

The development of this Annual Report was led by Tessie Laub on behalf of the SIOP Board of Directors. The report was copy-edited by Julia Challinor.

Acknowledgements:

The International Society of Paediatric Oncology (SIOP) expresses thanks to the following colleagues for their contributions during the development of the Annual Report: Susanne Wollaert, Julia Challinor, Kathy Pritchard-Jones and the leaders of the many SIOP Continental Societies, Committees, Working Groups, Task Forces, and Networks whose work is featured in this report. We are grateful to our partners for the close collaboration with SIOP in 2020.

Copyright: © International Society of Paediatric Oncology

February 2021

Learn More:

www.siop-online.org

www.siop-congress.org

Contact SIOP:

info@siop-online.org

+41 78 687 9163

Follow SIOP:

Facebook

Twitter

#SIOP2021

#CUREforMore_CAREforAll

<u>LinkedIn</u>



TABLE OF CONTENTS

ACRONYMS	4
MESSAGE FROM THE SIOP PRESIDENT	6
MESSAGE FROM THE SIOP SECRETARY-GENERAL	8
SIOP 2020 CONGRESS	9
MEMBERSHIP ANALYSIS	11
FINANCIAL REPORT	12
STRATEGIC PLANNING PROCESS	13
CONTINENTAL SOCIETIES	15
Africa Continental Society	16
Asia Continental Society	17
Europe Continental Society	18
Oceania Continental Society	19
North America Continental Society	20
Latin America Continental Society	21
ADVOCACY COMMITTEE	25
PUBLICATIONS AND SURVEYS COMMITTEE	26
GOVERNANCE COMMITTEE	27
FINANCE COMMITTEE	27
SCIENTIFIC COMMITTEE	28
NURSING GROUP	29
NUTRITION NETWORK	30
YOUNG INVESTIGATORS NETWORK	30
PAEDIATRIC PSYCHO ONCOLOGY WG	32
SUPPORTIVE CARE WG	34
PAEDIATRIC ONCOLOGY IN DEVELOPING COUNTRIES COMMITTEE	35
PODC Abandonment of Treatment WG	36
PODC Education and Training WG	37
PODC Traditional and Complementary Medicine WG	38
PODC Nursing WG	39
PODC Patient, Family and Stakeholder Engagement TF	40
PODC Nutrition WG	41
PODC Supportive Care WG	42
PODC WG on Twinning, Collaboration and Support	43
PODC Essential Drugs WG	44
PODC Adapted Treatment Regimen WG	45
PODC Adolescents and Young Adults TF	47
PODC Psychosocial TF PODC Onco-Pharmacy TF	48 49
PODC PROS LMIC TF	50
PODC Collaborative Wilms Tumour Africa Project and CANCaRe Africa	50
PODC Pallative Care WG	52
SIOP PARTNERS	53
Childhood Cancer International (CCI)	53 53
International Society of Paediatric Surgical Oncology	53
Paediatric Radiation Oncology Society (PROS)	55
FINANCIAL SUPPORT TO SIOP	56

ACRONYMS

AACR American Association of Cancer Research

AHOPCA Central American Association for Pediatric Hematology and Oncology

AMG Adapted Management Guidelines

ANZCHOG Australian and New Zealand Children's Haematology/Oncology Group

AORTIC African Organisation for Research and Training in Cancer

APHOG Asian Paediatric Hematology Oncology Group

APOS American Psycho-Oncology Society

ARIA Adapted Resource Implementation Application

ASCO American Society of Clinical Oncology
ASH American Society of Hematology

ASPHO American Society of Pediatric Hematology/Oncology

CANCaRe Africa Collaborative African Network for Childhood Cancer Care and Research

CCI Childhood Cancer International
CDC Congress Development Committee

CLEHOP Latin American Consortium for Pediatric Hematology and Oncology

COG Children's Oncology Group

EBMT European Society for Blood and Marrow Transplantation

ED Education Day of the SIOP Annual Congress

ESMO European Society of Medical Oncology
EURADO European Radiation Dosimetry Group

FY Fiscal Year

GALOP Latin American Group for Pediatric Oncology
GFAOP Groupe Franco-Africain d'Oncologie Pédiatrique

GICC Global Initiative for Childhood Cancer

HIC High-Income Country

IAEA International Atomic Energy Agency

IARC International Agency for Research on Cancer

IIPAN International Initiative for Paediatrics and Nutrition IPOG International Paediatric Oncology Guideline Network

IPOS International Psycho-Oncology Society

IPSO International Society of Paediatric Surgical Oncology

LIC Low-Income Country

LMIC Low- and Middle-Income Countries

MASCC Multinational Association of Supportive Care in Cancer

MASPORE Malaysia-Singapore Study Group
MDT Multidisciplinary Tumour Board
MOU Memorandum of Understanding

NAPHOS National Paediatric Haematology-Oncology Society

NCCN National Comprehensive Cancer Network

NCD Non-Communicable Diseases
NGO Non-Governmental Organization

NSA Non-State Actor

PAHO Pan American Health Organization
P-NOS Pakistan Neuro-Oncology Symposium

PODC Paediatric Oncology in Developing Countries Committee
POEM Paediatric Oncology East and Mediterranean Group

POPPI Psycho-Oncology Professionals and Providers International

PPC Paediatric Palliative Care
PPO Paediatric Psycho Oncology

PROS Paediatric Radiation Oncology Society

SC Scientific Committee

SIOP International Society of Paediatric Oncology
SIOP-NA Continental Branch of SIOP in North America
SLAOP Sociedad Latinoamericana de Oncología Pediátrica
SNOSSA Society of Neuro-Oncology in Sub-Saharan Africa

SOBOPE Brazilian Society of Pediatric Oncology
SOMERA Sociedad Mexicana de Radioterapeutas
SPAC Scientific Programme Advisory Committee

TF Task Force

TIPP Targeted International Paediatric-Oncology Partnership

TOR Terms of Reference

UHC Universal Health Coverage

UICC Union for International Cancer Control

WCC World Child Cancer WG Working Group

WHA World Health Assembly
WHO World Health Organization

YI Young Investigator

YI-Net Young Investigators' Network



MESSAGE FROM THE SIOP PRESIDENT



Dear SIOP Members and Partners,

The year 2020 brought many changes to SIOP. Some were anticipated developments for our Society, others were forced upon us as the COVID-19 pandemic erupted across the world. Our Board and membership have been very active in responding to these challenges. I hope you enjoy reading this Annual Report that summarises the huge efforts undertaken by our Committees, Working Groups (WGs) and the wider membership to advance the cause of children and adolescents with cancer worldwide.

We finalised our <u>new Strategy</u> for the next 5 years (2021-2015) and affirmed with our membership that the new strategic themes resonate with their needs and ambitions. We now look forward to implementing the projects that SIOP will support directly and to strengthening and expanding our work in partnership with other stakeholders in the field.

Early in 2020, we responded to the urgent need for professional guidance during the COVID pandemic. We led the publication of two 'rapid guidance' papers on maintaining and adapting childhood cancer services and worked with St. Jude Global to create a <u>collaboration platform</u> for sharing experiences and learning. This includes a <u>Global Registry</u> that had captured details of COVID-19 infection in 1,230 children with cancer by the end of the year and which continues to contribute valued evidence to inform clinical management.

The necessity to change our 2020 Annual Congress into an online 'virtual' format proved successful. The Congress attracted the largest ever number of delegates (3,361 from 131 countries) and included an increased participation from those in training or living in low- and middle-income countries. We intend to continue this widened access by delivering future Congresses in a hybrid format, with both in-person and virtual attendance possible.

The SIOP 2020 Congress was also the occasion where we announced <u>SIOP's first patron – Her Royal Highness Princess Dina Mired of Jordan</u>. Princess Dina is a well-known advocate for children with cancer and a global influential voice for cancer patients and improved services. She will support the Board in our advocacy work and delivery of our new Strategy.



"Covid-19 is Taking Over the World" by Avaneesh N., 8 years old boy from Bengaluru, India

We have strengthened our working with the World Health Organisation (WHO) as a recognised non-state actor, both renewing our second 3-year programme in July 2020 and supporting the detailed planning for implementing the Global Initiative for Childhood Cancer (GICC), announced on December 11, 2020.

Through 'All Hands In' with our close partners, SIOP aims to make a substantial contribution to saving the lives of an additional 1 million children with cancer worldwide by 2030. To that end, we continued working closely with our partners. We signed a Memorandum of Understanding (MOU) with St. Jude Global in September 2020, and we are continuing to work closely with the International Society of Paediatric Surgical Oncology (IPSO), Paediatric Radiation Oncology Society (PROS) and other strategic partners. We have strengthened our collaboration with Childhood Cancer International (CCI) and most recently worked on a joint 3-year advocacy and awareness raising plan.

In October 2020, several longstanding and eminent supporters of SIOP stepped down from the SIOP Board of Directors: Gregory Reaman (Treasurer), Eric Bouffet (Past-President and Advocacy Chair), Scott Howard (Secretary-General), Donna Jonhston (Local Organising Committee Chair), Sandra Luna-Fineman (Co-Chair of the Paediatric Oncology in Developing Countries [PODC] Committee) and Arturo Moreno (Continental President-Latin America), who sadly passed away in <u>January 2021</u>. SIOP is extremely thankful for the many years of service and leadership that these Board members brought to SIOP and pays tribute to the lifetime achievements of Arturo in helping children with cancer.

At the Annual Congress in October 2020, we also welcomed several new Board members: Julia Challinor (Secretary-General), Lisa Morrissey (Nursing Steering Committee Chair), Guillermo Luis Chantada (Continental President-Latin America) and Wade Kyono (Local Organizing Committee Chair).

In 2021, we look forward to working with our members and partners in implementing the new <u>SIOP Strategy 2021-2025</u>. We are confident that we will deliver a strong Annual Congress in 2021.

Sincerely, Wathy Pil Man Done,

Kathy Pritchard-Jones, SIOP President



MESSAGE FROM THE SIOP SECRETARY-GENERAL

Dear SIOP Members,

Since taking up the Secretary General position in late October 2020, and following the leadership of my predecessor, Scott Howard, MD, the focus has been to launch and begin implementing the new <u>SIOP Strategy 2021-2025</u>. The five Strategic Goals are:

Goal 1: Promoting research to improve outcomes for patients

Goal 2: Advocating globally for children and adolescents with cancer

Goal 3: Providing education and training

Goal 4: Increasing Membership and Engagement

Goal 5: Strengthen and Expand Strategic Partnerships

Committees have been formed (some are in the process) with Board leadership and SIOP member participation to meet the expected deliverables.

New committees for Congress Development, Governance and Finance will address SIOP higher-level, long-term best practices and continued strategic planning.

The Chairs of the Nursing Steering Committee and Advocacy Committee, and PODC Co-Chairs have provided critical input from the perspectives of their members. As always, Continental Branch leadership from all six regions (Oceania, Asia, Africa, Europe, North America, South America) is well engaged in the above-mentioned activities to ensure that regional membership and context are considered as the new Strategy is implemented.

After an unexpectedly successful virtual 2020 Annual Congress, we move to advance a robust agenda and dynamic SIOP workplan and strive to achieve the ambitious goal of the WHO GICC of 60% childhood cancer survival across the world. We look forward to drawing the increased participation of all SIOP members in this effort and rely on their expertise and commitment to the Society and the children/adolescents with cancer, their families, and the survivors we serve.

Sincerely,

Julia Challinor, SIOP Secretary-General

he M Challes

SIOP 2020 CONGRESS

Our Annual Congress promotes education about all aspects of Paediatric and Adolescent Oncology to all oncology professionals, parents and survivors of cancer. It represents a unique opportunity to stay up-to-date in this rapidly moving field and to bring the latest science to bedside.

Due to the uncertainties about the continuing impact of the COVID-19 pandemic on travel restrictions and physical distancing requirements throughout 2020, the SIOP 2020 Congress was held as an entirely virtual meeting with both pre-recorded and real-time sessions.

The <u>Scientific Programme</u> was broadcast live over the originally scheduled dates (October 14-17, 2020) and question-and-answer chats were maintained. The programme was then made available on the Congress website for 3 more months following the Congress, and will available longer term on the SIOP Knowledge Centre for our members (as of March 2021).

Holding our Annual Congress through an online platform was uncharted territory for our society. However, with the attendance of 3,361 multi-disciplinary health care professionals from over 131 countries, the virtual edition proved to be the best attended SIOP Congress in the history of our Society.

The online platform encouraged networking among our members and delegates. Furthermore, it was an opportunity to promote collaborative research, mentor young investigators and offer learning on paediatric oncology globally.



www.siop-congress.org

SIOP 2020 Around The Globe 3,361 Attendees from 131 Countries

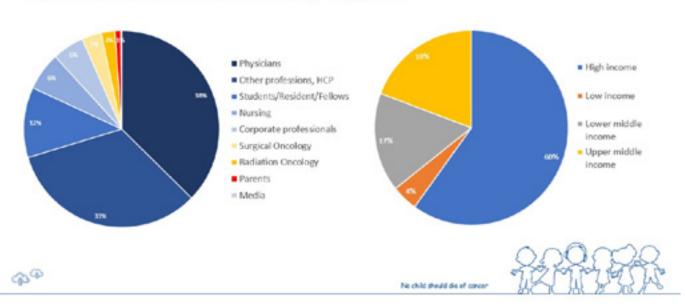




The 2020 Virtual Congress has shown us several advantages which we aim to exploit further in our upcoming Congresses. Our registration fee structure and scholarship programme provided increased opportunities for many more health care professionals around the world to access and benefit from attending the SIOP Annual Congress.







To see recordings of previous Scientific Congresses and other online learning materials, please visit the SIOP Knowledge Centre (separate registration is needed; open to SIOP members only).

MEMBERSHIP ANALYSIS

The number of the active SIOP members is steadily increasing. In 2020, SIOP reached the highest number of active members compared to previous years. There is a 68% renewal rate from 2019 membership year. 1,287 members of the total 1,926 active in 2019 continued their membership in 2020 as well.

The number of new members is also high compared to previous years – 993 new members, which is the highest number of new members in a year since 2015. Most of the new members – 386 – are from LICs and LMICs, and this tendency continues from 2019.

In terms of categories, there is a significant increase of new members in the following categories:

- Members in training 268%
- Associate members 107%
- Ordinary members from supported countries 73%
- Nurse members 70%

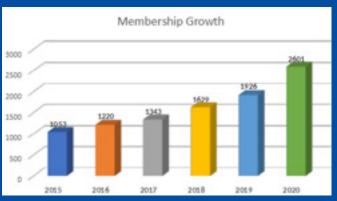
The USA remains the leading country in terms of number of members, followed by India, Canada, the United Kingdom and Ghana. In 2020, Ghana joined the list of the top 10 countries with the highest number of members.

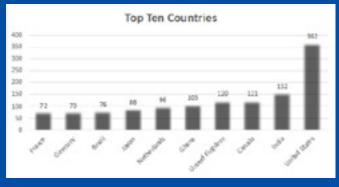
In 2020, thanks to scholarships, SIOP attracted members in Laos, Fiji, Uzbekistan, Togo, Oman, Mozambique, Madagascar, Lesotho, Guinea, Sudan, Rwanda etc.

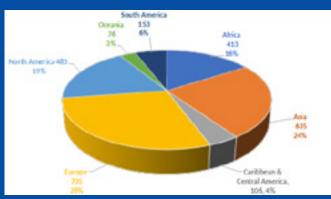
To join or renew your membership, please contract membership@siop-online.org.

Did you know that you could donate the cost of one or two-year membership for a member from a LIC or LMIC? Every donation helps!









DONATE NOW!

FINANCIAL REPORT

Stephen Hunger (USA), SIOP Treasurer

SIOP's Fiscal Year (FY) 2019/2020 ran from August 1, 2019, to July 31, 2020. The total FY income generated by the Society is 1,237,721 EUR, 57% of which (706,266 EUR) came from sponsorship funds from a number of pharmaceutical companies, 17% of which (216,041 EUR) came from membership dues and 25% of which (315,214 EUR) came from a financially profitable 2019 Congress in Lyon, France. The total FY expenses of the Society were 833,502 EUR, 34% of which (280,285 EUR) were expenses associated with organizing and delivering the Annual SIOP Congress, another 34% (282,678 EUR) were expenses for education activities and projects, and 23% (194,565 EUR) were administrative and operational expenses associated with the smooth operations of the Society. The overall profit for FY2019/2020 is therefore 404,219 EUR.

In August/September 2020, an external accounting firm conducted an independent examination of the Society's accounts in accordance with the Swiss Auditing Standard 910 Review. The Audit Report and Financial Statements are available online here.

Income Breakdown FY2019/2020	EUR	%
Income Congress	€ 315,214	25%
Membership Dues	€ 216,041	17%
Educational Grants	€ -	0%
Donation	€ 200	0%
Royalties	€ -	0%
Scientific Committee Meeting	€ -	0%
Sponsorship	€ 706,266	57%
TOTAL Income	€ 1,237,721	100%
Expenses Breakdown FY2019/2020	EUR	%
Board and Council Meetings	€ 20,962	3%
Advocacy	€ 4,755	1%
Bank Charges	€ 4,720	1%
Foreign Exchange Loss	€ 12,010	1%
Congress Expenses	€ 280,285	34%
Membership and Journal Subscriptions	€ 25,320	3%
Edu activities & Projects	€ 282,678	34%
Society Promotion & Marketing	€ 8,207	1%
General Admin Expenses	€ 194,565	23%
TOTAL Expenses	€ 833,502	100%
Total Profit/Loss FY2019/2020	EUR	
Income	€ 1,237,721	
Expenses	€ 833,502	
Total +Profit / -Loss	€ 404,219	

STRATEGIC PLANNING PROCESS

In 2020, under the leadership of Kathy Pritchard-Jones, SIOP President, the Society undertook a highly-collaborative strategic planning process.

The <u>Strategy 2021-2025</u> describes the practical steps that SIOP and its members will take towards achieving our vision that no child should die of cancer – Cure for more, Care for all. Please watch the <u>short video</u> of Kathy Pritchard-Jones, SIOP President, announcing the new Strategy.

By implementing this Strategy, SIOP will deliver on our mission to improve the lives of children and adolescents with cancer through global education, education, training, research and advocacy. Take a look at our <u>2-min video</u> on the Strategy!

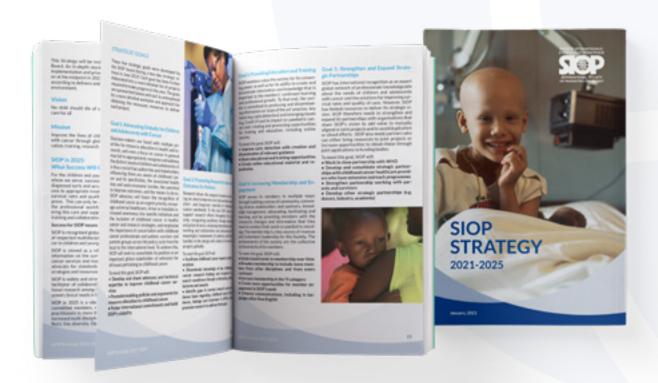
In the next five years, SIOP's work will focus on five Strategic Goals:

- Goal 1: Advocating Globally for Children and Adolescents with Cancer
- Goal 2: Promoting Research to Improve Outcomes for Patients
- Goal 3: Providing Education and Training
- Goal 4: Increasing Membership and Engagement
- Goal 5: Strengthen and Expand Strategic Partnerships

SIOP members can contribute towards the implementation of the SIOP Strategy by participating in SIOP's many Committees and WGs.

Follow our Strategy work on the social media channels:

- #CUREforMore CAREforAll
- #SIOP_Strategy



VISION

No child should die of cancer: cure for more, care for all

MISSION

Improve the lives of children and adolescents with cancer through global collaboration, education, training, research and advocacy.



Goal 1

Advocating Globally for Children and Adolescents with Cancer

Goal 2

Promoting Research to Improve Outcomes for Patients

Goal 3

Education and Training

Goal 4

Increasing Membership and Engagement

Goal 5

Strengthen and Expand Strategic Partnerships

CONTINENTAL SOCIETIES

The main body of the Society has Continental Branches, as follows:

- Europe
- Latin America
- North America
- Asia
- Oceania
- Africa



2,600 SIOP members in 130 countries

The purpose of the Continental Branches, each led by an elected President, is to provide a regional perspective of priorities for childhood and adolescent cancers and to contribute to addressing challenges specific to the respective continents. They also conduct activities and engage their respective Continental Branch members to support the mission and goals of SIOP, including advocacy, advancement of scientific knowledge and research, education, training and clinical practice. The Continental Presidents, who are standing members of the SIOP Board of Directors, also act as liaison with SIOP's strategic partners in their region. To achieve the goals and objectives of the Continental Branch and its membership, some Continental Branches have established themselves as separate legal entities.

Africa Continental Society

President: Laila Hessissen (Morocco)

Number of Members: 260

Welcoming New Members: Yes

Contact for Inquiries: africa@siop-online.org

Similar to other scientific communities, SIOP Africa has been strongly impacted by the COVID-19 pandemic but has stayed strong and has not lost sight of its mission, which is to treat children with cancer in Africa.

In 2020, SIOP Africa has strengthened contact and communication with the African and international paediatric oncology community through participating in webinars, relating to the management of COVID-19 in African paediatric oncology units and the challenge that this implies.

SIOP Africa representatives participated in WHO meetings about the implementation of GICC in Africa. SIOP Africa also participated in the advocacy activities including the International Childhood Cancer Day and Gold September advocacy campaigns

Despite the restrictions related to the pandemic, the African working groups (i.e. African Nurses group and Wilms Tumour Africa/SUCCOUR group) and the SIOP Africa Board members continued their activities, albeit online. The SIOP Africa Annual Business Meeting was held online on December 17, 2020.

During this year, Dr. Joyce Balagadde Kambugu was elected as SIOP Africa President-Elect and Nagm Azar joined the Board as the CCI representative.

SIOP Africa has been strongly impacted by the COVID-19 pandemic but has stayed strong and has not lost sight of its mission.



Asia Continental Society

President: Rashmi Dalvi (India)

Number of Members: 634

Welcoming New Members: Yes

Contact for Inquiries: rdphoc@gmail.com

The year 2020 was a very busy year for the SIOP Asia Continental Society. The Annual General Meeting of SIOP Asia was held in December 2020. There were 634 SIOP members in Asia and the continental society was well represented at the Virtual SIOP 2020 Congress. SIOP Asia colleague, Dr. Muhammad Saghir Khan (Pakistan), was elected as the new Co-Chair for SIOP PODC Committee. The SIOP Asia 2021 Annual Meeting bid was put to an online voting process, and the team from Guangzhou, China, represented by Dr. Yizhou Zhang won the bid. The Presidential elections for SIOP Asia were held earlier this year and Dr. Hiroki Hori from Japan will join us as President in October 2021.

"September 2020 GOLD Campaign, Tata Memorial Hospital, Mumbai."



The <u>SIOP Asia Annual Meeting</u>, originally scheduled at Mumbai, was postponed twice and will now be held virtually in March 2021. An exciting scientific programme awaits the 400+ registrants, with over 200 abstracts up for presentation and deliberation.

A special issue of the Paediatric Hematology Oncology Journal, "The Asian Age of Collaborations in Paediatric Oncology: A Call for Action" was released, featuring work from SIOP Asia members.

SIOP Asia continued to raise awareness about childhood cancer. The World Cancer Day, International Childhood Cancer Day, and Gold September Childhood Cancer Awareness Month were celebrated with enthusiasm across Asia. SIOP Asia worked closely with CCI-Asia in all advocacy activities. In addition, SIOP Asia represented the SIOP Board of Directors as non-state observer during the virtual Asia Regional WHO Meetings.

The WHO GICC held workshops in the Philippines and Myanmar, with Uzbekistan in the planning. Several members from SIOP Asia and PODC were involved in the development of technical packages for GICC this year. Following a 2019 multi-stakeholder exploratory meeting in India to develop an initiative following WHO GICC plans, a subsequent stakeholder webinar was held in November 2020.

Global Mapping of Childhood Cancer Care Resources is being planned for Asia in 2021, following the projects in Africa and Latin America under the aegis of SIOP CancerPOINTE with support from the Sanofi Espoir Foundation. Initially, the focus will be on five LMICs in Asia.

The Asian Paediatric Hematology Oncology Group (APHOG), led by an interim Steering Committee, held monthly meetings to develop and fund collaborative projects across Asia under the guidance and leadership of Dr. Akira Nakagawara, Dr. Godfrey Chan and the SIOP Asia Board. Plans exist for the development of clinical trials. Discussions are under way on how to support the GICC in LMICs in Asia through programmes for capacity-building in clinical research. Moreover, SIOP Asia participated in the Virtual Rare Cancers ESMO-Asia meeting in December 2020.

Future plans for SIOP Asia include expansion of its Board to enhance regional representation, develop Research Methodology Training modules for paediatric oncology, among many others.

Led by Dr. Maya Prasad, SIOP Asia issued several newsletters, which are available on the <u>SIOP website</u>. Members are encouraged to come forward with ideas and proposals for activities in the region. Members of national societies across Asian countries are also welcome to join SIOP and share about their work. If you have any meeting announcements, important publications or achievements from your departments or country, please share information through the SIOP Asia Twitter and the SIOP Asia newsletter.

Twitter: @SiopAsia2020 / @AsiaSiop Website: https://www.siopasia2020.com/

Europe Continental Society

President: Pamela Kearns (UK)
Number of Members: 2,000
Welcoming New Members: Yes

Contact for Inquiries: office@siope.eu

SIOP Europe (SIOPE) is very grateful for the commitment of our Board members, team members and partners in supporting our many activities throughout 2020 to meet the needs of our childhood cancer community. To mitigate the effects of COVID-19, a number of events were postponed to 2021 and some meetings took place in a virtual format. The 2nd_SIOP Europe Annual Meeting has been postponed to 28-30 April 2021 and will now be held virtually.

Thanks to the exceptional support of Ewa Kopacz, the Honourable Vice-President of the European Parliament, the <u>European Parliament in Brussels lit up in Gold (1-6 September)</u> in honour of September's Childhood Cancer Awareness Month. On this occasion, Stella Kyriakides, the European Commissioner for Health and Food Safety, spoke to the European childhood cancer community through a heartfelt <u>video address</u>.

The European Commission released the Pharmaceutical Strategy for Europe and launched the Roadmap Consultation on the Orphan and Paediatric Regulations. SIOP Europe and CCI Europe put forward a <u>statement</u> to highlight the unmet needs of children and adolescents with cancer in terms of access to innovative therapies, shortages, and financial accessibility.

SIOPE also mobilised the pan-European community of clinicians, researchers, and parents to take part in the development of a list of anticancer medicines that are essential to treat children and adolescents with cancer in Europe. This SIOP Europe Essential Medicines List will include all paediatric tumour types and will be based on current standard treatment protocols, registries, and regimens, literature review, and expert consensus.



Oceania Continental Society

President: Michael Sullivan (Australia)

Number of Members: 76

Welcoming New Members: Yes

Contact for inquiries: info@siop-online.org

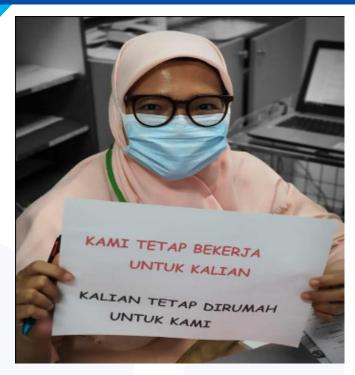
As we all know, the COVID-19 has resulted in great disruption to the services for children with cancer across the globe, especially in regions with a high prevalence of the virus in their community. While both Australia and New Zealand have been affected by COVID-19, the direct impact has been relatively limited (by comparison to Europe and the USA) due to the early closure of international borders and measures to control community spread by regional or national lockdowns. As has been seen in many other parts, the pandemic has led to significant disruption to child cancer services in our cancer centres, and we are now seeing the appearance of children with delayed or deferred diagnosis as a result of community lockdowns. While the response to COVID-19 has caused to significant parental concern and distress, it has also led to some rapid and welcome innovation. We are now all comfortable with Telehealth consultations which are safe and effective for supporting patients and families; in turn our families, especially in large metropolitan centres have welcomed the use of telehealth where they can be seen in their own home without the need to travel into regional cancer centres.

Fortunately, COVID-19 has had less of an impact in our Pacific Island countries many of which have been able to close their borders and prevent COVID-19 from entering the country; community spread of COVID-19 in Pacific Island nations could have overwhelmed their small health services. COVID-19 has been more of a problem in Papua New Guinea (population 9m) and Timor-Leste (population 1.5m) but many communities in these countries are geographically isolated limiting community spread, which could have also overwhelmed their health systems.

As has been seen in many other parts, the pandemic has led to significant disruption to child cancer services in our cancer centres.

SIOP Oceania and the WHO GICC

The WHO GICC is the most important global programme to improve the outcome for children with cancer wherever they may live. However, the great opportunity to partner with the WHO, St. Jude Global and our regional Governments has been very challenged with only limited progress during the COVD-19 pandemic. In 2020, we had to defer plans for national SIOP/WHO workshops and meetings with colleagues and their national organisations in Papua New Guinea and Timor-Leste. We hope to find ways to work together in 2021 to support the development of child cancer care across Oceania in 2021. One practical innovation for 2021 is a start of a formal Multidisciplinary Tumour Board (MDT) with colleagues in Papua New Guinea and Melbourne held weekly via Zoom. The MDT will also be capturing clinical data into the Papua New Guinea Children's Cancer Registry. Planning has also begun for a SIOP



supported seminar series to support medical and nursing training and leadership development; this will be in partnership with the New Zealand National Cancer Network Pacific Islands Group.

North America Continental Society

President: Lindsay Frazier (USA)

Number of Members: 491

Welcoming New Members: Yes

Contact for Inquiries: info@siop-online.org

The Continental Branch of SIOP in North America (SIOP-NA) is not a formally-established entity, unlike the Continental Branches of SIOP in Europe and Latin America. In 2020, a working group explored how a constituted SIOP-NA could better support SIOP's mission and goals, especially in light of the SIOP 2021-2025 Strategy.



Defining the role of SIOP-NA in an ecosystem that already includes strong organizations, such as COG, ASPHO, ASCO, American Society of Hematology (ASH) and AACR has required discussion and deliberation. Yet, SIOP-NA members should expect a drafted SIOP-NA Mission, Goals and By-Laws for comment in 2021. SIOP-NA is planning a SIOP-NA meeting to take place during the 2021 Annual Congress in Honolulu, Hawaii, which is scheduled to take place on October 21-25, 2021.

Latin America Continental Society

President (SIOP Latin America) and Past-President (SLAOP): Guillermo Chantada (Argentina)

Number of Members: 353

Welcoming New Members: Yes

Contact for Inquiries: info@siop-online.org

The President of SIOP Latin America is an integral part of the Board of the Latin American Society of Paediatric Oncology (SLAOP). The COVID-19 pandemic has stricken Latin America as hard as any other continent and paediatric oncology patients were not an exception. SLAOP provided a rapid response to support the health teams in this difficult situation.

In the pandemic days, it became urgent to establish effective communication tools to connect health care professionals for providing support to manage the COVIC-19 situation. The first action that SLAOP took was to set up a series of weekly online meetings open to all, where colleagues around the continent shared their concerns and looked for advice. At that moment, when the pandemic hit Europe first, it was of great help to have the support of the Hospital Sant Joan de Déu team from Barcelona and others who shared their procedures and experience in the hospital management at the emergency situation. Partnering with SIOP and St. Jude Global, SLAOP participated intensively in the COVID-19 Global Observatory and especially in the COVID-19 Global Registry where a high number of patients were reported from our continent. A series of online meetings to discuss difficult cases was set up at the St. Jude Global web platform. As part of the initial response, the SLAOP surveyed the membership about the impact of the COVID-19 pandemic in the care of childhood with cancer and that report was published in Lancet Oncology.¹ That study had two follow-up evaluations that are currently in the process of analysis before submission for publication.

It became urgent to establish effective communication tools to connect health care professionals for providing support to manage the COVIC-19 situation.

¹ Vasquez L, Sampor C, Villanueva G, et al. Early impact of the COVID-19 pandemic on paediatric cancer care in Latin America. Lancet Oncol. 2020;21(6):753-755.



The Continental Annual Meeting that was scheduled in Paraguay for April 2020 had to be moved to virtual to November 2020. The SLAOP virtual meeting could be held thanks to the support of a Sanofi Espoir Foundation's My Child Matters Programme and SIOP and it was a great success with more than 2300 registered health care professionals. Sessions on infectious diseases, psychosocial topics, paediatric oncology surgery and paediatric oncology were highly successful and had a >80% of attendees scoring it as very good/excellent. An online nursing course was developed, directed to more than 200 less-experienced nurses in the region. SLAOP also held a virtual meeting of the collaborative groups in the region with encouraging results presented from AHOPCA, SOBOPE, GALOP and CLEHOP, the major cooperative groups in the region. SLAOP also gave academic and scientific support to many online educational activities in surgery, palliative care, nursing, pathology and others.

SLAOP was actively involved in the WHO GICC, having Peru as the index country for the region of the Americas, achieving important milestones despite the pandemic such as the Childhood Cancer Law, national policies and educational material.

Overall, during 2020 SLAOP continued to grow, incorporating new members, carrying out educational activities, supporting the cooperative groups in the continent and advocating for childhood cancer for the voice of paediatric cancer in the region.



Continental branch	Overlapping society(s)	Relationship & infrastructure	Legal status
SIOP Europe	Comprises all National Paediatric Haematolo- gy-Oncology Societies (NAPHOS) in Europe	Close alignment. SIOPE members are enrolled through their NAPHOS, hence not all SIOPE members are SIOP members. SIOPE has developed a European Cancer Plan for children and young people and has a well-developed office that supports advocacy, research collaborations and grants awarded at a European level, and parent/patient involvement. They convene the European Clinical Trials Committee that consists of the chairs of each of the European tumour-specific clinical trial groups. SIOPE has a MOU with CCI Europe and Pancare in order to strengthen the efforts and the needs of all 3 societies by one voice represented by SIOPE on various levels (EU Parliament, Commission and other). SIOP Europe is one of the 2 founding members (SIOPE & ITCC) of the ACCELERATE platform. Joint SIOP-SIOPE policy officer role in place 2020-22.	Independent legal entity in EU
SIOP Africa	GFAOP (Franco- phone countries) AORTIC (Cancer all ages in Africa) POEM Group (Eastern and Mediterra- nean region)	SIOP Africa is chaired by a Board of nine members. A Secretary-General is nominated from within the Board and voted by Board members. Other members of the Board are elected as representative of North Africa, Southern Africa, West Africa, East Africa, Francophone Africa, Nursing and parent organizations. These members will be considered representatives of their regions. The SIOP Africa Secretary is contacting actively by email all people that appear in the SIOP Africa database as an active member in pediatric oncology in Africa and invite them to formalize their SIOP Africa membership. As a SIOP Africa member, you can enjoy the following benefits: 1. To be a member of a continental pediatric oncology network 2. Access to information and opportunities in the field (publications, training opportunities, meetings, scholarships.) 3. Sharing experience with African and international pediatric oncologists 4. Reduced registration fees at continental SIOP meetings in Africa. SIOP Africa members commit to being an active member: 1. Participate, whenever possible, in SIOP Africa activities (ABM, continental meetings etc.) 2. Keep SIOP Africa informed of activities related to pediatric oncology taking place in their country 3. Advocate for pediatric oncology nationally, continentally and internationally 4. Exchange useful information with members of the African Pediatric Oncology community. SIOP Africa is endorsing the global mapping project and has been the first SIOP continental branch to map the PO activity and facilities. SIOP Africa is supporting two other collaborative projects: 1. The WT group/ SUCCOUR project 2. The African Nurses Group project in partnership with WCC SIOP Africa Board members participated in the 2019 African union in Niger. They advocated for access to care and created a manifesto to support this initiative. The document has been translated to English and French	

Continental branch	Overlapping society(s)	Relationship & infrastructure	Legal status
SIOP Asia	Interacts with Region- al groups eg POEM, EURADO, MASPORE & NAPHOS for annual conferences and mailings but no formal relationship yet.	Asian Continental branch of SIOP, evolved since 1992 through interactions and participation in main SIOP meetings. The Board consists of the President, President-Elect/Past-President; plan to expand to add regional representatives. Official voting members are only those who are also current SIOP members. Broader membership for mailing includes a cumulative database of previous years' members or conference attendees. There is no separate membership fee and SIOP Asia has no financial or legal standing or liabilities. Receives an annual conference grant from SIOP. Holds annual SIOP Asia conference and provides a platform for local, regional and continental interactions. Publishes regular newsletters, has an informal relationship with CCI-Asia which holds their meeting jointly. Many SIOP Asia members have actively contributed to SIOP-PODC since 1993 as PODC consultants, through projects and as Working Group participants & leaders. An associated but autonomous arm, APHOG, is being developed for conduct of clinical trials across Asia. SIOP Asia is a supportive partner for WHO-GICC in Asia & will soon embark upon SIOP's Global Mapping Project.	None
SIOP North America	ASPHO COG ASCO AACR	Developing specific mission and goals. No direct financial or administrative support from SIOP.	None
SIOP Latin America	SLAOP	SLAOP is now defined as the Latin American continental branch of SIOP, but SLAOP retains its legal status as an organization and its identity as a professional society. The past president of SLAOP will serve as the SIOP Continental President. SLAOP members will be considered pre-qualified for SIOP membership, such that they need only register in the SIOP web page and pay their membership fee to become members of SIOP (without the need for review by the SIOP Secretary General, since they are pre-qualified by their peers in SLAOP). SIOP members who wish to join SLAOP will also be considered pre-qualified and need only register and pay membership fees (but do not need recommendations from peers or other paperwork to join SLAOP, since they will have been pre-qualified by SIOP. There will be no need for a second qualification (request for membership, signature/recommendation) of other Society members.	None
SIOP Oceania	ANZCHOG	Uses Secretariat of ANZCHOG who support Outreach activities. No financial support from SIOP.	None

ADVOCACY COMMITTEE

Chair: Eric Bouffet (France)

Number of Members: 7

Welcoming New Members: Yes

Contact for Inquiries: info@siop-online.org



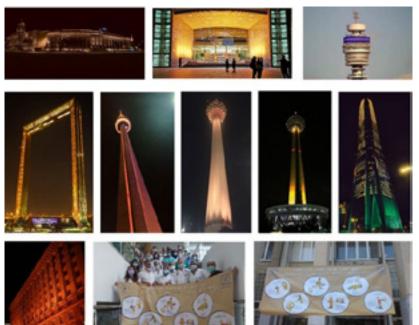
The year 2020 saw several milestones in SIOP's advocacy work: the renewal of Non-State Actor status with the WHO, continued engagement with the GICC, amplifying global awareness, and positioning childhood cancers as a key pillar of COVID-19 mitigation strategies.

On December 11, 2020, SIOP President Kathy Pritchard-Jones spoke at the launch of the WHO GICC Overview Document, designed to bring

the GICC a step closer to its global community. She acknowledged the unprecedented effort within the GICC and the contributions of SIOP members and partners have made towards its aim: at least 60% survival worldwide by 2030.

Gold September 2020 Campaign was celebrated by the SIOP community across the globe. Renowned landmarks lit up in gold and a special policy event attracted hundreds of participants.





To mark 2020 as the Year of the Nurse and the Midwife, paediatric oncology nurses worldwide shared their stories in a <u>video series</u> disseminated widely by SIOP.

In October 2020, SIOP's statement on COVID-19 and childhood cancer was published in the documentation of the special WHO Executive Board meeting.

Advocacy remains an integral part of SIOP's new <u>Strategy 2021 - 2025</u>.

PUBLICATIONS AND SURVEYS COMMITTEE

Chair: Susanne Wollaert (Switzerland)

Number of Members: 5

Welcoming New Members: No

Contact for Inquiries: info@siop-online.org

The Publications & Surveys Committee has reviewed publication endorsement at the request of the Board of Directors and the SIOP Secretariat. Publications that request the following are reviewed by this Committee: use of the SIOP logo, use of SIOP data and publications requesting SIOP endorsement. The existing Committee policy for publications is being revised to align with new Governance Committee guidelines under the SIOP Strategy 2021-2025.

In addition, this Committee has reviewed and proposed new criteria for survey endorsement and distribution. Criteria for endorsement are as follows: topic is of interest or significance to the SIOP member community, absence of duplication of other recent surveys and absence of an alternate strategy for obtaining the data. The Committee recognizes that there is endemic survey fatigue in the SIOP community, and in particular our members in low- and middle-income countries receive an excessive number of surveys, resulting in low response rates. Therefore, the Committee is creating a new policy for survey evaluation and appropriate action.

This Committee meets monthly and aims for swift turnaround time.



GOVERNANCE COMMITTEE

Chair: Julia Challinor (USA)

Number of Members: 6

Welcoming New Members: No

Contact for Inquiries: info@siop-online.org

In accordance with SIOP's new Strategy 2021-2025, a Governance Committee was established in November 2020 as a Committee of the Board. The Committee's focus is to address the 6 Governance Hallmarks identified in the Strategic Plan. These include 1: Clear about its Purpose and Direction; 2: A Strong Board; 3: Fit for Purpose; 4: Learning and Improving; 5: Financially Sound and Prudent; 6: Accountable and Transparent.

In addition, the Governance Committee will review the terms of reference for existing SIOP Committees, TFs, WGs and Networks and update policies for the creation of such groups to streamline and clarify processes. The Committee currently meets monthly and reports to the SIOP Board of Directors. Representation includes the SIOP President, Secretary General, who serves as the Chair of this Committee, three Continental Presidents, and one PODC Co-Chair.

FINANCE COMMITTEE

Chair: Stephen Hunger (USA)

Number of Members: 4

Welcoming New Members: No

Contact for Inquiries: info@siop-online.org

In 2020, the Board of Directors, following a Strategic Planning process, decided to establish a Finance Committee. The Committee was tasked by the Board with the following responsibilities:

- Develop, for approval by the Board, a reserves policy and keep this under regular review.
- Develop, for approval by the Board, an income generation plan.
- Develop, for approval by the Board, and monitor a longer-term financial strategy.
- To review periodically financial management procedures including payment approval process, reporting, policies and procedures.

The Committee plans to develop the reserves policy, income generation policy and longer financial strategy in 2021. The Committee does not deal with the day-to-day financial matters of the Society related to payments, bank accounts, budgets, new proposal budget approvals which are all in the scope of work of the Treasurer.

SCIENTIFIC COMMITTEE

In 2020, we introduced a new feature whereby all SIOP members could nominate ideas for future symposia, meet the expert or keynote lectures, and could nominate new SPAC members.

Chair: Lillian Sung (Canada) **Number of Members:** 9

Welcoming New Members: No²

Contact for Inquiries: info@siop-online.org

This year, we held our first virtual SIOP Congress. We quickly pivoted to an online format because of the COVID-19 pandemic and hosted a very successful 2020 meeting with a record number of attendees: 3,361 from 131 countries. We showcased 230 separate presentations that were held in 24 sessions and maximized the number of live symposia, meet the expert and keynote lectures. Plans for the Hawaii 2021 Congress are currently in progress and we are planning for virtual, live or hybrid contingencies.

The Scientific Programme Advisory Committee (SPAC) remains an integral part of SIOP. As part of our annual process, we are renewing the SPAC with a focus on enhancing geographic diversity





SIOP members were able to access the webcasts on the Congress platform for 3 months more months after the end of the Congress.

² Members of the Scientific Committee are elected periodically via open elections.

and inviting young investigators. We also increased the number of SPAC members to keep the number of abstract reviews reasonable.

In 2020, we introduced a new feature whereby all SIOP members could nominate ideas for future symposia, meet the expert or keynote lectures, and could nominate new SPAC members. We hoped this approach would increase the breadth of SIOP member involvement in scientific programme development.

NURSING GROUP

Chair: Lisa Morrissey (USA) **Number of Members:** 250

Welcoming New Members: Yes

Contact for Inquiries: info@siop-online.org

The <u>SIOP Nursing Group</u>, consisting of 250 registered members and led by a six-member Nursing Steering Committee, provides education, networking opportunities, support and advocacy within the SIOP community and beyond. In the



<u>Year of the Nurse and Midwife 2020</u>, and especially during the pandemic, the critical role of pediatric oncology nurses in the care and support of young cancer patients and their families has been celebrated.

In October 2020, Julia Challinor's term as Secretary-General began, and the Chair of the Nursing Steering Committee was formally welcomed to the Board of Directors, providing the opportunity to elevate the voice of nurses in SIOP's highest leadership structure. The same month, we also welcomed Yan Yin Lim, RN MSc, BSN (Singapore) and Dee Ann Omatsu, MS, PNP-BC, CPHON (Local Organizing Committee, Honolulu) to the SIOP Nursing Steering Committee.

The 2020 SIOP Congress Nursing Programme was very successful with 241 nurses registered. Sessions with highest attendance included a joint Nursing/YI presentation on "Communicating Bad News", Marilyn Hockenberry's keynote lecture, a round table on "COVID-19 and Ethical issues", and the opening ceremony where the 3rd annual Nursing Lifetime Achievement Award was proudly accepted by Rachel Hollis.



Other highlighted activities include the launch of the Sub-Saharan African Nursing Network, building on regional partnerships with the aim to develop harmonized nursing educational resources. In Ghana, a 12-month education programme for pediatric oncology nursing was initiated through collaboration between the Ghana College of Nurses and Midwives, local clinical experts and a faculty of international partners. SIOP nurses were represented in several publications and presentations advocating for nurses as key global stakeholders in the WHO GICC, including this <u>publication</u> in Lancet Oncology on strengthening the childhood cancer global workforce.

NUTRITION NETWORK

Co-Conveners: Maya Prasad (India) and Ronald Barr (Canada)

Number of Members: 40

Welcoming New Members: Yes

Contact for Inquiries: info@siop-online.org

The HIC subgroup of the Nutrition Network used the results of a survey of their members to plan a series of projects. For example, at the SIOP 2020 Congress, several young investigators (YIs) attended the SIOP lunch meeting session focused on nutrition. This encouraged the group to think about developing a mechanism on social media to promote communication within and beyond the network.

The LMIC subgroup of the Nutrition Network developed valuable information which is easily accessible through a <u>dedicated CancerPOINTE page</u>. It is a useful repository of informational resources and a good vehicle for communication. Since the site does not require registration, it is accessible by both SIOP members and non-members.

Maya Prasad took over the Co-Chair role from Paul Rogers in October 2020.

YOUNG INVESTIGATORS NETWORK

Chair: Gemma Bryan (UK)
Number of Members: 188

Welcoming New Members: Yes

Contact for Inquiries: young investigators@siop-online.org



The YI Network is young SIOP! It is an international multidisciplinary group of SIOP members under the age of 40 years from any clinical or academic background. YIs do not have to be actively engaged in research and no postgraduate qualifications are necessary.

We represent the interests of young SIOP members working in the field of paediatric oncology. We provide a platform for YIs to develop research and scientific skills, and facilitate an international research network with other young investigators in paediatric oncology.

In 2020, despite the challenges of COVID-19, the YI Network had a very successful year:

 The first virtual YI Education Day at the 2020 SIOP Congress was a great success, with over 600 people attending at least one



Khumo Myezo, a Young Investigator from South Africa, won the SIOP YI Social Media Contest.



A Young Investigator watching the 2020 Virtual Congress from home.

session. The varied programme included sessions on "Breaking Bad News: Team Based Patient and Family Centred Communication", "How to Get Involved in International Big Database Research, INRG and Beyond", and "Immunology Back to Basics: An Introduction to Immunotherapy" as well as our popular YI Expert 'Lunch', which transferred well to the virtual format.

- The YI Twitter account (@SIOPYI_Network) gained hundreds of followers and is currently followed by over 1,300 people with an interest in paediatric oncology, making it a fantastic resource for disseminating information.
- The YI blog had posts written by individuals working in paediatric oncology from around the world, including New Zealand, Brazil and Syria, and highlighted the work of our YI awardees.
- YI Board members made substantial contributions to the development of the new SIOP Strategy 2021-2025.
- The YI Board nominated five YIs to become junior members of the SIOP Scientific Committee Advisory Committee (SPAC): Jess Morgan (UK), Austin Brown (USA), Liliana Vasquez (Peru), Sarah Cohen-Gogo (France / Canada) and Gemma Bryan (UK).

We are always looking for new members for our YI Network sub-committees! Please come and join us!

Twitter: @SIOPYI_Network

Blog: https://siopyi.blogspot.com/

We represent the interests of young SIOP members working in the field of paediatric oncology.

PAEDIATRIC PSYCHO ONCOLOGY WG

Chair: Martha Grootenhuis **Number of Members:** 7

Welcoming New Members: Yes

Contact for Inquiries: info@siop-online.org

The Paediatric Psycho Oncology (PPO) WG's main objective is to incorporate psychological knowledge into paediatric oncology practice and thereby improve care for children with cancer. Our specific goals are:

- 1. To facilitate the exchange of research data on paediatric psycho-oncology issues among psycho-oncology and medical colleagues;
- 2. To support the integration of these data with current psychological research, theory, and practice;
- 3. To encourage the active incorporation of this psychological knowledge into paediatric oncology practice with the overall aim of improving the care for children with cancer and their families; and
- **4.** To provide psycho-education and support to survivors and parents interested in updates on psychological issues in paediatric psycho-oncology.

Specific responsibilities of the PPO WG involve, but are not limited to:

- 1. Organizing the annual SIOP PPO pre-meeting day;
- 2. Reviewing the psychosocial abstracts submitted to the SIOP Annual Congress;
- **3.** Facilitating communication between group members via monthly meetings, e-mail exchanges and updates, and sharing PPO newsletters;
- **4.** Responding to requests for information/assistance from the SIOP Board with respect to psychooncology matters;
- 5. Interacting with other SIOP committees, such as PODC; and
- 6. Fostering collaborations with relevant external organizations e.g., APOS, IPOS, ASPHO.

In 2020, the PPO WG has had monthly meetings via Zoom. Meetings have focused on planning for the upcoming SIOP Congress.

During the 2020 Annual Congress, the PPO organized a successful Educational Day (ED).

We believe it was a day with excellent learning opportunities and cutting-edge topics led by expert speakers. The virtual Congress was helpful in facilitating access for a variety of health professionals to participate. The ED included Sessions on: "Sleep Interventions: Practical Knowledge"; a joint session with SIOP YI on "Breaking Bad News: Team Based Patient and Family Centered Communication"; a session on "Sexual Health: Research and Practice"; and a final session on "The Psychological Impact of COVID-19 in Paediatric Oncology".

On the main programme, PPO had a joint free paper session with the nurses on "Adolescents, Survivors, and Psycho-Oncology". There was also a PPO free paper session on Day 2 of the Congress. Finally, a

PPO poster discussion session on "Sleep and Fatigue" was organised.

The members of the PPO WG have received two newsletters from Psycho-Oncology Professionals and Providers International (POPPI). This is an international and interorganizational collaboration between the chairs of the PPO (Martha Grootenhuis, the Netherlands), the International Psycho-Oncology Society (IPOS) Pediatric Special Interest Group (SIG) (Claire Wakefield, Australia), and the American Psycho-Oncology Society (APOS) Pediatric SIG (Lori Wiener, USA). The main goals of this newsletter 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.



SUPPORTIVE CARE WG

Co-Chairs: Rejin Kebudi (Turkey) and Wim Tissing (the Netherlands)

Number of Members: 126

Welcoming New Members: Yes

Contact for Inquiries: info@siop-online.org

The COVID-19 pandemic has had a major impact on our lives, on childhood cancer services, and on scientific meetings. The Supportive Care WG has collaborated with other committees and WGs as in previous years.

On the ED of the SIOP 2020 Congress, the Supportive Care WG had three joint sessions with the Nurse Committee. The main topics of the sessions were "Sleep Disturbances and Sleep Interventions in Children with Cancer"; "Fertility Problems and Recommendations for Fertility Preservation in Children and Adolescents with Cancer", "Nutritional Problems in Children with Cancer, Nutritional Assessment and Counselling of Long-term Survivors, Diet Supplements, and Treatment-related Toxicities in Childhood Cancer". The sessions were well attended with up to 472 participants per session. There were keynote lectures and symposia on COVID-19 and on "Palliative Care".

Members of the SIOP Supportive Care WG are collaborating with the Multinational Association of Supportive Care in Cancer (MASCC), the Paediatric Working Party of the European Society for Blood and Marrow Transplantation (EBMT), the <u>International Paediatric Oncology Guideline (IPOG) Network</u>, which set up an international network on the supportive care clinical practice guideline development, the Middle East Cancer Consortium, where studies on supportive and palliative care were held. Members also collaborated on the book "<u>Palliative Care for Chronic Cancer Patients in the Community</u>" (Springer, 2020), which was recently published.

Moreover, the fertility guidelines developed by the PanCareLIFE consortium in collaboration with the International Late Effects of Childhood Cancer Guideline Harmonization Group have been accepted for publication.

The Supportive Care WG held monthly webinars in 2020.

The <u>rapid guidance publications of SIOP on COVID-19</u> have been useful. SIOP has a wealth of <u>resources</u> and <u>reference documents</u> that may help us during the COVID-19 pandemic.

The Annual Congress sessions on Supportive Care were well attended with up to 472 participants per session.

PAEDIATRIC ONCOLOGY IN DEVELOPING COUNTRIES COMMITTEE

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

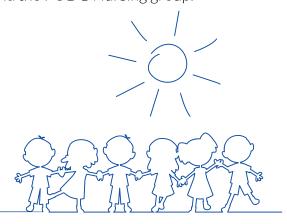
The Paediatric Oncology in Developing Countries Committee (PODC) is an important committee of SIOP, with more than 1,100 members from around 100 countries. It consists of 11 WGs and 5 TFs, including the newly launched Onco-Pharmacy and Adolescents and Young Adults TFs. Three new groups (IPSO LMIC, Young 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, 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

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

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 <u>CancerPOINTE's website</u>. 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:

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

Finally, the WG collaborated with the PODC Nursing Group to host <u>monthly education learning</u> resources, conducted 6 POINTE meetings and attended the annual meetings with other PODC groups.

For more info, please follow Cancer POINTE in social media:

- Facebook
- Instagram
- <u>Twitter</u>



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

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.³ Other publications of the WG are also available.⁴

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.

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

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

 $\label{lem:http://onlinelibrary.wiley.com/doi/10.1002/pbc.26501/abstract; jsessionid=09212438D534EF6C9EB5BD65F5F9294D.f04t02. \\ \label{lem:http://onlinelibrary.wiley.com/doi/10.1002/pbc.26501/abstract; jsessionid=09212438D534EF6C9EB5BD65F5F9294D.f04t02. \\ \label{lem:https://onlinelibrary.wiley.com/doi/10.1002/pbc.26501/abstract; jsessionid=09212438D534EF6C9EB5BD65F$

³ 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

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



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

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 <u>dedicated Nursing page</u> 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 <u>Global COVID-19 Observatory and Resource Center for Childhood Cancer</u>. 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

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. 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

⁵ 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

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 <u>Paediatric Oncology</u> <u>Nutritional Supplement</u> 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 <u>Sanofi Espoir Foundation</u>.







In addition, a <u>Nutrition page</u> 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

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

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 guidelines⁶ 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.

⁶ "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

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.⁷

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.

⁷ 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

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. 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)^{9,10} and subsequently adopted by ASCO¹¹, NCCN^{12,13} and SIOP¹⁴.

⁸ 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.

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

¹⁰ 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.

¹¹ 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.

 $^{^{12}}$ 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. 13 Koh W, Anderson BO, Carlson RW. NCCN resource-stratified and harmonized guidelines: A paradigm for optimizing global cancer care. Cancer , 2020 126: 2416–2423.

¹⁴ 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. 15 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.

¹⁵ 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

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

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 I MICs.



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

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 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.

knowledge regarding the disease.

PODC PROS LMIC TF

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

Number of Members: 54

Welcoming New Members: Yes

Contact for Inquiries: 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).¹⁶

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

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.¹⁷

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

¹⁶ 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

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



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

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%. 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 <u>SIOP</u> website where you can also find more information about the Project.

Please find short videos about the project and its impact <u>here</u> and <u>here</u>.

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.





















¹⁸ "Working Together to Build a Better Future for Children with Cancer in Africa," Journal of Global Oncology 2020.

PODC Pallative 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

Dr. Marisol Bustamante's completed her tenure as a Co-Chair of the PODC Pallative 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 Pallative 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.

SIOP PARTNERS

In 2020, SIOP worked with many partners around the world. In this section of the Annual Report, we share highlights of the work of the three partners who collaborated with SIOP in the development of the 2020 Annual SIOP Congress.

Childhood Cancer International (CCI)

President: João Bragança

https://www.childhoodcancerinternational.org/

From the perspective of CCI, it is impossible to write about 2020 without mentioning COVID-19 and the WHO GICC. Despite all the regional activities - advocacy, support to families, patients and survivors, nutrition programmes, access to essential medicines or palliative care - both COVID-19 and the WHO GICC had a global impact and required a global intervention from our side.

In 2020, CCI sent a questionnaire to its members. We wanted to know the impact of the pandemic on our community: how did the economic environment created by the COVID-19 impact the organizations' revenue? What happened to "family homes"? Was telemedicine being used as a (satisfactory) means of communication? Where were there any shortages in essential medicines? And the survivorship services during the pandemic? We received answers from more than 100 organizations all over the world, giving us an accurate picture of the situation.

The WHO GICC is more than an acronym, more than a global project – it is our commitment to the children with cancer all over the world. For CCI, a parent's organization, saving 1 million lives until 2030 means saving the lives of our sons and daughters. For our participation to be effective, we worked in a coordinated way: for every WHO region, we created teams of parents and other volunteers to act as interlocutors for the project; more than 30 people participated from Kenya to Chile, from Indonesia to Australia, from Honduras to Nepal.

International Society of Paediatric Surgical Oncology

President: Simone Abib https://ipso-online.org

In 2020, the International Society of Paediatric Surgical Oncology (IPSO) worked on several publications:

- IPSO COVID-19 statement was published. <u>ipso-online.org</u>
- IPSO Practice Guidelines was developed. ipso-online.org
- The COVID-19 PANDEMIC: A Rapid Global response for Children with Cancer from SIOP, COG, SIOP-E, SIOP-PODC, IPSO, PROS, CCI and St. Jude Global. (DOI: 10.22541/ au.158777298.87289192/v2)

In support of the WHO GICC, IPSO participated in the development of assessment tools (diagnostic and therapeutic capacity, workforce), focus countries, the economic decision tool for governments. Furthermore, IPSO developed a series of webinars on Paediatric Oncology Surgery for Peru, which is a target country for the WHO GICC.

IPSO also held partner meetings with SIOP and St. Jude Global representatives on the alignment for the WHO GICC initiative and on other priority topics for IPSO. Meetings were held with SIOP PODC and SIOP Board on the development of its strategic plan in order to find ways of collaboration. IPSO also contributed to the development of Adapted Resource Implementation Application (ARIA)

IPSO participated in several COVID-19 webinars (for example, St. Jude Global and SIOP: COVID conversations and Local Control for Paediatric Cancer during the COVID-19 Pandemic and the Cirugía oncológica pediátrica durante la pandemia COVID-19: Experiência Iberoamericana IPSO-SLAOP- St Joan de Déu)

- St. Jude Global Alliance Convening 2020
- World Health Organization (WHO), the International Agency for Research on Cancer (IARC) and the International Atomic Energy Agency (IAEA) meeting.
- IPSO Young Surgeons Committee is working together with SIOP YI group



Paediatric Radiation Oncology Society (PROS)

President: Natia Esiashvili

https://intpros.org/

Programme highlights of the PROS Joint Virtual Congress with the SIOP included: Clinical trial updates; Interventions for improving the paediatric radiotherapy experience; Medical physics advances; Tools for neuro-cognitive evaluation in children; Radiotherapy challenges in LMIC; Symposium on non-RST STS; PROS/SIOP/IPSO symposium on Desmoid tumors. PROS organized pre-congress online contouring workshop.

PROS held a general assembly on October 14, 2020, and the members voted on annual reports, activities, budget, and on the election of new Executive Committee members and a President.

In addition, PROS members collaborated with a number of initiatives:

- PROS members worked with the WHO GICC Working Groups.
- PROS initiated collaborative projects with SIOP-PODC and St. Jude Global on disease-specific guidelines to be added to the ARIA platform: PROS formed the writing groups for Wilms' Tumour, Rhabdomyosarcoma, Hodgkin Lymphoma, and Low-grade Glioma.
- PROS started a collaboration with the International Atomic Energy Agency (IAEA) on a handbook for Paediatric Radiotherapy Service.
- PROS participate in the annual imPACT partners' meeting for the WHO, IAEA and the International Agency for Research on Cancer (IARC).
- PROS participated in St. Jude Global Alliance Annual Meeting.
- PROS Working Group within SIOP-PODC continues to engage the LMIC members in various projects and activities.
- PROS endorsed and provided faculty for Latin American Virtual Contouring Workshop and First Pakistan Paediatric Neuro-Oncology Symposium.
- PROS members participated in joint virtual meetings: SIOP Covid-19 Series in LMIC; the Aga Khan/ Sanofi online Paediatric Neuro-Oncology series; the University of Gezira, Sudan, PODC lecture series; Video linked Tumour Boards: Pakistan, Cape Town/Uganda/Kenya; Webinar on Paediatric Radiotherapy for Global Access to Cancer Care Foundation.

Moreover, PROS continues to utilize <u>its online forum</u> for reviewing challenging cases. PROS members published a number of publications in 2020.¹⁹

¹⁹ 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

FINANCIAL SUPPORT TO SIOP

SIOP expresses its gratitude for the financial and educational support from the following institutions:

Support for Projects

Sanofi Espoir Foundation's "My Child Matters" Programme

- 2020 2021 My Child Matters Nursing Projects
- SIOP Global Mapping

Support for Online Education (Knowledge Centre)

- Bayer
- BTG International Inc.

Support for the Annual Congress (Sponsorship & Exhibition)

- American Society pf Pediatric Hematology/Oncology
- Bayer
- Bristol-Myers Squibb
- Dana Farber Cancer Institute
- EUSA Pharma
- Fenix Global Planning
- French African Group of Pediatric Oncology
- Jazz Pharmaceuticals
- Ology Medical Education
- ORPHELIA Pharma SAS
- Pfizer
- Rare Disease Therapeutics
- Roche
- Sanofi Espoir Foundation's "My Child Matters" Programme
- Servier
- St Baldrick's Foundation
- St. Jude Children's Hospital
- Texas Children's Hospital
- The Children's Hospital of Philadelphia
- Y-mAbs Therapeutics

SIOP MEMBERSHIP

We have achieved many milestones and records in the past year and all of this would not be possible without our committed and loyal members. We encourage you to renew your membership. Members are the backbone of the society.

• Renew now:

https://siop-online.org/renew-your-membership/

• Review the membership categories:

https://siop-online.org/become-a-member/

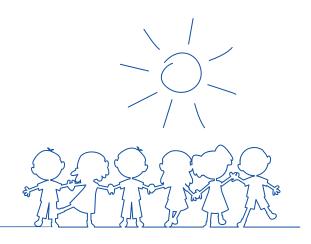
• if you have any questions, please contact our Membership Coordinator at membership@siop-online.org.

SIOP KNOWLEDGE CENTRE

The SIOP Knowledge Centre is designed for professionals committed to continuing their education and improving patient outcomes. Members need to create a login and password to access it (https://casehippo.com/spa/courses/catalog/siop/home).

You will find many e-learning opportunities of interest in the Knowledge Centre, including the following:

- Background of Difficult-to-treat Cancers in Children, by Scott Howard and Peter Adamson
- Genetic Testing Information: TRK Fusion Cancers, by Barbara Jones, David Jones and Scott Howard
- Management of Toxicities of High-dose Methotrexate, by Deepak Bansal, Scott Howard and Stephen Hunger
- The Consequences of COVID19 On Paediatric Oncology Care, by Kathy Pritchard-Jones





Established in 1969, the International Society for Paediatric Oncology (SIOP) is the only global multidisciplinary society entirely devoted to paediatric and adolescent cancers. With a steadily growing membership, SIOP currently unites over 2,600 healthcare professionals and researchers working with paediatric patients worldwide. The community shares a strong common purpose: to increase survival rates, to improve quality of survival and to ensure care for all.

What does SIOP mean to YOU?

