



PanCareSurFup Bulletin, Issue nr. 6

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

Dear Friends,

Since Bulletin #5 we have got a response from the Commission on our Financial report, and queries from this are being addressed at the moment. So far, no response from the Commission has been received on our Scientific report.

At present, we are preparing for the next General Assembly of PCSF that will take place in Wroclaw, Poland, on 14-15 May in connection with the 13th PanCare meeting on 12-14 May. In Wroclaw, we will summarize the first three years of our project and look towards the coming two years in relation to the remaining tasks and deliverables.

It is an important meeting since it will address the timely delivery of everything that we have set out to deliver and relate this to both the financial and the scientific agendas of PCSF.

In Bulletin #6, Ms. Aimilia Tsirou from Greece gives us both an insight into Kyttao, the Greek association of childhood and adolescence cancer survivors, as well as into her personal journey. Please have a look as this is both valuable and important information.

I wish you all a continued good spring and a long and relaxing Summer!

All the best,

Lars Hjorth

Coordinator PanCareSurFup



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PanCareSurFup Partners

The project's dissemination team this month interviews Ms. Aimilia Tsirou, founder of 'Kyttaro', the Greek Association of Childhood and Adolescence Cancer Survivors, and partner in PanCareSurFup.

Can you describe how you got involved in PanCareSurFup?

I represent 'Kyttaro', the Greek Association of Childhood and Adolescence Cancer Survivors, which established in 2007. I have attended a lot of ICCCP0 meetings since 2002 but the start was after ICCCP0 Europe meeting at Basel in 2013, where I met other survivors who were working on the PanCareSurFup expansion: since then, we are collaborating actively and closely in order to spread it out and involve more survivors and countries!

What are the main long-term effects you may have encountered after having been treated for cancer?

I have faced ototoxicity side effects and I have lost one's ear hearing ability completely.

Are GPs and/or researchers able to understand their cause in your opinion?

Yes, they are able to understand the cause because these days there are researches and studies that refer to the 'most common' long-term side-effects of childhood and adolescence cancer treatment. A GP should be responsible not only for patient's treatment, but also for the possible side-effects of it, even after years.

How did you react to this new challenge? How did your parents react?

When the hearing loss was found, I lost 'my world'. I had built a life philosophy without cancer, or any 'complication' of it, and this ruined my world. It took me a lot of time and thinking to appreciate that every victory has its cost. The point is that we survived. Wounds and limitations are 'medals' of our victory. My parents got worried but they stayed calm and tried to find a solution to this new health challenge.

Did you receive any support from patient/survivors' groups? Did PanCareSurFup partners help you to establish a contact with such groups?

I received great support from survivors of my group, former 'Kyttaro'. My side-effect appeared in 2001, so I think that PanCareSurFup didn't exist at that time. But in 2002 I attended the ICCCP0 meeting in Oporto and the survivors whom I met there were very supportive and able to understand. They helped me a lot.

What is the main thing you would change as concerns the public perception of young cancer survivors? Do you think 'survivor' is the appropriate word to describe your experience?

I would like to believe that survivors are normal persons as their peers, possibly with some special needs and surely with gifts that the 'battle against cancer' left behind. I don't really know if term 'survivor' is appropriate, because I find that include a sense of 'passive behavior'; it assumes that you have been left alive after a physical



Ms. Aimilia Tsirou

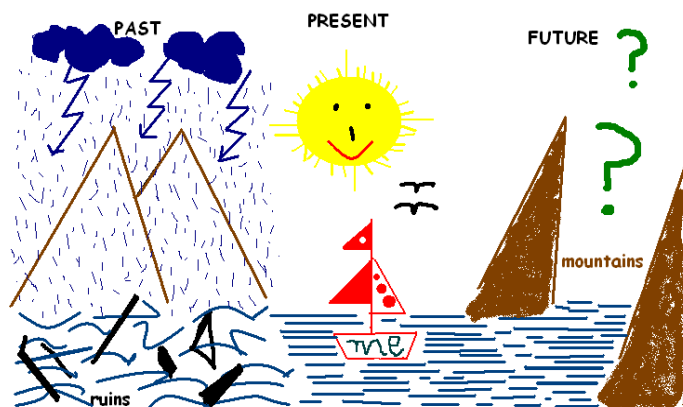
disaster without your involvement or actions. But, since it's useful for the medical community as a term referring to us, I don't mind. Besides, 'action speaks louder than words'.

Would you recommend other survivors like you to take part in an international research study?

For sure! It's the only way for survivors to 'be helped' in facing long-term side-effects and to 'offer help' to current and future patients.

Please describe one moment or an achievement that you are particularly proud of.

I think that I am really proud of managing to establish Kyttaro, the Greek Association of Childhood and Adolescence Cancer Survivors, in 2007. It is an achievement of every survivor who is involved and gives courage and hope to current patients and their families, and support and care to survivors!



The future is hidden behind the mountains.
And if these are the Clashing Rocks?
There is only one way to discover it, to live it!

For more information, please contact:

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