

ESF Research Networking Programme (RNP)

Network for Orofacial Clefts Research, Prevention and Treatment (EUROcleftNet) 09-RNP-023

First Steering Committee Meeting
9 June 2011, Strasbourg (FR)

Minutes

Participants:

Steering Committee Members

Professor Peter Mossey (UK)
Dr Elisabeth Mangold (DE)
Dr. Gareth Davies (NL)
Professor Bill Shaw (UK)

European Science Foundation (ESF)

Dr. Kirsten Steinhausen, ESF Science Officer,
Biomedical Sciences Unit

Ms. Blanche Facchini, ESF Administrator,
Biomedical Sciences Unit

Apologies:

Professor Anette Lohmander (-Agerskov) (SE)
Dr Mario Merialdi (CH)
Dr Rolv Terje Lie (NO)
Dr Borut Peterlin (SI)

Welcome and Introduction remarks

Kirsten Steinhausen welcomed the participants and gave an overview about the ESF and its funding philosophy (presentation attached). After a short tour de table and the approval of the agenda Peter Mossey informed the meeting about the history of EUROcleftNet (presentation attached). Since the application has been submitted in 2009, the existing network moved forward. He pointed out that he was previously involved in an ESF Network programme on “Development of methods to investigate the interaction between nutritional, environmental and genetic factors in early human development: demonstration project on orofacial clefts”, which lead to a successful application to the European Commission project (Framework Programme 5 - “EUROCRAN”) before now stepping into the ESF EUROcleftNet research networking programme. Bill Shaw, University of Manchester and Principal Investigator for the EUROCRAN project then presented the Cleft research background in Europe with a focus on research in treatment/quality of care (presentation attached). One major feature of cleft lip and palate research in Europe over these years has been the establishment of a close working relationship between scientists and clinicians.

Presentation of the ESF RNP Guidelines

Kirsten Steinhausen gave a 2nd presentation providing further details about the ESF/RNP Guidelines (presentation attached), and also mentioned other ESF research support schemes such as “Forward Looks”.

Constitution of the Programme Steering Committee

Peter Mossey was approved as Chair of the RNP and Bill Shaw as a permanent advisory expert in the Steering Committee.

Related activities/Future partners/additional funding

It was noted that the NIH funded RCT on cleft palate (CP) treatment (Timing Of Palatal Surgery, TOPS) was being conducted in Europe and Brazil, with Bill Shaw as PI and he would therefore the EUROcleftNet project would be ideally placed to participate in the programme or /and Bill could be our representative from NIH as a permanent advisory expert in the steering committee. The members of the steering committee suggested that among the major priorities were to (a) look for extra funds and (b) get further members and countries involved. Further activities should be developed to get additional funding - from the Commission, by lobbying at the FP7/FP8, by using contacts with university offices, by getting connection with ERANETs, and by making a brainstorming bringing up ideas how to best use the expertise.

Other activities or events were identified as linked to EUROcleftNet by the Chair (for details please look at the presentation attached)

Kirsten Steinhausen also mentioned the activities of EMRC in the field of Clinical trials and the Forward Look “Implementation of Medical Research in Clinical Practice”. It was agreed to add EUROcleftNet members in mailing lists and to send information about EMRC activities.

Information and Communication Issues

The ESF will host the RNP website on the ESF local website with the following link: www.esf.org/eurocleftnet.

It was agreed that rather than building a new EUROcleftNet website from scratch, the existing EUROCRAN website should be renewed (ESF logo to be added) as well as the link to the ESF website, and Gareth Davies advised that there would be a significant link and exchange of business between the EUROcleftNet and European Cleft Organisation (ECO) websites. Funds to this item and the maintenance of the external website were allocated.

To work on the external website and its updating, it was agreed to set up a Website meeting in Manchester with 6 people including Michele Rubini. 3000€ were allocated to this item.

Any production of abstracts for conferences, grantees’ articles, research articles or any other publications have to refer to the RNP EUROcleftNet using the ESF acknowledgement text (logo, remit and acknowledgement text to be provided).

EUROClleftNet Brochure:

An ESF template will be sent to the Chair. The budget to cover the costs for the brochure would amount to 2000€. Kirsten Steinhausen suggested members to have a newsletter as an alternative. Peter Mossey and Bill Shaw agreed to write an editorial for the brochure.

Programme Objectives and Planned Activities

Grants: it was decided to further discuss the special procedures for grants (advertising, evaluation procedures etc.) and that it would be very important to consider engagement with a wide range of stakeholders: This may include, over the next 5 years: EU Framework 7 topics (and perhaps lobby for FP8), ECO (TFW plus DG Sanco plus Esperanza etc.), WHO (GBD initiative including DisMod 3 and the PHG initiative), GOHIRA (IADR plus WHO plus FDI), EU Parliament (Brussels). The Genetic Alliance (Rare diseases) led by Alistair Kent, NIH, Country initiatives e.g. in the UK the Healing Foundation and possibly other charitable bodies, The Wellcome Trust, The James Lindhe Alliance, CSAG 2, CSO and Research Strategy for Scotland.

- **EUROClleftNet aims to hold 6 steering group meetings: (with 2 in first year), 4 Workshops (1st one in Salzburg in September 2011), 2 Conferences (years 1 and 3), and exchange visits across a range of sites.**

1st Workshop is planned to take place on 14 September 2011 in conjunction with the European Craniofacial Conference in Salzburg (AT) and will be organised by Peter Mossey. Gareth Davies will come up with a short list of 3 Eastern people to be invited. It was agreed to further discuss and decide on the content of the workshop agenda and to advertise it.

The workshop should be on strategic issues with a good working agenda, stimulating and focussed presentations. An electronic exchange aimed to discuss the workshop announcement with all Steering Committee members will be initiated by the Chair. It was agreed that at this meeting there would be a need to discuss the research priorities and strategy for a 5 year plan.

Budget

The detailed budget for 2011 as agreed at the launch meeting is attached.

It was pointed out that the networking budget for the 3 first years will be higher than the last 2 years, this because the DFG is going to contribute only for 3 years. It is hoped that the DFG will be persuaded to go further in its financial support, or to find other German funding agencies which contribute to EUROClleftNet.

It was mentioned that there is flexibility regarding the budget allocation (between budget lines, for instance) and that any unspent funds can be carried over the year after.

Date of Next Steering Committee meeting

A short Steering Committee Meeting is planned from 10 to 11am on 14th September in Salzburg (AT) in the context of the ECC 2011 – 9th European Craniofacial Congress (14-17 September 2011), and the workshop described above.

Any Other Business

The possible appointment of a EUROcleftNet administrator to support the Network and Chairman in Dundee was discussed and agreed. The allocated budget for this post would allow one day per week.

Note from the Chair after the meeting:

The University of Dundee issued a press release about the European Science Foundation network "EUROcleftNet". Please see below some links to related articles.

European Science Foundation RNP EUROcLEFT coverage report

Professor Peter Mossey, Associate Dean for Research in the Dental School, recently received grant from the European Science Foundation of approximately €450,000 (Euro) for the "ESF Network for Orofacial Clefts Research, Prevention and Treatment". The news of this grant received 17 pieces of coverage across the UK media. These items are detailed below:

Times Higher Education

Fresh Faces

<http://www.timeshighereducation.co.uk/story.asp?sectioncode=26&storycode=416499&c=1>

The Scotsman

Dundee to lead birth defect study

<http://news.scotsman.com/dundee/Dundee-to-lead-birth-defect.6781398.jp>

University of Dundee

Dundee dental experts leading cleft research

<http://www.dundee.ac.uk/pressreleases/2011/june11/dental.htm>

Virgin Media News

Researchers focus on cleft defects

http://latestnews.virginmedia.com/news/health/2011/06/07/researchers_focus_on_cleft_defects

Guide and Gazette

Researchers focus on cleft defects

http://www.guideandgazette.co.uk/news/scottish-headlines/researchers_focus_on_cleft_defects_1_1665786

The Public's Interest

University of Dundee leads fight against birth defects

<http://thepublicsinterest.wordpress.com/2011/06/08/university-of-dundee-leads-fight-against-birth-defects/>

Dundee

Dundee Dental Experts Leading Cleft Research

<http://www.dundee.com/news/dundee-dental-experts-leading-cleft-research.html>

Ayrshire Post

Researchers focus on cleft defects

<http://www.ayrshirepost.net/ayrshire-news/scottish-news/2011/06/07/researchers-focus-on-cleft-defects-102545-28836018/>

Dumfries and Galloway Standard

Researchers focus on cleft defects

<http://www.dgstandard.co.uk/dumfries-news/scottish-news/2011/06/07/researchers-focus-on-cleft-defects-51311-28836057/>

Falkirk Herald

Researchers focus on cleft Defects

http://www.falkirkherald.co.uk/news/scottish-headlines/researchers_focus_on_cleft_defects_1_1665786

Paisley Daily Express

Researchers focus on cleft defects

<http://www.paisleydailyexpress.co.uk/renfrewshire-news/scottish-news/2011/06/07/researchers-focus-on-cleft-defects-87085-28836027/>

East Kilbride News

Researchers focus on cleft defects

<http://www.eastkilbridenews.co.uk/lanarkshire-news/scottish-news/2011/06/07/researchers-focus-on-cleft-defects-68653-28836043/>

West Lothian Courier

Researchers focus on cleft defects

<http://www.westlothiancourier.co.uk/west-lothian-news/scottish-news/2011/06/07/researchers-focus-on-cleft-defects-62405-28836053/>

Perthshire Advertiser

Researchers focus on cleft defects

<http://www.perthshireadvertiser.co.uk/perthshire-news/scottish-news/2011/06/07/researchers-focus-on-cleft-defects-73103-28836041/>

Kilmarnock Standard

Researchers focus on cleft defects

<http://www.kilmarnockstandard.co.uk/ayrshire-news/scottish-news/2011/06/07/researchers-focus-on-cleft-defects-81430-28836029/>

University of Dundee

Dundee dental experts leading cleft research

<http://www.dundee.ac.uk/pressreleases/2011/june11/dental.htm>

Hamilton Advertiser

Dundee dental experts leading cleft research

<http://www.hamiltonadvertiser.co.uk/news/breaking-news/2011/06/07/researchers-focus-on-cleft-defects-51525-28836055/>