



# POPPI Newsletter

Pediatric Psycho-Oncology  
Professionals/Providers  
International

Issue 4: May 2019

## STEERING COMMITTEE

## WELCOME TO THE FOURTH ISSUE OF THE POPPI NEWSLETTER



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## A welcome note from the Chairs

by Martha Grootenhuis, Claire Wakefield, and Lori Wiener

Welcome to the fourth Issue of the POPPI Newsletter:  
Pediatric Psycho-Oncology Professionals/ Providers  
International!

The goals of POPPI are to stimulate international communication among professionals with a diversity of clinical and research backgrounds in order to foster collaboration in clinical care, research and education that relate to pediatric psycho-oncology, and to share resources, training opportunities, ongoing research, and upcoming events in the field of pediatric psycho-oncology.

Our hope is that this newsletter will provide information which will bring our field closer together and help each of us to deliver the highest quality of care to youth with cancer and their families.

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# Research “in the spotlight”

## Researcher in the spotlight: Dr Gisela Michel

*By Gisela Michel, Switzerland*

*Dr Gisela Michel is an Associate Professor in Health and Social Behaviour at the University of Lucerne in Switzerland. Gisela shares with us some of the research her group are currently working on.*

Hi. I am Gisela Michel. I am a clinical and social psychologist by training and have worked in childhood cancer research since 2004. With my research group, we are addressing psychosocial aspects of childhood cancer with a specific focus on survivorship, follow-up care and the family of patients and survivors.

We have recently completed data collection for a project on parents of very long-term childhood cancer survivors. Our aim was to find out about parents' well-being when they, as a family, survived cancer in one of their children. We wanted to know more about the disadvantages they encountered, but also about the positive changes they experienced.

First results indicate that even if parents reported diverse problems, and families could have used additional support at various stages of the cancer trajectory, they overall also reported many positive outcomes. Overall, cancer seems to have made them stronger as a person and as a family. In two ongoing studies, we address screening for psychological distress in follow-up care and psychosocial needs for support in survivors.

This research was initiated by survivors themselves, and we hope that we can soon help them improve their website with information on how and where to find adequate help and support if they encounter psychosocial problems.

Finally, we just started a project on the involvement of and care provided by grandparents when a grandchild is diagnosed with cancer. With the diagnosis of cancer in a child, family life falls apart for many families. Often grandparents help to get through the turmoil of this new family situation.

With our study, we want to find out about the care and support grandparents provide. With health economic analyses, we will also be able to value the informal care that grandparents provide. Additionally, we will address the experiences and long-term outcomes of the grandparents themselves. We hope that with this project we will be able to provide information and support to those who support the family system during the difficult time of cancer diagnosis and treatment.



*Pictured above: Dr Michel (third from right) and her team*

## Research article in the spotlight: Organ and tissue donation

**Darlington AS, Long-Sutehall T, Randall D, Wakefield CE, Robinson V, Brierley J. 2018. Parents' Experiences of Requests for Organ and Tissue Donation: The Value of Asking. Available at SSRN 3234866.**

*By Anne-Sophie Darlington, UK*

*Dr Anne-Sophie Darlington is an Associate Professor within Health Sciences at the University of Southampton. Dr Darlington describes her recent publication on the value of asking families about organ and tissue donation.*



A proportion of children die, making them potentially eligible to be organ and or tissue donors. Previous studies have investigated parents' experiences of discussions of organ and tissue donation (OTD), specifically the experiences of parents whose child was eligible for OTD.

However, we know that opportunities for OTD are missed and with increased awareness through national campaigns, parents are likely to know about the possibility of OTD. Experiences of parents whose child was not eligible have not been investigated. The aim of the study was to investigate to what extent OTD is discussed as part of end-of-life care and to explore

parents' and health care professionals' (HCPs) experiences.

We carried out a multicentre retrospective qualitative study, and interviewed bereaved parents, parents of a child with a long-term condition (LTC) and HCPs. In the interview we asked them whether OTD had been discussed and what their experiences were.

We interviewed 24 parents and 41 HCPs. In terms of new knowledge we found that when OTD is not discussed with parents they sometimes go on to make assumptions about the health and value of their child's organs (e.g. 'not useful', 'not good enough'). In addition, HCPs do not routinely ask, and are sometimes hesitant to ask in fear of damaging relationships. Given the current levels of awareness around OTD, the topic should be raised and we need to find a way to sensitively introduce this topic with parents more routinely as part of good end of life care.

*We will include a link to the article in the next POPPI Issue.*

# Psychosocial Standards of Care Update

## Evidence-based standards of care to be updated with implementation strategies

By Lori Wiener, United States

In 2015, the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)—a large interdisciplinary group of expert stakeholders, published 15 evidence-based standards for pediatric psychosocial care. The Standards have provided centers a blueprint on what evidence-based care should consist of.

They are available to download for free at:

<https://onlinelibrary.wiley.com/toc/15455017/62/S5>

Since the standards were published, we have had many requests for guidance on their implementation. In response, a Matrix (Institutional Scoring Measure) for each standard has been developed.

Additionally, Guidelines (how to) implement each of the standards has also been developed. The Guidelines include strategies and resources/tools to help sites improve their score on the matrix and enhance their current practice.

These have now been reviewed by members of APOSW through an online review system and through an in person focus group. They are currently being updated.

Next they will be reviewed by members of APOS, members of the COG Behavioral Science Committee, and several child life specialists. Once all revisions have been made, they will be made available to all! Future funding through APOS might also be available for centers who wish to study the use of the Matrix and Guidelines in their pediatric oncology programs.

# Global psychosocial services survey

## An invitation: What type of psychosocial Interventions are being used globally by pediatric providers? We need to learn from you!

By Lori Wiener, United States

In order to understand and learn more about the types of clinical/therapeutic interventions being used by professionals providing psychosocial services to children with cancer and their family members, you are invited to participate in a survey that will further our field by helping to clarify the current use and

implementation of interventions and where further training is needed! All answers are anonymous and confidential. We will share the findings in a future POPPI newsletter.

The survey should take between 10-15 minutes to complete. Those who complete the survey will have the option to be entered to win one of 4 \$50 Amazon gift cards.

For more information and to participate, link to:

[https://survey.az1.qualtrics.com/jfe/form/SV\\_6ETyyGPe0vxWYuN](https://survey.az1.qualtrics.com/jfe/form/SV_6ETyyGPe0vxWYuN)

The survey Team includes Lori Wiener (NCI/NIH), Cynthia Fair and June Burke (Elon University), Amanda Thompson (Children's National Medical Center), Marie Barnett (Memorial Sloan Kettering Cancer Center), and Stacy Flowers (Wright State University).

# PPO conference news

## Upcoming Pediatric Psycho-Oncology conferences

### SAVE THE DATE - 2019!

- [16th International Conference of Long-Term Complications of Treatment of Children and Adolescents for Cancer](#): June 20-22, 2019 in Atlanta, USA.
- [International Psycho-Oncology Society \(IPOS\) annual World Congress](#): September 23-26, 2019 in Banff, Canada.
- [The International Society of Paediatric Oncology \(SIOP\) 51<sup>st</sup> Annual Meeting](#): October 23-26, 2019 in Lyon, France.
- [International Society for Quality of Life Research \(ISOQoL\) 26<sup>th</sup> Annual Conference](#): October 20 - 23, 2019 in San Diego, California, USA.

### SAVE THE DATE - 2020!

- [American Psychosocial Oncology Society \(APOS\) Annual Conference](#): March 11-13, 2020 in Portland, Oregon USA.
- [Society of Pediatric Psychology Annual Conference \(SPPAC\)](#): March 19-21, 2020 in Dallas, Texas, USA.
- [Association of Pediatric Oncology Social Workers \(APOSW\)](#): April 27-29, 2020 in Brooklyn, New York USA.

## First symposium on Psychosocial Aspects of Childhood Cancer

By Pernille Bidstrup, Denmark



The aim of childhood cancer care is not only survival, but also reaching a normal life

after cancer - for the whole family. This was one of the take home messages at perhaps the first symposium held focusing exclusively on psychosocial aspects of childhood cancer. The symposium took place on 22 January 2019 at the Danish Cancer Society, Copenhagen, Denmark.

We were able to bring together four international speakers including Martha Grootenhuis, Claire Wakefield, Sofia Hjemstedt, and Raphaelle van Litsenburg, as well as eight Danish speakers together

representing psychology, oncology, rehabilitation, palliation, spiritual counseling as well as perspectives from childhood cancer survivors and their parents.

As the symposium was broadly attended by clinicians, researchers, counselors, representatives from health administration, and the general public this was an opportunity to bring together for the first time representatives of many of key the Danish stakeholders in pediatric psychosocial oncology, but also to discuss future directions of psychosocial aspects of childhood cancer internationally.

Despite improved survival rates, there are still important obstacles such as inequality in survival e.g. in low-income countries as well as

high psychological stress, existential concerns and socio-economic impact in the families of children with cancer. Several ongoing RCTs were presented with inspiration on interventions targeting sleep and rehabilitation of children with cancer as well as psychological stress in the families.

We were reminded how much we need a strong network to develop our research and clinical practice.



Martha Grootenhuis giving an overview of psychosocial interventions to children and adolescents with cancer

## 21<sup>st</sup> IPOS World Congress

By Fiona Schulte, Canada

In September 2019, the Canadian Association of Psychosocial Oncology (CAPO) will host a joint meeting with the International Psycho-Oncology Society (IPOS) called the 21st World Congress of Psycho-Oncology in Banff, Alberta. The conference venue is the Banff Centre for Arts and Creativity.

The shared mission of CAPO and IPOS is to foster the science and practice of psychosocial oncology to improve the care for people affected by cancer through partnerships, research, public policy, advocacy and education.

Our 2019 World Congress will create an opportunity to bring together an international body of health care professionals. This forum encourages new global partnerships and allows for the dissemination of ground-breaking research to professionals and the general public about psycho-oncology.

The theme for this year's meeting is: "A Global Call to Action: Implementing Psychosocial Oncology Research for Optimal Cancer Care".

Keynote speakers include Dr. Christine Chambers, an expert in the area of pediatric health and

knowledge dissemination as well as "SickBoy Podcast" a group of three young men who will speak about the patient experience of cancer and the important of patient-oriented research.

Currently we have received over 730 abstracts from more than 60 countries worldwide.

As the Conference Chair, I look forward to welcoming you to Banff!

### APOS 2019 Conference

By Lori Wiener, United States

In 2018, the Mattie Miracle Cancer Foundation (MMCF) partnered with APOS to provide funding to help support researchers who design high quality research that aims to help implement any of the 15 pediatric standards.

During this symposium, current initiatives were presented addressing novel interventions for caregivers, adherence, integration of palliative care, sibling support, school re-entry and parental bereavement (see below).

Victoria Sardi Brown and Peter Brown (Founders of MMCF) opened the session and provided exceptional discussant points.

• Kimberly Canter (Key Presenter), Community Implementation of eSCCIP

- Kristin Long, Nationwide study of Barriers and Facilitators of Implementing Psychosocial Care Standards
- Gillian Regan, A Novel Online Support Group for Bereaved Pediatric Cancer Caregivers
- Marie Barnett, Implementing the Pediatric Psychosocial Care Standards
- Alexandra Psihogios, Real-Time Medication Adherence Assessments
- Kathryn Kirkpatrick, "Evaluation of a Tiered Service Model to Support Academic Continuity and School Re-Entry for Children with Cancer"

Forty-five pediatric psychosocial oncology professionals attended the Pediatric SIG meeting. We very much enjoyed the multi-discipline representation (psychiatry, psychology, social work, chaplaincy, nursing and child life specialists).

A co-chair was named, (Dr. Marie Barnett, MSKCC) and a student representative was also selected (Dr. Glynnis McDonnell). APOS 2020 will be held in Portland, Oregon on March 11-13.

There will be a strong pediatric and AYA track, an exciting SIG session and a pediatric/AYA social event. We hope to see many of the POPPI readers there!

## 51<sup>st</sup> SIOP Congress 2019

By *Sasja Schepers, The Netherlands*

The 51st conference of the International Society of Pediatric Oncology will be held in Lyon, France, from October 23-26, 2019. Currently, abstracts are being reviewed by our scientific committee and submitters will soon hear about their abstract acceptance. Next to a full pediatric psycho-oncology educational day (planned on October 23rd),

psychosocial topics will be well represented throughout the general conference program. We will soon provide you with an update on the final PPO program and hope to see you all in Lyon!

## SPPAC Conference

By *Sasja Schepers, The Netherlands*

The 50<sup>th</sup> birthday of the Society of Pediatric Psychology was celebrated this year during the conference held from April 4-6 in New Orleans.

Psycho-oncology topics and professionals were well representing during the conference!



*Jeffrey Karst representing the pediatric Hematology, Oncology, & BMT SIG at SPPAC 2019 in New Orleans*

# PPO theses from around the globe

## International PhD Candidates and recent graduates in the field share their theses

By *Eden Robertson, Australia*



*Thesis title: The development and pilot of 'Delta': Supporting parents and young people deciding whether or not to enroll in a paediatric oncology clinical trial.*

Clinical trials are critical to improving outcomes for children with cancer. However, the enrollment process is complex for families and healthcare professionals.

Despite a clear need to better support families making a clinical trial enrolment decision, to our knowledge, no decision aids for parents or young people have yet been developed or evaluated for

this purpose. For my thesis, I incorporated a mixed-methods, multi-perspective, systems approach to guide the development and evaluation of 'Delta'. Delta is the world's first decision aid to support parents with a child with cancer, and adolescents with cancer, deciding whether or not to enrol in a clinical trial.



Delta is available as a hard-copy booklet and website. It incorporates general clinical trials information, the specific clinical trials information sheet, a question prompt list, and a values-clarification exercise.

You can find out more about the Delta website here:

<https://www.youtube.com/watch?v=-Z9aNlxn5Ruo&t=6s>

Participants in my before-after pilot evaluation rated Delta as acceptable and reported that it should be available to all families making an enrolment decision.

Parents had significantly higher levels of objective clinical trial knowledge after reading Delta compared to baseline.

Since the pilot evaluation, I have also developed a short animation to better explain clinical trials to young people. You can view it here: [https://www.youtube.com/watch?v=-29R\\_vsCkZA0&t=49s](https://www.youtube.com/watch?v=-29R_vsCkZA0&t=49s)

By *Luzius Mader, Switzerland*



*Thesis title: Long-term socio-economic consequences after cancer during childhood, teenage, and young adulthood.*

The intensive and long-lasting experience of a cancer diagnosis during childhood and young adulthood may affect the socio-economic situation of the whole family. The overall objective of my PhD thesis was to evaluate long-term socio-economic consequences in childhood cancer survivors, young adult cancer survivors, and parents of survivors.

This thesis revealed that survivors of childhood cancer were more likely to be unemployed in adult life. Among young adult cancer survivors, we observed that they followed different educational pathways towards higher education than comparisons.

Parents of survivors engaged in more traditional parenting roles than comparison parents with mothers being more often unemployed and fathers being more often full-time employed. Parents of survivors further reported a lower household income and were at higher risk-of-poverty than comparison parents.

In conclusion, although many survivors and parents recovered well after the cancer experience, a remarkable number experienced adverse socio-economic consequences in the long-term. Specific psycho-social support services should be systematically implemented and offered to survivors and their parents along the cancer trajectory in order to minimise adverse socio-economic consequences in the long-term.

**Contact us if you would like to feature your PhD thesis in the next issue of this newsletter, or if you know any students who have recently submitted their in the pediatric psycho-oncology field.**

# Recent PPO publications

Recently published articles in *Psycho-Oncology* (official journal of APOS and IPOS) and *Pediatric Blood & Cancer* (official journal of SIOP):

## Pediatric Blood & Cancer



1. Alam A. et al. [Impact of financial support and focussed group counselling on treatment abandonment in children with acute lymphoblastic leukaemia. Experience over 22 years from North India.](#) *Psycho-Oncology*.
2. Anthony S.J. et al. [The social impact of early psychological maturity in adolescents with cancer.](#) *Psycho-Oncology*.
3. Beaupin L.K. et al. [Photographs of meaning: A novel social media intervention for adolescent and young adult cancer patients.](#) *Psycho-Oncology*.
4. Cuvillo, Andrea, et al. [Utilization of palliative care consultations in pediatric oncology phase I clinical trials.](#) *Pediatric Blood and Cancer*.
5. Daniel L.C. et al. [Sleep, emotional distress, and physical health in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study.](#) *Psycho-Oncology*.
6. Fidler M.M. et al. [Challenges and opportunities in the care of survivors of adolescent and young adult cancers.](#) *Pediatric Blood and Cancer*.
7. Haunberger S. et al. [Experiences with a psychosocial screening instrument \(S-FIRST\) to identify the psychosocial support needs of parents of children suffering from cancer.](#) *Psycho-Oncology*.
8. Hinds P.S. et al. [PROMIS pediatric measures validated in a longitudinal study design in pediatric oncology.](#) *Pediatric Blood and Cancer*.
9. Isaevska E. et al. [Association between maternal education and survival after childhood cancer.](#) *Pediatric Blood and Cancer*.
10. Lazor T. et al. [Severity, change over time, and risk factors of anxiety in children with cancer depend on anxiety instrument used.](#) *Psycho-Oncology*.
11. Lai J. et al. [Using the Patient-Reported Outcomes Measurement Information System \(PROMIS\) to measure symptom burden reported by patients with brain tumors.](#) *Pediatric Blood and Cancer*.
12. Lehmann V. et al. [The perceived impact of infertility on romantic relationships and singlehood among adult survivors of childhood cancer.](#) *Psycho-Oncology*.
13. Mader L. et al. [Relationship status and quality of the partner relationship in parents of long-term childhood cancer survivors: The Swiss Childhood Cancer Survivor Study-Parents.](#) *Psycho-Oncology*.
14. Meenan C.K. et al. [Obesity in pediatric patients with acute lymphoblastic leukemia increases the risk of adverse events during pre-maintenance chemotherapy.](#) *Pediatric Blood and Cancer*.
15. Michel G. et al. [The long-term impact of cancer: Evaluating psychological distress in adolescent and young adult cancer survivors in Switzerland.](#) *Psycho-Oncology*.
16. Nicklin E. et al. [Long-term issues and supportive care needs of adolescent and young adult childhood brain tumour survivors and their caregivers: A systematic review.](#) *Psycho-Oncology*.
17. Pare-Blagoev E.J. et al. [Schooling in survivorship: Understanding caregiver challenges when survivors return to school.](#) *Psycho-Oncology*.
18. Salsman J.M. et al. [Understanding, measuring, and addressing the financial impact of cancer on adolescents and young adults.](#) *Pediatric Blood and Cancer*.
19. Salvador A. et al. [Parents' psychological well-being when a child has cancer: Contribution of individual and family factors.](#) *Psycho-Oncology*.
20. Sanchez-Egea R. et al. [Psychological treatment for family members of children with cancer: A systematic review and meta-analysis.](#) *Psycho-Oncology*.
21. Signoroni S. et al. ["Summer is you": Adolescents and young adults with cancer sing about their desire for summer.](#) *Pediatric Blood and Cancer*.
22. Sisk B.A. et al. [Persistently low peace of mind in parents of cancer patients: A five-year follow-up study.](#) *Pediatric Blood and Cancer*.
23. Weber E. et al. ["A change in perspective": Exploring the experiences of adolescents with hereditary tumor predisposition.](#) *Pediatric Blood and Cancer*.
24. Wilford J.G. et al. [Perceptions of changes in clinical, informational, and supportive relationships after end of treatment among parents of young childhood cancer survivors.](#) *Psycho-Oncology*.
25. Willard V.W. et al. [The impact of connectedness on social functioning in youth with brain tumors.](#) *Pediatric Blood and Cancer*.
26. Yang Y. et al. [Fear of cancer recurrence in adolescent and young adult cancer survivors: A systematic review of the literature.](#) *Psycho-Oncology*.

**HIGHLIGHTED PPO ARTICLE:** Lehmann V. et al. The perceived impact of infertility on romantic relationships and singlehood among adult survivors of childhood cancer. *Psycho-Oncology* 28(3), 622-628.



By **Vicky Lehmann**,  
*The Netherlands*

Many childhood cancer survivors are faced with fertility problems and

infertility. From studies among infertile but otherwise healthy couples, we know that infertility can cause extensive emotional strain and relationship problems, but little is known about such potential impact among young adult survivors of childhood cancer.

We interviewed 57 survivors of childhood cancer (aged 23-41 years) who had been treated at Nationwide Children's Hospital 12-28 years prior to this study. Phone interviews were transcribed and analyzed through thematic content analysis until saturation was reached (N=30).

The interviews revealed 3 major themes: the impact on survivors themselves, their partners/romantic

relationships, and considering alternatives to biological parenthood. Survivors started their stories by describing how they found out about infertility risks and their own (potential) fertility problems. They described the subsequent emotional impact it had on them, which included worries, concerns, distress, guilt, or no emotional reactions. Survivors then described the impact it had on their partners and romantic relationships.

They elaborated on the communication with their partners, partners' reactions, and their (often emotional) journey of actively trying to have children. Throughout this journey, many had considered alternatives to having biological children (e.g., adoption or surrogacy) and some decided to not have any children.

Across all interviews, an overarching theme of timing emerged, which indicated that an impact of (potential) infertility on

romantic relationships/singlehood among childhood cancer survivors varied across individuals and time.

Its presence or absence was depends on current life circumstances (e.g., marital status, life goals).

If present, negative effects were typically resolved over time by becoming pregnant/having a child. Nevertheless, some survivors found joy and comfort in having step-children, considering adoption, or embracing a life without children.

More research is certainly needed, but our findings indicate that discussions about reproductive health, infertility risk, and fertility testing should be tailored to individual survivors and their needs, which may change over time.

Timely referrals to reproductive specialists or adoption agencies are recommended for those who want children and have difficulties conceiving.

Have you recently published a relevant paper in *Pediatric Blood and Cancer* or *Psycho-Oncology* that you would like us to include in the next issue? [Contact us!](#)

**New IPOS Journal!**



By **Christina Signorelli & Claire Wakefield, Australia**

IPOS recently announced a new open access journal focused on the increasing body of psychosocial oncology research, called the Journal of Psychosocial Oncology Research and Practice. The journal is open to submissions on various designs including clinical trials, qualitative research, and systematic reviews and clinical research focusing on the behavioural

interventions and implementation into clinical practice. Priority topic areas include survivorship research and care, psychosocial oncology research and practice in developing countries, innovative research methods and research into global and regional health disparities as they relate to psychosocial oncology care and services. The journal is now open for manuscript submissions.

For more information visit: <https://www.editorialmanager.com/jporp/default.aspx>



# POPPI Newsletter

Our next newsletter will be circulated in August 2019.

**All feedback and suggestions are welcome!**

If you have any questions relating to the newsletter content, or if you would like to make a contribution to future newsletters, please contact the Editor [Sasja Schepers](#).