

# Fendlipo

Issue 10 December 2014

Fendlipo means Cleft Lip in Esperanto\*

Newsletter of the

 European  
Cleft  
Organisation

## Early cleft care workshop Gothenburg 23 June 2015

ECO will be organising a workshop in the early care of babies born with clefts, to coincide with the European Craniofacial Congress in Gothenburg in June 2015. There had been plans to combine this with a patient conference but with the finalisation of our European guidelines on early cleft care a workshop to launch these recommendations seemed logical. Separate funding will be sought to develop our work with user groups over a longer period of time.

The workshop will be aimed at all those who are involved in managing the care of babies with clefts in the period after diagnosis and through the first year of life, including referral processes, establishment of feeding, parental support and care pathways. We are hoping to be able to offer

*\* 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.*

some bursary assisted places which will also include entry to the Craniofacial Congress. These places will be restricted to those wishing to attend from Europe's less wealthy countries. More details to follow.

## Work begins on psychosocial support training

Kick off meetings have now taken place for two EU



Aleksandra and Luka from Niš, Serbia

Erasmus+ funded projects - *Face Value* in the Netherlands in November and *When Looks Get in the Way* in Lithuania in October. We received some good publicity in the Netherlands prior to the launch of *Face Value* and our press release was taken up by an online news provider. In summary, *Face Value* is aimed at producing a short course for NGOs and front line health professionals which

will equip participants with the knowledge to deal with the psychosocial aspects of looking different. *When Looks Get in the Way* aims to develop a formal university module course (70 hours) for all health professionals going through their medical or health – oriented training. ECO's immediate task is to look at what is currently available in these areas Europe-wide and this is being undertaken by face to face interviews and questionnaires for each project respectively.

## Exploratory visit to Serbia and Macedonia

ECO plans to visit Serbia during the first half of the year to support efforts being made by orthodontist Dr Julija Radojičić to establish a major cleft centre in Niš and a national Serbian cleft association. We hope to be able to meet the Health Minister and to formally present them with our European recommendations on early cleft care.

Prof Slave Naumovski, cleft surgeon in Macedonia, has invited us to visit his centre in Skopje which we may

combine with the trip to Serbia. Our presence in the Balkans is expanding.

### ECO in the Baltic States

Our plans to run a weekend course in Vilnius, Lithuania, at the end of January 2015, were publicised in the last issue of Fendlipo. This was read by the cleft team in Riga, Latvia who have since approached us and asked us to run a similar course in Riga at the end of May. These courses will focus on:

- training in the psycho-social support needs of families
- training for nurses and midwives to provide feeding
- advice and support on how to set up a parent support group.



Participants at the COST conference in Sweden were treated to a traditional St Lucia procession and songs

### COST Conference Sweden December 2014

The COST Action tackling dissatisfaction with appearance ([COST1210](#)) held a major conference in Kristianstad, Sweden, in December. Around 160 delegates attended from all over Europe representing diverse fields, but with a predominance of psychologists. The papers were correspondingly varied and there was an acknowledgement that there was perhaps too much emphasis on methodology and the need to focus on evidence-

based interventions. On the second day there was more emphasis on outcomes and suggestions for practical, simple steps to effect change. During the second evening there was a meeting of cleft team representatives and members of EU-ROCleftNet – opportunities were explored for collaborative approaches for future fundraising via EUROCleftNet and COST. There was a large input from Eastern Europe with Bulgaria, Croatia, Latvia, Macedonia, Romania and Serbia represented. Meeting face to face will ensure that networks con-

tinue to grow and expand.

### Rotary Club support

ECO is delighted to have been nominated by a Rotary Club in the UK as one of their charities for 2015. Thornbury Rotary Club near Bristol has chosen ECO as one of two charities to benefit from a swimming marathon in February 2015. As a small charity we do not have the resources to organise large fundraising campaigns and we rely heavily on the generosity of individuals and charitable

foundations to continue our much-needed and expanding work. Thank you!

### Photo project

We are pleased to report that another project aimed at raising our profile and generating funds has now been successfully completed. Two professional photographers, Clément Reisky and Stéphane Simone from France and Switzerland, respectively, spent a week with our project partners in Bulgaria in October doing a photo and video reportage. The resulting material will be used in exhibitions and featured in a book and has already caught the eye of the editor of one of France's top professional photography magazines, *Competence Photo*.

***Thank you to everyone who has supported ECO during 2014. Seasons Greetings and best wishes to all in 2015!***

**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](http://www.ECOonline.org)  
Tel: +31 (0) 174 643 979

Mariendijk 43  
2675 SX Honselerdijk  
Netherlands  
ANBI: 817849427