

Fendlipo

Issue 9 September 2014

Fendlipo means Cleft Lip in Esperanto*

Newsletter of the

European
Cleft
Organisation

ECO partners in two new EU grant programmes

ECO is delighted that two Erasmus+ grant applications in which ECO is a partner have been successful. *Face Value* and *When Looks Get in the Way* aim respectively at training within health professional and higher education environments. We will benefit financially from this but perhaps more importantly we are now partners in four EU-funded projects which gives us advantages for future funding applications. These latest grants will bring us into close contact with NGOs/health providers/educational establishments in Norway, Serbia, Turkey, Lithuania, Italy, Sweden and Latvia. The kick-off meeting for *When Looks Get in the Way* is in Klaipeda, Lithuania at the start of October and we have been asked to host the kick-off meeting

* 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.

for *Face Value* in the Hague at the start of November.

Romania hosts more international cleft meetings

ECO is pleased to report the continuing activities of RomaniaCleft, especially in developing dialogue with other countries on all aspects of cleft care. Roma-



Bulgarian parent group, ALA, celebrates a birthday

niaCleft, set up two years ago as Romania's first national multidisciplinary cleft association has been supported throughout by ECO and this year is hosting three international meetings. The March conference was already reported (issue 7) and a follow-up conference in Bucharest took place earlier this month, organised again by surgeon Radu Spataru and supported by the EEA Norway grants scheme. A large number of delegates

from the Oslo cleft team presented on all aspects of multidisciplinary care and we were pleased to note that there were delegates also from Bulgaria, Serbia, Ukraine and Poland in addition to a good local representation from Timisoara, Iasi, Craiova, Targu-Mures and Brasov. Another conference is now being organised in Timisoara in No-

vember with keynote speakers from India, the Netherlands, and Bulgaria. ECO will also be presenting. For more information contact Maria Corina Stanculescu of the organising committee stciulescucorina@yahoo.com

Cleft guidelines near completion

We are approaching the final stages of a process that started more than a year ago - to draw up a set of recommendations on early cleft care. There have been three meetings of our Technical Committee (CEN 424) with a lot of work in between. Comments have now been received on the final draft and we plan to present the document to CEN in Brussels by 23 October. It will then be finalised and translated before

being circulated for European voting. All being well we should have a finished document mid 2015. This will be an essential reference document that ECO can bring to the attention of health ministries in countries who currently have no national guidelines on cleft care.

Lithuania training

Dates have been agreed for a weekend training programme in Vilnius for January 2015. It will comprise:

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

We hope to build on, and adapt the same training model for use in other countries.

Craniofacial Congress supports ECO patient conference

We now have the endorsement of the organising committee of the 2015 European Craniofacial Congress to put on a patient focused conference/workshop during the Gothenburg Congress next June. We are looking at accommodation and venue options and will circulate a finalised date shortly. It is possible that CLAPA in the UK

may assist in the administration of the conference.

Bulgarian register puts patient first

The cleft team in Plovdiv have developed a register for facial anomalies which puts the patients in charge of their records. The patients (or their representatives) select the specialists they wish to have access to their personal data which is posted in different panels according to speciality. All selected specialists can add their notes and data (text, pictures,



Delegates from Belgium, Bulgaria, Estonia, Germany, Romania, Spain and the UK discuss European recommendations on early cleft care (Bulgarian Standards Institute BDS, April 2014)

video and PDF files) into the patient's "wall" in the Comment, Consultation and Therapy sections. The patient can add to the Comment section but only view the other sections. The register is uniquely 'patient centred' and the team hopes that it might be useful in other countries and for other pathologies. A paper describing the register has recently been submitted to the Cleft Palate Craniofacial Journal in the hope that if published the register will be brought to the attention of a wide audience of

potential users.

ECO exploratory trips for 2015

As a result of greater networking opportunities throughout 2014, ECO is being invited to more and more countries. Plans for 2015 include visits to Ukraine, Serbia, Greece, Macedonia and Slovakia.

Photo project

We are continuing to support two photographers from Paris and Geneva who will be promoting our work with a photo reportage in Bulgaria during October. Plans are nearly finalised and they will be meeting families, attending clinics, visiting wards and hope to also have access to an orphanage. Proceeds from exhibitions and sales will come to ECO.

The photographers need funds to finalise the project and if you want to help them you can visit the website:

www.bulgarie2014.com

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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