

Fendlipo

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Fendlipo means Cleft Lip in Esperanto*

Newsletter of the
European
Cleft
Organisation

We need your help !

ECO has been working in Bulgaria since 2009. Our priority is to try to reduce the number of babies being referred to orphanages and ensure families have the necessary support to enable their children to thrive in their growing years. Only surgery is covered by state funding – all the other key aspects of multi-disciplinary care have to be organised and financed through funding from charitable sources in Bulgaria and abroad. As a result of our training programmes, held jointly with local cleft charity ALA, the number of parents being advised to send their newborn to an orphanage went down from nearly 40% in 2010 to 27% in 2016. To reduce this further ECO is seeking funding to continue running a national pilot nurse network to provide hands on support to every family with a new baby born with a cleft in Bulgaria. The network has been running for two

years and has helped 147 babies and their families. However, with limited funding the future of the network is uncertain.

Please help us to continue funding the network— for as little as €36 (£32) we can ensure a specialist nurse is available to support a new baby and their

up some long term projects in Slovenia to support the development of cleft nursing care and a parent support network. There is a core group of parents really committed to supporting new parents, putting together information packs and developing fundraising activities to support the work of the cleft service. Our visit was at the request of the cleft team led by surgeon Andreja Eberlinc and orthodontist Martina Drevensek. We were grateful for their warm hospitality during our trip. We will be making concrete proposals for future training and support early in 2018.



ECO meeting with parents in Ljubljana, Slovenia, October 2017

family, putting a stop to babies with clefts being sent to orphanages. For ever. [Donate now by clicking this link](#) or by visiting our website at www.europeancleft.org. Thanks for your help.

Workshops in Slovenia

In October ECO ran a series of workshops on cleft nursing, psychosocial support and parent group activities, in Ljubljana, Slovenia. We plan to set

ECO in Greece

Following a successful preliminary visit to Greece a year ago, ECO and partners from Bulgaria and Romania contributed to a two day cleft congress in Thessalonki at the end of September. The event was coordinated by paediatric dentist Katerina Kovelenti who has been trying to establish international links to enhance the development of cleft services in Greece. The key theme of the congress was the importance

** 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.*

of a multidisciplinary approach to cleft care. Keynote speakers included Emma Southby and Martin Persson from ECO and Youri Anastassov and Radu Spataru, cleft surgeons from Bulgaria and Romania, respectively. Our links with Greece will be cemented, and training opportunities increased, as a result of the fact the cleft hospital in Thessaloniki is now a partner in two new EU-funded programmes coordinated by ECO (see below)

New European project partnerships

ECO is partnering in two new EU Erasmus+ funded programmes developing training that will enhance patient care across a wide age group. We are coordinating a new cleft nurse training project *Early Care Training Programme (ECTP)* which kicked off in

the Netherlands at the end of September. The aim of the two year project is to provide a comprehensive short training programme in cleft nursing that can be made available online and easily adapted for different settings. Our partners include Romania, Norway, Greece, Bulgaria, Latvia and Lithuania. First outputs – the results of national surveys illustrating current knowledge of early cleft care, will be discussed at the next meeting in Vilnius at the end of February. The other Erasmus + award, *Cutting Edge Training (CET)* kicked off in November and is being coordinated by the

University of Kristianstad in Sweden. CET will examine patient expectations of surgical outcomes and, through the development of a training programme, will make surgeons and other team members more aware of the psychosocial aspects of surgery and whether it will deliver what the patient hopes for. Other partners in this two year project are Norway, Romania, Bulgaria and the UK.

Action to ensure better cleft care for all

ECO has won a major EU grant to help it drive better cleft care



Partners from Norway, Romania, Bulgaria, Latvia and Greece attend the kick off meeting of the new Early Care Training project

across Europe. The COST Action grant (European Cooperation in Science and Technology) aims to ensure that children born with clefts and other craniofacial conditions receive optimum multidisciplinary care. This Action will coordinate and increase research across Europe and will forge crucial links between researchers, practitioners and policymakers, offering the potential for significant benefits to the families affected by clefts and other craniofacial conditions in Europe. The four-year Action was formally launched in Brussels at the start of October 2017. The first full meeting of

members will take place in Zagreb at the end of January 2018. Twenty two countries have so far signed up, including many from Eastern Europe. The Action Chair is ECO board member, Martin Persson. Full details appear on the [COST website](#)

Cleft guidelines, going global

In, 2015 ECO achieved its mission of developing a set of guidelines in early cleft care, agreed at a European level. You can download the guidelines [here](#).

Building on this, we have now been asked to coordinate the development of a global set of guidelines for use by international NGOs working in cleft care. These will focus on both long term sustainable cleft programmes and also on short term mission activities. We are leading a team comprising representa-

tives from the American Cleft Palate Association (ACPA) Global Smile Foundation, Smile Train, Operation Smile, and Transforming Faces.

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.europecleft.org

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