

**Co-Chairs:** Michael Sullivan (Australia) and Muhammad Saghir Khan (Pakistan)

**Number of Members:** 1,100

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

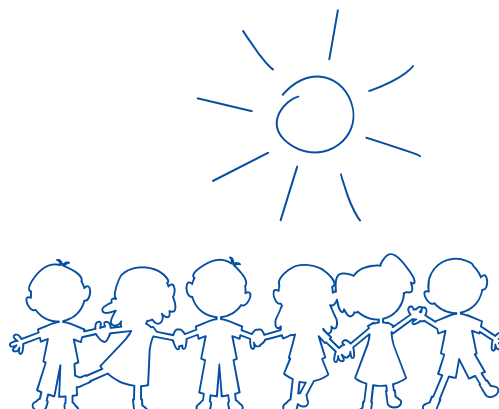
The Paediatric Oncology in Developing Countries Committee (PODC) is an important committee of SIOP, with more than 1,100 members from around 100 countries. It consists of 11 WGs and 5 TFs, including the newly launched Onco-Pharmacy and Adolescents and Young Adults TFs. Three new groups (IPSO LMIC, Young LMIC and Neuro-Oncology) will be launched within SIOP PODC very soon. Each WG/TF is led by two Co-Chairs, at least one of whom must be representing LMICs. SIOP PODC and its WGs/TFs carry out regular, periodic leadership transitions.


Over the years, SIOP PODC has been carrying out several educational, research and advocacy activities, mainly through [www.cure4kids.org](http://www.cure4kids.org), providing ample opportunities to stay engaged for paediatric oncology care providers serving in developing countries.

SIOP PODC is striving for better alignment of LIC and LMIC work force with SIOP's new Strategy and aiming to foster better engagement of its WG/TF members in WHO GICC. In this context, SIOP PODC Strategic Meeting was conducted virtually in November 2020. In that session, we thoroughly explored various collaborative avenues within PODC entities, and also those within the SIOP, WHO GICC and St. Jude Global ARIA project. PODC WGs/TFs leaders also shared their proposed plans for 2021-22. We also focused on the ways to increase the SIOP membership particularly from LMICs, and also discussed the ways to improve the membership engagement in various activities of SIOP PODC.

As SIOP PODC leadership had contributed very actively in Global Mapping Project since its launching from Africa, we are very keen to contribute towards this project's expansion to the Asian Continent. SIOP PODC is also very much looking forward to collaborate with SIOP Continental Branches and St. Jude Global Alliance team in joint collaborative endeavors.

In a collaboration between St. Jude Global and SIOP, the ARIA project is developing a shared online platform for hosting detailed Adapted Management Guidelines (AMGs) for the diagnosis, treatment and supportive care of children with cancer. This ARIA project led by Drs. Nickhill Bhakta, Manoo Bhakta, Miguel Bonilla and Professor Michael Sullivan, with the support of St. Jude Global, will integrate the revised SIOP PODC Adapted Treatment Regimens (ATRs) with a resource-adapted platform to produce practical treatment guidance. The focus till now has been developing and testing the platform and we are now completing the initial phase of developing AMGs for the 6 index cancers for the WHO GICC. The ARIA team is also partnering with PROS, IPSO and the PODC Nursing group.





The WG heard about many challenges but also about many opportunities about reutilization of tracking systems, connections with community practices, and reach out strategies.

## PODC Abandonment of Treatment WG

**Co-Chairs:** Nuria Rossell (El Salvador) and Paola Friedrich (USA)

**Number of Members:** 187

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The Abandonment of Treatment (TxA) WG was created in 2010. In the first several years, the group dedicated itself to scholarly work related to documenting a consensus definition, the magnitude of the problem, challenges related to terminology, and the determinants or predictors of refusal and abandonment. Although refusal and abandonment of treatment in its most absolute terms remain a challenge in many LMICs, there has been, in recent years, a recognition of: (1) the need for understanding adherence to treatment throughout the quality patient care continuum, (2) the opportunity to work collaboratively with the SIOP PODC Psychosocial WG to more comprehensively address this challenge, (3) the need to provide practical guidance for the implementation of TxA prevention programmes (beyond what is typically published in scholarly work).

In 2020, during the COVID-19 pandemic, the TxA WG conducted several meetings to inquire about how TxA WG members were leveraging services or connections they had established before the pandemic. The WG heard about many challenges but also about many opportunities about reutilization of tracking systems, connections with community practices, and reach out strategies.

The WG encouraged participation in the SIOP-St. Jude COVIMPACT study and decided to reactivate the initiative to utilize a podcast format to collect and disseminate practical experiences on how individuals and centers around the world prevent and address treatment abandonment. Mark Zobeck from Texas Children's Hospital is leading the interviews. In the first cohort, the project is recruiting participants from Brazil, Guatemala, Colombia, India, and Bangladesh to tell their story. The podcast will be hosted in the CancerPOINTE website and will launch in 2021.

## PODC Education and Training WG

**Chairs:** Elianeth Kiteni (Tanzania) and Neil Ranasinghe (UK)

**Number of Members:** 147

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The overall goal of the PODC Education and Training WG, also known as CancerPOINTE, is to make existing information regarding paediatric oncology more accessible to healthcare workers from resource-constrained settings. This has been made successfully through [CancerPOINTE's website](#). The website has several pages such as experts, nursing, resources, podcasts and others, which allows people to access useful information. In 2020, the WG continued to support the provision of information to health professionals, including sharing educational materials and news, courses, conferences, and finding mentors. Using social media, CancerPOINTE increased the awareness of SIOP activities, events, publications, and the Annual Congress; publicized many events, seminars, and webinars around the world that were of interest to healthcare professionals in LMIC. In addition, CancerPOINTE updated the website regularly and added more pages including:

- [COVID 19 page](#), providing information and papers on COVID-19 and paediatric oncology with a focus on LICs and LMICs
- [Published papers](#), featuring published papers relating to paediatric oncology in LICs and LMICs
- [Nutrition](#), providing information, documents and events from the SIOP PODC Nutrition Group
- [Links page](#) with links to various websites for informational purposes only

Finally, the WG collaborated with the PODC Nursing Group to host [monthly education learning](#) resources, conducted 6 POINTE meetings and attended the annual meetings with other PODC groups.

For more info, please follow CancerPOINTE in social media:

- [Facebook](#)
- [Instagram](#)
- [Twitter](#)



The second research project was a review of nutritional approaches in T&CM used in paediatric oncology. These included nutrient supplements, antioxidants, probiotics, immuno-nutrition, ketogenic diets, and cannabinoids.

### PODC Traditional and Complementary Medicine WG

**Co-Chairs:** Mohammad Alqudimat (Canada) and Glenn Mbah (Cameroon)

**Number of Members:** 27

**Welcoming New Members:** Yes:

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The Traditional and Complementary Medicine (T&CM) WG conducted two research projects in 2020. The first project was the survey on the use of T&CM among children with cancer in Africa. The data collection for Cameroon was completed and the manuscript is being finalized to report the rates of use of T&CM, the types and determinants of use. The WG is inviting anyone willing to conduct a similar survey elsewhere to contact the Co-Chairs.

The second research project was a review of nutritional approaches in T&CM used in paediatric oncology. These included nutrient supplements, antioxidants, probiotics, immuno-nutrition, ketogenic diets, and cannabinoids. The findings were published in *Pediatric Blood & Cancer*.<sup>3</sup> Other publications of the WG are also available.<sup>4</sup>

For 2021, the WG plans to hold monthly journal clubs on T&CM and conduct joint education sessions with other PODC WGs to promote open discussions between patients and professionals necessary to encourage disclosure of T&CM use and promote safe integration.

In 2020, Mohammad Alqudimat replaced Dr. Stacey Marjerrison as Co-Chair of the WG.

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<sup>3</sup> Diorio, C., Kelly, K.M., Afungchwi, G.M., Ladas, E.J. and Marjerrison, S., 2020. Nutritional traditional and complementary medicine strategies in paediatric cancer: A narrative review. *Pediatric Blood & Cancer*, 67, p.e28324

<sup>4</sup> <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0209738>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5735959/>

<https://link.springer.com/article/10.1007%2Fs00520-017-3908-0>

<http://onlinelibrary.wiley.com/doi/10.1002/pbc.26501/abstract;jsessionid=09212438D534EF6C9EB5BD65F5F9294D.f04t02>

<https://doi.org/10.1093/jncimonographs/lgx014>





## PODC Nursing WG

**Co-Chairs:** Yuliana Hanaratri (Indonesia) and Liz Sniderman (USA)

**Number of Members:** 181

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

In 2020, the International Year of the Nurse and the Midwife, the PODC Nursing WG focused on developing and implementing initiatives to promote paediatric oncology nursing education and professionalism; collaboration with other groups to promote the role of nursing; regional collaborations; and participation in advocacy for paediatric oncology nursing.

Educational sessions on a variety of nursing issues were held, including in collaboration with the PODC Palliative Care WG, Nutrition WG, and Supportive Care WG. Additionally, collaboration with CancerPOINTE allowed the PODC Nursing WG to make education widely available, creating a repository of materials and sharing educational opportunities on a [dedicated Nursing page](#) and through social media.

To promote the role of paediatric oncology nursing, nurses from all regions shared their personal journeys as paediatric oncology nurses. Advocacy efforts for paediatric oncology nurses have included the Making Global Connections Newsletters ([February 2020](#) and [COVID-19 Special Issue](#)), and the video project [20 Stories for 2020: Paediatric Oncology Nurses in the Year of the Nurse and the Midwife](#), a series of 5 videos celebrating nurses from around the world and highlighting their work.

Finally, the PODC Nursing WG supported nurses during the COVID-19 pandemic through webinars and collaboration on the [Global COVID-19 Observatory and Resource Center for Childhood Cancer](#). Despite a challenging year, the PODC Nursing WG has stayed connected and supported nurses around the world to provide the best care possible for children with cancer.

### Join Us:

- **Facebook:** SIOP PODC Nursing
- **Twitter:** @SIOPpodcNursing
- **WhatsApp:** Join via the QR code



## PODC Patient, Family and Stakeholder Engagement TF

**Co-Chairs:** Alta Bence (South Africa), Marcela Zubieta (Chile), and Julia Challinor (USA)

**Number of Members:** 47

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The purpose of the PODC Patient, Family and Stakeholder Engagement (PFSE) TF is to support the PODC members in engaging patients, families and stakeholders in global efforts to improve the care and survival of children and adolescents across LICs and LMICs. We liaise across PODC WGs and TFs and other external parties to ensure that their voices are present and active.

In 2020, we wrote and presented data collected in 10 LMICs in 2019. We actively recruited additional TF members with expertise in stakeholder engagement and survivorship in LMICs to continue to craft our strategic action and build our “in house” leadership.

“We worked jointly on papers, publications, and newsletters.”

We worked jointly on papers, publications, and newsletters. Six abstracts authored by the TF members were accepted for the SIOP 2020 Congress (3 oral and 3 posters) and a paper, “Parent Engagement and Agency in Latin American Childhood Cancer Treatment: A Qualitative Investigation,” was published in the Journal of Global Oncology.<sup>5</sup> We contributed to the CCI Fall Newsletter and CCI Latin America Fall Newsletter. Manuscripts under development include:

- Latin American young survivor data
- Solicited paper by Royal Anthropological Institute (London) – on study’s methodological approach collaborating with CCI and local CC NGOs
- South African study findings

Future efforts will focus on:

- Continue publishing the 2019 research data on patient and caregiver engagement during childhood cancer treatment collected in 10 LMICs and begin advocacy (Spanish, English).
- Consider link with CancerPOINTE (podcasts/social media)
- Communicate with the Pan American Health Organization (PAHO) to determine how to emphasize the importance of this for outcomes (survivorship) and decrease abandonment.
- One of our goals is to create guidelines for personnel in health care settings in LMICs: communication and parent/patient and survivor engagement

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<sup>5</sup> Olarte-Sierra, M. F., Rossell, N., Zubieta, M., & Challinor, J. (2020). Parent Engagement and Agency in Latin American Childhood Cancer Treatment: A Qualitative Investigation. JCO global oncology, 6, 1729-1735.

## PODC Nutrition WG

**Co-Chairs:** Karina Viani (Brazil) and Ligia Fu (Honduras)

**Number of Members:** 193

**Welcoming New Members:** Yes

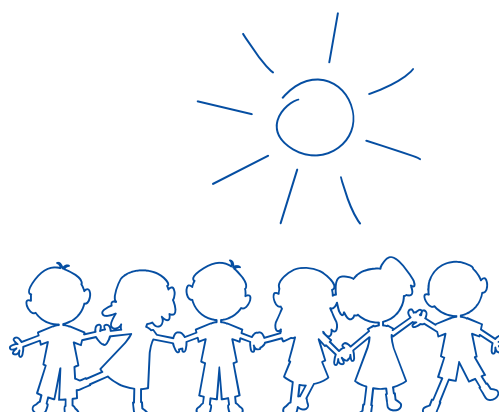
**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The PODC Nutrition WG currently has 193 members. This year our group welcomed 24 new members, 16 from LMICs. The increase in new membership was greater than in previous years.

In January 2020, the PODC Nutrition WG, along with partner IIPAN (International Initiative for Paediatrics and Nutrition), had a successful regional training in Nairobi, Kenya. Other already planned workshops and educational events for 2020 were cancelled or postponed to 2021 due to the COVID-19 pandemic. Similarly, research initiatives were mostly suspended in March 2020, and have been gradually resumed in the last quarter of the year.

Pediatric Blood and Cancer published the [Paediatric Oncology Nutritional Supplement](#) in June 2020 with seven articles on the topic of nutrition in children with cancer. This is a significant accomplishment of the PODC Nutrition WG along with the Nutrition Network and we thank all of the contributors. The supplement was sponsored by the [Sanofi Espoir Foundation](#).

In addition, a [Nutrition page](#) has been created on the CancerPOINTE website. This describes the aims of the PODC Nutrition WG and provides information, documents and events from the group, including a number of open access articles on nutrition in paediatric oncology in low resource settings.



## PODC Supportive Care WG

**Co-Chairs:** Paola Angelini (UK) and Miguela Caniza (USA)

**Number of Members:** 298

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)


Despite the global pandemic, which made significant changes and moved priorities in healthcare all over the world and many members of our group were busy with the COVID-19 response, the WG continued organizing online educational meetings via the Cure4Kids platform. In 2020, following educational meetings were organized:

- Organizing Survivorship Programme in Resource-Limited Setting: A Report from Mexico, led by Farina Arreguin Gonzalez (Mexico)
- Cardiovascular Disease in Childhood Cancer Patients and Long-Term Survivors, led by Saro Armenian (USA)
- Management of central lines and ports in oncology patients, led by Shant Shekherdimian (USA)
- Visceral Leishmaniasis in Paediatric Cancer Patients, led by Tatevik Grigoryan (Armenia)
- Supportive Care and Nursing Working Groups Joint Educational Meeting: Central Venous Catheters: Routine Maintenance Care and Nursing Care Priorities, led by Lauri Linder (USA)

In October 2020, there was a leadership transition for the WG – Miguela Caniza and Sadaf Altaf were elected as the new Co-Chairs of the WG, taking over from Paola Angelini and Gevorg Tamamyan.







A major accomplishment of the PODC WG on Twinning, Collaboration and Support in 2020 was publishing detailed guideline on the role of twinning in sustainable care for children with cancer.

### **PODC WG on Twinning, Collaboration and Support**

**Co-Chairs:** Nihad Salifu (Ghana) and Vikramjit S Kanwar (India)

**Number of Members:** 75

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

With the WHO GICC, there is an interest in sustainable interventions to improve childhood cancer care in LMICs. “Twinning” is a well-recognized intervention that refers to a targeted international paediatric-oncology partnership (TIPP) between one or more institutions in a HIC and LMIC [“North-South twinning”], or between LMIC centres [“South-South twinning”]. Such arrangements are not an end in themselves, but can yield tangible targeted gains.

A major accomplishment of the PODC WG on Twinning, Collaboration and Support in 2020 was publishing detailed guidelines<sup>6</sup> on the role of twinning in sustainable care for children with cancer, describing key components in successful TIPPs and highlighting common pitfalls.

Moving ahead, in 2021, the WG looks to improve support for local physician champions who drive successful TIPPs. Specifically, we would like to develop information resources and create an associated space/blog on the CancerPOINTE website where physician champions can easily reach out and post their intentions, locate potential partners, and share their experiences. TIPPs will be mapped on CancerPOINTE with more granularity and accuracy, including metrics such as abandonment rates and event-free/overall survival. We will coordinate efforts with the CancerPOINTE website and Care4Kids to support regional tumor boards, and web-based learning to foster regional physician training, nurse training, and facilitate ongoing transfer of knowledge to local teams.

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<sup>6</sup>“The role of twinning in sustainable care for children with cancer: A TIPPing point? SIOP PODC Working Group on Twinning, Collaboration, and Support.” *Pediatric Blood Cancer*. 2020 Nov; 67(11): e28667



## PODC Essential Drugs WG

**Co-Chairs:** Federico Antillon (Guatemala) and Parth Mehta (USA)

**Number of Members:** 40

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The PODC Essential Drugs WG is currently led by two Co-Chairs: Parth Mehta, who will rotate out in October 2021, and Federico Antillon. Scott Howard is coming in as a Co-Chair in October 2021. The new Hematology Drug Champion will be Dr. Vicky Breakey from McMasters University.

The WG is welcoming interested new members. The WG will support priority endeavours on improved access to essential medicines.

The WG remains open to expressions of interest to collaborate on drug access study in additional sites where local leadership and resources permit.

Lancet Commission has published a paper, “Lancet Oncology Commission on Sustainable Care for Children with Cancer,” co-authored by a number of WG members among others.<sup>7</sup>

In 2021, the WG will be working closely with the SIOP Advocacy Committee on a variety of tasks, associated with SIOP being a non-state actor in official relations with WHO, in the area of essential medicines.

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<sup>7</sup> Atun R, Bhakta N, Denburg A, Frazier AL, Friedrich P, Gupta S, Lam CG, Ward Z, Yeh J, Allemani C, Coleman M, di Carlo V, Loucaides W, Fitchett E, Girardi F, Horton S, Steliarova-Foucher E, Sullivan R, Aitken J, Banavali S, Binagwaho A, Alcasabas P, Antillon F, Arora R, Barr RD, Bouffet E, Challinor J, Fuentes S, Gross T, Hagander L, Hoffman R, Herrera C, Kutluk T, Marcus K, Moreira C, Pritchard-Jones K, Ramirez O, Renner L, Robison LL, Shalkov J, Sung L, Yeoh A, Rodriguez-Galindo C. Lancet Oncology Commission on Sustainable Care for Children with Cancer. Lancet Oncol 2020;21:e185-224.

## PODC Adapted Treatment Regimen WG

**Co-Chairs:** Michael Sullivan (Australia), Raya Saab (Lebanon) and Sandra Luna-Fineman (USA)

**Number of Members:** 127

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

In 2017, the 70th World Health Assembly (WHA) adopted Resolution 70.12 (article 2.1) on Cancer Prevention and Control and requested the WHO Director General to:

“develop or adapt stepwise and resource-stratified guidance and tool kits in order to establish and implement cancer prevention and control programmes, including for the management of cancers in children and adolescents, leveraging the work of other organisations.”

At SIOP 2019 Congress in Lyon, the PODC Adapted Treatment Regimen WG began a very productive collaboration with St. Jude Global to develop ARIA (Adapted Resource Implementation Application), a freely accessible and online platform of practical guidance for cancer care across all treatment resource settings. ARIA will complement the series of PODC adapted treatment regimens published over recent years and will be based on the SIOP PODC Adapted Treatment framework.<sup>8</sup> Following the SIOP 2020 Congress, SIOP and St. Jude Children's Research Hospital signed a master collaborative agreement and now have sub-agreement for the joint SIOP-St. Jude ARIA project. Considerable work has already been done to develop the platform and prepare draft adapted management guidelines. Over the next 12 months, we plan to work with each of the PODC ATR disease WGs to update and revise the existing PODC ATRs, develop new ATRs, and integrate these into detailed harmonised adapted management guidelines (AMGs). Our focus for the next 6 months will be the revision and update of ATRs with AMGs for each of the 6 index cancers (ALL, Burkitt Lymphoma, Hodgkin Lymphoma, Retinoblastoma, Wilms Tumour and Low-Grade Glioma).

The SIOP Governance Committee and Board of Directors wish each SIOP WG to have written terms of reference (TOR) and a workplan. The ATR leadership has drafted a detailed TOR that will specify the ATR/AMG WG membership and define the process for the development and publication of adapted treatment/management guidelines and ARIA. A crucially important element of the TOR is the detailed description of the methodology and process for the development of resource-stratified guidelines that were first developed in 2003 by the Breast Health Global Initiative (BHGI)<sup>9,10</sup> and subsequently adopted by ASCO<sup>11</sup>, NCCN<sup>12,13</sup> and SIOP<sup>14</sup>.

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<sup>8</sup> Howard SC, Davidson A, Luna-Fineman S, Israels T, Chantada G, Lam CG, Hunger SP, Bailey S, Ribeiro RC, Arora RS, Pedrosa F, Harif M, Metzger ML. A framework to develop adapted treatment regimens to manage pediatric cancer in low- and middle-income countries: The Pediatric Oncology in Developing Countries (PODC) Committee of the International Pediatric Oncology Society (SIOP) [Internet]. *Pediatr Blood Cancer*, 2018 64: e26879.

<sup>9</sup> Anderson BO, Duggan C. Resource-Stratified Guidelines for Cancer Management: Correction and Commentary. *J Global Oncol*, 2017 3: 84–88.

<sup>10</sup> Anderson BO, Shyyan R, Eniu A, Smith RA, Yip C, Bese NS, Chow LWC, Masood S, Ramsey SD, Carlson RW. Breast Cancer in Limited-Resource Countries: An Overview of the Breast Health Global Initiative 2005 Guidelines. *Breast J*, 2006 12: S3–S15.

<sup>11</sup> Al-Sukhun S, Temin S, Chavez-MacGregor M, Denduluri N, Oliver TK, Pyle D, Shah MA, Gralow J. ASCO Resource-Stratified Guidelines: Methods and Opportunities. *J Global Oncol*, 2018 1–8.

<sup>12</sup> Carlson RW, Scavone JL, Koh W-J, McClure JS, Greer BE, Kumar R, McMillian NR, Anderson BO. NCCN Framework for Resource Stratification: A Framework for Providing and Improving Global Quality Oncology Care. *J Natl Compr Canc Ne*, 2016 14: 961–969.

<sup>13</sup> Koh W, Anderson BO, Carlson RW. NCCN resource-stratified and harmonized guidelines: A paradigm for optimizing global cancer care. *Cancer*, 2020 126: 2416–2423.

<sup>14</sup> Howard SC, Davidson A, Luna-Fineman S, Israels T, Chantada G, Lam CG, Hunger SP, Bailey S, Ribeiro RC, Arora RS, Pedrosa F, Harif M, Metzger ML. A framework to develop adapted treatment regimens to manage pediatric cancer in low- and middle-income countries: The Pediatric Oncology in Developing Countries (PODC) Committee of the International Pediatric Oncology Society (SIOP) [Internet]. *Pediatr Blood Cancer*, 2018 64: e26879.



A key issue for SIOP PODC to address is defining the difference between evidence-based guidelines and resource-stratified (adapted) guidelines. Evidence-based cancer guidelines, such as those from ASCO, ESMO, NICE, and the NCCN (the National Comprehensive Cancer Network (USA)) are usually based upon evidence accrued from clinical trials conducted in fully-resourced settings, and are designed to be implemented in treatment centres where there is little, or no resource constraint.<sup>15</sup> However, SIOP, ASCO, the NCCN and other international cancer organisations recognise that most children and adults diagnosed with cancer live in LMICs where multiple barriers exist that prevent treatment in fully resourced settings. Moreover, the development of resource-stratified guidelines for cancer diagnosis and treatment must address the absence of resource-related evidence. While evidence-based guidance is optimal, the absence of resource-specific evidence is in itself an important observation, and a compelling justification for the process developed by BGHI and adopted by SIOP, NCCN and ASCO where representative disease specific expert panels engage in a formal consensus process to recommend adaptation of treatment to resource-stratified settings. This process has been included in our draft TOR which will be circulated for consultation and discussion amongst the PODC leadership and members. We welcome any SIOP members, especially those in resource limited settings, young investigators and nursing members, who have the time, to become involved by contact us with expressions of interest.

Thanks to all the members who have contributed to the PODC and ATR groups over the year and for ongoing engagement in the WHO GICC.

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<sup>15</sup> Koh W, Anderson BO, Carlson RW. NCCN resource-stratified and harmonized guidelines: A paradigm for optimizing global cancer care. *Cancer*, 2020 126: 2416–2423.

## PODC Adolescents and Young Adults TF

**Co-Chairs:** Elysia Alvarez (USA) and Ligia Rios Lopez (Peru)

**Number of Members:** 50

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

As childhood cancer survival has increased significantly in recent decades in LICs and LMICs, attention is starting to shift to adolescents and young adults (AYA) 15-29 years of age with paediatric cancers, who are yet to be included in most twinning partnerships and nascent paediatric oncology programmes in these countries. There are 1 million new cancer diagnoses in AYA patients worldwide, the majority in LMICs. Global data on cancer care delivery in this age group is scarce. However, due to a lack of beds and space as well as traditional age cut-offs, many LMIC paediatric units have capped patients' eligibility at 12 or 13 years of age, although several units have increased eligibility to 16 or 18 (e.g., Guatemala, Morocco).

There are 1 million new cancer diagnoses in AYA patients worldwide, the majority in LMICs.

HIC rates of AYA survival do not approach that of younger patients due to scarcity of AYA-specific clinical trials, lack of access to appropriate care (diversion to adult oncology programmes that lack expertise in paediatric cancers) and possible biological differences in tumours. Outcome disparities – the “AYA Gap” – are not clearly documented in LMIC, but are beginning to be recognized. Therefore, the PODC AYA Task Force (TF) explores the AYA experiences in LMIC to determine how best to support them and their medical providers over the entire cancer continuum including end-of-life care or survivorship. We expect that the TF may contribute to the WHO GICC.

The TF had its first meeting and successfully recruited approximately 50 members, majority from Mexico at present. We have also worked on an AYA TF members survey to identify where AYA patients are treated in Mexico and the barriers and facilitators to care.

The TF has identified collaboration with adult haematologists/oncologists as a key focus. We plan on developing models of clinical care and research to enhance collaboration between paediatric and adult haematologists/oncologists (e.g. consultation services, joint conferences, registry) for a variety of settings to improve AYA care in LMIC. We also plan on documenting best practices in LMIC paediatric units that do accept AYA patients. We will identify various successful patient care models in multiple settings (e.g. oncology hospital, paediatric hospital, etc.).



## PODC Psychosocial TF

**Co-Chairs:** Nicole Schneider (USA) and Nuria Rossell (El Salvador)

**Number of Members:** 48

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The PODC Psychosocial TF exists in order to contribute to a comprehensive approach for the treatment of childhood cancer in less advantaged settings. Furthermore, it exists because of

- The specific attention that deserves the psychological and socio-cultural issues particular to LICs and LMICs which are embedded in the delivery of medical therapy and its outcomes.
- The need to bring awareness about such issues and give voice to health care teams working in those settings.
- The need to consider a priority scale of needs in such settings

In 2020, the TF circulated a survey about psychosocial needs and services in paediatric oncology programmes in LICs and LMICs. We explored LIC and LMIC providers' perceptions of patient/family needs, and collected information about the scope of psychosocial services available at their programmes. A hundred respondents completed all or most of survey. Professionals included physicians, nurses, nutritionists, social workers, psychologists, NGO staff, and others. Results were highly variable in terms of resources available, though respondents generally noted similar concerns with regards to psychosocial issues. The two most urgent/frequent needs that the survey identified were: "myths and disinformation" and "abandonment of treatment and adherence concerns."

An abstract about the results of the survey was presented in a poster format at the SIOP 2020 Congress. An article is being written and is expected to be submitted for publication consideration by March 2021.

In 2021, the TF will work to recruit new TF members interested in taking on active roles in assessing and addressing global needs. We will also seek to document best practices for psychosocial care across LMICs.



## PODC Onco-Pharmacy TF

**Co-Chairs:** Sherif Kamal (Egypt) and Brooke Bernhardt (USA)

**Number of Members:** 32

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The PODC Onco-Pharmacy TF succeeded in establishing connections and networking for 32 pharmacists working in oncology. In 2020, the TF discussed more than 23 documents and shared a lot of experience and agreed to start our scientific meetings in March 2021.

Phase 1 was orientation about the TF vision, mission and objectives. The TF works towards the following objectives:

1. To explore ways to increase pharmacists' body of knowledge of pediatric hematology/oncology
2. To empower pharmacists to participate more effectively in managing hematology/oncology patients

Phase 2 was about engagement of the founding group of members so that all the TF members presented their pharmacy services. Phase 2 also involved building leadership capacity by book club discussion with Dr. George Velez. We finished discussing our first book. We started to discuss the Zero Harm concept to build our way to High Reliability Organization.

Phase 3 will start every third Friday of the month by scientific activity and case discussion that focuses on pharmacotherapy and oncology pharmacy issues. Our first topic will be Leukemia. Members will prepare a case discussion, their intervention and questions, and Dr. Scott Howard and Dr. Muhammad Saghir Khan will share their scientific knowledge regarding the disease.

Phase 3 will also focus on collaborating with other SIOP WGs to find support regarding recruiting more pharmacists. This will include restarting the collaboration with St. Jude Pharmacy Group as monthly meetings and also recruiting more pharmacists from Jordan, Lebanon and other countries.

## PODC PROS LMIC TF

**Co-Chairs:** Natia Esiashvili (USA) and Jeannette Parkes (South Africa)

**Number of Members:** 54

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

From an outreach perspective, PODC PROS LMIC TF has been involved in the GICC with several members involved in WHO WGs. As part of a PROS team, we are also involved in the radiotherapy aspect of the ARIA Children's Cancer Guidelines as well as with IAEA in the writing of a Paediatric radiotherapy guideline, which will be published in 2021.

From an educational perspective, PROS LMIC TF hosted an excellent session at the SIOP 2020 Congress, with talks by Mithra Ghalabafian and Maryann Dadzie. PROS LMIC TF also supported and endorsed SNOSSA (Society of Neuro-Oncology in Sub-Saharan Africa) held online in August 2020, a series of PODC lectures at University of Gezira in Sudan, a Paediatric Neuro-Oncology Series at University of Aga Khan in Pakistan and the First Pakistan Neuro-Oncology Symposium (P-NOS) held in Pakistan in November 2020 as well as Sociedad Mexicana de Radioterapeutas (SOMERA) in partnership with University of Florida to provide a neuro-radiotherapy teaching course in Mexico in November 2020.

The PROS LMIC TF was part of the SIOP Covid-19 online series providing information to LMIC countries regarding management of paediatric radiotherapy patients during the pandemic. We also were co-authors on 6 publications including several adapted treatment guidelines (through PODC).<sup>16</sup>

## PODC Collaborative Wilms Tumour Africa Project and CANCaRe Africa

**Co-Chairs:** Vivian Paintsil (Ghana), Glenn Mbah Afungchwi (Cameroon), George Chagaluka (Malawi), and Trijn Israels (Netherlands)

**Number of Members:** 8 participating hospitals in Malawi, Kenya, Ghana, Cameroon, Zimbabwe

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

The Collaborative Wilms Tumour Africa Project has been implementing SIOP PODC Adapted Treatment Guidelines in eight hospitals in sub-Saharan Africa with uniform outcome evaluation since 2014 (see Figure 1).

In 2020, we published the results and impact of Phase I of the Project (see Figure 2); end of treatment survival without evidence of disease increased from 52% to 69% and abandonment of treatment decreased from 23% to 12%. The two year event free survival is 49.9% with abandonment of treatment considered an event.<sup>17</sup>

The Collaborative Wilms Tumour Africa Project is currently one of the three projects of the Collaborative African Network for Childhood Cancer Care and Research (CANCaRe Africa). Our vision is that children with common and curable cancers in sub-Saharan Africa will achieve survival

<sup>16</sup> 1. <https://pubmed.ncbi.nlm.nih.gov/32743983>; 2. <https://pubmed.ncbi.nlm.nih.gov/32790146>; 3. <https://pubmed.ncbi.nlm.nih.gov/32790118>; 4. <https://pubmed.ncbi.nlm.nih.gov/32400924>

<sup>17</sup> "Improvement of Overall Survival in the Collaborative Wilms Tumour Africa Project," Pediatric Blood and Cancer 2020.





**Figure 1.** Countries of centres participating in the Collaborative Wilms Tumour Africa Project

Outcome	Baseline 2012-2013	Impact 2014-2018	P-value	Aim
Alive, NED	52%	69%	P=0.002	
Abandonment	23%	12%	P=0.0009	<10%
Death during treatment	21%	15%	P=0.14	<10%
(Estimated) 2 year EFS	35%	49.9%		>60%

**Figure 2.** Results and impact of Phase I of the Collaborative Wilms Tumour Africa Project

rates greater than 60% in line with the GICC. Our mission is to develop, implement and assess locally appropriate treatment guidelines and to decrease both abandonment of treatment and death during treatment to below 10%.<sup>18</sup> The other two projects are “SUCCOUR” to improve supportive care for children with cancer in Africa and “Towards Zero Percent Abandonment.”

Phase II of the Collaborative Wilms Tumour Africa Project will start in January 2021. We revised the treatment guideline based upon lessons learned and included guidance for radiotherapy and relapse of disease. The new and comprehensive guideline is available on the [SIOP website](#) where you can also find more information about the Project.

Please find short videos about the project and its impact [here](#) and [here](#).

We are very grateful for continued financial support from SIOP and World Child Cancer. A My Child Matters grant from the Sanofi Espoir Foundation will support local data management capacity for Phase II of the Collaborative Wilms Tumour Africa Project.



<sup>18</sup> “Working Together to Build a Better Future for Children with Cancer in Africa,” Journal of Global Oncology 2020.

## PODC Palliative Care WG

**Co-Chairs:** Justin Baker (USA) and Resham Shahzadi (Pakistan)

**Number of Members:** 222

**Welcoming New Members:** Yes

**Contact for Inquiries:** [info@siop-online.org](mailto:info@siop-online.org)

Dr. Marisol Bustamante's completed her tenure as a Co-Chair of the PODC Palliative Care WG. The WG thanked her for all her years of incredible service. The WG welcomed a new Co-Chair, Dr. Resham Shahzadi, who joined with a passion to create a huge impact globally and in LMICs.

The Palliative Care WG seeks to develop and facilitate issues surrounding access, education, support, quality and outcomes with regard to palliative care for children globally and LMICs. Twenty-two new members have joined the WG in 2020.

In 2020, the WG began collaborating with the St. Jude Global's Transversal WG on Palliative Care/Quality of Life/Clinical Bioethics. This transversal WG is led by Justin Baker, Karen Williams and Mike McNeil of St. Jude Global.

### Educational Updates and Annual Congress

Bi-monthly educational sessions were conducted on the Cure4kids platform. Topics discussed included Paediatric Palliative Care (PPC) programme development in LMIC setting, Emotional and Behavioral Symptoms in Children with Chronic Illness and their Management, Palliative Care for Children with Brain Tumors, Nursing and Practical aspects of Palliative Care and Case Discussions in Palliative Care.

During the 2020 Annual Congress, the WG also held multiple sessions on Paediatric Palliative Care for both LMICs and HMICs. Sessions on PPC were very well-received.

- UNOP – Dr. Marisol Bustamante



- Sub-Saharan Africa – Michelle Meiring
- KHCC – Jordan – Middle East update – Anwar Alhassan
- General Programme Development and PPC – Justin Baker

### Way Forward

In 2021, the WG look forward to further collaboration with the St. Jude Palliative Care Transversal WG. We will also look for ways to better partner with groups such as ICPCN and PATCH Africa as we all advocate for access to high quality palliative care for our patients and their families. Future plans include promotion of research to improve outcomes for patients, increasing membership and engagement in the WG, and expanding education opportunities and access.