

# Fendlipo

Issue 7 April 2014

Fendlipo means Cleft Lip in Esperanto\*

Newsletter of the



European  
Cleft  
Organisation

## Fact-finding trip to Lithuania

ECO is delighted to have been invited to Lithuania to discuss ways in which we might be able to support cleft care in the country. During the trip, Gareth Davies from ECO and Michel Grupper from the Resurgens Foundation will meet cleft specialists and parents to get a picture of current cleft care in Lithuania and, in line with our policy in other countries, look at ways in which we can work together to address any needs. We are very grateful to Dr Vaiva Mickevičienė from Vilnius for organising the visit and will feature a report of the trip in the next edition of *Fendlipo*.



Romanian twins Andrei and Alexandru Marcu

## RomaniaCleft Organises first conference

ECO is delighted to report the success of an international cleft workshop in Bucharest, Romania, 31 March – 2 April 2014 focusing on improving surgical outcomes by comparing Eu-

*\* 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.*

ropean protocols and featuring 'live view' surgical sessions. The event, *Challenges in the treatment of cleft lip and palate*, was organized by Radu Spataru, cleft surgeon at the Maria Sklodowska Curie paediatric hospital in Bucharest, who invited colleagues from around Europe, many of whom he had remained in contact with after the Bulgaria cleft conference in Plovdiv in Sep-

tember 2013, *Completing the circle*, organised jointly by ECO and the European Science Foundation. The Bucharest conference included representatives from cleft teams in Bulgaria, Ukraine, Latvia and Sweden as well as cleft team members from all over Romania. During the conference we were delighted to be introduced to twins Alexandru and Andrei Marcu (see picture above). Their father, Sorin, would like to set up a patient sup-

port group and was keen to seek advice on the subject from ECO director Gareth Davies. A follow-up cleft conference is being organized by cleft surgeon, Calin Popoiu from Timisoara, Romania, in November 2014 and there are plans to invite representatives from neighbouring Balkan countries as well as those from further afield.

## Francophone cleft congress

ECO was pleased to be able to participate in the bi-annual cleft congress near Grenoble in March. We were given the opportunity of presenting ECO's work to an audience of cleft specialists from France, Belgium and

Switzerland. The centres in Lille and Lyon have shown an active interest in assisting ECO and we hope to be able to use volunteers from these centres for future training courses in different parts of Europe. We are very keen to develop an international network of training partners.

## Photo Project

We are continuing to support the efforts of two photographers from Paris and Ge-

neva who have kindly offered to promote our work with a photo reportage culminating in an exhibition and book, with proceeds coming to ECO. They are seeking their own funding to finalise the project and if you want to help them visit the project website at [www.bulgarie2014.com](http://www.bulgarie2014.com)

### European Cleft Guidelines

The first draft of our document setting out guidelines for early cleft care has been completed and circulated for comments around Europe. The feedback will be discussed and the document reviewed at a meeting in Sofia, Bulgaria at the end of April. In addition to the 9 counties represented at the kick-off meeting in September 2013 we now have delegates attending from Germany and Spain, ensuring this is truly an international exercise. We have also had recent interest in the guideline from the United States.

### Bulgaria - setback for Centre of Reference

Last September ECO and our Bulgarian partners in Plovdiv met with the chair of the healthcare committee of the Bulgarian parliament to press for the creation of a national centre of reference for cleft care. Signs were encouraging but after 6 months of negotiations it seems the Ministry of

Health is not willing to pursue this at this stage. We have been advised to use the media to try to push this forward and will use every opportunity to try to generate media interest in this issue. ECO representatives will be in Bulgaria in June and October.

### Plovdiv - a Bulgarian centre of excellence

Despite the reluctance of the Bulgarian Health Ministry to formally designate a special-status Centre of Reference for



Post-op picture of twins Andrei and Alexandru

cleft care, the work of our partner cleft team in Plovdiv is going from strength to strength. Last year they established a national network of specialist cleft nurses—the first of its kind in the region. They are planning to develop similar networks for orthodontists and speech therapists over the next two years and have recently appointed a psychologist to the cleft team. They are now formally signed up to the European Science Foundation EUROcleftNet network and as such will benefit from short visits and exchanges with other specialists around Europe. It

is envisaged that three team members will take part in research and knowledge-sharing trips during the year which will further enhance Plovdiv as a regional centre of excellence.

### European cleft support group workshop 2015

**FIRST ANNOUNCEMENT:** ECO is planning a cleft user group workshop in spring 2015. The aims will be to engage with patients and parents and listen to how ECO can meet their needs and to offer some training in common areas of interest. We also plan to launch an ECO membership scheme. **More to follow.**

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### Training school in Poland

Cost Action 1210, [Appearance Matters](http://AppearanceMatters.org), is organising a training school

in Poland in April

aimed at identifying key measures for collaborative research into appearance related issues. ECO has been awarded a place in the training and will have the opportunity to share insights around facial difference and specifically cleft lip and palate.

**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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