

Pediatric Psycho-Oncology Special Interest Group

Chair: Professor Claire Wakefield

Deputy Chair: Dr Fiona Schulte

1. Summary of achievements against 2019-2020 objectives

a) Continue to discuss with IPOS Board regarding possible scholarship in honour of Prof. Patenaude.

<u>Progress:</u> Successful establishment of IPOS LMIC Development Award in honour of Prof. Patenaude. Review committee successfully selected award recipient out of 17 applicants. Unfortunately, this is now on hold due to Covid-19.

b) Continue to support the Sleep in Pediatric Oncology Collaborative as they publish their first position paper and commence work on their second.

<u>Progress:</u> Successful publication of the first SPOC position paper on behalf of the IPOS Paediatrics SIG:

Daniel, L.C., van Litsenburg, R.R.L., Rogers, V.E., Zhou, E.S., Ellis, S.J., Wakefield, C.E., Stremler, R., Walter, L., Crabtree, V.M. (2020) A call to action for expanded sleep research in pediatric oncology: A position paper on behalf of the International Psycho-Oncology Society Pediatrics Special Interest Group. Psycho-Oncology. 29(3): 465-474.

c) Continue to ensure IPOS Pediatrics SIG representation at WHO Global Initiative for Childhood Cancer through ongoing key activities in treatment abandonment and health literacy.

Progress:

- 1. Professor Wakefield was selected as a member of Working Group II: Assessment Tool. In 2019-2020 she reviewed over 100 possible measures to include in the assessment battery. Virtual meetings with Working Group are ongoing.
- 2. Our SIG member, Dr Benedict Akimana, travelled to Zambia to represent IPOS at the WHO Global Initiative in Childhood Cancer National Stakeholder Workshop.





"The goal of the workshop was to connect National priorities to commitments and global targets.
Objectives were to summarize the current landscape and priorities for cancer control in children and adolescents in Zambia,

introduce the concepts of WHO CURE All and defining core projects to accelerate progress for children and adolescents with cancer in Zambia between 2020-2023."

This travel was very kindly supported by IPOS President Professor Jane Turner. More information on the meeting can be found in the POPPI Newsletter (Issue 5).

d) Continue to promote pediatric psycho-oncology as a discipline on social media.

<u>Progress</u>: Many of the IPOS Pediatric SIG members promote their research and the discipline on Twitter and through their respective institutions. On Twitter, the group reaches over 18K followers, further amplified through sharing by their institutions and other organisations they are involved in.

e) Continue to promote the IPOS Pediatrics SIG to IPOS members, particularly through the POPPI newsletter.

<u>Progress:</u> The POPPI newsletter continues to be a successful tool to exchange information, promote research and extend networks in the pediatric psycho-oncology field. It is now in its 6th issue and reaches over 1000 pediatric psycho-oncology professionals with overwhelmingly positive feedback from our recipients and colleagues.

f) Continue to support Dr Breyer with the distribution of the book "When your child in sick".

<u>Progress</u>: The IPOS Pediatric SIG continues to support Dr Breyer's book 'When your child is sick'. Currently, the book is launching in the UK and discussions to create an Australian edition are underway.

- 2. Additional activities/achievements through 2019-2020
- a) COVID and Childhood Cancer research project



- a. **Preliminary study.** Dr Fiona Schulte has led a global research team investigating "COVID-19 and childhood cancer survivorship: Investigating the health beliefs and psychosocial impacts of the COVID-19 pandemic on survivors of childhood cancer" out of the University of Calgary. The study explored the health beliefs and perceived psychological impact of COVID-19 among survivors of childhood cancer amid the pandemic. The response to the study has been impressive, with 194 survivors from 9 countries already participating. Briefly, a substantial proportion of survivors rated their mental health as being worse now than before the COVID-19 pandemic. Most survivors felt that they were more at risk of severe COVID-19 complications yet, only a small proportion reported having received information about their specific risks as survivors. Most survivors reported that they would like to receive information specific to their risks. These findings are already proving useful in considering supports for childhood cancer survivors living through the pandemic across the globe.
- b. **Presentation.** Caitlin Forbes, Research Coordinator leading the research team, presented the preliminary data at the Canadian Association of Psychosocial Oncology (CAPO) and winner of the Bultz Best Student Oral Presentation Award (2020).
- b) Distribution and support of IPOS members' projects
 - c. The SIG distributed and participated in IPOS member Ray Roberto Andrade Nascimento's (ECPP) survey. His research in Brazil has the aim of investigating psychosocial strategies that are used by psychologists, from around the globe, with children/adolescents with cancer in a hospital context.
 - d. The SIG distributed and participated in IPOS and Pediatric SIG member Dr Ursula Sansom-Daly's survey on adolescent and young adult end-of-life care, led out of Australia. The team are developing international consensus around what 'best practice' end-of-life communication with AYAs should look like, and what sort of training healthcare providers most need to improve care in this space.
 - e. Pediatric SIG member Yeva Asribabayan reached out to IPOS and the Pediatric SIG to connect with possible collaborators for her project in Armenia, focused on psychooncology and art, in Hungary, Czech Republic, Poland and Slovakia. The SIG supported the study and contributed to the connection of psycho-oncology professionals, furthering its reach in Eastern Europe.
- c) Increase in IPOS Pediatric SIG membership



The IPOS Peds SIG recorded a 50% growth in membership from 31 members reported in 2018-2019 to 47 members in 2019-2020.

3. Issues/concerns arising during the past year

The IPOS Pediatrics SIG has continued to work together and focus on its goals. Like all SIGs, the cancellation of the 2020 world congress meant that we did not have a chance to meet in person, however considering the challenges of this year, we believe we have managed well.

4. Coordination with any other IPOS Committees/SIGs

The IPOS Pediatrics SIG worked closely with the Nominations Committee to establish the IPOS LMIC Development Award in honour of Prof. Patenaude.

Multiple members of the Pediatrics SIG are also members of the Early Career Professionals SIG, the IPOS Research Committee and the Guidelines Committee.

We have commenced dialogue with the new Chair of the IPOS Survivorship SIG to identify potential synergies between these two SIGs.

5. Goals for the IPOS Pediatrics SIG for the next 12 months

- a) Re-establish and award the IPOS LMIC Development Award in honour of Prof. Patenaude when possible.
- b) Continue to support the Sleep in Pediatric Oncology Collaborative as they aim to publish their second position paper
- c) Continue to ensure IPOS Pediatrics SIG representation at WHO Global Initiative for Childhood Cancer through ongoing key activities in treatment abandonment and health literacy.
- d) Continue to promote pediatric psycho-oncology as a discipline on social media.
- e) Continue to promote the IPOS Pediatrics SIG to IPOS members, particularly through the POPPI newsletter.
- f) Continue to distribute and support of IPOS members' pediatric projects.
- g) Continue to build SIG membership internationally



1. Appendix 1: Active Special Interest Group Members

NAME	EMAIL
Alina Khain	Khain.alina@gmail.com
Alisa Kamalyan	alisakamalyan@gmail.com
Amanda Thompson	althomps@cnmc.org
Amanda Wurz	ajwurz@ucalgary.ca
Benedict Akimana	akimben@gmail.com
Brindha Sitaram	drbrindha@yahoo.com
Brittany McGill	b.mcgill@unsw.edu.au
Brooke Russell	kbrussel@ucalgary.ca
Caitlin Forbes	caitlin.forbes@ucalgary.ca
Caridad R. Moreno	cmoreno@barnabashealth.org
Christina Signorelli	c.signorelli@unsw.edu.au
Claire Wakefield	c.wakefield@unsw.edu.au
Eden Robertson	Eden.robertson@unsw.edu.au
Ekaterina Shutkova	eshutkova@gmail.com
Elisa Maria Perina	elisaperina@gmail.com
Elizabeth Akin-Odanye	Toyin_akinodanye@yahoo.co.uk
Fiona Schulte	Fiona.Schulte@albertahealthservices.ca
Hailey Zwicker	hailey.zwicker@ucalgary.ca
Hanan El Malla	hananelmalla@hotmail.com
Hanin Salem	salem@cancer.dk



Heather Chambliss	heather.chambliss@stjude.org
Jenny Hoag	jhoag@mow.edu
Joanna Breyer	Joanna.breyer@yahoo.com
Juanita Rojas Restrepo	juanitarojarestrepo@gmail.com
Kristin Bingen	kbingen@mcw.edu
Lauren Heathcote	lcheath@standford.edu
Lauren Kelada	l.kelada@unsw.edu.au
Lori Wiener	lori.wiener@nih.gov
Malin Ander	Malin.ander@pnbcare.uu.se
Martha Grootenhuis	M.A.Grootenhuis@prinsesmaximacentrum.nl
Maru Barrera	maru.barrera@sickkids.ca
Mary Jo Kupst	Mkupst@mcw.edu
Mehak Sandhu	sandhm@ucalgary.edu
Michaela Patton	michaela.patton@ucalgary.ca
Michelle Peate	mpeate@unimelb.edu.au
Nadine Kasparian	n.kasparian@unsw.edu.au
Natalia Klipinina	nklip@mail.ru
Natalia Nikolskaya	nsnikolskaya@mail.ru
Nicole Englebert	nicole.englebert@childrensmn.org
Pamela Mosher	pjmosher@yahoo.com
Pernille Envold Bidstrup	pernille@cancer.dk
Raphaele van Litsenburg	r.r.l.vanlitsenburg@prinsesmaximacentrum.nl



Sokhna Ndiaye	ndiayesokhna@gmail.com
Tatiane Riabova	riabova07@mail.ru
Ursula Sansom-Daly	Ursula@unsw.edu.au
Valerie Crabtree	Valerie.crabtree@stjude.org
Zeynep Yazici	Psk.zeynepyazici@gmail.com