



PanCareSurFup Bulletin, Issue nr. 1

PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies

We are delighted to present to you the first regular bulletin of PanCareSurFup. The EU-funded Seventh Framework Programme (FP7) project PanCareSurFup - Pancare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies aims to improve research on the several late physical and psychological effects of childhood cancer or its treatment. As part of a pan-European network of professionals and survivors and their families, PanCareSurFup will carry out a series of epidemiologic studies on the most serious complications of long-term survival and the consequences of cancer therapies.

[Download the brochure in different languages](#)

Why is this project so important?

Currently 80% of children and adolescents are expected to survive. However, many of these survivors may face significant long-term risks to their health and well-being. The most serious health risks are the late recurrence of the disease, as well as second cancers, cardiovascular diseases, endocrinological and neuropsychological abnormalities. Since the cancer treatment is received during a period of growth and development, late effects are usually more severe than those experienced by adult cancer survivors.

The project will develop evidence-based guidelines for long-term care of childhood cancer survivors. 16 research institutes from 11 European countries have joined forces to realise this ground-breaking study.

[More information on project partners](#)

Over five years (2011 – 2016), PanCareSurFup will develop risk estimates for cardiac disease, second cancers and late mortality. A key component will be to establish the doses of radiotherapy to each organ, enabling tighter estimates of risk. This data, with results from other studies, will be the basis for establishing guidelines for follow-up in Europe, including suggestions for clinical networks to enable care to continue seamlessly from paediatric to adult settings. Finally, dissemination of the results will be achieved through conferences, workshops, newsletters and blogs, as well as partnerships with survivors and parents. PanCareSurFup's studies are intended to lead to increased cooperation between treatment and advocacy groups, reduce disparities in survival and improve outcomes for children and adolescents diagnosed with cancer in Europe.



Latest developments in PanCareSurFup

European Cancer Congress

Issues related to paediatric cancer survivors feature in several sessions of the European Cancer Congress in Amsterdam, the largest of its kind in Europe.

Sunday, 29th September, 17.15-18.15 – Patient and Ethics Track 'Empowering young people with cancer – a passport for survivors'

This session relates to the 'passport' created for survivors of paediatric cancer, in order to track the treatment they received and ensure care is followed up in case of late effects. Chaired by Gerlind Bode from ICCCP (International Confederation of Childhood Cancer Parent Organisations), who is also a member of PanCareSurFup's Ethical and Scientific Advisory Board, this session links the work of PanCareSurFup and **ENCCA** (the European Network for Cancer research in Children and Adolescents) led by Riccardo Haupt.

Monday, 30th September, 09.00–11.00 – Paediatric Oncology Track 'Empowering Survivors of Childhood and Adolescent Cancer'

The challenges facing survivors will be discussed during this session chaired by PanCareSurFup Coordinator Lars Hjorth and Prof. Kathy Pritchard-Jones, which will include a presentation from a young cancer survivor. A discussion on the possible genetic predisposition to late complications after cancer treatment and the aims and achievements of PanCareSurFup will be disseminated throughout this session.

Indeed, as childhood cancer survivorship is such an important topic as the number of survivors increase in Europe, this topic is sure to be discussed in each of the Paediatric Oncology Track Sessions.

Overview of the key sessions

More information on the European Cancer Congress

Wednesday, 2nd October 2013 – Thursday 3rd October 2013

On 2nd October 2013 PanCareSurFup will also have its General Assembly in Amsterdam for project partners.

MSC Cruise Event: All aboard for research against leukaemia!

A splendid fund-raising two-day event will take place on 24-25 October 2013 in Genoa, Italy. The PanCare network and other charities are working with the MSC Cruise line to prepare an event which will attract about 1,200 guests, who will be joined by celebrities from the movie and TV worlds. Starting with a gala dinner on Thursday, 24 October, the event will continue with a press conference on Friday 25 October in the morning, attended by experts from Italy (AIEOP), Europe (PanCare) and the USA. These experts will be questioned by national and international journalists about results, problems and projects concerning childhood cancer. Our aim is to engage people not directly involved in childhood cancer, so that they can understand the outstanding results obtained in Europe in the last decades in treating children and adolescents affected by cancer, the importance of the cooperative work of European groups like PanCare, as well as the task of caring about the health status of long term survivors.

In this context, the main sponsors' name acronym (MSC cruises) could be interpreted as **M**eglio **S**uperare il **C**ancro (to better overcome cancer). See you in Genoa!



PanCareSurFup Partners

In this first Bulletin, the PanCareSurFup dissemination team interviews Dr. Lars Hjorth from Lund University in Sweden, the Coordinator of this project.

In your opinion, why should the long-term follow up of survivors of childhood cancer be prioritised?

All types of cancer treatment, and especially the one which was broadly provided in the past, deeply impact the lives of former childhood cancer patients. Therefore it is extremely important to provide an extended and detailed follow-up on the late effects of treatment to all survivors. In a wider context, societies and health care systems need to be aware of this ever-growing population of former patients, who rightly want to lead a normal life and find their place in society, and can do so with the correct assistance.

PanCare and PanCareSurFup are relatively new consortiums. Where did the concepts for these initiatives come from?

The first European conference on long-term complications after childhood cancer was the ESLCCC (European Symposium on Late Complications after Childhood Cancer), held in Lund in 2007. Before this, several professionals had been talking about joining forces in Europe and doing research together on all kinds of survivorship issues. Together with Dr. Rod Skinner from Newcastle, UK and Dr. Riccardo Haupt from Genova, Italy in March 2008 we invited people to a meeting in Lund, where the PanCare Network was founded. Since the beginning a key issue for the network was to look for research funds: therefore, we conducted together a lot of research and networking to find out more about Europe-wide funding opportunities. Finally, we managed to apply to the 7th Framework Programme in 2010, which then led to the 5-year project PanCareSurFup, which started in February 2011.

What are the main challenges in your position as Coordinator of PanCareSurFup?

I would say that it is the width and complexity of the project, together with the fact that our Consortium consists of 16 institutions from 11 European countries, which are not always used to do things in the same (or even similar) way. Of course, at the same time, this is also part of the fascinating day-to-day work within the project.

From your perspective, what have been the achievements to date of this unique initiative?

The fact that we are half-way into our fifth project year and we are on track is something we all should be proud of. This doesn't mean that we haven't had our problems or difficulties, but we have been able to sort them out. The next year and a half is an extremely important part of our work and a lot of data in our Cohort and Case-Control studies needs to be gathered and analysed, in order not to lose precious time. In parallel, the work on Guidelines, Long-term Follow-Up and Transition also needs to be brought forward in a timely fashion. I feel that we are prepared for this, although it will be an extremely busy period for almost everyone in the Consortium.



Dr. Lars Hjorth together with Dr. Momcilo Jankovic



Dr Lars Hjorth and Dr. Gabriele Calaminus, SIOP President

Currently, childhood cancer patient advocates generally play an active role in engaging with both professionals and policymakers.

Do you think survivors need to also make their voice heard? What kind of specific issues do they face?

Survivors of childhood cancer do play an important role in both PanCare and PanCareSurFup, as do parents' representatives. It is crucial that we know their views and opinions, so that we focus on the right issues and do not stray too far in any direction. Due to the increasing numbers of former childhood cancer patients who reach adulthood, one of the most important things is to raise their own awareness of potential problems they may encounter and prepare them to face these by themselves (although they should always be able to ask for the support of professionals if and when they may need it). The issues they may face depend on which treatment they received and to what part of their body. An important issue relates to the psychosocial impact, which is not readily visible but can have a long-lasting effect.

As a paediatric oncologist, why did you decide to specialise in long-term follow-up?

There are two reasons basically. The first is the great inspiration and on-going learning that Professor Stanislaw Garwicz has given me on this subject for more than twenty years, and the second is the consequences that some of our children have to face after the end of their treatment. It comes back to the moral obligation not to leave them alone with this.

What do you love most about your job?

Most of all I am a clinician; I enjoy working with the children and their families in the ward during the day-to-day activities, but I am not able to do this as much as I would like, because the project takes so much of my time that there really isn't room for that as well. In the project, I enjoy working with so many motivated and smart people that we have the fortune to have within our Consortium.

How does your experience as a paediatric oncologist add value to this project?

I hope that having worked clinically for over twenty years makes me aware of the issues that we need to focus on, to keep 'on-track' as much as possible.

A sister project, PanCareLIFE, also funded by the EU, is in the pipeline.

How can this bring forward the important work of PanCareSurFup?

I hope that PanCareLIFE, together with PanCareSurFup, can help the PanCare Network achieve even more visibility than it already has. For PanCareLIFE and PanCareSurFup it is extremely important that similar activities in both projects are harmonised as much as possible, to avoid duplicating the efforts.

How do you relax? Any hobbies?

I try to relax at home or at our summer house, which is only one hour away. I enjoy music and play occasional rounds of golf, although without great success. I also like reading and try to stay updated on current events.

Why is it so important that the activities of PanCareSurFup and other European projects in paediatric oncology are sustained, beyond 2015?

If our project, like some other projects before it, only works for five years without leaving a legacy or results that are of importance after it, I think it would represent a massive failure for our survivors, the research community and our funders (i.e. the taxpayers). What we deliver should be of such quality that some sort of sustained activity must be made available. Therefore, sustainability is part of the work we all need to do, both in PanCare and its daughter projects and within larger paediatric oncology projects, including the ENCCA (European Network for Cancer Research in Children and Adolescents) project. Very recently a new consortium, ExPO-r-Net (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment) has been invited to negotiations for a three-year project by DG SANCO, and together with the other projects it should hopefully also be able to make a major impact that the paediatric oncology community in Europe can continue to build on.

For more information, please contact:

PanCareSurFup, Work Package 7 'Dissemination'
c/o Lars Hjorth, Coordinator, PanCareSurFup, lars.hjorth@skane.se
Elise Kvarnström, Project Manager, elise.kvarnstrom@med.lu.se
Momcilo Jankovic, WP Leader, m.jankovic@hsgerardo.org

