

# Fendlipo

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*Fendlipo means Cleft Lip in Esperanto\**

Newsletter of the



## 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, including 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 Romanian Cleft Association. We welcome the participation of delegates from Eastern Europe - we are able to offer a limited number of bursaries towards travel costs. Please book early to ensure a place. Full details are available [here](#).

## Training in Latvia

We were pleased to be invited to Latvia in May to put on a specialist workshop in cleft nursing. This was a very successful event and we were joined by one of our trained nursing experts from Bulgaria who was also able to attend a parallel meeting of the [COST 1210](#) programme.



Speech therapist Maria Kazakova from Plovdiv who will benefit from an ESF funded visit to the cleft team in Bristol

The event was well promoted and attended (around 60 present) with the active support of the surgeon in addition to the two team orthodontists. We were also very pleased to be able to organise a two hour workshop for parents (around 30 present) and they have now set up a Facebook group and hope to organise some coordinated activities

in support of the work for the cleft team over the coming months. They are particularly keen to improve understanding and knowledge of clefts at maternity units.

## EUROcleftNet

The ESF-funded EUROcleftNet programme will be winding up in a year's time and the budget has been finalised for all proposed activities over the next 12 months. There is a focus on 5 major workshops covering aspects of treatment and prevention. ECO is the lead organiser in two of these - the nurse workshop

(above) and a workshop focusing on research and implementation of the recently published CEN early care guidelines. Also in the budget are allocations for the speech therapist and nurse from the Plovdiv team to spend some time training in the UK, together with further funds for continued development of the [Gateway](#). It is testimony to our collaboration with

*\* 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.*

EUROcleftNet that we are now actively forging links with more and more countries. It was EUROcleftNet that took clefts to the European Parliament at a key meeting in 2012 which paved the way for greater European collaboration.

### EU funding partnerships

We are delighted to learn that we are a partner in another successful Erasmus + funding application which will mean we will continue to build on existing working relationships with colleagues from the UK, Sweden Norway, Latvia, Bulgaria, Serbia and Turkey. The aim of the project is to improve the long-term outcomes in children with congenital anomalies by implementing an Innovative Health Educational Module for staff in health-care and NGO settings.

### Ukraine: surgeon seeks training opportunities

We have recently been in contact again with cleft surgeon Dmytri Luchynski from Kiev who attended the ECO Plovdiv conference in 2013. He has let us know that as a result of that conference they have revised their protocols around bone grafting. He is now looking for further training opportunities in Europe and we have suggested we possibly schedule a visit to Ukraine later this year to identify their needs and see in what ways we may help. We may be

able to find some funds through EUROcleftNet to enable him to seek a long term learning relationship with a cleft team elsewhere in Europe. If you are an experienced cleft surgeon and feel you might be able to 'host' Dr Luchynski and offer some training please contact [gareth.davies@econline.org](mailto:gareth.davies@econline.org)

### Bulgaria: survey update

In 2009 ECO and the Bulgarian patent's group ALA were asked by UNICEF Bulgaria to conduct a survey to find out what infor-



Colleagues from Serbia, Bulgaria, Turkey, Norway, Latvia, UK and Sweden (Erasmus+ [Face Value](#) training project)

mation parents were given about clefts at time of diagnosis. Alarmingly the results of the survey showed that nearly 40 % of parents were advised to leave their baby in care on the basis that 'they would not be able to look after them at home'. In most cases this advice was given by health professionals. Since 2009 ECO and ALA have been working hard to address this issue by running training programmes for nurses and front line health professionals. There is now a coordinated network of cleft nurses in the country, as well as

trained parent contacts which who are all readily contactable via the ALA website. In order to see whether we have been successful at addressing the abandonment issue ALA is now re-running the 2009 survey and the results will be published later in the year. Early signs are extremely promising.

### European Craniofacial Congress

The 4-yearly European Congress took place 24-27 June in Gothenburg, Sweden, with over 600 specialists from across Europe and beyond present. ECO was able to present a paper on the CEN early cleft care guidelines which we are striving to make available online. A new European health professional association-the European Cleft Palate and Craniofacial Association (ECPCA) was also launched at the meeting which will further aid European collaboration in cleft care.

### Thornbury Rotary, UK

We are very grateful to the club for raising over €4000 towards our work. Thank you!

**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)  
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