

Fendlipo

Issue 14 December 2015

*Fendlipo means Cleft Lip in Esperanto**

Newsletter of the

 **European
Cleft
Organisation**

Early cleft care guidelines

The early cleft care guidelines approved by the European Committee for Standardisation (CEN) earlier in the year will soon hopefully be available as a free download from our website. We have been negotiating with CEN who hold the copyright and an agreement should be finalised in the new year. 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 these guidelines is scheduled to take place in Brussels on 21 March 2016.

This event is being funded by the European Science Foundation and will comprise delegates who helped to compile the guidelines as well as high level representatives from the EU Directorate-General for Health and the European Committee for Standardisation.

New website launched

ECO is delighted to announce the launch of our new website at www.europeancleft.org. This is a new address but our old ecoonline.org address will automatically redirect traffic to the new site. We hope to be able to update the site more regularly and to include blogs and video clips to keep everyone up to date with what is

the psychosocial aspects of cleft care 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 also hope to be able to facilitate a round table discussion amongst cleft clinicians from different hospitals in Serbia to discuss the adoption of a national strategy for cleft care and some common protocols.



Christmas in Malmö, Sweden, venue for the new Erasmus+ project meeting

Educating parents

A kick off meeting for a third Erasmus + EU funded project took place in Malmö, in 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 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. This new project will last for 2 years, like the other projects. All of these programmes increases our networking opportunities which is valuable.

going on. We would welcome any feedback or ideas for features on the new site. Thanks!

Serbia—follow up

Further to our successful exploratory trip to Serbia in November, we are now planning training activities for February 2016. This will include a workshop on

** 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.*

Christmas appeal: please support our training activities!

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. 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.

My story

Here is an extract from a series of stories written by families in Bulgaria who have had a child with a cleft. This story is taken from an account by Dani Markova. When her son was born 15 years ago the doctors separated him from her and tried to put him in care.

Now, when I look back, I realise that what I had considered a punishment had actually been an award. What I had thought was a shame was in

fact pride. What I had thought was a disaster turned out an oasis with fertile soil. We are faced with a social stigma that the affected child's mother has done something bad and now has to pay for her sin. I do not think so. We – the parents of children with a problem – have been chosen because we are strong enough to cope. It is necessary to find people like Dr Anastasov, the ALA people, [local support group] Gareth, Anton [European Cleft Organisation] and all our friends all over the world who will help us give the best of ourselves.



Donny telling his story at the European Parliament in 2012

What I want you to remember my story with is Donny's success and the fact that he is an artistic, emotional, curious and lively child who, very energetically but already showing the typical teenager resistance, is developing his potentials. He has diverse interests but his favourite occupation is music: he plays the piano, and he is also the soloist in a vocal group. His last award – the first prize in the Istoki competition in Moscow, was my biggest pride. He studies 2 languages: English and Russian, and is doing very well at school. Last year he won his place in a new school, he managed to find his position

among his new classmates and overcome both the ridicule and the isolation. Donny succeeded thanks to the cares of his family and the team headed by Prof. Anastasov. I found that doctor early on and we walked a long way step by step to put the child on the international stage. My boy is very happy; I am also happy because I am part of the Association which takes care of children and their families. Sometimes Donny wonders. I wonder, too. How is it possible for anyone, especially a medical specialist, to separate a baby from his or her mother in the 21st century? How is it possible for people to fail to understand simple things like a mother's love, or one's right to a normal life..?

Published with the kind permission of the Bulgarian patients' group, ALA. We plan to make the collection of stories available on our website.

SEASON'S GREETINGS AND BEST WISHES FOR 2016!

Gareth Davies

Executive Director

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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