Pan European Network for Care of Survivors after Childhood and Adolescent Cancer
PanCare

Meeting held at
Department of Pediatrics and Adolescent Medicine
Graz

13 and 14th November 2008

Present

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<tr>
<th>Participant</th>
<th>f/ m</th>
<th>Country</th>
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Apologies          Dr Rod Skinner

Chairs             Dr Lars Hjorth, Dr Ricardo Haupt
Dr Rod Skinner unable to attend

Welcome:           Prof Dr Christian Urban  Head Division of Pediatric Hematology/Oncology Graz
DAY 1 14.00-18.30

**Item 1**  
Towards funding from the EU an - update

After e-mails, phone calls, letters and document delivery to the EU, the steering committee (LH, RH, RS) went to Brussels on 10.11.08 to present PanCare to the Directorate-General for Research. They had a two hour meeting with 2 scientific officers (Holland and Poland) who were interested in other areas besides research (e.g. awareness) but it was noted that the European Policy Objectives Seventh Framework FP7 for research has the largest funds.  
**The EU will, by the end of 2008/early 2009, produce (supposedly still classified) draft document outlining its favoured funding initiatives.**  
PanCare members are asked to produce letters of support for PanCare from as many countries and agencies (including parents and survivors groups) as possible within the next month. These letters should indicate particular areas of interest (e.g. research, awareness, specific issues for survivors and families) in order to influence the content of the draft document.  
**Write to** the National Contact Point for your country (see link below).  
When the EU **draft** becomes known (late Jan/Feb 09) the Network through the steering committee will consider a proposal to fit the funding.

**Links**

Directorate-General for Research:
http://ec.europa.eu/dgs/research/organisation.cfm  
(The link previously given to the Advisory Group for health does not work any more)

National Contact Points for each country responsible for the Programme Committee for Health:

**ACTION Everyone**

Letters to EU re PanCare  
See attached sample but individualise with differing emphases. Explain which group you are writing on behalf of.  
Remember: Awareness, Advocacy, Equality, Access, Research
ITEM 2  Affiliation to SIOP-E
The meeting in Brussels had suggested that PanCare might sit under the SIOP-E umbrella. It is not certain whether we would fit their objectives. The next SIOP-E president, Ruth Ladenstein, is from Vienna; there are also other contacts. The offices are in Brussels and an infrastructure is in place.

ACTION: Steering committee to explore, Kathy Pritchard-Jones, Ruth Ladenstein, Andrea Biondi and others to be approached

ITEM 3  Towards a research proposal.

At the Meeting in Lund the research group decided to focus on Late Mortality. Subsequently the steering committee, mindful of the need to produce a strong research proposal for Brussels, called for further debate on this topic.

Presentations which will be circulated were made by:
MH / FdV  Second Primary Neoplasms
SG /GP  Late Mortality
LK/ES  Chronic Health Conditions

Points made:
A good research question must have a firm end point, be clinically and socially relevant and need a pan European approach to complete in a reasonable time scale; applicants for grants should have a good international reputation.
The time scale of funding is likely to be only 3-4 yrs.

‘Second Primary Neoplasms’ is a firm end point which some registries have collected already. (UK, Nordic)
Relatively small number encourages a European wide study.
With longer follow up SPN’s are seen increasingly in the clinic and becoming a public health problem. Parents and physicians are interested in SPN’s.
Long established registries would be needed to capture all SPN’s because of their long gestation.
A study on SPN’s would link with the Gene - Rad - Risk work (model of MH /FdV);
survivors could be asked to produce saliva samples to investigate interplay of genetics and radiation.
This biological slant might improve chances of a grant but is it feasible?

‘Late Deaths’ would not include good prognosis SPN’s (eg breast, meningioma). A study of late deaths could occur in individual countries.

Late mortality studies (Mertens 2008, Moller 2001) have shown recurrence, followed by SPN and non-cancer deaths, as causes of death in order of frequency.
Health outcome studies indicate that 60-70% of survivors have significant health problems and at least 30% serious ones (Oeffinger 2006, Geenen 2007) with death in some.
Important to determine risk groups for survivors.
All late effects small numbers so increasing the cohort will help.
**Discussion**

Late Mortality is a clinically based question.
It would be enhanced by increasing numbers even if could be done within each country
Studies might/not show differences between countries and would encourage improvement

*Since all SPN’s are to be registered, they would not be missed in a Late Mortality study.
*(It is not clear whether this point was made during the meeting or in discussion afterwards.)*

Aspects of a study could involve research, clinical care and stimulation of interest in LTFU, development of lifestyle and other prevention strategies as well as promotion of awareness.

The verification and validation of cause of death is not easy.
Is it possible to do late mortality study without treatment information? – we often only have chemo/RT yes/no – but this is true for any late effects study. Radiotherapy data is also needed for SPN’s.

Risk of development of late effects increases with time yet surveillance is reduced over time because of patient discharge.
One of the aims of the EU is to ‘Optimise Health’
We have a growing number of survivors and older survivors moving into middle and older age. We do not know what is going to happen to them.

There was a lot of tough debate on the relative merits of a well defined scientific research question (e.g. second neoplasm) and a broader more inclusive approach. There was a lot of interest in looking at care across Europe in terms of awareness, access to care, opportunities and employment for survivors and care for families. Some mentioned this as the foundation principle of PanCare. Risk of death important but life and health the main aim and across Europe in 2003 63% survived 5 yrs (ACCIS web site).

The eventual consensus was that there should be an effort to do both! One project would be to establish a data base across Europe with collection of an agreed set of data. The aim of this would be to improve care as well as to provide cohorts for further studies. The other, a specific research question, which one still to be resolved, although perhaps depending on the draft document expected from Brussels.

**DAY 2**

8.30-12.30
ITEM 4 National and group registries and databases, report on Questionnaire

Presented by Desiree Debling on behalf of the audit and questionnaire group. This presentation will be circulated as a PDF.

DD circulated a list of the 28 members who had responded to the online questionnaire (launched 13.10.08) with details of institution, country, e-mail address, numbers of survivors on data bases and other experts known.

It was agreed that this information could be available to group members only, for the time being, since it was considered preliminary.

16 countries are represented. We need others to join. 26 data sets were completed. Five reported on population based registries, 4 on other registries or late effects networks and 17 on clinical centres, individual or countrywide.

Overlap of data bases was certain but even so would account for more than 100,000 childhood cancer patients currently registered.

The definition of ‘survivor’ varies in registries between 3 and 5 yrs from diagnosis or end of treatment. Information is collected on those diagnosed from 0 to a variable age (15-25yrs or more) and the extent of the collection differs between data bases. Standardisation is required.

Data bases started between 1940 and 2001 and 16 have collected up to the present. Long term follow up started between 1967-2007 in 22, and is variable in frequency and length. Figures indicate more than 90,000 in various forms of follow up (See the presentation for more details)

Each country then commented on their data base.

Agreed:

It was agreed that any information sent around the group would be confidential unless otherwise specified.

Action The steering committee will ask for nominations of one member from each country to liaise with national colleagues and submit available data base information to the audit group. This should avoid duplication. A phone conference within each country might be necessary.

Action Representative from each country to prepare a one page description of data collection and long term follow up in their country.

The audit and questionnaire group will produce a template with headings.

MH said the decision about what data to collect would depend on the research question

Attention was drawn to the following sources:


[http://www-dep.iarc.fr/accis.htm](http://www-dep.iarc.fr/accis.htm)

JCO 2005; 23: 3742-3751 Childhood Cancer Survival Trends in Europe: A EUROCare Working Group Study Gemma Gatta, Riccardo Capocaccia, Charles Stiller, Peter Kaatsch, Franco Berrino, Monica Terenziani, the EUROCare Working Group

http://www.eurocare.it/

After discussion the following was agreed.

A register of data bases has been established and can be used to ask for opinion on future research topics.
The number of persons on follow-up/ type of follow-up can be evaluated.
The audit and questionnaire development group has made an excellent contribution and should continue as a working group.

DD was thanked for doing this significant task very efficiently and successfully

**Tasks for this working group:**
Identify duplication.
By the end of January 2009 a cohort should be defined to capture the extent of follow up (clinical or just data base) second malignancy, late mortality.

**ITEM 5 Transition and a questionnaire to cohorts of survivors,**
Eva Frey for the transition models group (EF, TL, JBo, HL)

This presentation will be circulated as a PDF.

Needs of LTFU patient fear, high risk treatments, surveillance, screening
Barriers to LTFU cost, lack of understanding of need, inconvenience, need to be healthy

Four models outlined, led by: 1 survivor, 2 primary care, 3 ped one, 4 adult service

EF has tried **patient led** but this resulted in multiple clinic visits with minor complaints. They are now using an internal medical colleague.

Literature review had found these particular papers relating to questionnaires.

The willingness of **general practitioners** to be involved in the follow-up of adult survivors of childhood cancer.
Blaauwbroek R, Zwart N, Bouma M, Meyboom-de Jong B, Kamps WA,
J Cancer Surviv. 2007; 1:292-7

GPs were willing as long as there were guidelines, a full medical history and quick and clear communication lines.

Assessing the health care needs of adolescent and young adult cancer patients and survivors Zebrack, Brad (B); Bleyer, Archie (A); Albritton, Karen (K); Medearis, Sandra (S); Tang, Julia (J)
Cancer 2006; 107 : 2915-23

This paper reported that both physicians and survivors agreed on the importance of health insurance and oncology care but survivors placed higher emphasis on meeting other survivors and less on the support of family and friends than did the physicians.

Proposal for questionnaire re transition discussed.

The experience within the PanCare group re age and nature of transition would be a start. 
**Suggestion that questionnaire sent to one centre in each country for distribution to every survivor in that centre.**
The questions would have to be easily answered (tick box with comments)
Ethical permission would be needed in most countries
Development of a survivors’ web site might facilitate getting survivors’ opinions

**ITEM 6 DIRECT initiative**
EF informed the group about this initiative to raise awareness re survivorship. Groups of survivors had done a bicycle tour in Germany and mountain climbing in Austria.

**ITEM 7 Survivor care group (RS, AM, GL, EBA, LZ) Guidelines**

Gill Levitt presented in place of RS.

Aim to produce questionnaire to determine number and nature of guidelines available to the group, their scope, when updated and whether they are followed.

Need to determine how comprehensive and detailed the guidelines should be - recommendations/ practice statement /evidence based / expert opinion?
Are they used to generate for individual patients? This could be audited.

Should the aim be to produce a PanCare guideline?

After discussion - suggestions for this group:
**Have the questionnaire results available at the next meeting.**

To facilitate the questionnaire approach, each country to decide on reps (e.g. one clinical, one registry, one political) to act as a conduit for information, i.e. to be the Networks steering group.
The steering committee will send out a letter about this within the near future.
ITEM 8  Publications on Late Effects by members of PanCare  
Ricardo Haupt

RH has captured on an access data base 278 publications by group members relating to Late Effects. It was agreed that this would help to emphasise the research credentials of the group and help in grant applications. References and maybe abstracts could be on web site (even the abstract not allowed in Germany – publication regulations).

ITEM 9  Survivor/family representation (RS, EBA, LZ)  
presented by Edit Bardi

Information is needed from the network about the involvement of survivors and parents. Is their involvement a success and what are the aims of these groups?

Discussion about involvement of survivor/s &/or parent/s in this meeting raised the concerns of language problems; whether we would be more likely to get grants for research if they were involved; that we would lose a potential great benefit if they were not included; that we need their representation for decisions about future work; that it would help to demonstrate any differences and inequalities across Europe.

Tasks
International Confederation of Childhood Cancer Parent Organisations  
(ICCPO) is an international organisation of parent groups (including US), the current chair is from Holland, It was agreed that JB would approach him/her to discuss the involvement of parents in PanCare.

A request for contact details of survivor groups should be added to the questionnaire on long term follow up. ?DD

ITEM 10  Web-page presented by Leontien Kremer

LK has identified someone to design a web page. For preparation and changes the cost would be 2500 euros.
This start up money and a web master would be needed.
Questionnaire handling not included.

Group pointed out that would need further costing because of maintenance.
Julie Byrne is the chair of the ‘Establishing a web page’ group. It was suggested that Tomas Kepac would join the group and he agreed.

ITEM 11  Logo

The name PanCare might need to be changed. On the www it has already been used. It was agreed to have the map of Europe behind the logos.
ITEM 12

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<th><strong>Summary</strong></th>
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<tr>
<td>Letters of support for PanCare requesting funding</td>
<td>Everyone</td>
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<td>Explore whether PanCare can sit under SIOP-E umbrella</td>
<td>Steering Committee</td>
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<td>Research topic – no consensus reached</td>
<td>Research Group, Steering Committee</td>
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<td>Consensus for a research topic and work towards having equal access to and standards of care for survivors across Europe</td>
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<td>Steering Committee to work towards nominating national representative(s)</td>
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<td>National rep to produce a one page description of data collection and long term follow up in their country</td>
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ITEM 13  Next meeting

By kind invitation of RH in Modena, Italy
This meeting will take place from 16th March to 18th March 2009

Minutes by Elaine Sugden
Oxford

Finalised 09.12.08