



# POPPI Newsletter

Pediatric Psycho-Oncology  
Professionals/Providers  
International

Issue 2: September 5, 2018

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## WELCOME TO THE SECOND ISSUE OF THE POPPI NEWSLETTER

### A welcome note from the Chairs

by Martha Grootenhuis, Claire Wakefield, and Lori Wiener

Welcome to second 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 Fiona Schulte, PhD

By *Dr Fiona Schulte*

Dr Schulte is a Clinical Psychologist and Assistant Professor at the University of Calgary in Canada. Here Fiona shares with us on her role as chair PPO in Canada.

Hi! My name is Fiona Schulte and I am the incoming president of the Canadian Association of Psychosocial Oncology (CAPO). CAPO is the sister organization of the American Association of Psychosocial Oncology (APOS) and the International Organization of Psychosocial Oncology (IPOS). CAPO's roots began early in the 1980's with founding members from Toronto, Calgary, and Edmonton, Canada.

The first annual congress was held in 1985. I was lucky enough to join the board of directors of this organization in 2012 and to be a voice representing pediatric psychosocial oncology among this group. Since joining the board, we have embarked on a number of exciting initiatives to promote pediatric psychosocial oncology amongst our organization. To begin, we officially endorsed the pediatric psychosocial standards of care in 2017. Also in 2017 we officially launched a pediatric/adolescent and young adult special interest group (Peds/AYA SIG).

The Peds/AYA SIG met for the first time at our annual convention in Vancouver (May 2017) and again for a second time this past year in Toronto (May 2018). The primary goal of our Peds/AYA SIG is to foster and encourage excellence in pediatric and adolescent/young adult specific psychosocial oncology research and clinical care across Canada by supporting activities in diverse areas, including interdisciplinary work. We also plan to establish enough momentum from our Peds/AYA SIG that will allow us to host a Peds/AYA stream at our next annual conference that is being co-hosted by IPOS and being held in Banff, Canada, in September 2019.

Planning for the world congress is currently underway. We have an excellent planning committee in place and we will be happy to share our planning progress with you as we move forward. I am thrilled to be chairing this meeting and look forward to welcoming many of you to Banff in 2019!

*Fiona Schulte*  
Incoming President, CAPO



### Research project in the spotlight: the PROMOTE study

By *Dr Kim Bull*

Dr Kim Bull is a Senior Research Fellow at the University of Southampton, UK. Here, Dr Bull & Prof Kennedy tell us about the PROMOTE study.

Quality of life in children treated for brain tumours can be significantly impaired but there is no systematic screening for problems. Referral to appropriate services is reactive rather than proactive. If problems are identified early and interventions well-timed, quality of life may improve. We therefore aimed, in the UK, to develop and adapt an available online Dutch method (KLIK) to systematically assess health, well-being, and concerns using patient-reported outcome measures (PROMs) relevant to children treated for brain tumours and their families and feedback the information to clinicians at routine outpatient clinics.

The PROMOTE (Patient reported outcome measures to enhance communication and quality of life) study, funded by The [Brain Tumour Charity](#), aims to achieve this goal. It is a qualitative study in three centres: Southampton General Hospital, Great Ormond Street Hospital, and Queen's Medical Centre in Nottingham. Our informants are children 8-17.9 years in whom a brain tumour has been diagnosed within the previous 5 years, off treatment and under outpatient review more than 6 monthly, their parents (and also parents of some patients aged 5 to 7 years), and the clinicians providing their clinical care. In the first phase of the study, we have identified relevant PROMs through

systematic review and interview. Six families in each centre have advised us on the acceptability and relevance of these PROMs which will be uploaded onto KLIK. These families and clinicians have also provided feedback about the KLIK platform and method of feedback which we are refining in an iterative cyclical process of development.

We are also currently adapting the Dutch training for clinicians in how to use KLIK and assessing the three centres for facilitators or barriers to the implementation of KLIK. In the second half of the study, we will move on to testing the feasibility of using this refined method in outpatient clinics at the three hospitals. In addition to this work, we have made a film with students and alumni from the University of Southampton to explain the KLIK method in English. You can view this on YouTube by clicking [here](#).



Picture taken at PROMOTE study meeting in Southampton, UK, 2018. Left to right: Andy Newman, Anita Freeman, Sasja Schepers, Christina Lioffi, Shelly Stubley, Kim Bull, Anne-Sophie Darlington, Sammy Hornsey, Colin Kennedy, & Chris Morris

## Standards of care

### Winner of Mattie Miracle Foundation grant!

By Dr Lori Wiener

APOS and The Mattie Miracle Cancer Foundation partnered in the first early investigator grant request to fund research designed to implement any of the 15 evidence-based psychosocial standards of care published in *Pediatric Blood & Cancer*, in 2015.

Twenty-six strong Letters of Intent (LOIs) were submitted and 12 were invited to submit full proposals. Each proposal was reviewed by three experts in the area of the proposal.

The following areas were scored:

- Significance to psychosocial oncology and the implementation of the pediatric standards
- Scientific Merit

- Innovation
- Appropriateness of Methods
- Qualifications of the investigator (research team) to conduct the study

Dr. Kimberly Canter (pictured right) from Nemours Center for Healthcare Delivery Science, will be awarded the 1st APOS/Mattie Miracle Grant at \$10,000.



The title of her grant is *“Community Implementation of a Psychosocial eHealth Intervention for Parents of Children with Cancer”*. Dr. Canter’s mentor is Dr. Anne Kazak.

eSCCIP (the Electronic Surviving Cancer Competently Intervention Program) is a brief, cognitive-behavioral and family systems eHealth intervention for parents and caregivers of children with cancer. The recently funded study will be a community-centered pilot test of eSCCIP, in partnership with Life with Cancer in Northern VA, and will focus on evaluating intervention feasibility and acceptability, as well as key psychosocial outcomes (posttraumatic stress, anxiety, and family functioning).



## Survivor perspective

### Childhood cancer survivor Christian Mueller tells us about his visit to Australia!

By Christian Mueller

When I started to work at the German Late Effects Surveillance System study group (LESS) for childhood cancer late effects at the beginning of 2014, it didn’t take a long time until I found information about activities of the Behavioural Sciences Unit (BSU) in Sydney. Based on my own childhood cancer survivors’ experiences, I’m interested in psychosocial problems after treatment.

Unfortunately, there was never a chance to travel to Australia but fortunately we kept in touch via email and Twitter. In the meantime, I changed my job to the Gert and Susanna Mayer Foundation in Wuppertal (Germany) which supports childhood cancer research projects but I’ll never lose my interests in research topics like late effects and long-term care and so in August 2018 my dream has finally come true: I could visit Claire Wakefield and her team at the BSU for one week! My first flight for 20 years led me to a distance of more than 20,000 km.

To my own surprise I had no jet lag issues and had a great Sunday for sightseeing. I stood in front of the Harbor Bridge and Sydney Opera House which I had only known from television. I am not sure anyone could really understand the meaning of such an emotional moment for me.

My visit began on Monday at the BSU in the “Ethics and Genetics” team. On Tuesday and Wednesday I was

in the “Mental Health” team and on Thursday and Friday in the “Health Behaviours” and “Cognition and Education” teams.

During the whole week I took part at team lunches and meetings, practice talks for the Cancer Counselling Professionals Conference, Journal Club, team talks, observed exercise testing of former childhood cancer patients and got informed in detail about each current research project or study.

It was great to visit an amazing city like Sydney but even more amazing were the wonderful people I met in person after being connected for so many years via social media. I have never been so warmly welcomed in one place before. I flew back to Germany with countless impressions after a week in Sydney and at the BSU. I will return. Thanks to everyone who cared for me. These are too many people to be listed here but I would like to mention Claire Wakefield on behalf of her staff.



Christian with some members of the Behavioural Sciences Unit team, Sydney Australia.

# Sleep in pediatric oncology

## NEW! Sleep in Pediatric Oncology Working Group

By Prof Lauren Daniel

We are an interdisciplinary and international group of psychologists, pediatricians, and nurse researchers who are devoted to advancing the understanding and treatment of sleep and circadian disturbances in pediatric oncology during treatment and into survivorship.



Sleep is rarely prioritized during cancer treatment, yet the importance of supporting sleep and circadian rhythmicity in adjusting to cancer, and in maximizing treatment effectiveness, recovery post cancer therapy, and survival is emerging, particularly in adult cancer research.

We are seeking to change the perception that sleep is an afterthought, and encourage our colleagues in pediatric oncology to consider sleep in both research and clinical endeavors.

To begin the task of reaching this goal, our newly formed group is collaborating on two papers: 1) Research agenda: proposing specific ways that the broader

pediatric oncology community can integrate sleep into existing research and clinical trials and 2) Clinical Agenda: compiling evidenced-based guidelines for enhancing sleep and treating sleep disturbances during pediatric cancer treatment.

We very much look forward to collaboration with and feedback from members of POPPI as we advance our written works.

For more information on the group please contact:

Raphaele van Litsenburg

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or Lauren Daniel

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# PPO conference news

## Upcoming PPO conferences

### 2018

- [EPPC](#): September 20-21, 2018 in Ghent, Belgium.
- [Palliative care symposium](#): September 26-28, 2018 in Memphis TN, USA.
- [ISOQoI](#): October 24-27, 2018 in Dublin, Ireland.

- [IPOS](#): October 31- November 2; in Hong Kong.
- [Onco-Fertility Consortium](#): November 13-15, 2018 in Chicago, Illinois USA.
- [SIOP](#): November 16-19, 2018 in Kyoto, Japan.

### 2019

- [APOS](#): February 28 - March 2, 2019, in Atlanta, Georgia USA.
- [SPPAC](#): April 4-6, 2019 in New Orleans, Louisiana, USA.
- [APOSW](#): April 8-10, 2019, in Phoenix, Arizona USA.

## SAVE THE DATE!

**APOS/AOSW Symposium**  
301 EAST 17<sup>TH</sup> STREET, LOEB AUDITORIUM, NEW YORK, NY 10003 | SEPTEMBER 28, 2018  
[LEARN MORE](#)  
Registration Pricing: APOS/AOSW Member \$110 • Non-member \$140 • Student \$75 • CEs: \$25  
"Acceptance Based Therapies Throughout the Cancer Trajectory"

**APOS/AOSW Symposium**  
The conference will be held September 28<sup>th</sup>, 2018 in New York, NY and the theme is: 'Acceptance Based Therapies Throughout the Cancer Trajectory'. Learn more [here](#).

**APOS**  
16<sup>th</sup> Annual Conference  
February 28 - March 2, 2019  
Sheraton Atlanta Hotel  
"We're All In This Together: Bringing Together Diverse Perspectives, Professionals, and Programs"

**APOS 16<sup>th</sup> Annual Conference**  
The conference will be held Feb 28<sup>th</sup>-Mar 2<sup>nd</sup>, 2019 in Atlanta, Georgia and the theme is: 'We're All In This Together: Bringing Together Diverse Perspectives, Professionals and Programs'. Learn more [here](#).

**APOSW 43<sup>RD</sup> ANNUAL CONFERENCE**  
APOSW 2019 Conference  
Embracing the Diverse Landscape of Pediatric Oncology Social Work  
April 8-10, 2019  
Phoenix, Arizona

**APOSW 43<sup>rd</sup> Annual Conference**  
The conference will be Held April 8<sup>th</sup>-10<sup>th</sup>, 2019 in Phoenix, Arizona and the theme is 'Embracing the Diverse Landscape of Pediatric Oncology Social Work'. Learn more [here](#).

## Palliative care symposium

The 2nd Annual Pediatric Palliative Oncology Interdisciplinary Symposium will be held at St. Jude on Wednesday, September 26, 2018 8:00 AM - Friday, September 28, 2018 5:00 PM.

The focus will be on the comprehensive care of children with cancer and their families. Featured experts and a panel of bereaved parents will cover a host of challenging subjects, including communication of difficult news, ethical issues in pediatric oncology, management of refractory pain and complex symptoms, and legacy building and bereavement care.

There will be a preconference workshop and plenary on integrating psychosocial standards into pediatric palliative oncology care (Dr. Lori Wiener and Anne Kazak) and sessions on incorporating bereaved parents into education and parent-to-parent support programs.

Oncology and palliative care clinicians as well as psychosocial professionals (psychologists, social workers, child life specialists, chaplains, etc.) are invited to attend.

For more information please click on the following [link](#).

## 50<sup>th</sup> SIOP Congress 2018

By *Martha Grootenhuis & Sasja Schepers*



This year the SIOP conference will be in Kyoto, Japan from November 16-19, 2018. It will be a special conference, as SIOP will mark its 50<sup>th</sup> birthday and several events will be organized at the conference to celebrate this. What is also worth to celebrate, is that psycho-oncology has become an integral part of the SIOP program!

**Registration:** Registration for the conference is still possible until October 23, 2018. Please register under the HCP category to profit from reduced rates, also for the educational day.

### SIOP PPO

#### Educational day

The educational day will take place on November 16, 2018. More than 20 abstracts were

selected from the abstract submission and cultural representation was taken into account. More information can be found at the [SIOP website](#).

#### Main program

For the main program from November 17-19, 2018 abstracts for three free paper sessions were selected.

Also, a symposium will take place on *Cultural differences in truth telling to children* and a keynote on *Sleep disorders*.

#### SIOP PPO committee

We are happy to share that after the loss of our dear member Andrea Patenaude, we have three new members in our SIOP PPO committee: Dr. Christopher Recklitis (USA), Dr. Sasja Schepers (the Netherlands) and Dr. Fiona Schulte (Canada).

Ms. Kelly van Bindsbergen (the Netherlands) is our new secretary. We believe SIOP 2018 will have a very psychosocial flavor making it very worthwhile to come.

Please find the [full SIOP PPO program](#) at the end of this newsletter!

# PPO theses from around the globe

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

By *Christina Signorelli, Australia*

**Thesis title:** Improving the long term follow-up of childhood cancer survivors: a new model of care

I recently completed my PhD thesis, which was aimed at developing a new model of survivorship care for long-term childhood cancer survivors. My research included multi-perspective analyses involving key stakeholders (including primary and tertiary health professionals, childhood cancer survivors and their parents) and a rigorous mixed-methods design.

I proposed a new online, nurse-led program, called 'Re-engage', which is designed for survivors who are not accessing cancer-related follow-up care. Re-engage is specifically designed to address patient- and clinician-reported barriers and preferences for care, such as the distance to, and cost of attending, face-to-face survivorship clinics.

As a part of this program, I also led the development of a comprehensive "top to toe" risk assessment and triage tool to facilitate risk stratification and ensure survivors receive the best follow-up care for their needs.



**Contact us** if you would like to feature your PhD thesis in the next issue of the POPPI newsletter, or if you know any students who have recently submitted their thesis in the 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. Baenziger J. et al. [Can the theory of planned behavior help explain attendance to follow-up care of childhood cancer survivors?.](#) *Psycho-Oncology*. 27(6).
2. Barrera M. et al. [A randomized controlled trial of a group intervention for siblings of children with cancer: Changes in symptoms of anxiety in siblings and caregivers.](#) *Psycho-Oncology*.
3. Besani C. et al. [A family-based intervention to promote adjustment in siblings of children with cancer: A pilot study.](#) *Psycho-Oncology*.
4. Creutzig U. et al. [Acute myelogenous leukemia in adolescents and young adults.](#) *Pediatric Blood and Cancer*. 65(9).
5. Desandes E. et al. [Adolescent and young adult oncology patients in France: Heterogeneity in pathways of care.](#) *Pediatric Blood and Cancer*. 65(9).
6. Diorio C. et al. [Psychosocial determinants of physical activity and dietary behaviors in adolescents and young adults with cancer and survivors.](#) *Pediatric Blood and Cancer*. 65(9).
7. Frederick N.N. et al. [Barriers and facilitators to sexual and reproductive health communication between pediatric oncology clinicians and adolescent and young adult patients: The clinician perspective.](#) *Pediatric Blood and Cancer*.
8. Geue K. et al. [Prevalence of mental disorders and psychosocial distress in German adolescent and young adult cancer patients \(AYA\).](#) *Psycho-Oncology*.
9. Graef D.M. et al. [Sleep and mood during hospitalization for high-dose chemotherapy and hematopoietic rescue in pediatric medulloblastoma.](#) *Psycho-Oncology*.
10. Hamilton J.G. et al. [Maternal perceptions of BRCA genetic counseling communication processes about disclosing cancer risk information to children and adult relatives.](#) *Psycho-Oncology*.
11. Hochberg J. et al. [NHL in adolescents and young adults: A unique population.](#) *Pediatric Blood and Cancer*.
12. Jenkins B.N. et al. [Emotion regulation and positive affect in the context of salivary alpha-amylase response to pain in children with cancer.](#) *Pediatric Blood and Cancer*.
13. Jibb L.A. et al. [Using the MEDiPORT humanoid robot to reduce procedural pain and distress in children with cancer: A pilot randomized controlled trial.](#) *Pediatric Blood and Cancer*. 65(9).
14. Kahn J.M. & Kelly K.M. [Adolescent and young adult Hodgkin lymphoma: Raising the bar through collaborative science and multidisciplinary care.](#) *Pediatric Blood and Cancer*.
15. Karst J.S. et al. [Assessment of end-of-treatment transition needs for pediatric cancer and hematopoietic stem cell transplant patients and their families.](#) *Pediatric Blood and Cancer*.
16. Lavi I. et al. [Stress and marital adjustment in families of children with cancer.](#) *Psycho-Oncology*.
17. Liu W. et al. [Behavioral symptoms and psychiatric disorders in child and adolescent long-term survivors of childhood acute lymphoblastic leukemia treated with chemotherapy only.](#) *Psycho-Oncology*.
18. Long K.A. et al. [Psychosocial functioning and risk factors among siblings of children with cancer: An updated systematic review.](#) *Psycho-Oncology*. 27(6) (pp 1467-1479).
19. Mostert S. et al. [Health-care providers' perspectives on health-insurance access, waiving procedures, and hospital detention practices in Kenya.](#) *Pediatric Blood and Cancer*.
20. Niemitz M. & Goldbeck L. [Outcomes of an enhancement study with additional psychoeducational sessions for healthy siblings of a child with cancer during inpatient family-oriented rehabilitation.](#) *Psycho-Oncology*. 27(3) (pp 892-899), 2018.
21. Skaczkowski G. et al. [Do Australian adolescents' and young adults' experiences of cancer care influence their quality of life?.](#) *Psycho-Oncology*. 27(3) (pp 990-997), 2018.
22. Tillery R. et al. [Longitudinal examination of family efficacy following pediatric stem cell transplant.](#) *Psycho-Oncology*.
23. Tomasello C. et al. [Scrambler therapy efficacy and safety for neuropathic pain correlated with chemotherapy-induced peripheral neuropathy in adolescents: A preliminary study.](#) *Pediatric Blood and Cancer*.
24. White J. et al. [Falling through the cracks. A thematic evaluation of unmet needs of adult survivors of childhood cancers.](#) *Psycho-Oncology*.
25. Whitford B. et al. [Burnout in pediatric hematology/oncology-time to address the elephant by name.](#) *Pediatric Blood and Cancer*.
26. Zucchetti G. et al. [Exercise program for children and adolescents with leukemia and lymphoma during treatment: A comprehensive review.](#) *Pediatric Blood and Cancer*. 65(5).

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

**HIGHLIGHTED PPO ARTICLE:**

Baenziger et al 2018. Can the theory of planned behavior help explain attendance to follow-up care of childhood cancer survivors? *Psycho-Oncology*, 27(6):1501-1508.

DOI: 10.1002/pon.4680.

By Julia Baenziger

Regular attendance to long-term follow-up care is recommended for childhood cancer survivors as it helps to monitor their overall health. We applied the theory of planned behavior to investigate predictors of the intention to attend follow-up care and examine the associations between perceived control and behavioral intention with actual follow-up attendance.<sup>1</sup>

Swiss childhood cancer survivors (aged <16 years at diagnosis, ≥5 years since diagnosis) were surveyed on their, attitude, subjective norm, perceived control and attendance in regard to follow-up care.

Among 299 survivors (55.5% female, mean age 25.1 years), only 145 (48.5%) reported attending follow-up care. We found that subjective norm, i.e. survivors' perceived social pressure and support (coef = 0.90,  $P < 0.001$ ), increased the intention to attend follow-up; attitude and perceived control did not.

Perceived control (OR = 1.58,

95%CI:1.04-2.41) and intention to attend follow-up (OR = 6.43, 95%CI:4.21-9.81) were positively associated with attendance. Women and survivors with more time since diagnosis also showed a higher intention. No other cancer-related characteristics were associated with intention nor attendance.

Our findings are strengthened by similar observations among Swiss adolescent and young adult (AYA) cancer survivors.<sup>2</sup> However, for AYAs, attitude towards follow-up care also played a role in their intention to attend follow-up care.

To increase intention and actual attendance, promotional interventions should focus on improving socio-environmental aspects such as social support and easy organization of follow-up care.

An effort should be made to raise awareness among partners, friends, parents, and health care professionals on their important

role in supporting the survivor's continuing follow-up care. Informing them on risk of late effects and consequences may help them express their opinions about follow-up care and emphasize its value. Establishing specialized follow-up clinics and survivorship passports may help empower survivors to actively manage their follow-up care.

#### References:

1. Ajzen I. The theory of planned behaviour: reactions and reflections. *Psychol Health*. 2011;26(9):1113-1127.
2. Roser, K., Baenziger, J., Mader, L., Christen, S., Dehler, S., & Michel, G. Attendance to Follow-Up Care in Survivors of Adolescent and Young Adult Cancer: Application of the Theory of Planned Behavior. *J Adolesc Young Adult Oncol*. 2018 Jun 20. doi: 10.1089/jayao.2018.0010 [Epub ahead of print]

If you would like to feature as our "Researcher Profile" in our next issue, [contact us!](#)



## POPPI Newsletter

Our next newsletter  
will be circulated in  
December 2018.

**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](#).