



POPPI Newsletter

Pediatric Psycho-Oncology
Professionals/Providers
International

Issue 2: September 5, 2018

STEERING COMMITTEE



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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 Stubbley, 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:

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



APOS 16th Annual Conference
 The conference will be held Feb 28th-Mar 2nd, 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 43rd Annual Conference
 The conference will be Held April 8th-10th, 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](#).

50th 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 50th 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.¹

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.² 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](#).

Program Educational Day 2018

Friday, November 16, Kyoto, Japan



Program Educational Day 2018

Friday, November 16, Kyoto, Japan

Time slot	Topic	
08.15 - 08.30	Opening of the Educational Day (Hall 6) <i>By: Martha Grootenhuis</i>	
08.30 - 09.45	Session 1 - Genomics and Precision (Hall 6) <i>Chair: Martha Grootenhuis</i>	
	08.30-09.00	Maria McCarthy Genomics and personalised medicine: What are the psychosocial and ethical considerations?
	09.00-09.20	Jonathan Marron Patients' and parents' perspectives on genomic sequencing and paediatric precision cancer medicine
	09.20-09.40	Claire Wakefield Working in a new way, with a new team: Scientists' and health professionals' experiences launching a national precision medicine trial
09.40-09.45	General discussion by Martha Grootenhuis	
09:45 - 10:15	Coffee break	
10:15 - 11.15	Session 2 - Survivorship (Hall 6) <i>Chair: Christopher Recklitis</i>	
	10.15-10.40	Sean Phipps Resilience and psychological growth in children with cancer
	10.40-10.50	Steven Hardy Brief psychosocial screening to identify patients in need of a mental health treatment referral in a childhood cancer survivorship clinic
	10.50-11.00	Liisa Korhonen Risky health behavior related deaths in childhood cancer survivors - A population-based register study from Denmark, Finland, and Sweden
11.00-11.15	General discussion by Christopher Recklitis	
11.15 - 11.45	Session 3 - Parenting Issues (Hall 6) <i>Chair: Sasja Schepers</i>	
	11.15-11.25	Lynn Katz Parenting stress and sibling conflict: Temporal relations across the first year of pediatric cancer treatment
	11.25-11.35	Luzius Mader Relationship status and quality of the partner relationship in parents of long-term childhood cancer survivors
11.35-11.45	Eygló Guðmundsdóttir Parental vital exhaustion in the aftermath of a child's cancer diagnosis	
11.45 - 13.45	Lunch break and poster viewing	
13.45 - 14.35	Session 4 - Neuropsychology (Hall 6) <i>Chair: Stephen Sands</i>	
	13.45-14.05	Kevin Krull Brain stimulation (tDCS) and cognitive training
14.05-14.15	Michiko Yamada Evaluation of late-life subjective neurocognition using a Japanese version of the neurocognitive questionnaire (NQC) among childhood atomic bomb survivors	

Program Educational Day 2018

Friday, November 16, Kyoto, Japan



	14.15-14.25	Jin-Shei Lai Using patient- and parent-reported outcomes to predict survival of children with brain tumors
	14.25-14.35	Megumi Nukui Follow up system of neurocognitive function in pediatric brain tumor survivors in Japan
14.35 - 15.15	Session 5 - AYA (Hall 6) Chair: Fiona Schulte	
	14.35-14.45	Ozawa Miwa The psychological current status of siblings in adolescent and young adult with cancer patients in Japan
	14.45-14.55	Susie Aldiss Top 10 research priorities for teenage and young adult cancer in the United Kingdom: Prioritising need for psychosocial research
	14.55-15.05	Danielle Weidman A multiphase project to improve the cancer journey for adolescents and young adults (AYA) in a pediatric setting
	15.05-15.15	Celeste Phillips Resilience as a mediator of well-being in adolescents and young adults with cancer
15.15 - 15.45	Coffee break	
15.45 - 17.15	Session 6 - Interventions (Hall 6) Chair: Maria McCarthy	
	15.45-16.15	Don Mabbott Neurocognitive interventions: Current approaches and future opportunities
	16.15-16.30	Daisuke Masumoto Development of computer-based self-learning tools for childhood cancer survivors
	16.30-16.45	Nadia Natanzon-Bracha "Listening to the soul" - A mindfulness meditation program for children with cancer and their parents
	16.45-17.00	Ka Wai Katherine Lam Effectiveness of an integrated experiential training program with coaching by nursing students in reducing fatigue among children with cancer in Hong Kong
	17.00-17.15	Fiona Schulte The need for innovative interventions in pediatric oncology
17.15 - 18.00	Session 7 - Sleep (Hall 6) Chair: Raphaële van Litsenburg	
	17.15-18.00	Lindsay Steur Subjective but not objective increase in sleep problems during dexamethasone treatment in pediatric acute lymphoblastic leukemia
	18.00-18.15	Niki Rensen Prevalence of parental sleep problems in pediatric oncology: An opportunity to improve quality of life
	18.15-18.30	Sarah Ellis Psycho-oncology in Russia: Parent psychological distress and sleep outcomes on the paediatric oncology ward
18.00 - 18.05	Closing of the Educational Day (Hall 6) By: Martha Grootenhuis	
18.30 - 19.00	Opening Ceremony	
19.00 - 20.30	Network Reception	

SIOP PPO Main Program 2018

Saturday-Monday, November 17-19, Kyoto, Japan



SIOP PPO Main Program 2018 Saturday, November 17, Kyoto, Japan

Time slot	Topic
09.40 - 11.10	PPO Free Paper Session I (Hall 7) <i>Chairs: Christopher Recklitis, Satomi Sato, & Don Mabbott</i>
	09.40-09.55 L. Desjardins Mapping psychosocial screening to resources: A pilot intervention study
	09.55-10.10 R. Daruvala When the going gets tough: Psychiatric diagnoses in children with haematological and oncology conditions referred to paediatric psycho-oncology services
	10.10-10.25 S. Schepers Daily mood profiles predict psychosocial adjustment in children with newly diagnosed cancer
	10.25-10.40 N. Ouyang Effects of group-based physical activity intervention for children with cancer
	10.40-10.55 H.C.W. Li A pilot randomized controlled trial of using musical training in promoting psychological well-being and quality of life in childhood brain tumours survivors
	10.55-11.10 S. Ellis Improving sleep in parents of children with cancer: development and evaluation of a hospital-based cognitive behavioral therapy intervention

Sunday, November 18, 2018, Kyoto, Japan

Time slot	Topic
10.40 - 12.10	Symposium: Multidisciplinary Palliative Care (Hall 2) Chair: Justin Baker Invited speakers: Alessandro Inserra, Hiroshi Fuji, & Justin Baker
14.00 - 15.30	PPO symposium: Cultural differences in truth telling to children (Hall 2) Chairs: Lynn Gilam & Maria McCarthy Invited speakers: Lynn Gilam, Yukiko Tsunematsu, & Bridget Young
16.00 - 16.30	PPO keynote: Sleep quality and disorders in pediatric cancer patients and survivors (Hall 1) Invited speaker: Raphaële van Litsenburg
20.00 - 21.30	SIOP Networking Event

Monday, November 19, 2018, Kyoto, Japan

Time slot	Topic
10.40 - 12.10	PPO Free Paper Session II (Hall 6) <i>Chairs: Martha Grootenhuys, Sasja Schepers, & Claire Wakefield</i>
	10.40-10.55 L. Linder Priority symptoms identified by adolescents and young adults receiving chemotherapy using an ipad-based symptom heuristics app
	10.55-11.10 H. Salem Risk of first prescription of psychotropic medication in parents of children diagnosed with cancer

SIOP PPO Main Program 2018

Saturday-Monday, November 17-19, Kyoto, Japan



	11.10-11.25	I. Schwartz Atias Positive emotions, hope, and social support facilitate the coping of pediatric cancer patients and their parents
	11.25-11.40	C. Phillips Feasibility, acceptability, and usefulness of the resilience enhancement for adolescents and young adults with cancer and healthcare providers (reach) intervention
	11.40-11.55	C. Wakefield Families' and healthcare professionals' hopes and expectations participating in a precision medicine trial for children with high-risk cancer: the prism-impact study
	11.55-12.10	M. Warby How can we help you? Identifying and addressing parents' concerns in paediatric cancer genetic counselling
15.00 - 16.00	PPO Free Paper Session III (Hall 8) <i>Chairs: Sean Phipps, Fiona Schulte, & Kevin Krull</i>	
	15.00-15.15	S. Phipps The (mis)measure of posttraumatic stress disorder in pediatric medical settings
	15.15-15.30	K. Howard Sharp Profiles of mother and father general and cancer-specific family communication following diagnosis of pediatric cancer
	15.30-15.45	F. Schulte Social adjustment in adolescent survivors of pediatric CNS tumors: A report from the childhood cancer survivor study
	15.45-16.00	I. Moxon-Emre Children treated for posterior fossa brain tumours have difficulty recognizing facial emotions: insights from viewing patterns and white matter structure

12.00 - 13.00	Registration, sandwiches & coffee
13.00 - 13.15	Conference Opening and Welcome
13.15 - 14.00	PLENARY SESSION I Behavioral flexibility: a key factor in chronic pain management <i>Rickard Wicksell (Sweden)</i>
14.00 - 14.45	PLENARY SESSION II E-health and the use of technology in the context of pediatric psychology: examples from healthy lifestyles research <i>Ann Davis (USA)</i>
14.45 - 15.15	Coffee break
15.15 – 16.45	PARALLEL SESSIONS
15.15	<u>Symposium: Bright ideas for everyday living: development, implementation, evaluation, and dissemination of a research-tested psychosocial intervention</u> Chair: <i>Sasja A. Schepers (USA)</i> Bright IDEAS: Development, Implementation, and Evidence <i>Michael J. Dolgin (Israel)</i> Testing an Online Version of Bright IDEAS for Parents of Children Newly Diagnosed <i>Sean Phipps (USA)</i> Translating Bright IDEAS to New Populations: Adolescents and Young Adults (AYA) <i>Katie Devine (USA)</i> Using an Adaptive Dissemination Strategic Planning Process to Bring Bright IDEAS from Bench to Bedside <i>Olle Jane (USA)</i>
15.15	<u>Symposium: Innovative (cognitive-behavioral) interventions in the children's hospital</u> Chair: <i>Elisabeth M.W.J. Utens (The Netherlands)</i> Eye movement desensitization and reprocessing (EMDR) in children and adolescents with subthreshold PTSD following medical events: a randomized controlled trial <i>Maya G. Meentken (The Netherlands)</i> The multidisciplinary CHIP-Family intervention to improve psychosocial wellbeing of young children with congenital heart disease and their families: a randomized controlled trial <i>Malindi van der Mheen (The Netherlands)</i> Effectiveness of disease-specific cognitive behavioral therapy on anxiety, depression and quality of life in youth with inflammatory bowel disease: a randomized controlled trial <i>Luuk Stapersma (The Netherlands)</i> Health-Related Quality of Life of children and their parents six months after critical illness <i>José Hardijk (The Netherlands)</i>
15.15	<u>Symposium: Clinical pediatric neuropsychology: a developmental perspective. Recent findings on risk factors and evolution of neuropsychological problems and their impact on daily life</u> Chair: <i>Jurgen Lemièr (Belgium)</i> Effects of maternal cancer diagnosis and treatment during pregnancy on cognitive development in toddlerhood <i>Tineke Vandenbroucke (Belgium)</i> Deficits in neuropsychological functioning of children with a neuromuscular disease: an often forgotten issue in infancy and primary school <i>Sam Geuens (Belgium)</i> Comparison of cognitive abilities and social responsiveness skills in children with 22q11.2 deletion syndrome (22q11DS) and children with idiopathic intellectual disability (IID) <i>Ann Swillen (Belgium)</i> Neurodevelopment in childhood cancer patients and long-term treatment-related effects <i>Charlotte Sleurs (Belgium)</i>
15.15 - 16.15	<u>Clinical Workshop: ACT as a behavioral medicine approach to treat pediatric chronic pain</u> <i>Rikard Wicksell (Sweden)</i>
17.00 – 18.00	DEBATE “To tweet or not to tweet” pro-con debate: we should (not) use social media <i>Judith Young & Martha Deiros Collado (United Kingdom)</i>
19.00 - ...	Social Programme

08.30 – 09.00		Registration + coffee
09.00 – 10.30		PARALLEL SESSIONS
		<u>Symposium: Resilience in the context of pediatric pain</u>
		Chair: Rikard Wicksell (Sweden)
09.00		Adolescents' adaptive and maladaptive pain-related behaviors in context: a daily diary approach <i>Melanie Beeckman (Belgium)</i>
09.20		How do basic psychological needs and parental autonomy-support help adolescents to live adaptively with chronic pain? <i>Annina Riggenschach (Switzerland)</i>
09.40		Capturing resilience through engagement in life: Exposure-based treatment for youth with chronic pain <i>Laura Simons (USA)</i>
10.00		ACTsmart - feasibility and preliminary outcome of smartphone delivered ACT for adolescents with chronic pain and their parents <i>Linda Holmström (Sweden)</i>
		<u>Symposium: Psychosocial aspects in children and adolescents with type 1 diabetes and their parents</u>
		Chair: Cynthia Van Gampelaere (Belgium)
09.00		Illness identity in youth with type 1 diabetes: A person-centered approach <i>Leen Oris (Belgium)</i>
09.20		Worries, mindfulness and parenting: A diary study in parents of children with type 1 diabetes <i>Cynthia Van Gampelaere (Belgium)</i>
09.40		Youth with type 1 diabetes in transition to adolescence: the role of executive functioning and changing diabetes responsibilities on glycemic control <i>Maartje de Wit (The Netherlands)</i>
10.00		A model of the influence of psychosocial and treatment-related variables on adherence and metabolic control in adolescents with type 1 diabetes mellitus <i>Mikael Thastum (Denmark)</i>
		<u>Paper session: Children in the NICU</u>
		Chair: Kiki Mastroyannopoulou (United Kingdom)
09.00		A sensory processing perspective on symptoms of attention deficit hyperactivity disorder and autism spectrum disorder in very preterm children <i>Tinka Bröring (The Netherlands)</i>
09.20		Parental mental health in the first months after discharge from the neonatal intensive care unit: a pilot study <i>Mieke Ouwendijk (The Netherlands)</i>
09.40		Trajectory of pain and distress in hospitalized children <i>Nátali Castro Antunes Caprini Oliveira (Brazil)</i>
10.00		Beyond gestational age: parenting during toddlerhood predicts cognitive and behavioural functioning in 6-year-old moderately preterm born children <i>Lilly Bogičević (The Netherlands)</i>
09.00 - 10.30		<u>Clinical workshop: A multidisciplinary approach to the evaluation and treatment of feeding disorders in toddlers from the psychological perspective</u> <i>Ann Davis (USA)</i>
10.30 - 11.00		Coffee break & Poster session I
11.00 – 12.30		PARALLEL SESSIONS
		<u>Paper session: The role of parents in the context of children's chronic health conditions</u>
		Chair: Laura Simons (USA)
11.00		Parental presence during child burn wound care procedures: child and parent experiences <i>Marthe Egberts (The Netherlands)</i>
11.20		Parent outcomes of an interdisciplinary pediatric chronic pain treatment program <i>Julia Z. Benjamin (USA)</i>
11.40		Parents' experiences of discussions about organ and tissue donation at end of life: The value of asking <i>Anne-Sophie Darlington (United Kingdom)</i>
12.00		Understanding children's with epilepsy perceptions of stigma in the context of the family: the moderating role of their parents' social comparison orientation <i>Teresa Paula Gameiro Pompeu Mendes (Portugal)</i>
		<u>Paper session: The clinical practice of pediatric psychology</u>
		Chair: Chris Verhaak (The Netherlands)
11.00		<i>The role of a psychologist in a multidisciplinary approach in helping children and adolescents managing their chronic illness</i> Thomas Fondelli & Veerle Maelbrancke (Belgium)
11.20		<i>Understanding perceptions of paediatric advanced care planning</i> Lyndsey Carlson (United Kingdom)
11.40		<i>Use of KLIK in clinical practice: implementation of electronic patient reported outcomes</i> Hedy van Oers (The Netherlands)
12.00		<i>When I grow up – designing a standardised hospital-wide transition service for non-standardised diseases</i> Alice Morgan (Australia)

	<p><u>Symposium: Coping with STRESS: biological and behavioral pathways to psychopathology and excess weight gain in youth</u></p> <p>Chair: Sandra Verbeken (Belgium) Discussant: Nathalie Michiels (Belgium)</p> <p>11.00 Stressors and emotion regulation as predictors of perceived stress and stress biomarkers in adolescents Joanna Klosowska (Belgium)</p> <p>11.20 <i>Salivary metabolomics as a new tool for unravelling stress obesity pathways in adolescents from a clinical public health perspective</i> Sandra Verbeken (Belgium)</p> <p>11.40 Stress and (un)healthy food behavior: the moderating role of emotional eating and emotion regulation: An Ecologically Momentary Assessment study <i>Taaïke Debeuf (Belgium)</i></p> <p>12.00 The stress reducing effect of a short emotion regulation (ER) training for adolescents at risk Brenda Volkaert (Belgium)</p>
11.00 - 12.30	<p><u>Publishing workshop: Publishing your work in Pediatric Psychology: Maximizing Your Chances of Success</u></p> <p><i>Jennifer Verrill Schurman (Editor Clinical Practice in Pediatric Psychology) & Melissa Alderfer (Associate Editor Journal of Pediatric Psychology) (USA)</i></p>
12.30 - 13.30	Lunch & Poster session II
13.30 - 14.15	<p>PLENARY SESSION III</p> <p>Transition from pediatric to adult health care: an opportunity for psychology <i>Adrienne Kovacs (USA)</i></p>
14.15 - 15.45	PARALLEL SESSIONS
	<p><u>Symposium: Perspectives of patients, parents and siblings on family adjustment to childhood cancer: contrasts, associations, and prospective predictors</u></p> <p>Chair: Marieke Van Schoors (Belgium) Discussant: Melissa A. Alderfer (USA)</p> <p>14.15 Longitudinal analyses of coping and post-traumatic growth in children and adolescents diagnosed with cancer: Coping near diagnosis through 5 years later <i>Kemar V. Prussien (USA)</i></p> <p>14.35 Parents' perspectives of change within family functioning after a pediatric cancer diagnosis <i>Marieke Van Schoors (Belgium)</i></p> <p>14.55 The adjustment of siblings of children with cancer, their parents, and family functioning: A comparison to families of healthy children <i>Melissa A. Alderfer (USA)</i></p> <p>15.15 Adjustment in childhood cancer survivors, healthy peers, and their parents: The mediating role of parenting perceptions <i>Sasja A. Schepers (USA)</i></p>
	<p><u>Symposium: Utilizing mixed methods to elucidate biopsychosocial factors in pediatric chronic pain</u></p> <p>Chair: Christine B. Sieberg (USA)</p> <p>14.15 Psychophysical factors contributing to chronic pelvic pain in adolescent and young adult women with endometriosis <i>Christine B. Sieberg (USA)</i></p> <p>14.35 Which passengers are on your bus? A qualitative analysis of the hurdles adolescents with chronic pain need to overcome to make progress <i>Konrad VA Jacobs (United Kingdom)</i></p> <p>14.55 Parental appraisals of injustice in the context of pediatric pain: A mixed methods approach <i>Fleur E. J. Baert (Belgium)</i></p> <p>15.15 Diagnostic and treatment dilemmas in chronic pain and somatization disorders: Neurobiological factors, stigmatization of the sufferer, and longitudinal outcome data in children <i>Bruce Dick (Canada)</i></p>
	<p><u>Symposium: Challenges for children and adolescents with gender dysphoria and sex chromosome DSD</u></p> <p>Chair: Arianne Dessens (The Netherlands) Discussant: Jolien Laridaen (Belgium)</p> <p>14.15 Emotional and behavioural problems in Flemish youth with gender dysphoria measured by the CBCL and YSR <i>Gaia Van Cauwenberg & Jolien Laridaen (Belgium)</i></p> <p>14.35 Highlights in working with (younger) children with genderdysphoric feelings <i>Heidi Vanden Bossche (Belgium)</i></p> <p>14.55 Social, emotional and behavioral problems in individuals with Klinefelter syndrome (47, xxy): a focus on underlying neurocognitive mechanisms Sophie Van Rijn (The Netherlands)</p> <p>15.15 What's new in clinical management for girls with Turner syndrome? Updated clinical guidelines for psychologists <i>Arianne Dessens (The Netherlands)</i></p>
14.15 - 15.45	<p><u>Clinical workshop: The transition from pediatric to adult care: From guidelines to clinical practice</u></p> <p><i>Adrienne Kovacs (USA)</i></p>
15.45 - 16.15	Coffee break & Poster session III

16.15 – 17.15	PARALLEL SESSIONS
16.15	<p><u>Paper session: The use of technology in pediatric psychology interventions</u></p> <p>Chair: Anne-Sophie Darlington (United Kingdom)</p> <p>Virtual reality analgesia: effectiveness with children and adolescents undergoing venipuncture <i>Barbara Atzori (Italy)</i></p> <p>Game on! Gamification and development of an online game to improve self-management and transition in children and young people with a chronic renal condition <i>Anne-Sophie Darlington (United Kingdom)</i></p> <p>How do children with diabetes evaluate the usability of a personal robot buddy supporting self-management, at camp? <i>Sylvia van der Pal (The Netherlands)</i></p>
16.15	<p><u>Paper session: Innovative research in childhood cancer survivors</u></p> <p>Chair: Marta Grootenhuis (The Netherlands)</p> <p>Coping trajectories and the health-related quality of life of childhood cancer survivors <i>Rachel S. Fisher (USA)</i></p> <p>Childhood cancer impact on parenting – a qualitative study with parents of childhood cancer survivors <i>Margarida Custódio dos Santos (Portugal)</i></p> <p>Nourish-t: intervening with parents to improve the eating and physical activity behaviors of pediatric cancer survivors with obesity <i>Marilyn Stern (USA)</i></p>
16.15	<p><u>Symposium: Fairies at the incubator: family-centered care in the NICU</u></p> <p>Chair: Bieke Bollen (Belgium)</p> <p>A new concept of family-centered care in neonatology <i>Gunnar Naulaers (Belgium)</i></p> <p>Fairies at the incubator: psychotherapy with (preterm) infants and their parents <i>Sarah Van Ransbeek & Janne Houben (Belgium)</i></p> <p>Innovative research in the NICU, building better family-centered care <i>Bieke Bollen & Chiara Bernagie (Belgium)</i></p>
16.15	<p><u>Symposium: Eating and weight problems from childhood to adolescence</u></p> <p>Chair: Lien Goossens (Belgium)</p> <p>The role of specific Executive Function abilities in obese youngsters <i>Tiffany Naets (Belgium)</i></p> <p>Unravelling the Association between Inhibitory Control and Loss of control over Eating among Youngsters. <i>Eva Van Malderen (Belgium)</i></p> <p>Parental school-based intervention to promote young children's eating behaviors: effectiveness and predictors of outcome <i>Luisa Barros (Portugal)</i></p>
17.15 - 17.45	Closing + Best Poster Award

European Pediatric Psychology Conference Programme

THURSDAY, SEPTEMBER 20th 2018					
12.00 - 13.00	Registration, sandwiches & coffee				
13.00 - 13.15	Conference Opening and Welcome				
13.15 - 14.00	PLENARY SESSION I - Rikard Wicksell - BEHAVIORAL FLEXIBILITY: A KEY FACTOR IN CHRONIC PAIN MANAGEMENT				
14.00 - 14.45	PLENARY SESSION II - Ann Davis -E-HEALTH AND THE USE OF TECHNOLOGY IN THE CONTEXT OF PEDIATRIC PSYCHOLOGY: EXAMPLES FROM HEALTHY LIFESTYLES RESEARCH				
14.45 - 15.15	Coffee break				
15.15 - 16.45	PARALLEL SESSIONS	SYMPOSIUM BRIGHT IDEAS FOR EVERYDAY LIVING: DEVELOPMENT, IMPLEMENTATION, EVALUATION, AND DISSEMINATION OF A RESEARCH-TESTED PSYCHOSOCIAL INTERVENTION	SYMPOSIUM INNOVATIVE (COGNITIVE BEHAVIORAL) INTERVENTIONS IN THE CHILDREN'S HOSPITAL	SYMPOSIUM CLINICAL PEDIATRIC NEUROPSYCHOLOGY: A DEVELOPMENTAL PERSPECTIVE RECENT FINDINGS ON RISK FACTORS AND EVOLUTION OF NEUROPSYCHOLOGICAL PROBLEMS AND THEIR IMPACT ON DAILY LIFE	CLINICAL WORKSHOP ACT AS A BEHAVIORAL MEDICINE APPROACH TO TREAT PEDIATRIC CHRONIC PAIN
17.00 -18.00	DEBATE - Judith Young & Martha Deiros Collado - TO TWEET OR NOT TO TWEET" PRO-CON DEBATE: WE SHOULD (NOT) USE SOCIAL MEDIA				
19.00 -	Social Programme				
FRIDAY, SEPTEMBER 21st 2018					
08.30 - 9.00	Registration + coffee				
09.00 - 10.30	PARALLEL SESSIONS	SYMPOSIUM RESILIENCE IN THE CONTEXT OF PEDIATRIC PAIN	SYMPOSIUM PSYCHOSOCIAL ASPECTS IN CHILDREN AND ADOLESCENTS WITH TYPE 1 DIABETES AND THEIR PARENTS	PAPER SESSION CHILDREN IN THE NICU	CLINICAL WORKSHOP A MULTIDISCIPLINARY APPROACH TO THE EVALUATION AND TREATMENT OF FEEDING DISORDERS IN TODDLERS FROM THE PSYCHOLOGICAL PERSPECTIVE
10.30 - 11.00	Coffee break + POSTER SESSION I				
11.00 - 12.30	PARALLEL SESSIONS	PAPER SESSION THE ROLE OF PARENTS IN THE CONTEXT OF CHILDREN'S CHRONIC HEALTH CONDITIONS	PAPER SESSION THE CLINICAL PRACTICE OF PEDIATRIC PSYCHOLOGY	SYMPOSIUM COPING WITH STRESS: BIOLOGICAL AND BEHAVIORAL PATHWAYS TO PSYCHOPATHOLOGY AND EXCESS WEIGHT GAIN IN YOUTH	PUBLISHING WORKSHOP PUBLISHING YOUR WORK IN PEDIATRIC PSYCHOLOGY: MAXIMIZING YOUR CHANCES OF SUCCESS
12.30 - 13.30	Lunch + POSTER SESSION II				
13.30 - 14.15	PLENARY SESSION III - Adrienne Kovacs - TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE: AN OPPORTUNITY FOR PSYCHOLOGY				
14.15 - 15.45	PARALLEL SESSIONS	SYMPOSIUM PERSPECTIVES OF PATIENTS, PARENTS AND SIBLINGS ON FAMILY ADJUSTMENT TO CHILDHOOD CANCER: CONTRASTS, ASSOCIATIONS AND PROSPECTIVE PREDICTORS	SYMPOSIUM UTILIZING MIXED METHODS TO ELUCIDATE BIOPSYCHOSOCIAL FACTORS IN PEDIATRIC CHRONIC PAIN	SYMPOSIUM CHALLENGES FOR CHILDREN AND ADOLESCENTS WITH GENDER DYSPHORIA AND SEX CHROMOSOME DSD	CLINICAL WORKSHOP THE TRANSITION FROM PEDIATRIC TO ADULT CARE: FROM GUIDELINES TO CLINICAL PRACTICE
15.45 - 16.15	Coffee break + POSTER SESSION III				
16.15 - 17.15	RAPID PARALLEL SESSIONS	PAPER SESSION THE USE OF TECHNOLOGY IN PEDIATRIC PSYCHOLOGY INTERVENTIONS	PAPER SESSION INNOVATIVE RESEARCH IN CHILDHOOD CANCER SURVIVORS	SYMPOSIUM FAIRIES AT THE INCUBATOR: FAMILY-CENTERED CARE AT THE NICU	SYMPOSIUM EATING AND WEIGHT PROBLEMS FROM CHILDHOOD TO ADOLESCENCE
17.15 - 17.45	Closing + Best Poster Award				