonline.org

Tel: +31 (0) 174 643 979

Mariendijk 43
2675 SX Honselerdijk
Netherlands
ANBI: 817849427



One of the portraits taken by Stéphane Simone, part of the photo reportage project in Bulgaria

fessionals and NGOs are progressing well. It is a great privilege for ECO to be working with partners from all over Europe. We are on target with our project outputs and have produced two reports from the perspective of a European NGO looking at different attitudes to appearance and disfigurement across Europe and a survey examining how health professionals meet the needs of people who have appearance concerns. Thank you to everyone who assisted in this—and especially