SUMMARY OF OUR SIOP OCEANIA ANZCHOG WORKSHOP

Sydney, 27th July 2022

It is a pleasure to share a summary of our SIOP Oceania ANZCHOG workshop, entitled “Caring for children with cancer across Oceania: A SIOP Oceania-ANZCHOG workshop”, which was co-chaired by Claire Wakefield and Michael Sullivan.

Session 1: Opening

The day opened with Claire Wakefield welcoming guests from 9 countries across the Oceania continent and outlining the objectives and goals of the day. Claire set the tone for the day’s meeting with the Samoan proverb, “Through collaboration, the most difficult challenges can be overcome.” Simon Lala (New Zealand) also welcomed everyone on behalf of the World Child Cancer Charitable Trust (WCCT), sharing that it was his daughter’s life changing cancer diagnosis that motivated him to form the WCCT, which is a not-for-profit organisation, with a dedicated fund-raising team, committed to partnering with other islands to improve childhood cancer care. Michael Sullivan (Australia) then shone a spotlight on the high survival gap between high- and low-income countries, due to challenges of diagnosis and treatment initiation, completion, and toxicities. Michael emphasised that cure is not dependent on smart technology, but rather by correctable practice, good policies, timely access to care and available resources/facilities. “Not smart drugs, but smart care.” Effective change can only be achieved from within, by local champions supported by good data. Michael looks forward to us working together with an understanding of our colleagues’ resources, culture, ethnicity, beliefs and aspirations.

Session 2: Child cancer in our region: Current care, challenges and goals

The next session saw each of our international representatives provide a snapshot of cancer care in their region. Gwenda Anga (Papua New Guinea) is PNG’s first paediatrician to specialise in oncology. Gwenda shared her excitement that Port Moresby General Hospital was undergoing renovations that would increase both capacity and services. They are working with authorities to increase drug supply, develop a post-graduate diploma in paediatric oncology, and establish a registry and a formal parent group. She thanked the organisers for supporting her and her colleague, Benjamin Daur’s visit. Pauline Rose shared her experiences of providing radiation therapy training to seven nurses in PNG via Zoom, over the past 12-months. Pauline
plans to visit PNG in October to meet collaborators, help identify context-specific challenges, and is very happy to provide paediatric oncology nurse education also.

**Miriama Tukani (Fiji)** is a paediatrician from the Colonial War Memorial Hospital and feels that her families’ greatest needs are financial security, childcare, and food security. Miriama talked highly of the support, Walk On Walk Strong (WOWs), provides for patients to access medication where it isn’t accessible from private pharmacies, but that they still need greater funding to support timely lab services.

**Gregory Harvet (New Caledonia)**, himself a haematologist/oncologist, shared that his small country did not have a dedicated paediatric oncology unit. He shared that his team relies heavily on their relationships with Westmead Children’s Hospital (Australia) and several paediatric oncology units in mainland France. There are challenges transporting patients to off-shore clinical care centres and families often feel very isolated. Gregory attended the workshop with his nursing colleague, **Jessica Kreyer**, from Noumea.

**Milena Lay Santos (Timor Leste)** represented her region and shared that they have no paediatricians or nurses specially trained in oncology. Milena looks forward to establishing capacity to identify and safely manage paediatric cancer cases, strengthening and expanding relationships with partners including pharmacy and lab services, and working with SIOP to strengthen the capacity of their paediatric workforce. **Joao Amaral** also shared about his experiences in adult oncology services in Timor Leste, including identifying many common challenges but also exciting plans to develop a new oncology unit in Timor Leste which will be able to provide in-country care for cancer patients.

**Meleane Toafa (Tonga)** is a general paediatric registrar who attended the workshop day with her colleague, **George Fifita (Siaosi)**, a paediatric nurse. Meleane shared that Tonga’s childhood cancer patients are seen by a general practitioner and it is a challenge to retain oncology-trained nurses. Tonga is able to send some childhood cancer patients for off-island cancer treatment in New Zealand, however not all patients meet eligibility criteria. Families receive valued support from the Child Cancer Foundation Tonga (CCFT), including both financial and psychosocial support.

**Wade Kyono (Hawai’i)** shared how delighted he was to be included in the Oceania group and that even though Hawai’i is part of a high-income country, they can still relate to the challenges of transporting patients from the Pacific Islands. Wade looks forward to collaborating with all of Oceania, not just mainland USA, and learning how his team can assist and play a larger role within this group. Wade was joined by his paediatric oncology colleague, **Kellie Hutchins**, who is also passionate about global health and medical education.

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**Session 3: Taking a global perspective**

**New Zealand partnerships across Oceania:** **Jane Skeen (New Zealand)** shared that she initially became involved because of a desire to increase expertise in oceanic countries and not rely only on treating children in New Zealand. Jane looks forward to building capacity to enable pacific island health professionals to deliver
more cancer care in their designated countries, but acknowledges the challenges, including maintaining expertise among doctors and nurses, providing palliative and supportive care, geography, weather, and the pandemic. Siobhan Cross then highlighted the importance of research, as it improves outcomes, as well as the importance of honesty and strategic planning with our pacific partners.

The nurse and chemotherapy: giving safe cancer treatment with care and compassion: Jayne Harrison and Michele Casey (Australia) highlighted the importance of nurses in resource limited settings, but also the challenges of high nurse-to-patient loads and lack of specialisation. Jayne and Michele delivered a presentation on basic chemotherapy principles, including safe handling and administration, and risks of occupational exposure, and provided a booklet on these topics for all attendees to take home.

Retinoblastoma early detection: "The time is now": Sandra Staffieri (Australia) a clinical and research orthoptist, presented an overview of retinoblastoma and challenges associated with timely diagnosis and risk factors for survival. Sandra discussed the latest research in paediatric retinoblastoma and opportunities for improving eye health and diagnostics, such as through linking eye screening to vaccination in LMICs.

Global resource adapted guidelines for children with cancer: The ARIA project: Michael Sullivan returned to the stage to discuss the Adapted Resource and Implementation Application (ARIA) Project which is a platform which will offer comprehensive yet accessible content about various diagnoses and aspects of childhood cancer care, in addition to decision-aids. ARIA will provide practical, resource adapted management guidelines initially for the six WHO focus cancers as well as providing resource adapted guidelines for supportive care, palliative care and many other domains. The ARIA platform will be accessible online, via mobile and tablet devices, and offline.

WHO Global Childhood Cancer Initiative and the WHO Lived Experiences Study: On behalf of Julie Cayrol (WHO consultant and paediatric oncologist in Melbourne), Claire presented on the stark contrast between LMIC’s and HIC’s access to chemotherapy, cancer surgery and radiotherapy, and the consequent survival outcomes. Claire presented a history of WHO’s Global Initiative for Childhood Cancer (GICC) that was launched at the United Nations General Assembly in September 2018, and discussed the GICC’s CureAll framework. An overview of the WHO GICC project can be found here: who-childhood-cancer-overview-booklet.pdf. Claire also presented on the WHO Lived Experiences Study (also called the ‘ACKnowledge study’, which will assess the psychological and financial impact of cancer on survivors worldwide. She encouraged all attendees to share the survey with patients and families when it is launched later this year.

Session 4: New initiatives in our region

Childhood cancer registries across our region: Michael Sullivan (Australia) emphasized that the merits of consistent record-keeping and registries ranged from cost-saving benefits, to better understanding of cancer epidemiology, supporting future planning and providing advocacy. Michael highlighted that while multiple types of registries exist, including a comprehensive classification of childhood cancer (ICCCv3.0) is critical. REDCap-hosted registries have been developed in 137 centres, factoring in data sovereignty and governance, and are modifiable to suit region-specific needs. Registries need to be maintained carefully and have someone appointed to look after it. He concluded his presentation by reiterating that ‘data saves lives’.

Medical and nursing professional development across Oceania: Facilitated discussion: Trisha Soosay Raj (Australia) shared her passion for global oncology and medical education, focusing on the key enablers of learning and frameworks for professional development. Shared guidelines, staff education, online resources such as the ARIA platform and SIOP Knowledge Centre, and face-to-face or virtual workshops are some of the
many ways we can support professional development. We agreed to focus on specific plans for professional education in our region in a future Advisory Board meeting, in particular considering formation of an Education and Training Sub-committee for SIOP Oceania to progress this work further.

“The way forward” – facilitated discussion, and thank you: Claire announced that SIOP Oceania has a new logo, as voted for by attendees of the workshop (see left!). A group discussion was had, starting with the concept of training ‘oncology-focused paediatricians’. Claire thanked all the members of the workshop organising committee, especially Jenny Clough, who worked tirelessly to ensure that all of our international delegates were able to join us for this important event. Claire again thanked everyone for a productive day and the close collaborations that were forming.

Wishing you all the very best,

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With many thanks to Jordana McLoone and Jessica Gereis for serving as our incredible writers for this important day!