



## **Pediatric Psycho-Oncology Special Interest Group**

Chair: Fiona Schulte, PhD

### **1. Goals, objectives, and results for 2023**

#### *a) Co-Chair Transition*

The IPOS Pediatric SIG was sad to see Dr. Claire Wakefield step-down as Co-Chair. Dr. Wakefield was the founder of the SIG and has been involved of the growth and evolution of the SIG since its inception. Her stepping down from this role is a huge loss to the Peds SIG.

#### *b) Call for Deputy Chair*

A call for a new co-chair of the Pediatric SIG was released in July 2023. Expressions of interest were received from many exceptionally qualified candidates representing impressive diversity from around the globe. The successful applicant for the position was Dr. Joanna Fardell. Dr Joanna Fardell is a Senior Research Fellow, for Maridulu Budyari Gumal (SPHERE) Cancer Clinical Academic Group, working in the Living Better with and After Cancer area of focus. She is also Deputy Director of Australia's largest psycho-oncology research groups - The Behavioural Sciences Unit, part of the Kids Cancer Centre at Sydney Children's Hospital. She also holds a clinical appointment as Neuropsychologist for the Western Sydney Youth Cancer Service, Crown Princess Mary Cancer Centre, Westmead Hospital. Dr Fardell's research interests focus on improving quality of life of people of all ages impacted by cancer, particularly through improving cognitive, social cognitive, and education or work outcomes, addressing unmet information needs and fear of cancer recurrence. Dr Fardell has experience with quantitative, qualitative and mixed methods research methodologies. Other applicants have been contacted to form a larger, SIG committee. The Peds SIG Chairs will plan to three times over the course of the year (2 virtual, 1 face-to-face) to discuss goals, objectives and progress within the SIG.

#### *c) Pediatric SIG Collaboration with the Survivorship SIG*

The Peds SIG collaborated with the Survivorship SIG to review pediatric specific survivorship abstracts presented at the IPOS conference over the past 4 years. Results of this work were published in the official IPOS journal, Journal of Psychosocial Oncology Research and Practice.



Gitonga, I., Thornton, C. P., Schulte, F., Jefford, M., Luigjes-Huizer, Y., Ruble, K. (2023). Survivorship representation at IPOS World Congress: Abstract Review and Analysis. *Journal of Psycho-oncology Research and Practice*.

*d) WHO Global Initiative for Childhood Cancer under the Sponsorship of the American Childhood Cancer Organization (ACCO)*

The IPOS SIG continues to be represented on the WHO-ACCO project. This project focuses on the Lived Experience of People affected by cancer, including cancer survivors (both of adult and childhood cancer), their caregivers, and families. The WHO-ACCO project aims to evaluate the psychosocial and financial impact of cancer on children and adults who have finished treatment, through the dissemination of a Global Survey available in a variety of languages. This will allow us to identify ways in which professionals and governments may support people facing a cancer diagnosis, and their families. WHO is currently developing a Framework to better engage with the Lived Experience of People living with non-communicable diseases and we are conducting this project in the context of this new approach.

Dr. Julie Cayrol is responsible for leading this initiative alongside chief investigators, Dr. Claire Wakefield, Dr. Lori Wiener and Dr. Clarissa Schilstra, among many other contributors. Dr. Schulte has been invited to participate as part of the study Advisory Panel. The Advisory Panel is comprised up to 50 stakeholders including people with Lived Experience of cancer, representatives from relevant cancer community organisations around the world, WHO staff in regional offices, members of the Global Childhood Cancer Initiative, and other individuals as relevant.

*e) Continued IPOS Pediatrics SIG representation in major global projects*

Members of the IPOS SIG continues to serve on multiple additional committees and projects including the WHO Global Initiative for Childhood Cancer (GICC), the International Guideline Harmonization Group, the SIOP Pediatric Psycho-Oncology (PPO) Network.

*f) POPPI - Pediatric Psycho-Oncology Professionals and Providers International*

The POPPI newsletter, distributed by the chairs of the SIOP Pediatric Psycho-Oncology Group, the IPOS Pediatric SIG and the American Psycho-Oncology Society Pediatrics SIG, continues to receive overwhelming support and is now at its' ninth issue. Dr. Schulte contributes to the development and dissemination of the POPPI newsletter. The main goals of this newsletter are to stimulate international, interorganizational 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.

## **2. Description of issues/challenges experienced in 2023**

### ***a) Change in leadership***

Dr. Wakefield stepped down as Chair of the IPOS-SIG. This is a huge loss to the SIG. Dr. Wakefield has a long history of leading this SIG. The transition of leadership to Dr. Schulte has resulted in some delays to the progress of the SIG but may present new opportunities for the SIG.

### ***b) IPOS World Congress***

Since the COVID-19 pandemic, travel to the IPOS world congress has become more problematic. Opportunities to meet with the SIG outside of the world congress may be needed. Virtual meetings will be prioritized moving forwards.

## **3. Goals for the Next 12 Months (2024)**

- a) Review and revise Peds SIG Terms of Reference
- b) Create a Peds SIG executive from members who applied to Deputy Chair position.
- c) Continue to meet as a SIG to identify opportunities for collaboration.
- d) Continue to ensure IPOS Pediatrics SIG representation on major global projects, including those led by WHO, the International Society for Pediatric Oncology (SIOP) and St Jude.
- e) Identify key topics of interest (e.g, screening) that may benefit from this global collaboration, e.g., pain in pediatric oncology.
- f) Consider Peds SIG symposium to be submitted to IPOS 2025.
- g) Develop a communication strategy across multiple platforms including social media.
- h) Continue to promote the IPOS Pediatrics SIG to IPOS members, particularly through the POPPI newsletter.
- i) Develop opportunities to engage students within the SIG.



#### **4. Any special requests/needs for the next 12 months**

None.

#### **5. List of current committee members**

1. Alina Khain Russia
2. Alisa Kamalyan Armenia
3. Amanda Thompson US
4. Amanda Wurz Canada
5. Benedict Akimana Uganda
6. Brindha Sitaram India
7. Brittany McGill Australia
8. Brooke Russell Canada
9. Caitlin Forbes Canada
10. Caridad R. Moreno US
11. Christina Signorelli Australia
12. Claire Wakefield Australia
13. Eden Robertson Australia
14. Ekaterina Shutkova Russia
15. Elisa Maria Perina Brasil
16. Elizabeth Akin-Odanye Nigeria
17. Fiona Schulte Canada
18. Hailey Zwicker Canada
19. Hanan El Malla Egypt
20. Hanin Salem Denmark
21. Heather Chambliss US
22. Jenny Hoag US
23. Joanna Breyer US
24. Juanita Rojas Restrepo Columbia
25. Kristin Bingen US
26. Lauren Heathcote US
27. Lauren Kelada Australia
28. Lori Wiener US
29. Malin Ander Sweden
30. Martha Grootenhuis The Netherlands
31. Maru Barrera Canada
32. Mary Jo Kupst US
33. Mehak Sandhu Canada
34. Michaela Patton Canada
35. Michelle Peate Australia
36. Nadine Kasparian US



37. Natalia Klipinina Russia
38. Natalia Nikolskaya Russia
39. Nicole Englebert US
40. Nele Loecher US
41. Pamela Mosher Canada
42. Perri Tutelman Canada
43. Pernille Envold Bidstrup Denmark
44. Raphaelle van Litsenburg The Netherlands
45. Sasha Schejpers The Netherlands
46. Sokhna Ndiaye Canada
47. Tatiane Riabova Russia
48. Ursula Sansom-Daly Australia
49. Valerie Crabtree US
50. Zeynep Yazici Turkey