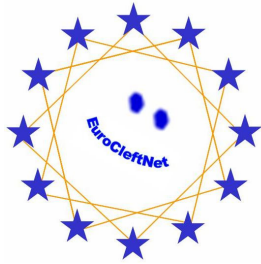


**Network for orofacial Clefts Research, Prevention and Treatment
(EUROCleftNet) 09-RNP-023**



EuroCleftNet research conference

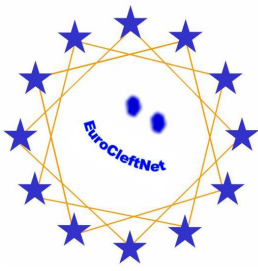
Plovdiv, Bulgaria, 27 - 27 September 2013

'Completing the circle: shared opportunities to address the challenge of orofacial clefts.'

Pre-conference meeting 23 April 2013

Summary

The meeting was scheduled to discuss the above conference taking place in Plovdiv (application 4994) in September concentrating on the venue, speakers and budget.



Meeting of EUROCleftNet

Research Conference Organising Committee

Plovdiv 23 April 2013

Present: *Boriana Koeva, Milena Videnova (CIM event management company), Sidonia Susanu (Romania), Vesna Kozelj (Slovenia), Youri Anastassov (Bulgaria, conference host), Jana Angelovi (Bulgaria, patient group president), Savina Maneva (Bulgaria – patient group fundraiser), Gareth Davies (European Cleft Organisation – meeting Chair), Peter Mossey (EUROCleftNet) – by Skype*

Apologies: *Bill Shaw*

Please Note: *Committee member Emma Southby was not able to be present for the meeting but will be joining local hosts and Gareth Davies later in the week to see the venue and discuss programme and workshop arrangements – especially regarding nursing input*

Gareth thanked everyone for attending.

Because of other commitments, **Peter Mossey** was only able to join the meeting for the first half hour so we dealt points he had brought up in advance, at the start of the meeting.

- EUROCleftNet steering group meeting on Wednesday 25th September commencing lunchtime or early afternoon perhaps? Would this be possible?

It was agreed arrangements for a meeting would be made around lunchtime on 25 September

- Promotion of the Plovdiv meeting at Orlando – availability of a colour flier (home made ok)?

The committee agreed and this was discussed more fully, later in the agenda

- Consider inclusion of workshop entitled ‘Orlando Task Force Feedback’.

Gunvor Semb will be speaking on this but it was agreed extra time should be added for feedback

- Invitation of industrial partners who came to our EUROcleftNet meeting in Bonn – and beyond?

This was deemed useful and appropriate. Peter will action this

- Budget for meeting – airport shuttles seemed expensive?

The shuttle cost (50 euros return) did seem high which is why we were keen to subsidise the cost for each delegate that uses it (subsidy of 50 per cent to come from EUROcleftNet conference budget). Most delegates will have to fly to Sofia which is about 120 km from Plovdiv so that is a considerable distance. Making ones way on a bus is possible but you need to know where you are going (and deal with the language), and pay a taxi to get from the airport to the bus station. Likewise with the trains. We will look at this again but there may be no other realistic option. On the plus side the very favourable accommodation costs in Plovdiv more than compensate for the transfer costs.

- Capacity and what if we are oversubscribed?

The facilities at the venue can cater for 200 + but it is doubtful the uptake will be that high given this is a ‘single condition’ conference. However we will need to review the situation as registration comes in over the coming months.

- Uptake in Eastern Europe – does this need further promotion?

Promotion is something that will be discussed later in the agenda and we will report back.

- What is our expected or ideal outcome of the meeting? I would suggest that in addition to stimulating or inspiring research, particularly collaborative research, we need to keep the item on the agenda.

Yes, this needs to be discussed by both the EUROcleftNet steering committee and the conference committee. An all-embracing mission statement would be a useful focus.

- Do we need session chairs?
- *Yes these will be discussed.*
- Do we have a scientific committee dealing with Abstracts (multidisciplinary)?

Yes, this will be discussed

The meeting continued with the agenda headings previously circulated to the committee

1) Venue and facilities

The committee were given a tour of the conference facilities which were excellent and we have a choice of room sizes depending on eventual numbers. We are not yet clear on the number of workshops we will hold on the second day but if more than three we may need to double-up in rooms. We will look at the practicalities of this nearer the time. Room and dining/catering facilities are excellent and at a very favourable price. An elegant suite is available for the welcome reception. Delegates arriving at the airport in Sofia will be greeted by event company representatives and directed to the shuttle transfer – it was important that requests for this service are made and paid for doing the registration process. Once in Plovdiv, delegates will be greeted in the lobby area for registration.

The gala dinner (paid by delegates as extra cost) will be held in a magnificent restaurant in the heart of the old town serving traditional Bulgarian cuisine. Depending on the weather, guests will be seated in a secluded courtyard or in the vaulted cellars of the fine 18th century building.

2) Conference company

The event is being organised locally with the help of CIM – Company for International Meetings – who were recommended to us by another NGO. They have 20 years of experience and are able to handle planning, event website, registration, and organisational logistics of the conference. For further details see their website at www.CIM.bg

The conference website is online <http://eurocleftnet2013.cim.bg/index.php> and the registration process is working (there is one registration so far). Payment is not required at the time of registration which will make it easier for delegates to quickly sign up – but they must pay by the due dates otherwise they will be penalised by paying the late registration fee. The website is viewable on a range of devices including tablets and smartphones. If we have other items for the site we should pass on details – e.g. photos of previous events, events upcoming etc. they will be posted and featured.

The delegate pack will comprise an eco-friendly cloth bag with conference logo, branded notepaper, pen, complete programme and either memory stick or CD containing abstracts.

Gareth was reminded that the company still needed summary CVs and photos of keynote speakers Gunvor Semb, Michel Rubini and Ingeborg Barisic. He will chase these.

3) Promotion

a) International

- Immediate

It was felt imperative that this should be widely promoted at the International conference in Orlando at the start of May. The conference company have promised within one week to redraft and rebrand the earlier conference flier

produced by Gareth in time for Orlando and will produce a PDF version that can be printed locally. Gareth will contact Orlando conference organiser Jeffrey Marsh and request he makes this available via an email circulation list to delegates. Copies will also be sent to Bill Shaw, Gunvor Semb and Peter Mossey so they can take print and take with them some copies handing out to interested individuals.

- Ongoing

Event websites – medical conferences
All Cleft Gateway survey respondents
All patient groups in Europe
ECO Newsletter recipients
Known European Craniofacial societies
Gareth to action all the above

European Science Foundation
Industrial partners
Other EUROcleftNet connections
Peter to action

Romania – **Sidonia to promote**
Southern Balkans – **Vesna to promote**

Other channels – All keynote speakers have been asked to promote in their own circles/countries

More?

b) Promotion within Bulgaria

This was deemed crucial in terms of whether the conference would have a longer term impact on cleft care in Bulgaria. A clear message should be sent out;

- This is an international conference.
- The European Science Foundation had endorsed an East European setting
- The venue, Plovdiv in Bulgaria, was identified by an international organising committee as an appropriate host because of longstanding international collaboration in cleft lip and palate care and research
- The location will attract a good turn out from neighbouring east Europe and central European countries who will share knowledge with delegates from the rest of Europe. A unique and bold opportunity *welcomed throughout the region*
- A propos – the Bulgarian Standards Agency (BD) has just agreed a twinning agreement with the Austrian Standards Agency (ASI) to coordinate the

development of a European guideline on early cleft care through the European Standards Agency (CEN) in Brussels.

The above points should all be included in approaches for high level Bulgarian participation from e.g. Presidency, Health Ministers, MEPs, local and regional politicians. The attraction of a high level participation will have a direct impact on sponsorship opportunities for industry.

Specific media to target:

TV - Mother and Baby programme

Radio

Parenting magazines

Science Journals

Bulgarian Academy of Sciences

News Agencies e.g. BTR, BTA

Other NGOs via NPO

Other?

It was suggested that perhaps some of the items that CIM were planning to produce for the delegate pack (conference branded merchandise) might be available well in advance of the conference to be used to raise publicity and give visibility to the event.

4) Budget considerations

As a general principle, we have been asked, where possible, to invoice Dundee University directly for services in connection with the conference. It was agreed that CIM would work on this basis and send (if feasible) a single invoice itemising costs incurred that are not covered by either the conference delegate fees or sponsorship.

Regarding sponsorship, Gareth made the point that this would all go into the general conference budget i.e. EUROcleftNet would stand to gain from this 'and thus be able to plan more events in the future. If in the unlikely event the conference made a profit we would need to discuss where this would be applied. It was noted that in the overall budget ECO and ALA would receive some recompense for their part in organising the event – this had been set at 10% of overall conference costs but this formula may need revision in the light of successful sponsorship. A final decision will rest with the EUROcleftNet steering committee.

There was a lot of discussion about 'unforeseen costs' and whilst these might be included in a contingency budget, we needed to building safeguards. In particular Gareth was asked to give guidelines to the keynote speakers on travel costs and what was, and was not included in their allowable costs (e.g., spouses, colleagues would need to register separately)

Bursaries were potentially complicated and there were no fixed criteria. These would be agreed on a case by case basis by the organising committee. It was noted this was not an automatic process and bursaries would need to be applied for, which meant a degree of commitment before being considered. The sum in the budget of 5500 Euros should not be exceeded – unless extra funds could be found through sponsorship.

5) Conference programme

The committee went through the programme and made the following observations and comments.

- 1) As already noted, there will be a pre-conference EUROleftNet steering committee at lunchtime on 25 September.
- 2) The Welcome Reception should be put back to 19h.30 because of the warmer weather and late arrival times of some delegates
- 3) Youri's slot will include an official opening by a dignitary (Bulgarian president?)
- 4) The total time for free papers is not great – 6 hours. We need to see what kind of response we get after publicising the event but we may need to shorten the workshop times and extend the programme on the final day. We will review.
- 5) There may not be interest or capacity to run five workshops. Perhaps a workshop preference could already be added to the registration form?
- 6) Most delegates will not be able to get connecting flights home from Sofia in the evening of the final day (event closes at 17h15 or later – transport to Sofia will take 2 hours) . We can assume that most people will need to request an extra night (at their expense). Perhaps something could be organised as an outing/meal for the Friday night (everyone paying?)

6) Workshop leaders

As acknowledged, we do not know whether we will run all the workshops. However, we can tentatively begin to put nominate workshop leaders.

The following were suggested (but not finalised)

Nursing - Emma Southby with xxxx

Diagnostics and audit - Peter Mossey with xxxx

Genetics - Michele Rubini with xxxxx

Surgery - Brian Sommerlad with xxxx

Patient Perspectives - Gareth Davies with xxxxx

7) Scientific Committee

A panel of experts needed to be in place to review abstracts in themed areas.. The list below (no particular order) is not exhaustive and we need to find one or two people in each discipline/scientific area to comment on submitted abstracts.

Michel Rubini – genetics

Regine Steegers - environment
Elizabeth Mangold - genetics
Natasha Tul - obstetrics/screening
Borut Peterlin - genetics
Rosanna Preston – patient groups
Helen Dolk – congenital abnormalities
Nichola Rumsey – Psychology
David Penman - Obstetrics/diagnosis
Sidonia Susanu - surgery
Brian Sommerlad - surgery
Vesna Kozelj - surgery
Peter Mossey – collaborative research, epidemiology
Annette Lohmander - speech
Liz Albery - speech
Gunvor Semb – collaborative research orthodontics
Bill Shaw – collaborative research and audit
Pierpaolo Mastroiacovo - birth defects

There are more to add to the list but this is a good start.

8) Session Chairs and Faculty

This was seen to be important and the choice would be based on those attending from the above list and keynote speakers. In this context a question came up about having a faculty. This needs further discussion but it could be a good way of getting big names onto the conference website who may not in fact be able to attend the conference itself.

9) Any other business

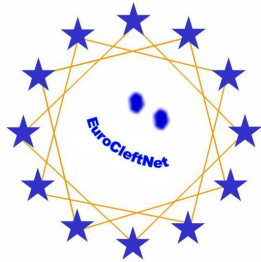
- Poster submissions
- At present there was no option for submitting posters. However this may need to be discussed if the number of submitted free papers becomes excessive. It was noted that

these days poster presentations were often done electronically – i.e. on screen which greatly reduced costs but we would need several computers to view the posters on.

- Checking presentations – we needed somewhere to view presentations once uploaded onto the conference projector. Would some space and expertise be made available for this?
- Audio visual equipment – it is assumed that the projection and sound requirements (and technical expertise) will be provided by CIM. Is this the case?

Gareth said he would circulate notes of the meeting and that we could all perhaps connect again via Skype at date to be arranged.

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Pre-conference meeting 23 April 2013

**Meeting of the Organising Committee of
EUROCleftNet Research conference - Plovdiv 2013**

<http://eurocleftnet2013.cim.bg>

Craniofacial Surgery Unit, Medical University of Plovdiv

Tuesday 23rd April 2013

15.30	Arrival and check in, Hotel Sankt Petersburg, Plovdiv
16.00	Tour of conference facilities, Hotel Sankt Petersburg
16.30	Taxis to Medical University of Plovdiv (conference host)
17.00	Presentation by CIM, local conference company organiser. Questions.
17.30	Discussion of draft conference programme – approval of amendments
17.50	Conference workshop coordination – who to lead sessions?
18.15	Suggestion of candidates for membership of Scientific Committee to evaluate abstracts. Coordination of evaluation process
18.45	Budget considerations and funding flows (ESF - Dundee – ECO – ALA – CIM?)
19.15	Formal meeting closes

Adjourn for informal working dinner

Present:

Boriana Koeva, boriana@cim.bg

Milena Videnova (CIM event management company), milena@cim.bg

Sidonia Susanu (Romania), s.susanu@gmail.com

Vesna Kozelj (Slovenia), vesna.kozelj@mf.uni-lj.si

Professor Youri Anastassov (Bulgaria, conference host), yanastassov@gmail.com

Jana Angelovi (Bulgaria, patient group president), angelovi@dominion777.com

Savina Maneva (Bulgaria – patient group fundraiser), savina.maneva@gmail.com

*Mr Gareth Davies (European Cleft Organisation – meeting Chair),
davieszak@googlemail.com*

Professor Peter Mossey (EUROcleftNet) – by Skype, p.a.mossey@dundee.ac.uk