



PanCareSurFup

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PanCareSurFup Bulletin, Issue nr. 8

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

Dear Friends,

Since Bulletin #7 we have sent in all clarifications to the second EU-report to the Commission and we await their reply.

The next General Assembly will take place in Lucerne (Switzerland) all day October 7 and half day October 8 (followed by the PanCare meeting noon-noon Oct 8-10) so it is advisable to arrive in the afternoon/evening of Oct 6. We have generous help by Gisela Michel and her co-workers to set up a good meeting at the University.

In this issue of the Bulletin you will learn about the work in WP7 (Dissemination and Training) from the Work Package Leader, Momcilo Jankovic from Monza (Italy) and from the deputy leader Julianne Byrne from Drogheda (Ireland). I hope you will find their answers and stories as interesting as I do.

I wish you all a continued long and relaxing Summer!

All the best,

Lars Hjorth
Coordinator PanCareSurFup



Dr Momcilo Jankovic
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PanCareSurFup Partners

The project's dissemination team interviews the leader of Work Package 7 Dr Momcilo Jankovic from Fondazione Monza e Brianza per il bambino e la sua mamma, Monza, Italy, and Ms Julianne Byrne from Boyne Research Institute, Drogheda, Ireland, also partner in WP7.

Can you describe how you got involved in PanCareSurFup?

JB: As part of the original ELTEC committee I was present when Lars Hjorth and Rod Skinner came to Budapest to seek our involvement in the initiation of what became the PanCare Network. PanCare since has become the mother of two EU-funded consortia – PanCareSurFup and PanCareLIFE. I spent 10 days in Lund side by side with Lars writing the second stage of the PCSF application to the EU in January-February 2010. It was a very gratifying experience to work with the 13 other partners, most of whom had strong track records in funded research projects, and whose involvement ensured an excellent application.

MJ: My story started a long time ago. Inside the BFM family (I-BFM-SG), I was the Chairman of ELTEC (Early and Late Toxicity Educational Committee) for more than 10 years, with Riccardo Haupt as Co-Chairman,. We made a profitable work producing a hand-pocket booklet for young oncologists about specific, tricky and complex case reports, based on the true clinical events or analysis from died children. Further we produced some recommendations on how to manage long term survivors from childhood cancer. Contacting Lars Hjorth and Roderick Skinner, Riccardo promoted the extension of this care and attention to a European network to balance, in some way, looking at long-term survivors, the data produced by cooperative American Groups. So we decided to move from I-BFM-SG to a larger European group, to maintain a similar educational purpose and to consider some problems of long-term survivors. PanCare was born with these purposes and, from PanCare, PanCareSurFup found its existence, for making research and producing data and guidelines on scientific issues related to survivors.

What has been achieved so far in terms of dissemination of the project?

JB: The role of the Boyne Research Institute in PCSF is not confined to deputy leadership of WP7, the dissemination work package. Boyne also chairs a joint subgroup shared by WP6 and WP7. After some discussion we agreed to call this subgroup PLAIN, which stands for Producing Recommendations in Plain Language Intended for Parents and Survivors. Our first task deals with the first publication arising from a joint PanCareSurFup/international Guideline Harmonisation Group. The paper describes breast cancer surveillance for female survivors of childhood, adolescent, and young adult cancer given chest radiation (Mulder et al, 2013) At present PLAIN is engaged in "translating" these recommendations into language that can be easily understood by survivors and their families.

Other dissemination tasks include creating brochures about PanCareSurFup into several European languages, including French, German, Italian, Polish, Czech, Romanian and Hungarian. PCSF members distribute these at all the meetings they attend.

MJ: So far we have organized several important social and media events to disseminate the PanCareSurFup (PCSF) projects: the first one in Dublin (organized by Julie Byrne) in the wonderful frame of a rugby stadium, with the participation of parents' associations, long-term survivors, parents, besides international physicians and other healthcare team members; two editions of the "The Race of Brave Bikers" in Marostica (Italy) – organized by myself and linked to an official bike race – where long-term survivors coming from different European Countries could take part in a competition and were also involved in a scientific round-table, open to general public, where they could discuss and promote some social initiatives; more recently, PCSF



Dr Momcilo Jankovic



Ms Julianne Byrne

was officially introduced and explained at a MSC-cruise gala dinner in Genoa (Italy), together with Associations for adulthood haematology, in presence of journalists and local authorities. These social events were sustained also by dissemination through pamphlets (translated in different languages for distribution in different countries), banners and other printed material to inform people about the scientific/social projects promoted by PCSF. Finally, a linkage to Facebook and Twitter was also established by survivors.

Why is it so important to communicate?

JB: Most people seem to think that research is something distant, unrelated to their everyday lives. In fact, research is behind everything we do, from making toast in the morning (who invented the toaster?) to our sandwich at lunch (how do we make food safe?) to flying to a PanCareSurFup meeting (how do planes stay up in the air?). The job of WP7 is to show people how the work of PanCareLIFE has direct consequences for the health of long-term survivors of cancer diagnosed during childhood. For instance, how can we develop better care systems if we do not first understand what are the long-term health risks? WP7 shows how the results of research can be turned into guidelines to help deliver the best quality care, and further, to empower survivors and their families to advocate for their own health care. As scientists, we do a poor job of communicating our work to the general public. After all, the general public is asked to pay for PanCareSurFup; they should understand what they are paying for.

MJ: Communication is the essential basis to share and accompany any decision, any project, any plan of cure and care. If we are able to start a truly effective communication we are half-way to achieving great results. Communicate does not only mean to speak, but also to listen to and to be able to involve people with both a scientific and non-scientific background.

It is important to communicate, but it is not an easy task. We should believe in what we are doing and, in this way, create a feeling and a connection with people, able to induce in them an acceptance of what we want to share with them. Seriousness, credibility, simplicity, effectiveness are the main elements and aspects that we should have in mind.

What has been the most important moment during the events promoted so far?

MJ: The most important moment during the events promoted so far has been the dinner in the Castle of Marostica, in a terrific scenario on the top of a hill (outside) and the “magic” environment in the dinner room (inside) where doctors, survivors, parents, organizers, “athletes” (thus a mixed group of people) laughed and ate together as “old friends”, with the same purpose of disseminating the information that survivors are normal people and require attention and care to achieve their best concept of cure from a medical, psychological and social point of view, as claimed by WHO.

How do you plan the future awareness-raising events?

MJ: This is a hard “challenge”. I believe, and I am working in this direction, that it is necessary to involve in our promotion some important companies or some acclaimed and famous testimonials (from the sport or movie or TV field).

The two main goals are: a) dissemination of information and credibility on what we are doing for our survivors; b) fundraising to implement and increase some scientific/research initiative. Without research, there is no progression.

Who are your main partners? Do they work at the European or at the national/local level?

MJ: PCSF is working both at the national and international level. At the national level it is supported in a great way by the local parents’ association or charities (wonderful examples could be found in different European countries) that made a terrific job in promoting the media initiatives already carried out in a winning way. At international



level a unique support was achieved by ENCCA (European Network of Cancer Research in Children and Adolescents) and SIOP Europe through their initiatives and by their members. A great help also came from ICCCP (International Confederation of Childhood Cancer Parent Organizations – Mrs Gerlind Bode belongs to PCSF).

Why should the work coming from PanCareSurFup be sustained on the long-term?

JB: Survivors of childhood cancer diagnosed in the decades to come will be exposed to the best medicines we have, designed to cure their cancer and reduce the late effects. But our best evidence obtained with current studies, like PanCareSurFup, concerns treatments that may become obsolete. We must sustain these types of studies so that we can document the existence of new late effects, or the reduction of well-understood late effects into the future.

MJ: The way is long and the process for obtaining visibility is slow. Now, after 3 years, PCSF is not a neglected or dark entity, but, it counts something in the scientific and social landscape and the work, from a scientific point of view (data, analysis, creation of essential guidelines, building of transition process), is going on and PCSF has now a privileged role in the promotion of health care of survivors from childhood cancer. We have to remember that young people are the future of our society and we should care them at the best. So what we have started and developed requires time to be sustained effectively.

Do you think it is easy to illustrate and explain the project to the lay public?

JB: No, it is not easy. Imagining being the parent of a child with cancer is any parent's worst nightmare, so naturally, people don't want to imagine how we do our work. Further, development of risk estimates for second malignancies and cardiac disease is far removed from most people's everyday concerns that it seems exotic. Explaining research like PanCareSurFup to the average person-in-the-street is not easy.

MJ: Yes, if we, as promoters, believe in the PCSF activity and projects. Two important steps: methodology and time. The process is possible, but it is a long-lasting process and the barriers are not easy to be overcome. Methodology is based on specific strategic ways, addressed to a common purpose: make sensitive and receptive people, without pietism but with concreteness. Time, because to sensitize people you should be continuous and not in a hurry; it is important to promote something periodically, and to have published stuff for dissemination.

What do you love most about your job?

JB: Mostly, I love working with people. I find it rewarding and creative to help people understand something that was previously vague, and to 'get' scientific concepts. At the same time, every dataset carries a story within it; working with the data to expose the story inside is totally immersive and very satisfactory. I am lucky to be an epidemiologist, to be able to work with both people and data.

MJ: I decided to become a doctor during my high school because I love the contact and the sharing with people. I love to be a pediatric haemato-oncologist (despite my fear of blood when I was a young student) because I wanted to care the entire body of a person (Internal medicine) and Paediatrics realized this my dream, haemato-oncology because my first fellowship was done in Paediatric hematology and it was "love at first sight".

What I most love in my job, even if I am now 61 years old, is to learn from kids. Kids are the "best teachers of life" but we have to look at them, to listen to them, to bend to their level... it is the only way to learn! It is a hard job (as any type of job if developed at the best) but full of humanity and I am still happy even more than 35 years elapsed.. You should have the ability and the skilfulness to transfer enthusiasm to your children and families for fighting the disease with the ultimate goal of winning. Winning is not only to get a complete cure (nowadays obtainable in about 80% of children with cancer) but to offer the best quality of life at 100% of children.



PCSF activity is part of my daily duty and absolutely I must find time for developing the content of its issues: research both clinical and basic are mandatory in our job.

Please describe one of your proudest moments or an achievement you are particularly proud of.

JB: Getting the PanCareSurFup consortium funded was one of the most amazing days of my life. I would never have dreamed that this project, among many other worthy projects, would be approved and funded by the EU. I am fortunate to work with this dedicated and talented bunch of people. The existence of the PanCare network and the two consortia that I am affiliated with (PanCareSurFup and PanCareLIFE) has brought new friendships, and new interests into my life, at a time when most people would be thinking of retiring. I have been blessed.

MJ: I would like to report the following event that occurred few years ago.

I was attending two adolescents (girls) aged respectively 12 and 17 years, in terminal phase from ALL in second relapse not responsive to any treatment but still in quite good clinical conditions. They wished (and asked me for) to meet and spend some time with their favourite actor, George Clooney... not an easy task! They pled me with enthusiasm and expectation for realizing their dream, and this has been hard trouble for me. In any case, I used all my means and contacts and I finally obtained -with the help of his Italian body-guard - an appointment with Mr Clooney. It was on Sunday 31 July 2005, at 2.30 p.m. at Clooney's Villa in Lario on the Como Lake. The 2 girls and 1 boy affected by AML, son of the American Ambassador of U.S. in Italy for 3 years, came with me in my car. The happiness and the excitement of the 3 guys as well of those of their parents were "at the top of the sky". The 2 girls were so nicely dressed and wearing make-up that it was really hard to believe that they were in terminal stage from their disease. My car where the 3 guys were seated entered to the Villa half an hour in advance (you can imagine the emotion), a man in t-shirt and jeans was waiting for us. He opened the car door and the 2 girls dropped astonished in his arms....he was George Clooney himself! We spent 2 intensive lovable hours in his luxury kitchen where the cook prepared sweets, cakes and ice-creams, and we talked with him about different topics. Later he gave to each child a gift: a leather suitcase containing the DVD of his last movie "Good night, good luck" to both girls and the Ocean 12's suit to the boy. A lot of pictures as memory of this unique event were taken.

It was a great success, although both girls died 3 weeks later. Today their parents still call me not for the anniversary of their death but for the anniversary of that unbelievable Sunday, when the happiness and the lighted eyes of their daughter represented for them the worthiest gift... as for me too.

The laugh of a child doesn't have a price and is able to make my job and my efforts more acceptable and workable... Charlie Chaplin said: "A day without laugh is a lost day".



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