



**PanCARE**

Pan-European Network for Care of Survivors  
after Childhood and Adolescent Cancer

# *PanCare Newsletter*

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**Dear Friends,**

**Coming to the Holidays season, PanCare can look back at yet another productive year, not least thanks to the successful meeting in Lucerne in October which was very generously hosted by Gisela Michel and her team. We know that the next meeting in Dublin in May, 2015 will be an equally great meeting and look forward to working together with Patricia McColgan and Garry Owens as the local organizers. Please have a look under "meetings" for other events coming in the next year.**

**Finally on behalf of the entire Board I would like to wish you and your families a Very Merry Christmas and a Happy New Year.**

**Lars Hjorth, Chairperson**

### **INSIDE THIS ISSUE:**

Greetings from the PanCare Board .....	1
Report from the 14th PanCare Meeting .....	2
Access to information, health management, support services- a Romanian cancer survivors study .....	3
News on internet-based information portal for German survivors .....	3
SIOPE-ENCCA meeting conference 2014.....	4-5
Survivor group meeting in Vienna .....	5-6
Upcoming meetings .....	7

[www.pancare.eu](http://www.pancare.eu)

## 14th PanCare meeting- Lucerne, 8-10th October 2014

The second 2014 PanCare meeting took place at the beginning of October in a lovely location in the middle of Switzerland. Close to the historic city center of Lucerne and surrounded by high mountains, the conference was hosted by Gisela Michel in one of the hotels near the lake (Vierwaldstättersee).

During first day we saw impressive presentations on the Swiss Childhood Cancer Registry and the Survivor Studies, as well as updates from PanCareSurFup, PanCareLIFE and ENCCA WP13.

The second day of the meeting was split between project leaders sharing news on the first results from the existing projects, the future plans, process of developing guidelines and survivors/parents issues.



In the invited abstracts section we heard among other things about Czech "My new life project" and a very interesting German initiative for an internet-based information portal dedicated to childhood cancer survivors (you can read more on page 3). During the General Assembly a proposal for new committees and working groups was raised.

The second day ended with an outstanding moonlit dinner served on board of a boat that took us on a cruise on Lake Lucerne. Many thanks to the parents who made this lovely evening possible.



On the last morning of the meeting we could see how various transition programmes are being developed and how much input from the nursing staff can help with follow-up for late effects after cancer treatment. Then as a farewell we learned about the next meeting that will be organized by Patricia McColgan and Garry Owens in May in Dublin.

Thanks to the authors you can find most of the presentations from the meeting at the **PanCare website** (<http://www.pancare.eu/en/meetings/lucerne-2014/>).

Anna Panasiuk, Poland



**ACCESS TO INFORMATION, HEALTH MANAGEMENT, SUPPORT SERVICES  
- A STUDY ON HOW YOUNG ROMANIAN CANCER SURVIVORS PERCEIVE THEIR OWN  
HEALING JOURNEY AND FUTURE PERSPECTIVES**

Authors: Katie Rizvi, Amalia Axinte (Little People Association, Romania)

**SUMMARY:** The study investigates young Romanian cancer survivors' perceptions about their treatment period as well as their lives after end of treatment, particularly exploring their views on access to information, effective support services, reintegration and readjustment difficulties, as well as health-related concerns after end of treatment. The study group was represented by 117 young Romanian cancer survivors aged between 14 and 29 years who anonymously responded to a questionnaire developed by the Little People Association. The results show the importance of supporting health professionals who interact most with the teenage and young adult demographic, and whose means of communicating and connecting have a profound effect on the way young people perceive their own illness, treatment options and hope for healing. The study also reveals possible causes behind the young survivors' reluctance in showing up for regular medical checks, as well as what the young people believe would improve treatment adherence of teenage and young adult patients in general.

Full text at the PanCare webpage:.....

**News on the internet-based information portal on (long-term) aftercare  
and services for childhood cancer survivors in GPOH-associated countries:  
Online-survey now open for data entry by health care providers**

By Katja Baust, Germany

(Thorsten Langer, Ursula Creutzig, Ingrid Grüneberg and Gabriele Calaminus  
for the working group „long-term surveillance“ within the GPOH)

As announced at the PanCare Meeting in Lucerne, the online-survey has been open for data entry to health care providers since mid-November in GPOH-associated countries. The project aims at presenting (long-term) aftercare and services for childhood cancer survivors, parents and other health care providers by utilizing a central internet-platform to improve information accessibility for those services. The basis for the information portal will be built upon the currently used online-survey.

Health Care Providers are asked to complete the online-survey, which assesses details on their potential services. If a service is not offered by them yet, but they are aware of someone who does it, they are asked to indicate the mail-address of a corresponding contact partner. The survey link was distributed via mailing lists, which included e.g. GPOH members, the members of the psychosocial branch of the GPOH and parent organizations.

More than 50 health care providers have already completed the online-survey. A great majority of them have indicated more than one service. As of 08.12.2014, 96 data sets are available. Due to the overwhelming interest in the survey, services offered in Austria, Switzerland and Luxembourg have also been included. Currently collected services span the entire range of possible care, including (special) medical consultations as well as (neuro)psychological counselling, re-integration support for school and career, sport therapy and regular meetings or activities organized by self-help initiatives.

Following a final reminder planned for January 2015, the data sets will be reviewed and validated by experts and the managing group. Only validated data-sets will be included in the information portal for (long-term) aftercare and services. Regular updates are scheduled yearly. **The expected launch date for the information portal for survivors and parents is spring 2015 via “kinderkrebsinfo” (www.kinderkrebsinfo.de), supported by “Deutsche Kinderkrebsstiftung”.** Diversified search options including e.g. details on region, age appropriate services and regular availability will simplify the search.

The online-survey was initiated by the GPOH long-term surveillance working group, granted by the GPOH and realized by the VIVE Group and the “kinderkrebsinfo” team. The assistance of all working group members is greatly appreciated. Thanks to all health care providers who have already completed the online survey. The high interest reflects the growing need for (health) care services for former patients of childhood cancer.

**SIOPE-ENCCA Conference 2014:  
“Joining Efforts for a Brighter Future for Children and Adolescents  
with Cancer”**

*By Sabine Karner, Lars Hjorth and Giulia Petrarulo*

The unique SIOPE-ENCCA Conference 2014 "Joining Efforts for a Brighter Future for Children and Adolescents with Cancer- The European Roadmap to Horizon2020" took place on 18-19 September 2014 in Brussels.

The SIOPE-ENCCA Conference co-organized with the parents' representatives from ICCPO Europe, aimed to ensure the widest possible consensus on a comprehensive Roadmap. The objectives are to increase the cure rate in poor prognosis malignancies, to eradicate inequalities in childhood cancer care in Europe and to increase the quality of life of childhood cancer survivors. This Roadmap is the outcome of the coordinating efforts of SIOPE (the European Society for Paediatric Oncology) and ENCCA (the FP7 project 'European Network for Cancer research in Children and Adolescents') at the European level.

Some 160 stakeholders from 31 countries attended this unique event of the paediatric oncology community. MEPs (via video message), representatives from national authorities as well as the European Commission (DG Research, DG Sanco), parents and patients representatives, charities and healthcare professionals representing paediatric haematology oncology and adult oncology came to Brussels. Participants strongly agreed on the need for concerted efforts of health professionals, researchers, parents, industry, policy-makers, regulators and charities, in order to speed up developments with regards to the newly agreed roadmap.

SIOPE and the European paediatric-haemato-oncology community joined forces to create a brighter future for all children and adolescents with cancer: this ground-breaking event successfully ended with the commitment of all participants to jointly work on a '**European Paediatric Cancer Plan**' addressing both care and research.

This Conference- taking place in September, the international 'Childhood Cancer Awareness Month' - has been a crucial step towards making this future a reality.

The following objectives (see the next page), together with the necessary tools and structure to address them, have been integrated in a comprehensive document published in Paediatric Blood and Cancer (September 2014 issue, open access at <http://onlinelibrary.wiley.com/doi/10.1002/pbc.25044/full>). They have analysed, shared and fully endorsed during the SIOPE-ENCCA Conference. The final document emerging from the event will be published and circulated in the first half of 2015.

## ***The 7 objectives of the Roadmap:***

1. Introducing safe and effective innovative treatments (new drugs, new technologies) into multidisciplinary standard care;
2. Driving therapeutic decision by improved risk classification and use of molecular characteristics (tumour, patient) – precision medicine;
3. Increasing knowledge on tumour biology and speeding up translation to benefit patients;
4. Increasing equal access across Europe to standard care, expertise and clinical research;
5. Addressing the specific needs of teenagers and young adults, in cooperation with adult oncology;
6. Addressing the long-term toxicity and cancer treatment consequences including the genetic background/risk – quality of survivorship;
7. Understanding the causes of paediatric cancers and setting prevention where possible.



### ***More information:***

Full text Roadmap: <http://www.siope.eu/wp-content/uploads/2014/09/Paediatric-Haematology-Oncology-The-European-Roadmap-to-Horizon-2020.pdf>

View presentations and photos: <http://www.siope.eu/news-and-resources/conferences-and-events/siope-encca-conference-2014/>

## **SURVIVORS GROUP MEETING IN VIENNA**

By Sabine Karner and Zuzana Tomasikova

A "Survivors group meeting" organized by the Austrian Survivors group and Österreichische Kinder-Krebs-Hilfe (Austrian Childhood Cancer Parents Organisation) took place in Vienna on the 22nd of November 2014.

More than 25 participants from Croatia, Czech Republic, Poland, Romania and Slovakia came to visit Austrian survivor group representatives and some of those even enjoyed pre-Christmas Vienna. The main aims of this exchange meeting were to share the experiences of the Austrian survivors group with the participants, to offer insight into the different Austrian activities and to inspire regional/national future activities of the 'colleagues' abroad.

### **Why setting up a survivors group?**

It is not always so obvious that former paediatric childhood cancer patients (and now adults) get active, set up a survivors network/group/organization and offer special activities for survivors or patients within their country. Even though the Austrian survivors are quite active, it was wonderful to see that these activities attract also a wide interest from survivors and survivors supporters from different countries. And so, further steps for the long way of strengthening of European collaboration of survivors could be taken.

Survivors groups/networks/organisations can be an essential support for survivors themselves, as well as for current patients and families. Since their aims differ and range from providing social contact, sharing experiences and knowledge up to giving back hope to those, who are still living with cancer, it makes the groups very important.

### Sharing experience and give inspiration

Within the first half of the day the Austrian survivors group provided a lot of information about the history, development and the structure of the group, as well as presented the current activities, especially the mentoring project and linked training course. Beside the focus on the national activities it was also very useful for the participants to give information and raise awareness of the International Childhood Cancer Survivors Network (ICCSN), which is an existing network within the CCI/ICCCPO organization.

ICCSN offers already some helpful tools for survivors groups (initiatives), like a handbook "How to establish a survivors group and keep it going" and is responsible for organizing session dedicated for survivors representatives at the international and European CCI/ICCCPO meetings (for more info look at ICCSN). All the presentations were opened for questions anytime during the talks and so a lively discussion started already before lunch break.

The second half of the meeting focused on the needs of the participating countries, where the group could work on country-specific issues. Afterwards their output and challenges were presented in a plenary session.

Participants from Czech Republic, Poland and Slovakia worked intensively on the topic how to set up a survivor group, since there is no legal/formal existing group YET (☺) in these countries. Croatian survivors looked into and gathered information about how to set up a mentoring program. For Romanian participants the future needs how to be more active on a health political level and the improvement of the long-term follow-up care for survivors played an important role. The meeting was very productive and exhausting (☺) at the same time, we were not even able to discuss all of the upcoming topics in detail.

### Next activities

We all had the impression of a high level of interest and need. Survivor groups from across Europe should get connected and share their experiences to strengthen their national activities/aims as well as the pan-European survivors collaboration. The next (short cut) opportunity is the Open Summit organized by the Romanian organization "The Little People", the weekend before Christmas in Bucharest, where already some participants from this exchange meeting will meet again. Following that the next meeting is the 6th CCI/ICCCPO Europe Regional Meeting in Malmö (Sweden) from 8-10 of May 2014.

Looking forward to see you there!



## UPCOMING MEETINGS 2015

<b>January 15- 16</b>	ENCCA General Assembly, Brussels, Belgium
<b>May 8-10</b>	ICCCPO meeting, Malmö, Sweden
<b>May 18-20</b>	PanCareLIFE General Assembly, Mainz, Germany
<b>May 26-27</b>	PanCareSurFup General Assembly, Dublin, Ireland
<b>May 27-29</b>	15th PanCare meeting, Dublin, Ireland
<b>June 11-13</b>	14th International Conference on Long-Term Complications of Treatment of Children and Adolescents with Cancer, Arlington Virginia, USA
<b>June 24-27</b>	Paediatric Radiation Oncology Society meeting, Ljubljana, Slovenia
<b>September 22-23</b>	PanCareSurFup General Assembly, Vienna, Austria
<b>September 23-25</b>	16th PanCare meeting, Vienna, Austria
<b>September 25-29</b>	European Cancer Congress, Vienna, Austria
<b>October 8-11</b>	SIOP, Cape Town, South Africa
<b>November 4-6</b>	PanCareLIFE General Assembly, Mainz, Germany
<b>December 17-18</b>	ENCCA General Assembly, venue to be decided



*Warmest wishes  
for a happy holiday season  
and  
lots of inspiration and gratifying  
work in the New Year!*