

Fendlipo

Issue 18 April 2017

*Fendlipo means Cleft Lip in Esperanto**

Newsletter of the
 European
Cleft
Organisation

ECO heads up new global cleft coalition

ECO was asked to take a leading role at the International Cleft Congress in Chennai, India in February, putting together an event attended by the world's major NGOs working in cleft care. Gareth Davies, Executive Director of ECO, co-chaired the day with

Esteban Laso (formerly of Transforming Faces) which featured presentations from specialists from India and around the globe. The overriding message was that NGOs should work together, sharing good practice and knowledge, to prevent malpractice

and ensure all babies born with clefts receive not only the best surgical care but also the full range of multidisciplinary treatment needed to enable them to reach their full potential in life. At the end of the event it was agreed that ECO would head up a global collaborative body that will

look at NGO models of cleft care, focusing on good ethical practice. The new collaboration will be known as the World Cleft Coalition - *A global community of NGOs working for the promotion of core principles in cleft care in all parts of the world.* Organisations which have shown an interest in participating include major international players in cleft care such as Operations

pleased to attract interest from around the world in its new [Cleft Gateway](#) web resource which is currently being redeveloped. We are nearly ready to launch an upgraded version where families and healthcare professionals will be able to use an interactive map to see where their nearest cleft centre is. There will also be a facility to look up individual clinicians who specialise in cleft care

and a forum for researchers to connect and share their projects and ideas. This may now have a global reach and full details of the site's capabilities and functionalities will be announced soon and featured in the next newsletter. Watch this space!



Gareth Davies and Emma Southby (centre) with representatives from Transforming Faces and Global Smile Foundation.

Smile, Smile Train, Global Smile Foundation, Transforming Faces and ECO.

ECO has for many years campaigned for minimum standards of care in cleft treatment and in 2016 achieved a European consensus in developing agreed guidelines for the early care of babies born with clefts. The new World Cleft Coalition will draw from this experience and expertise. ECO was also

Strengthening ties with Transforming Faces

The World Congress in Chennai gave us an opportunity to meet with the new management team at Transforming Faces, a Canadian cleft NGO who have provided significant support to us in the past. We have agreed on closer working ties and, in particular, to make available to each other resources and skills that will complement each organisa-

* 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.

tion. Specifically we will look at how we can share training knowledge/personnel, methods of evaluating impact of country programmes, and organisational management tools.

Training Manager, ECO

Emma Southby has been in post as our new Training Manager since December. She has had a very busy three months bringing new skills and extra capacity to the charity in all areas—training, fundraising web development and policy. You can read a progress report in the form of an online [blog here](#). She is keen to increase our visibility and will be developing a social media presence shortly.

Fundraising

Securing funds for ECO's work is always difficult and we have put in a lot of work in the past three months seeking funds through European Union (EU) grant programmes. We are leading on three project applications and partners in two others. The focus of the applications is broad, ranging from promoting minimum standards in cleft care (implementation of our own [guidelines](#)) to education programmes around cleft nursing, support for young people with clefts, and psychosocial support. We will know the results later in the year. Previous EU grants have enabled us to develop downloadable education courses such as [Face Value](#) and [When Looks Get in the](#)



Help us give every baby born with a cleft in Europe the right start!



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www.europecleft.org
info@europecleft.org

New ECO poster launched at International Cleft Congress in Chennai

[Way](#). Partnering with teams across Europe also provides opportunities for developing our own training programmes in countries that have asked for our input such as Greece, Serbia, Lithuania, Latvia and Romania.

Launch of European Reference Networks

ECO was pleased to be invited to a high-level launch of the new rare disease networks (ERNs) which took place in Vilnius, Lithuania, in Fe-

bruary. We are on the management board of the Craniofacial ERN and our role will be to bring the patient voice into craniofacial care, and specifically cleft care, in Europe. A full report of the launch can be [seen here](#). Over the coming months we will be contacting cleft NGOs around Europe to understand what the current priorities are for them and bringing their voices to future discussions on care management.

Meeting with MAM

We were pleased to be able to have another meeting with the baby products manufacturer, MAM, in Vienna, during March. It was the first meeting since they sponsored the development of our early care cleft guidelines and we were able to report on the impact of the guidelines and training proposals regarding their implementation. We discussed future scenarios of joint working, and they will be sending us a sample product pack to see if any of their cur-

rent product range may be of interest to parents/families and those that we train in early cleft care. We will remain in contact

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Verrijn Stuartlaan 28
2288 EL Rijswijk
The Netherlands

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