

Fendlipo

Issue 5 December 2012

Fendlipo means Cleft Lip in Esperanto*

Newsletter of the

 **European
Cleft
Organisation**

New cleft nurse network gets go ahead in Bulgaria

ECO has been involved in 'front line' nurse/midwife training in Bulgaria since 2008 and has developed and supported four courses which together have reached about 100 nurses/midwives. This year we began to think in terms of creating a nurse network that would be available nationally, supervised and supported by a core group of three trained cleft nurses.

Further training and a framework for supervision needs to be put place but we plan to launch the scheme in April 2013. The aim is to create a sustainable network which will in part support itself but will be brought together at least once a year for refresher training and supervision. It will be funded jointly by ECO and the Bulgarian patient organisation, ALA.

Foundation of first national cleft association in Romania

ECO Chief Executive Gareth Davies was in Romania in November to witness the launch of a new national multidisciplinary cleft association. This is something we have been striving towards for the past three years and we are delighted



that this initiative has been taken by clinicians in Romania. Founding members include representatives from three different cleft units which will encourage dialogue between them. It is hoped representatives from other centres will join up soon. The association, RomaniaCleft, was launched at a surgical training weekend organised by cleft surgeon, Dr Radu Spataru. A visiting team from Stockholm, Sweden, headed by Prof Jan Lilja, provided

hands-on training in techniques for pharyngoplasty. In future it is hoped that RomaniaCleft will host a range of training opportunities across all disciplines and will be the main instigator of the development of national protocols for registration and treatment of clefts.

European guidelines on early cleft care

ECO's proposal to develop agreed guidelines in early cleft care via the European standards agency in Brussels (CEN) continues to draw support but is still facing opposition by some countries who believe such a

plan would conflict with national health policy. Our aim is to get an agreed blueprint in place for early cleft care which can be used as a model in those countries that currently have no national protocols in place. However, it seems we have more lobbying and discussions ahead of us before we can launch a further proposal. We want to try to get broad consensus on the overall concept before we focus on the details.

* 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.

ECO takes cleft care to the European Parliament

In October ECO took the floor at the European Parliament along with representatives from eight other organisations to get across to MEPs the huge discrepancies in cleft care across Europe. Having had this opportunity we now need to capitalise and maximise the benefits. Our strategy is to get the message transmitted from MEPs to officials in EU grant-making departments, with a view to having cleft lip and palate and other birth defects placed on the European Framework programme agenda in 2014 through the Horizon 2020 initiative. We were grateful to have had this opportunity thanks to the support of Seán Kelly, MEP and EUROcleftNet.

ECO launches training in Spain

Following an information meeting with the newly-established federation of Spanish patient support groups, we have agreed to run a pilot 'front-line' nurse/midwife training course in Bilbao in January 2013. The cleft team are keen to support this and in fact have a long history of international collaboration in multidisciplinary cleft care. The European Craniofacial Congress was hosted by Bilbao in 2007. We plan to take the course to other cleft centres in Spain. We learned during our talks with

parent groups that mothers often feel isolated at time of diagnosis (pre- or post-natal) and that referral systems to experts are not always in place leading to misinformation and subsequent distress. The training will address these issues and will be facilitated by specialist cleft nurses from the UK and from Bulgaria.



Talking clefts at the European Parliament

Research conference 25–27 September 2013 Plovdiv, Bulgaria

We are delighted that our partners in Bulgaria have been selected by EUROcleftNet to run this key conference. **Plovdiv 2013** will showcase current research into aetiology, prevention and improved treatment outcomes. This conference, supported by the European Science Foundation and the World Health Organisation, will provide a unique platform, bringing together clinicians, academics and representatives from industry to explore future research collaborations and discuss how knowledge can be translated into action for the benefits of the patient, their families and society. The conference website will be online early in 2013 and a call

for abstracts will be sent out by the end of January, along with online registration details.

Psychosocial support training

ECO is linking up with the Centre for Appearance Research at the University of the West of England in Bristol, UK, to seek funding for a collaborative vocational training programme aimed at enhancing support given by health professionals to families who have a child born with a cleft. This programme will add another dimension to our strategies towards the prevention of abandonment of children with clefts in some European countries.

ECO recruits new patient group representative

We are pleased to announce that Jana Angelova, president of the Bulgarian patient group, ALA, is now a board member of ECO. We hope her appointment will ensure that user-led perspectives remain an important focus for ECO. We say a fond farewell to Mariette Vermeulen-Nuyts, head of the Belgian patient group, VAGA, who has been with us since the start in 2008. Thank you.

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