





## Report: European Bone Sarcoma Networking Meeting June 29-30, 2011, Leiden/NL

#### **Summary and scientific content:**

#### Background:

This meeting was held on the subject of integration of translational research in clinical bone sarcoma trials. The meeting was a joint venture of the EUROPEAN NETWORK for CANCER research in CHILDREN and ADOLESCENTS (ENCCA), the European network to promote research into uncommon cancers in adults and children: Pathology, Biology and Genetics of Bone Tumours (EuroBoNeT) and the Pan-European Clinical Trials (ECT-) EUROCORES program of the European Science Foundation (ESF), through which it also received financial support. Meeting organizers were Pauline de Graaf and Pancras Hogendoorn (Leiden / The Netherlands), representing EuroBoNeT, and Miriam Wilhelm and Stefan Bielack (Stuttgart / Germany), representing ENCCA Work Package 7 (Bone Sarcoma) and ECT-EURAMOS.

#### Proceedings of the Meeting

The aim of the meeting was to provide a forum for broad-based discussion by key stakeholders regarding the role of translational studies to be integrated into a program of clinical trials, particularly in osteosarcoma and Ewing sarcoma. In addition to members of the co-ordinating networks, representatives were present from, in alphabetical order, the Cooperative Osteosarcoma Study Group (COSS), the European Osteosarcoma Intergroup (EOI), the European Organisation for Research and Treatment of Cancer Bone and Soft Tissue Groups (EORTC-STBSG), European Clinical trials in Rare Sarcomas within an integrated translational trial network (EuroSarc), the Italian Sarcoma Group (ISG), the French Sarcoma Group (SFCE/GSF-GETO), and the Scandinavian Sarcoma Group (SSG). In short, the meeting comprised a rich and diverse assembly of current European clinical and basic researchers in bone cancer.

#### Challenges to successful translational bone sarcoma research

There is a lack of sufficient tumor material for translational research was experienced as an important obstacle to translational research. Although in general current experience appeared to

be slightly inferior to the rated importance of each item, there were four areas which appeared in need of attention. These were the link between clinical and biological information; the integration of biological research into clinical trials; the transfer of basic research into clinical trials design; and the level of funding available for this work. Apart from the last point, it is clear that there is broad perception from clinicians and scientists that clinical trials represent an essential forum of understanding the biology of disease and treatment effects. As to funding, several issues became apparent. First, the current economic climate is likely to pose challenges to research activities generally. Second, a particular challenge is the funding of research into rare cancers (like bone sarcomas) where that research involves engagement across national boundaries—and even between continents. There are few mechanisms that, at one blow, will provide funding for both basic and clinical components of a trial, and also fund partners in multiple countries. Funding is especially difficult for the mundane but essential components of biospecimen collection, storage retrieval and processing, and shipping. Consortia like EuroBoNeT and now ENCCA have been remarkably effective in providing such support, and other groups will hopefully emerge to fill the gap created by the completion of some of these programs.

We reviewed the experience of different groups, to see what could be learnt for the future. A most important observation was that, for tumor specimens, there was a real challenge in obtaining consistently high quality material on a majority of trial participants. In Euro-E.W.I.N.G 99, only about one quarter of patients had adequate material for molecular studies on their tumors.

Resection specimens for both Ewing sarcoma and osteosarcoma are almost always affected by neoadjuvant therapy and of limited use biologically. It appeared that mandating collection of pretreatment tumor material for biological studies would preclude participation of some centers and many patients. Given the importance of large scale trials to clinical outcomes, both within the study and as a standard of care, it was agreed (but not universally) that mandating biospecimen collection was not practicable. However, it was agreed that substudies could still be developed using tumor material involving key sites where this was feasible.

One issue that was raised was how to engage the enthusiasm of more sites in biological studies. A discussion was held regarding integration of databases. At the 'front' end, it was noted to be desirable for the clinical, biospecimen and molecular databases to be linked. One key issue is the de-identification of individual patients for ethical reasons.

#### <u>Upcoming studies in osteosarcoma and Ewing's sarcoma</u>

After the broader discussions about the general principles and priorities, the group then reviewed imminent studies in both osteosarcoma and Ewing sarcoma. These studies provided concrete examples for considering many of the issues discussed above.

#### Conclusion

Overall, there was a striking mood of optimism at the meeting, many fruitful ideas were discussed, and future translational and clinical research proposals are likely to emerge from the process. In addition to the importance of biology to clinical outcomes for patients with these cancers, another key theme was the importance of collaboration. It was heartening to see representatives from ten European countries as well as partners from overseas at the meeting, representing more than a dozen translational and clinical research organizations. Only by such a collaborative effort can progress in the treatment of rare cancers be achieved. The delegates all agreed that there would be benefit in repeating the meeting, to see the ideas of this meeting turned into research studies in the coming years.

Number of participants: 37

No co-sponsorship

#### Assessment of the results and impact of the event on the EUROCORES Programme:

The aim of the meeting was a networking meeting, to provide a forum for broad-based discussion by key stakeholders regarding the role of translational studies to be integrated into a program of clinical trials, particularly in osteosarcoma and Ewing sarcoma.

#### **Publication:**

"Workshop report on the European Bone Sarcoma Networking Meeting: Integration of clinical trials with tumor biology" to be published in Journal of Adolescent and Young Adult Oncology

(JAYAO).

Klinikum Stuttgart Verwaltung

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#### Annexes:

- Workshop report
- Agenda (final)
- List of participants
- Financial report







## **European Bone Sarcoma Networking Meeting** Integration of clinical trials with tumor biology Leiden, NL, June 29, 2 p.m. - June 30, 2011, 2 p.m.

### Agenda Wednesday - June 29, 2011

14:00	1 Welcome		
	Chair: Pan	cras Hogendoorn/Stefan Bielack	
14:15	2 Current clinical and translational research activities		
		cras Hogendoorn/Stefan Bielack	
	Brief groupwise presentations (~3`each)		
14:15-14:18	1. EOI/EORTC	Hans Gelderblom	
14:18-14:21	2. EUROSARC	Hans Gelderblom	
14:21-14:24	3. ECT-(EURAMOS	Jeremy Whelan	
14:24-14:27	4. EuroBoNeT	Pancras Hogendoorn	
14:27-14:30	5. ENCCA WP7	Stefan Bielack	
14:30-14:33	6. EURO-E.W.I.N.G. Heribert Jürgens		
14:33-14:36	7. COSS Miriam Wilhelm		
14:36-14:39	8. ISG	Piero Picci	
14:39-14:42	9. SFCE/GSF-GETO	Natacha Entz-Werlé, Laurence	
		Brugieres	
14:42-14:45	10. SSG	Lars Hjorth	
14:45-14:48	11. EURAMOS Biology Group	David Thomas	
14:48-14:51	12. CCG Osteosarcoma	Michaela Nathrath	
15:00	3 Defining and overcoming challenges to	integrated research	
		Chair: Stefan Bielack	
	Presentations:		
15:00-15:10	1. Survey: Issues in bone sarcoma	Miriam Wilhelm,	
		Stefan Bielack	
15:10-15:15	2. ECT-EURAMOS	Jeremy Whelan	
15:15-15:25	3. EURO-E.W.I.N.G.	Uta Dirksen	
15:25-15:30	4. ENCCA WP5/WP7 link Heinrich Kovar		
15:30-16:30	Open discussion (obstacles, successful solutions,	, remaining challenges)	
16:30	Coffee break		
17:00	4 Optimizing the availability of bone sa	rcoma tissue for biobanks Chair: Piero Picci	
	Presentations:	Chan: Helo Ficci	
17:00-17:15	EuroBoNeT: Biobank and other sustainable	Pancras Hogendoorn	
17.00-17.13	features	1 anotas 110gendoom	
17:15-17:30	<b>Open discussion</b> (Perpetuation and expansion of	the virtual hone tumor highark)	
17.15-17.50	open discussion (1 espectation and expansion of	the virtual bolic tullior bloballs)	

17:30	5 Linking trials, biobanks and labs	
		Chair: Pancras Hogendoorn
	Presentations:	
17:30-17:45	1. R2: Analysis and visualization platform	Jan Koster
17:45-19:00	<b>Open discussion</b> (What is needed for translational concept integrating the needs of trials groups and	, <u>+</u>
19:00	6 ENCCA WP7 steering group meeting	
		Chair: Stefan Bielack
	ENCCA WP7 steering group members only	
20:00	Networking dinner	

Agenda Thursday - June 30, 2011

till 8:30	Networking breakfast	·
8:30	7 Collaborative research proposals: oste	eosarcoma
		Chair: Jeremy Whelan
	Presentations:	
8:30-8:40	1. Understanding the biology of osteosarcoma	David Thomas
	risk and therapeutic response	
8:40-8:50	2. Collaborative research proposal: CCG	Michaela Nathrath
	Osteosarcoma_COSS	
8:50-9:00	3. EuroBonet datasets (Expression arrays and	Anne-Marie Cleton-Jansen
	cell lines) and role of macrophages in	
	osteosarcoma progression	
9:00-9:20	4. The osteosarcoma trial within EUROSARC	Bass Hassan/Hans Gelderblom
9:20-9:30	5. Potential immune targets in osteosarcoma	Arjan Lankester
9:30-10:30	Open discussion	
10:30	Coffee break	
11:00	8 Collaborative research proposals: Ewi	ng sarcoma
	• •	Chair: Heribert Jürgens
	Presentations:	<u> </u>
11:00-11:10	1. The Ewing sarcoma trial within EUROSARC	Bass Hassan
11:10-11:25	2. Immune targets in Ewing sarcoma	Arjan Lankester
11:25-12:30	Open discussion	
12:30	9 Next steps / conclusion	
	-	eras Hogendoorn/Stefan Bielack
13:00	Networking lunch	
13.00	networking functi	
14:00	Meeting adjourned	
14.00	Miccuing aujourneu	

Acknowledgement: This work is supported by the European Science Foundation under the EUROCORES Programme European Clinical Trials (ECT) - EURAMOS,

through contract No. ERASCT-2003-980409 of the European Commission, DG Research, FP6.

The European Science Foundation (ESF) provides a platform for its Member Organisations to advance European research and explore new directions for research at the European level. Established in 1974 as an independent non-governmental organisation, the ESF currently serves 79 Member Organisations across 30 countries.







# **European Bone Sarcoma Networking Meeting Integration of clinical trials with tumor biology**

Leiden, NL, June 29, 2 p.m. - June 30, 2011, 2 p.m.

### **Agenda**

Wednesday - June 29, 2011

19:00	6 ENCCA WP7 steering group meeting	
		Chair: Stefan Bielack
	ENCCA WP7 steering group members only	
	Institutions	
19:00-19:03	1. LTHTNHS	Ian Lewis
19:03-19:06	2. LUMC	Pancras Hogendoorn
19:06-19:09	3. OLGA	Stefan Bielack
19:09-19:12	4. St.Anna	Heinrich Kovar
19:12-19:15	5. UCL	Jeremy Whelan
19:15-19:18	6. WWU	Heribert Jürgens, Uta Dirksen
	Task presentation	
19:18-19:23	7.1	Miriam Wilhelm
19:23-19:28	7.2	Pancras Hogendoorn
19:28-19:33	7.3	Jeremy Whelan
19:33-19:38	7.4	Ian Lewis
19:38.19:45	7.5, 7.6	Heribert Jürgens, Uta Dirksen
19:45-20:00	Future meetings, next steps, open discussion	
20:00	Networking dinner	

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# **European Bone Sarcoma Networking Meeting Integration of clinical trials with tumor biology**

Leiden, NL, June 29, 2 p.m. - June 30, 2011, 2 p.m.

**Participants** 

Farticipants	
Registrated	Representing
Ian Lewis	EURO-E.W.I.N.G, ENCCA WP7
Pancras Hogendoorn	EuroBoNeT, EURO-E.W.I.N.G, ENCCA WP7, ECT-EURAMOS
Stefan Bielack	COSS, ENCCA WP7, ECT-EURAMOS
Heribert Jürgens	EURO-E.W.I.N.G, ENCCA WP7
Jeremy Whelan	EOI, The London Sarcoma Service & NCRI CSG Bone Sarcoma
	Subgroup, ENCCA WP7, ECT-EURAMOS
Miriam Wilhelm	COSS, ENCCA WP7, ECT-EURAMOS
Heinrich Kovar	EURO-E.W.I.N.G, ENCCA WP5&7, EE99
Gernot Jundt	COSS, ECT-EURAMOS
Michaela Nathrath	COSS, ECT-EURAMOS, KKG
David Thomas	ECT-EURAMOS, EURAMOS2
Uta Dirksen	EURO-E.W.I.N.G, EuroBoNeT
Hubert Mottl	COSS, ECT-EURAMOS
Katja Zils	COSS, ECT-EURAMOS, ENCCA WP7
Piero Picci	ISG, EuroBoNeT
Luca Sangiorgi	ISG, EuroBoNeT
Ola Myklebost	SSG, EuroBoNeT
Susan Burchill	EURO-E.W.I.N.G, EE99, NCRI Sarcoma Group
Hans Gelderblom	ECT-EURAMOS, EOI
Laurence Brugieres	SFCE/GSF-GETO
Bass Hassan	EuroBoNeT
Anne-Marie Cleton-Jansen	EuroBoNeT
Daniel Baumhoer	
Judith Bovee	EuroBoNeT
Natacha Entz-Werlé	SFCE/GSF-GETO
Adrienne Flanagan	
Jan Koster	
Antonio Llombart Bosch	EuroBoNeT
Massimo Serra	EuroBoNeT, ISG
Jan Peter Poulsen	SSG
Katia Scotlandi	EuroBoNeT
Arjan Lankester	EuroBoNeT
Nick, Athanasou	EuroBoNeT
Maria Serena Benassi	EuroBoNeT, IOR
Laura Pazzaglia	EuroBoNeT, IOR
José Antonio Lopez Guerrero	EuroBoNeT
Jakob Anninga	
Max Gibbons	

#### corrected version

#### **Detailed report of Expenditures**

<u>Accommodation (</u> from June 28 - 29, 2011): Dr. Daniel Baumhoer (29/06/2011; Best Available R Prof. Dr. Stefan Bielack (29/06/2011; Kamerprijs LU	€ 131.00		
Euro/master card)			€ 97.00
Prof. Dr. Gernot Jundt (29/06/2011; Best Available Rate, Touristenbelasting, Restaurant Rubens, Euro/master card)			€ 133.50
Mrs. Miriam Wilhelm (29/06/2011; Kamerprijs LUMC, Toeristenbelastung, Visacard)			€ 97.00
Dr. Katja Zils (29/06/2011; Kamerprijs LUMC, Toeris	€ 97.00		
Total			€ 555.50
Accommodation (from June 29 – 30, 2011):			
(18/07/2011;			600000
24 hour package (29x): bed and breakfast			€ 2,929.50 € 202.00
wo-day package (2x): bed and breakfast single room supplement (-2)			€ 202.00 - € 50.00
3% discount (-1)			- € 477.76
/AT 6%			€ 156.19
Total			€ 2,759.43
Travel:			
Dr. Daniel Baumhoer			€ 143.20
Prof. Dr. Stefan Bielack			€ 150.70 € 137.30
Dr. Laurence Brugières Prof. Dr. Susan Burchill			€ 127.20 € 313.25
Prof. Dr. Susan Burchill Prof. Dr. Uta Dirksen			€ 313.25
Dr. Natacha Entz-Werle			€ 432.28
Prof. Adrienne Flanagan			€ 411.57
Prof. Dr. Gernot Jundt			€ 147.40
Prof. Dr. Heribert Jürgens			€ 144.50
Prof. Dr. Heinrich Kovar			€ 432.16
Prof. Dr. Ola Myklebost			€ 422.93 € 236.40
PrivDoz. Dr. Michaela Nathrath Pierro Picci, MD			€ 236.40
Jan Peter Poulsen, MD PhD			€ 400.60
Dr. Luca Sangiorgi			€ 450.00
Dr. Jeremy Whelan			€ 467.87
Mrs. Miriam Wilhelm			€ 172.00
Dr. Katja Zils			€ 10.00
F <b>otal</b> Meals (from June 29 – 30, 2011)			€ 4,846.68
	Nb of participants	Item price	Total price
29*24 hour package diner	29	€ 39.50	€ 1,145.50
unlimited coffee/tea	29	€ 19.50	€ 565.50
lunch	29	€ 28.50	€ 826.50
1x package excluding accommodation diner	1	€ 39.50	€ 39.50
lunch	1	€ 39.50	€ 28.50
unlimited coffee/tea	1	€ 28.50	€ 28.50
1x afternoon arrangement	4	6 10 00	6 10 00
unlimited coffee/tea 2x morning package	1	€ 19.00	€ 19.00
lunch	2	€ 28.50	€ 57.00
unlimited coffee/tea	2	€ 9.50	€19.00
1x two day package excl. Bed & breakfast and dinner	1	€ 28.50	€ 28.50
lunch unlimited coffee/tea	1	€ 28.50	€ 28.50
2x two day package			
Diner and unlimited coffee/tea	2	€ 52.50	€ 105.00
/AT 6%			€ 173.46 € 570.50
Beverages	N. Committee of the com		€ 579.50 € 3,643.96
otal .ocal administrative costs:			€ 3,043.30
ocai auministrative costs.			€ 637.50
Roerhaavezaal			€ 50.00
Beamer (first day) (1x)			€ 135.38
Beamer (first day) (1x) Beamer (second day) (1x)	15		€ 847.88
Beamer (first day) (1x) Beamer (second day) (1x) /AT 19%	2004	1	0 0471.00
Beamer (first day) (1x) Beamer (second day) (1x) /AT 19% Total Other costs:		4.	
Beamer (first day) (1x) Beamer (second day) (1x) VAT 19% Total Other costs:	Klinikum Stut	tgart	€ 51.15
Boerhaavezaal Beamer (first day) (1x) Beamer (second day) (1x) VAT 19% Total Other costs: CITY TAX Grand Total	Klinikum Stut	tgart	N N N N N N N N N N N N N N N N N N N