Greetings from the PanCare Board

Dear members,

On behalf of the entire PanCare Board I would like to wish you a Happy New Year 2013. We had a very successful and well-attended meeting early October in London after SIOP, thanks to the generous work and time of Gill Levitt and co-workers. The Board has since then held two telephone conferences and work is ongoing on matters of the Constitution and Membership. In order to structure the work of the Board more, Heleen van der Pal from Amsterdam has been elected Honorary Secretary, and Gill Levitt from London has been elected Honorary Treasurer.

From 2013 we will be asking for a membership fee but the exact details and the value of being a member remain to be decided upon. The next PanCare meeting will be hosted by Riccardo Haupt and held in Genoa in Italy from lunch to lunch April 17-19. Details for this meeting will be forthcoming early this year.

Once again, best wishes for 2013 for you and your families from the entire Board.
Report from the 10th PanCare Meeting,
October 8-9, 2012 in London
by Gisela Michel

The PanCare meeting was taking place after the SIOP conference 2012 in London, at the Barbican on Monday and at the Institute of Child Health on Tuesday. Maybe it was due to the previous SIOP conference, which many of the PanCare members attended, that we were able to listen to some very interesting talks such as a presentation on quality of life after childhood cancer from Sarka Karova from Brno, Czech Republic. More information about the PanCare’s own projects was then presented by Alex Bronwsdon on the Survivornet and Stefan Essig, Eva Frey and Heleen van der Pal and Gill Levitt on Follow-up Care and transition. The day then ended in the near Pub “The Jugged Hare” with great English food, wine and beer and intense discussion between all the attending PanCare members.

The second day started in a rather crowded room at the Institute of Child Health. This day was mostly concerned with PanCare business aspects resulting in lively discussion were throughout the day. It now seems that the PanCare constitution, on which we have been working for several meetings and which was discussed repeatedly, is now gaining substance and could finally be launched in one of the next meetings. An important achievement of PanCare are certainly the collaborative projects, one of them already running for almost two years (PanCare SurFup), and the second just being submitted to the European Union before the meeting in London (PanCare LIFE).

However, another interesting meeting is not the end of our work, and we are looking forward to the next meeting in Genova in April, 2013.
As a result of advances in treatment, 70 - 80% of children with cancer become long-term survivors. In Japan, the estimated number of childhood cancer survivors (CCS) is more than 50,000-- or about 1 of every 700 adults between the ages of 20 and 39 years. During the past 8 years, we conducted three kinds of clinical research regarding the long-term FU (LT-FU) for CCS. First, we established a LT-FU committee as part of the Japanese Pediatric Leukemia/Lymphoma Study Group in 2005, in which we created a standardized treatment summary form recording disease characteristics, treatments received, and complications that may have occurred during therapy. Now we have almost finished the original LT-FU guideline for standardizing clinical practice in Japan. Second, we conducted several retrospective studies on CCSs, including an exploration of how many CCS are lost to FU and reasons why survivors dropped out of LT FU care. Our study revealed that attending pediatricians and CCS/families tend to have a very intimate long-term relationship in Japan. This is a double-edged sword as many CCS want to continue seeing their previous treatment providers well after completion of their treatment and into adulthood. In addition, most CCSs quit regular medical visits after their attending pediatrician transfers to another area or retires, one of the main reasons for FU loss for CCS in Japan. In another cross-sectional survey, we used self-rating questionnaires to determine late effects, QOL and psychological problems of CCS. In this study, late effects were found in information provided by the attending physician in 50% of females and 64% of males in the CCS group. Third, we created a model for LT-FU clinics in 16 hospitals across Japan, initially creating a CCS database for LT-FU candidates in these hospitals. Currently, 5,500 living CCSs are registered in total. Among these hospitals, we have conducted a retrospective cohort study on secondary neoplasms. We are planning to establish a centralized LT-FU center to connect these LT-FU clinics, facilitating larger cohort studies in the future. To optimize risk-based care and promote health for CCS through adulthood, we have been pursuing appropriate LT-FU programs and models. One of the most promising and useful model is PanCare project which was presented by Prof. Hjorth in the 54th Annual Meeting of the Japanese Society of Pediatric Hematology and Oncology in Yokohama. We enjoyed the elegant dinner cruising tour in Yokohama which is the first city introduced to the world as the entrance to Japan. Not only the members of Japanese LT-FU committee but also Japanese CCSs had enjoyed the sharing time with Prof. Hjorth very much.
The annual ICCPPO conference was held jointly with the Congress of the International Society of Paediatric Oncology (SIOP) in London (United Kingdom) from October 4th – 8th, 2012. Actually in parts too good, too busy, too many interesting topics going on at the same time, which made it hard to choose between the ICCPPO representations and those from the general SIOP-program. The room was packed most of the time – not only by parents and survivors, but also by many professionals. As London was (relatively) easy to get to for many people – not only from Europe, there was a record attendance. The program, set up mainly by Val Figliuzzi (Canada) and Anders Wolmén (Sweden) encompassed topics like the 5-year report of World Child Cancer about successfully supporting projects in developing countries, on medical information, on long-term effects, the importance of healthy life-style, early detection campaigns, and on organizational strategies for parent support groups such as how to keep a group going and fundraising issues. One important item on the agenda is the annual “Meet the Experts panel” this time on late effects. Mark Greenberg, Lars Hjorth and Susan Mehta gave a good overview of possible late effects and the importance of transition care for survivors. After this the experts were available for questions from the parents and survivors. Delegates from all around the world, from almost all European countries but also as far as India, Bangladesh, Africa, USA, Canada, Latin-America came to listen, to exchange and interact. And it was good to see many 'old' faces among them besides all those new ones from known as well as new groups. Our local hosts, the Childhood Cancer Parents Alliance UK (CCPA), especially Abby White and Rachel Olley have done a tremendous job to find nice places for the Meet&Greet as well as the ICCPPO-Dinner and organized those events perfectly. But still, both events were again perfect opportunities to 'mingle' and get known to each other. This year around 30 survivors from 17 countries attended the conference and as usual some sessions were especially for survivors. Sabine Karner and Michaela Willi, who were responsible for the survivors programme tried to make diversified sessions. The topics ranged from country reports of national survivors activities and initiatives, comparison of mentoring projects, how to establish a survivors group and keep it going to a workshop on how to raise more awareness of childhood cancer. Additionally, this year external presenters were involved: Jean-Claude Dupont gave an overview of the views from parents and patients about tissue-banking and Stefan Essig presented current results of his research about the "Quality of web-based medical information for childhood cancer survivors". After all those pre- and post-meetings, the numerous board- and ad-hoc meetings most of us were extremely tired and ready to go home – not without the sincere feeling: we should have had more time to cover more and should have had more time to talk with others. But isn't that always the fact? Now we will have to get ready for next year's meeting in Hong Kong or in the intervening time the ICCPPO Europe meeting in Basel.
Little People’s activities in 2012
by Katie Rizvie

One of Little People’s highlights in 2012 was hosting the 9th PanCare meeting in Bucharest. It was wonderful to have so many of you visit Romania. Others include the birth of our glossy news magazine for survivors, titled Revista TEMERARII – which is also available for teenagers and young people currently fighting cancer, and is freely distributed in hospital wards across Romania.

We also organised two exciting events, each with more than 150 survivor participants. Our summer camp became an international event, where Czech and Moldovan young people discovered their strength and talents, learned about themselves through self-awareness workshops, improvisation and situational games, participated in leadership training, carrier orientation and project management amongst their Romanian counterparts. An elegant Christmas Gala closed the year in the historic city of Iasi in northern Romania, close to the Ukrainian and Moldovan borders, featuring our first masquerade ball, complete with chamber music, ballet, dinner accompanied by the lovely tunes of the piano, and the unforgettable waltz danced by every single pair in attendance. The young people were spoiled by live performances throughout the night and the elected king and queen of the ball then led us into games and fun until the early hours of the morning. Besides all the glamour and fun, TEMERARII, the Romanian survivors group was also instrumental in carrying out one of the furthest reaching community campaign that Little People organised to date. In October 2012, using social media and the press to reach schools, businesses and the general public, we inspired people in all walks of life to wear yellow for one day in honour of cancer survivors. For more than a week the association’s Facebook page was flooded with photo responses and comments from fans across Romania, and more than 3000 people sent in their pictures wearing yellow that day. Within a week of the campaign we reached more than 200 000 people on Facebook alone, 75 000 through bloggers and millions through national television and radio broadcasts.