

Fendlipo

Issue 8 June 2014

Fendlipo means Cleft Lip in Esperanto*

Newsletter of the

European
Cleft
Organisation

Projects planned in Lithuania

ECO has just completed a fact-finding trip to Lithuania. Gareth Davies from ECO and Michel Grupper from the Resurgens Foundation met cleft specialists and parents to get a picture of current cleft care in the country. Nearly all of the 30-40 babies born with clefts each year in Lithuania are treated at the Zalgiris Clinic in Vilnius, with more complex cases referred on to the Children's Unit at the Vilnius University Hospital. We were warmly hosted by Dr Laura Linkeviciene, orthodontist, and Dr Vaiva Mickevičienė, audiologist. We were pleased to also have a meeting in the Health Ministry with Dr Romalda Baranauskienė, Director, Mother and Child Health Department.

We were very impressed with the dedication and commitment of the cleft team, and the medical facilities were of high quality. It was agreed that there

were three areas where ECO might be able to extend support offered to families and patients:

- Training in the psycho-social support needs of families
- Training for nurses and midwives to provide feeding advice and support
- Help and advice in how to set up a parent



Parents exchange stories in Vilnius

support group.

We will be looking at budgets and discussing a time frame for carrying out the above.

Gateway to Greece

In an effort to ensure all countries are featured on the European Cleft Gateway www.gateway.ecoonline.org we have been establishing links with cleft specialists in Greece with a potential ex-

ploratory visit being discussed for the autumn. No Greek cleft units have registered yet on the European Science Foundation funded directory which is an important resource for health professionals and patients alike.

Call for assistance from Serbia

Consultant orthodontist Julija Radojcic who presented a paper at last year's ECO/EUROCleftNet research conference in Bulgaria, has asked for help in establishing a national cleft centre in Serbia. We will work with the team in Nis to try to bring pressure on the authorities, with

support from other professionals and patients, to establish a designated cleft centre, as we have been trying to do in Bulgaria. The CEN guidelines in early cleft care (see below) will provide a useful tool in this process.

European Cleft guidelines on track

The European guidelines in early cleft care being put together by ECO and a team

* 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 international experts are on track to be completed by the autumn. We are at the second drafting stage and the full technical committee will have the summer to review the document before it is circulated amongst standards bodies in each European country for approval later in the year. The aim is to have a set of agreed guidelines that can be adopted in countries where no national guidelines in cleft care exist at present.

Bulgaria : full team care

The Annual Meeting in Plovdiv of the parent association ALA provided an opportunity to talk about the need for psycho-social support for families with children born with clefts. ECO board member, Dr Martin Persson, a psychologist from Sweden currently working with the Centre for

Appearance Research in Bristol, UK, gave a talk on the issues faced by parents and children with clefts from a psychological perspective. The following day he presented on a similar theme to groups of health professionals. We hope to provide further training through the EU funded COST and/or Erasmus programmes. A psychologist is now regularly attending the cleft clinics, which is positive news. Other key events around the Annual Meeting included a dental hygiene 'fun day' for the children (see picture) and a meeting of the ECO/ALA national network

of nurses. This network is continuing to prevent babies with clefts being left in institutions.

EUROcleftNet is working

ECO board member and Chair of the EUROcleftNet programme, Prof Peter Mossey, has submitted a mid-term project report for this 5 year ESF funded network. ECO have contributed to and benefitted significantly from the achievements to date. The report highlights key successes: the Plovdiv research conference in

better cleft care for all children with clefts in Europe.

Patient conference 2015

Further to news in the last edition of *Fendlipe*, we are planning to organise a patient support group conference in mid 2015. Dates are not yet confirmed but we may link this with the European Cleft Congress in Gothenburg in June. More details to follow.

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. Proceeds of exhibitions and sales will come to

ECO. They 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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Dental hygiene lesson for children in Plovdiv

2013, the development of the European Cleft Gateway, the promotion of networks in Eastern Europe and the coordination of exchanges through the short visit programme. It is testimony to our collaboration with EUROcleftNet that we are now actively forging links with more and more countries, some of which have been featured in this edition of the newsletter. Furthermore our position on the management committee of another major European research network, COST 1210, means that more than ever we are in a key position to effect and influence moves towards