

PANCARE NEWSLETTER

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Greetings from the newly elected PanCare Board

On October 1 in Amsterdam the new PanCare Board was elected. Since then a telephone conference has been held and it was decided that Lars Hjorth stays on as Chairperson at least for the next year and that Julianne Byrne is Treasurer. A decision on electing a Secretary is pending. Below the new Board is presented in more detail. Work is ongoing towards the next meeting in Bucharest May 9-10, 2011, generously hosted by Katie Rizvi and the Little People organisation.

The new PanCare Board

NAME	COUNTRY	PROFESSION
Edit Bárdi	Hungary	Paediatric Oncology
Julianne Byrne	Ireland	Epidemiology
Stephan Essig	Germany	Epidemiology/Survivor
Mike Hawkins	England	Epidemiology
Peter Kaatsch	Germany	Cancer Registry
Sabine Karner	Austria	Project worker ICCCPO/Survivor
Gill Levitt	England	Paediatric Oncology
Caroline McManus	Scotland	Survivor/Nurse
Gisela Michel	Switzerland	Psychology and Cancer Registry
Marios Paulides	Germany	Paediatric Oncology
Monica Terenziani	Italy	Paediatric Oncology
Heleen van der Pal	Netherlands	Medical Oncology
Riccardo Haupt	Italy	Paediatric Oncology/Epidemiology
Rod Skinner	England	Paediatric Oncology
Lars Hjorth	Sweden	Paediatric Oncology

MEETINGS...MEETINGS...

9th PanCare Meeting, Bucharest, May 10-11, 2012

The PanCare Bucharest meeting will be from lunch May 9 to afternoon on May 10. The first half day (May 9) will concern mostly administrative and logistical PanCare matters (open to all of course) while all day May 10 will be the scientific and more public part of PanCare in Romania. Finally, there will be a half day PanCareSurFup meeting on May 11 from morning to lunch.

ECRS (European Cancer Rehabilitation & Survivorship Symposium) 2012, Copenhagen, September 17-18, 2012

SIOP London, October 5-8, 2012



**Report from the 8th PanCare Meeting,
October 1st 2011 in Amsterdam, Netherlands
by Elaine Sugden**

We met on a Saturday in the Amsterdam Academic Medical Centre at the invitation of the Netherland members. As usual this was a happy event with people meeting old friends and making new ones. At previous meetings we had wished for more nurses to join us and this time they did. We also welcomed more survivors and delegates from European countries not previously represented as well as visitors from Japan. There were 81 delegates, the largest meeting so far. There was a point of sadness however as we remembered Claudia Kuhni, a member from Switzerland, and her family on the recent accidental death of her son. We signed a card together. We met for just one day; many of us had attended the ELSCCC meeting in Amsterdam the previous two days where there had been presentations and posters about ongoing Late Effects work. Do read the minutes of the meeting to get the full story of what went on. There were reports from the newly formed fertility and ototoxicity groups; both are keen to have more members. We heard reports from the Dutch fertility study and survivor questionnaire which picked up physical, psychological or social problems in most survivors surveyed but with an interesting variation between diagnostic groups. PanCare SurFup (the FP7 project) is underway with all eight work-package members preparing reports on work done so far in order to receive the promised funds because money comes only for completed work. PanCare must bid for future EU grants. We are all asked to help by lobbying EU National Contact Points (NCPs). More details are in the minutes. ENCCA – the European Network for Cancer research in Children and Adolescents – was awarded money from FP7 to set up a network of excellence. Number 13 of their 18 work packages is on Quality of Survivorship and so overlaps with PanCare. One area of work will be on medulloblastoma and will build on work done by the SIOPE Brain Tumour Quality of Survival Working Group. Colin Kennedy leads both groups. Anyone interested to be involved should contact Colin.

The liveliest discussion was about the survivorship passport, also part of ENCCA work package 13. There are strong feelings about what should/should not be included and who it should be for. Survivors are keen to continue to be involved in this important debate. Let Riccardo Haupt know if you have comments. Alex Brownsdon for Survivornet reported that the web site built by Marios Paulides will be fully functioning soon and that she had been making bracelets featuring a humming bird - symbol of perseverance - selected by Survivornet as their logo. These will be used for fund raising; more help is needed in this area as well as in translation and web site construction and maintenance. The meeting also saw the formation of the first PanCare Board. In addition to the three executives (Lars, Riccardo and Rod) 12 members were needed. All those who had previously attended PanCare meetings were invited to stand for election by sending in a short profile and a photograph. The board was chosen and will oversee the protection and implementation of the aims of PanCare. An important task is to establish PanCare as a legal entity. Future events will be the Irish Conference for survivors (Dublin Nov 26 2011) and the ninth PanCare meeting in Romania in May 2012. This meeting closed with the traditional PanCare photograph. The dinner followed on Saturday evening - I cannot tell you about that, I left to visit cousins in the Netherlands which gave me another opportunity to use the excellent Dutch transport system.

PanCare members, Amsterdam, 2011



Travel to Brussels by Julie Byrne



Lars Hjorth, chairman of PanCare, Julie Byrne, board member of PanCare and Elise Kvarnström, Project Manager for PanCareSurFup, travelled to Brussels on 17-18th October for meetings with our Program Manager Dominika Traszka, (Scientific Officer, PhD Directorate-General Research and Innovation, European Commission) and with the Chief Executive Officer of ECCO -- Michel Ballieu. Edel Fitzgerald of ECCO and SIOPE joined us for meetings with staff of Commissioner Máire Geoghegan-Quinn, and MEP Mairead McGuinness, who represents the North-East of Ireland, including Drogheda, and is involved in health matters.



Lars Hjorth

Julie Byrne

Mairead McGuinness

Elise Kvarnström

Edel Fitzgerald

SurvivorNet Update (coordinated by Alexandra Brownsdon)

SurvivorNet; ‘The international patient group of childhood cancer survivors, supported by medical health care professionals in their efforts to improve aftercare, follow-up and also prevention of new conditions’ was officially founded on the 27th October 2010 at the 4th PanCare meeting in Mainz, Germany.

Where are we now? SurvivorNet now has a registered web domain at www.survivornet.org. A secure PHP (HypertextPreprocessor) forum (webforum) is also under construction and will be installed onto the website soon. Dr. Marios Paulides and I have been cross linking with other websites and integrating with social media including, Facebook and Twitter. Use of the social media to enhance the dissemination of information for Adolescent and Adult survivors of childhood cancer (www.survivornet.org in particular) was recently promoted in a presentation given by Alex at SIOP 2011. The development of a logo has been fundamental to establishing the identity of SurvivorNet. The current logo is temporary but we are hoping to have a professional logo designed. Plans are also in place to register SurvivorNet as a UK charity in order to become a legal entity and we are seeking the commitment of more survivors to become directors for the registration. In order for us to progress further, we also require support with website construction and with translation of the website into more languages. We will continue to raise awareness about SurvivorNet and we look forward to working in conjunction with PanCare in the future. I would like to thank the PanCare members for providing us with the opportunity to create SurvivorNet.

Alexandra Brownsdon
Chairperson of SurvivorNet.

Acknowledgement to Dr. Marios Paulides for building the website and for his on-going support for SurvivorNet.

What's going on in the PanCareSurFup work packages?

During the last PanCare meeting in Amsterdam, the decision was made to give a short update on the activities within the different PanCareSurFup work packages. The first presentations (work package 1, 7, 8) are given now, the remaining presentations will be published in the next newsletter.



Work Package 1: Data Collection and harmonisation (coordinated by Desiree Grabow)

The stress of the first 6 months of this project was on Tasks 1.3 "Mapping of data sources for establishment of study cohorts for WP3-5" and the definition of the study protocol for the dataproviders designated as "key players" as this was the most important delivery for their preparation of handing in the study protocol to national Ethical Boards for ethical advice and permission.

Within this study protocol WP1 took an active role together with WP2-5 in defining a list of baseline-variables relevant for the studies that we plan to conduct.

At the same time we started to prepare a Study Database for WP1, together with the data protection elements



Work Package 7: Dissemination and training (coordinated by Momcilo Jankovic)

WP7's dissemination and training group aims to add the results of its research projects and its guidelines group by working with stakeholders, both professionals and survivors and families, and other FP7 projects in order to disseminate information about PanCareSurFup to the general public and among health professionals and survivor/parent groups, and train health care professionals through conferences, workshops, booklet and web based information: Wp7 will also establish partnerships between providers and survivor/parent groups to empower and educate survivors to be as informed as possible concerning their long-term risks. General dissemination of findings from PanCareSurFup to the general public will be achieved via media such as press releases, blogs, video webcasts. WP7 aims to provide better health care management of adverse effects from therapy, and to close the feed-back loop with collaborative groups conducting clinical trials. The WP7 is also connected inside the European network with ENNCA for promoting together some educational projects avoiding unusefull overlapping. Meetings together and periodical teleconference help us in promoting at the best these initiatives. So far the first important event promoted by WP7 is the first Irish Conference on Survivorship after Cancer during Childhood and Adolescence that will be held in Dublin on November 26 2011 open to all people, health care members, long term survivors, families, media (www.ccs2011.ie).

Momcilo Jankovic WP7 leader



Work Package 8: Management and coordination (coordinated by Lars Hjorth)

The Coordinator and Project Manager of WP8 are in close contact with WP leaders and monitor that collaboration runs smoothly and according to plan. The Project Manager and the Coordinator also keep regular communication with all partners as well as internal meetings. The Study Protocol for WP 1-5 has been developed which contains a detailed plan of the work and interaction between the partners and data providers. Ethical approvals are on-going. Internal Project Reports similar to the periodic project reports was collected by the Project Manager for the first 6 months and will be repeated at month 12. The Ethical and Scientific Advisory Board (ESAB) consisting of: Dr. Gerlind Bode (Germany), Dr. Meriel Jenney (the UK), Dr. Jörn Beck (Germany) and Dr. Peter Inskip (the US) has been made even stronger with the addition of Professor Guiseppa Masera from Milan. A project website has been running since April 2011 (www.pancaresurfup.eu). Collaboration with other EU projects (e.g. ENCCA and Eurocourse) and the PanCare network ensures that patient and parent organizations, policy makers and other stakeholders are involved. The first General Assembly was held in Amsterdam October 2.

Lund November 15, 2011

Lars Hjorth

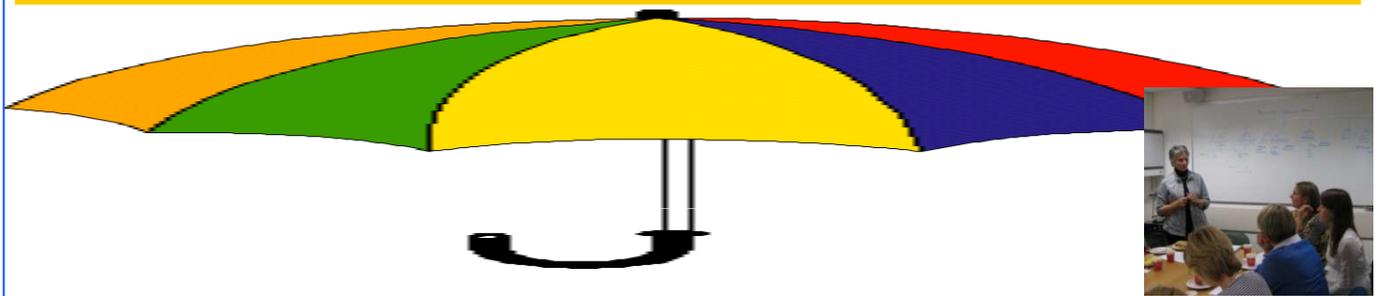
Coordinator PanCareSurFup

WPL WP8

Activities of the working groups

Fertility working group, co-chaired by Julie Byrne and Anja Borgmann-Staudt

The fertility working group had two activities during the last PanCare Meeting in Amsterdam: Anja Borgmann-Staudt summarized the results of previous FeCt - Studies and presented the ongoing FeCt - Offspring and - Longitudinal Study. In the FeCt - Nationwide Survey 2008 90% of 2770 participants, treated since 1980, average age 26 years, indicated the desire to have children. One third of the participants had signs of suspected infertility with significant risk factors being pelvic radiotherapy and postpubertal status at diagnosis. The following FeCt - Berlin Hormone and Spermanalyses 2009 confirmed these results and identified Cyclo/Ifo as an additional risk factor for women. The Austrian-Czech-German Study FeCt - Fertility after allogeneic HSCT 2010 in childhood and adolescence showed a fertility impairment in 69% males and 83% females with an additional RF for women being Busulfan. In 2012 the International Longitudinal Study and - Offspring Study shall be conducted. The Longitudinal Study examines the dynamics of the fertility impairment of 344 patients from 7 centres from Austria, Czech Republic, Germany following allogeneic HSCT - The Longitudinal Pilot study 2011 also includes brain tumor patients. The Offspring study with estimated 1500 offspring of survivors and participating countries being Austria, Czech Republik, Germany, Poland and Switzerland examines the general health status off the offspring of survivors. In the lunch break Julie Byrne created "an umbrella" by collecting ideas among interested participants of 13 European countries for fertility studies: An application in the final year of FP7 – Health 2013 was discussed. This programme is currently under construction in Brussels.



Umbrella for Fertility Studies

Work Package 1 Fertility Assistance	Work Package 2 Fertility Preservation	Work Package 3 Menopause	Work Package 4 Quality of Life	Work Package 5 Epidemiology	Work Package 6 Genotoxicity	Work Package 7 Guidelines & Ethics	Work Package 8 Dissemination	Work Package 9 Coordination
Task 1: Adverse events of fertility preservation procedures	Task 1: Primary loss of fertility Task 2: Secondary loss of fertility Task 3: Dynamics of fertility recovery	Task 1: Outcomes of premature menopause – osteoporosis Task 2: Outcomes of premature menopause – Cardiovascular disease Task 3: Outcomes of premature menopause – cognitive deficits Task 4: outcomes of premature menopause – hormone replacement therapy		Task 1: Pregnancy outcome Task 2: Health of offspring Task 3: treatment dosimetry	Task 1: Specimen collection and storage Task 2: DNA extraction and studies			

Ototoxicity Working Group, co-chaired by Thorsten Langer and Amedeo Azizi

The Ototoxicity Working Group (OWG) in PanCare was formed in the Brno meeting earlier this year, following recognition for the necessity for collaborative studies at a european level in this area as well. The first official meeting of the OWG took place in Amsterdam within the confines of the PanCare meeting. The main results were reaching consensus on submitting a collaborative project regarding pharmacogenic factors in platinum-induced ototoxicity for the HEALTH 2013 programme of the EU and the election of Thorsten Langer as chair of the working group.

Report of the Childhood Cancer Foundation, Brno by Martina Smukova and Tomas Kepak



KRTEK - the Childhood Cancer Foundation - was established by Professor Jaroslav Sterba in 1999. The main aim of it is to raise funds and awareness to conquer childhood cancer. KRTEK supports the work of the Children's Oncology Department of Faculty Hospital in Brno, dedicated to discovery and search for comprehensive cures for infants, children, teens and young adults with cancer. The funds raised by KRTEK are channelled into KRTEK'S advocacy, re-socialisation and education efforts on behalf of children with cancer and their families, into treatments not covered by the health care system, as well as departmental clinical and biological research. The vision of the KRTEK Childhood Cancer Foundation is to reach the day when every child with cancer in the Czech Republic can be offered the chance for a cure.

Each year more than 130 children with cancer are admitted to the Children's Oncology Department in Brno and are subsequently treated here. Since 1999, KRTEK helps infants, children, teens and young adults with cancer to improve the quality of their day-to-day life during a long, physically and psychologically demanding treatment. As opposed to 40 years ago, over 80% of today's young patients recover and are able to return to their normal lives. The oncology diagnosis, which has a tremendous impact not only on the ill child itself, but also on the life of the whole family, can take up to many months. During this difficult period it is important for children to maintain as much contact with their normal social environment as possible, spend time with their parents and keep in touch with friends and school. KRTEK has opened new dormitories for parents and children that arrive to the hospital from various parts of the Czech Republic to undergo specific short-term treatments, as well as for long-term stays of parents with hospitalised children. KRTEK has equipped a playroom and an outdoor playground., collects toys, books, games, computers with internet connection, CD and DVD players, celebrates birthdays with children and invites sport and cultural celebrities for visits. It also finances and organises summer and winter camps, weekends and other re-socialising events for children and their families during and after treatment. KRTEK raises money to purchase smaller medical equipment, such as self-dosing infusion pumps, ventilators, etc. Once children have left the hospital, KRTEK focuses on the continuous care and social support of the young patients and their families.

Lately, as a new initiative, ONKA – the Czech parent's organisation - was established to complete the complex care of the cancer patients and their families. KRTEK foundation, together with ONKA, is keen to support the international cooperation of the young cancer survivors and their parents.

Report of the first Irish Conference on Survivorship after Cancer during Childhood and Adolescence

by Julie Byrne



Top: Amber Singleton, 10, a survivor & Ciara McKeivitt.

Middle top: Elvira van Dalen addressing the conference

Left bottom: L to R: MEP Nessa Childers, Ciara McKeivitt, 12 & Andrea McKeivitt, 14, a cancer survivor, Julie Byrne

Right bottom: L to R: Lars Hjorth (with tie), MEP Nessa Childers, Harry Comber and Momcilo Jankovic

This conference was held on 26 November, 2011 in the Croke Park Conference Centre, Dublin from 10 am to 4 pm. It was organised by the Boyne Research Institute, Drogheda, Ireland, in association with PanCareSurFup's Work Package 7 (WP7), and the Irish Cancer Society. Co-sponsoring organisations were the Children's Medical & Research Foundation of Our Lady's Children's Hospital, Crumlin, Dublin, Novartis Ireland and Bristol-Myers Squibb Ireland.

The conference targeted survivors and their families and also, specialists, general practitioners, nurses and other health professionals. Registration was free. A total of 111 guests attended; about 70% were survivors and family members.

Speakers were primarily drawn from PanCareSurFup and included Lars Hjorth, Mike Hawkins, Momcilo Jankovic, Elvira van Dalen and Gill Levitt. Other speakers included Alex Brownsdon, Harry Comber, director of the Irish Cancer Registry, Michael Capra, paediatric oncologist at Our Lady's Children's Hospital, Crumlin, John McCormack, CEO of the Irish Cancer Society, and representatives from CanTeen Ireland, Barretstown Castle and ICCCP (Gerlind Bode).

The keynote speaker was Irish MEP Nessa Childers, who reminded survivors not to even think about smoking, and to take control of their health.

A survey of those who attended showed a high level of satisfaction with the conference, the speakers and the arrangements. Most rated all elements on the survey as „Excellent“. BRI staff are currently analysing the data from the surveys. A final report will be placed on the conference website – www.ccs2011.ie. The website carries the full programme and the presentations from each speaker. Numerous photos from the event can be viewed on <http://www.facebook.com/BoyneResearch>, as well as on the conference website.

