
Health System Strengthening for Childhood Cancer in the Caribbean

Report of the meeting held in
Port of Spain, Trinidad & Tobago, 11-12 February 2020



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EXECUTIVE SUMMARY

Cancer is among the leading causes of death in children under the age of 15 years. In high-income countries, pediatric cancer mortality has been reduced significantly, as a result of earlier diagnosis and effective treatment, survival rates are 80% or higher. In the Caribbean pediatric cancer mortality continues to be high and survival rates significantly lower than high-income countries, where several Caribbean countries report 2-year overall survival of about 55%.

As a result, there is increasing interest in the global health community to strengthen health systems to improve outcomes and survival rates for children with cancer. The SickKids-Caribbean Initiative (SCI), established in 2014, is building capacity in pediatric cancer care in six countries. In addition, the Pan American Health Organization established a regional working group on pediatric cancer in 2017 to develop strategies and recommendations for health system strengthening for childhood cancer. And in 2018, the World Health Organization launched a global childhood cancer program with leading stakeholder institutions, including St. Jude's Research Hospital, The Hospital for Sick Children, International Society of Paediatric Oncology, the Childhood Cancer International, among others. Against this backdrop, the Pan American Health Organization, convened a Caribbean wide, multi-stakeholder health policy dialogue on childhood cancer, together with The Hospital for Sick Children, St. Jude's and local leaders to discuss strategies to improve childhood cancer care in the region.

Participants included approximately 40 representatives from Ministries of Health and from pediatric oncology from 9 Caribbean countries (The Bahamas, Belize, Barbados, Guyana, Jamaica, St. Lucia, St. Vincent & the Grenadines, Suriname and Trinidad & Tobago) along with representatives from PAHO, St. Jude Children's Research Hospital, and The Hospital for Sick Children.

The meeting was structured with formal presentations, plenary discussions, and small group work along the following topics: global and regional overview of pediatric cancer; organization and delivery of pediatric cancer care services; access, availability, quality and rationale use of pediatric cancer medicines; health human resource strengthening for pediatric cancer care; and financing and quality assurance for pediatric cancer. The main challenges and needs that were identified through the discussions, and that are proposed to be addressed through in country work are summarized as follows.

- Improve early detection and referral pathways: there is a need to train providers at the first level of care to improve early detection; establish a clear referral mechanism; create information systems to be able to follow children suspicious for cancer through the system to ensure timely diagnosis and treatment.
- Build a cadre of health human resources: there is a lack of medical specialists to diagnose and treat children with cancer, especially nurse oncologists, paediatric oncologists and pediatric surgical oncologists, as well as pharmacists trained in chemotherapy management.
- Treatment protocols: while much advancement has been made through the Sick Kids Caribbean Initiative to standardize treatment protocols, this is still lacking in several Caribbean countries.
- Weak pathology and treatment services: availability of diagnostic services is a challenge, especially for immunohistochemistry, and cytogenetics. There is also limited capacity for blood product management, radiotherapy, and pediatric palliative care, as well as continuous challenges with essential supplies such as ports. In countries with no

capacity to treat children with cancer (eg Suriname, Belize) children are sent to foreign countries for treatment with huge financial, social and emotional impact.

- Medicine quality and availability: planning, forecasting and procurement of pediatric cancer drugs continue to be a challenge in the region, as is issues of quality and quality assurance for pediatric cancer drugs.
- Blood banks: there is a need to improve availability and consistent supply of safe blood products, especially to cover the needs of the pediatric cancer population.
- Psychosocial and family support: there is very limited support and a big need to create more community and mental health support services for children and families dealing with cancer.

The meeting concluded with each country team and partner organization discussing the needs and gaps in care and beginning to develop a 3-5-year project plan for country specific, and region wide activities to strengthen the health system response for childhood cancer. Following this meeting, the next step will be for PAHO to coordinate with local leaders and partner organizations the respective national pediatric cancer plans and the implementation of the region-wide activities.

MEETING OVERVIEW

On the occasion of International Childhood Cancer Day, pediatric cancer experts and health authorities were convened by the Pan American Health Organization (PAHO), and together with the Hospital for Sick Children (SickKids), and St. Jude Children's Research Hospital discussed action to improve children cancer care in the Caribbean.

Cancer is among the leading causes of death in children under age 15, in the Caribbean and globally. In high-income countries, more than 8 in 10 children with cancer survive the illness, thanks to early diagnosis and effective treatment. But in several Caribbean countries, 2-year overall survival is only about 55%. Higher toxicity of cancer treatments and patients' abandoning their treatment are the main barriers to successful outcomes and strengthening health systems is the best way to address these challenges.

Pediatricians, pediatric oncologists, and noncommunicable disease program managers from nine Caribbean countries and territories, along with representatives of ministries of health and other collaborating organizations met in Port of Spain Trinidad, on Feb. 11 and 12 to map out ways to increase support and action—at both the country and regional levels—to reduce deaths in children and adolescents with cancer in the Caribbean.

The main objectives of the meeting were to:

- discuss current health system capacities and needs in respect of childhood cancers in the region, and identify priorities and opportunities for health system strengthening to improve outcomes for children with cancer in the Caribbean;
- unite health policy makers, medical professional associations, academics and childhood cancer organizations to discuss the perspectives on how to improve childhood cancer outcomes in the Caribbean;
- mobilize the existing evidence base to identify and prioritize key strategies that need to be implemented at regional, subregional and country level to improve childhood cancer outcomes in the Caribbean;
- develop a sub-regional initiative, as well as country specific projects, that with support from relevant international organizations and stakeholder groups, will improve the health system response for childhood cancer.

The meeting included a series of plenary presentations, country case reviews and small group work. Priority areas of action were identified as follows: earlier detection and diagnosis of childhood cancer in primary care, with timely referral for specialized treatment; increased access to essential medicines for childhood cancer; training and continuing multi-disciplinary medical education for specialists and primary care providers; improved continuity of care, including for children who live far from treatment centers to prevent abandonment of treatment; and the production and sharing of evidence for public health use and to mobilize political and financial support.

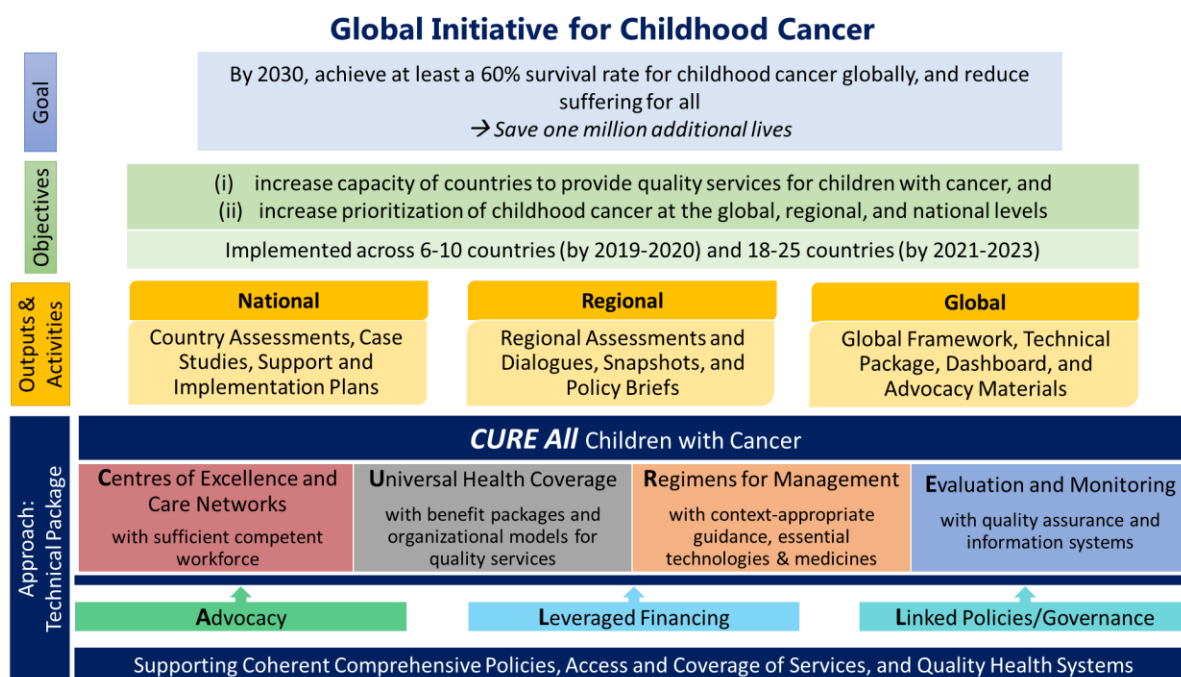
DAY ONE

Session 1: Global and Regional Overview of Pediatric Cancer

Moderated by Silvana Luciani, this session began with an overview of the WHO Global Childhood Cancer Initiative and how the Caribbean subregion fits in, delivered by Dr. Catherine Lam from the WHO Collaborating Centre for Childhood Cancer at St. Jude’s Children’s Research Hospital.

The WHO Global Initiative for Childhood Cancer, launched in 2018 set a bold target - *By 2030, double the cure rate, ensuring at least 60% survival for children with cancer globally, and reducing suffering for all – saving one million more children.* The objectives are to increase capacity of countries to provide quality services for children with cancer; and to increase prioritization of childhood cancer at the global, regional, and national levels. The following figure describes the initiative’s goal, objectives, outputs & activities, and approach.

Fig. 1: Global Initiative for Childhood Cancer



The Initiative is focused on six index cancers, which share various commonalities – being that they are highly curable with proven therapies, prevalent in all countries, and represent 50-60% of all childhood cancers (age 0-19). The index cancers are: acute lymphoblastic leukemia which is the most common worldwide, Burkitt Lymphoma which is common in many low-income countries, Hodgkin Lymphoma, common in adolescents, Retinoblastoma, Wilms Tumor, and Low Grade Glioma. Using the *CURE ALL* framework or approach, 10 core projects have been identified as part of the WHO Global Initiative for Childhood Cancer, as starting points from which local leaders can choose and prioritize next steps and resource needs.

As a WHO Collaborating Center for Childhood Cancer, St. Jude’s conducted a review of national cancer plans and Dr. Lam presented the following snapshot of national cancer plans in the Caribbean.

Table 1: National Cancer Plan Existence

Country	2010	2013	2015	2017	2019
Bahamas	No data	No	No	No	No
Barbados	Yes	Yes	Yes	Yes	Not in effect
Belize	No	No	Yes	Yes	Yes, under development
Jamaica	No	No	Yes	Yes	Not in effect
Saint Lucia	Yes	No	No	No	No
Saint Vincent and the Grenadines	No data	No data	No	No	No
Suriname	No	Yes	Yes	Yes	Yes, under development
Trinidad and Tobago	No	Yes	No	No	Yes, being updated

Hospital for Sick Children on the Sick Kids - Caribbean Initiative

This was followed by a presentation by Dr. Sumit Gupta, The Hospital for Sick Children on the Sick Kids - Caribbean Initiative (SCI), established in 2014 to build capacity in pediatric cancer care in six countries – The Bahamas, Barbados, Jamaica, St. Lucia, St. Vincent and the Grenadines and Trinidad and Tobago. The SCI has established an oncology registry with patient data to provide an accurate picture of the number of pediatric oncology patients presenting at participating treatment centers, causes of treatment failure and evaluation of implemented changes in therapy or supportive care. The database includes the following elements:

- Secure online platform with common variables
- Data managers in each site entered anonymized patient, disease, and treatment data on each patient in each of the 7 SCI participating centers
- Uniform training of data managers
- Real time review and validation of each case by local clinicians and database managers
- Regular meetings of all data managers and database co-chairs
- Each site owns its own data; no site could access any other site’s information
- Approved by each site’s hospital administration, REB, and Ministry of Health as appropriate

Data are available for the period 2011 to 2019, with a total of 665 people diagnosed and with data entered into the database (approximately 75 per year). There is a total of 308 treatment failures documented for this period with various causes of treatment failure, including:

- Relapse/Progressive Disease (41.5%)
- Treatment Related Mortality (38%)
- Refusal or Abandonment (20.1%)

Table 2: Number of children registered in the SCI Database

Cancer type	Number	Proportion of total cases
Leukemia	217	32.7%
ALL	154	23.2%
AML	51	7.7%
Other	12	1.8%
Lymphoma	55	8.3%
HL	23	3.5%
NHL	32	4.8%
Solid Tumor	272	41.0%
Neuroblastoma	48	7.2%
Wilms	59	8.9%
Other	165	24.9%
CNS	119	17.9%

In summary, childhood cancer outcomes in the SCI-participating centers are superior to those in many other parts of the world, but there is still a survival gap compared to high income countries (HICs). The causes of treatment failure are similar to those in other resource-limited settings, but perhaps in different proportions. Outcome data are crucial to inform families, providers, and Ministries, to inform the most important interventions, and to continuously evaluate such interventions.

Civil Society Perspective: The Just Because Foundation

Mr. Noel Joseph, founder of The Just Because Foundation (JBF) presented a very moving civil society perspective on pediatric cancer care and the importance of supportive care for the child and family. The Just Because Foundation, a non-profit organization in Trinidad & Tobago established by the Joseph family who lost their son to cancer, offers support and assistance to families whose children have been diagnosed with cancer. These programs include:

- A Home Away from Home
- The Siblings Club
- Pediatric Specialty Unit
- Transportation
- Onco Dads
- Embrace – Parent Bereavement Support Group
- Intervention/Navigation
- Advocacy



Session 2. Organization and Delivery of Pediatric Cancer Care Services

This session was moderated by Dr. Jonas Gonseth-Garcia, PAHO and included panelists from various countries presenting on their situation and challenges with childhood cancer.

Jamaica

Dr. Sharon McLean-Salmon, from Jamaica noted that care is provided in Bustamante Hospital for Children, the University Hospital of the West Indies (UHWI), and Cornwall Regional Hospital. Universal Health Coverage is available for all children in the government funded hospitals, but at UHWI, payment for service is expected Assistance is provided from CHASE and Compassionate fund through Ministry of Health (set limits per patient). Currently there is no accreditation process for centers providing pediatric oncology care. Nurses rotate due to a severe nurse shortage, nurse to patient ration is 1: 8-10.

There are issues with availability of IHC and trained expertise (pathology), levels for HDMTX. Local hospitals can administer linear accelerator external beam radiation (LINAC) to older children and adults; however, centers are not adequately equipped for young children. On average, there are 10 patients seen daily, 21 average number of admissions per month, 4 outpatients seen per day, and 51 new patients diagnosed annually.

Areas of concern include continuous delivery of drugs especially, second line medication, shortages of IV pumps and central lines/ports, lengthy pathology processing time, periodic shortages of blood products, abandonment of therapy, failure to access clinical trials, lack of psycho-social support and palliative care, lack of a dedicated space, and lack of specialized surgical equipment which hinders ability to perform certain types of surgery.

There is substantial international assistance provided, such as regular case discussions, through SCI and St. Jude. The collaboration with SCI has fostered more accurate diagnosis in some cases as this site lacks IHC. Working with collaborators allows for transparency and quality control and facilitates workforce training.

Barbados

Dr. Cheryl Alexis, from Barbados presented on the National Cancer Control Plan, noting that cancer care is fully funded by the government. The Queen Elizabeth Hospital (QEH) has capacity for 600 beds, including 49 pediatric beds: 28 medical; 17 surgical; and 4 PICU. There are 2 dedicated 'isolation rooms' and 7 outpatient beds shared with adults. On average, 2 inpatients are seen daily with 6 average monthly admissions, 3 average daily outpatients and 10 annual new cases.

There is 1 pediatric hematologist/oncologist, 3 general pediatricians, 3 senior registrars, 5 general pediatric residents, 3 PAHO trained nursing staff, 4 social workers, 2 pharmacists, 1 pediatric surgeon, and 1 radiation oncologist. There are also 4 trained pediatric hematology/oncology nurses, the oncology ratio is 1 nurse per 2 patients, while PICU ratio is 1 nurse per 1.5 patients. Other available medical care includes a facility for cytotoxic preparation, availability of blood products, laboratory investigations, 24-hour access to specialists, and drug access and availability.

Despite the solid infrastructure that exists in Barbados, gaps in care remain. There are obstacles to early diagnosis, delays at primary and surgical levels, delays in pathology reports. Retaining staff is challenging. Psychosocial support as well as palliative care are much needed. There are limited diagnostics in public sector, erratic drug availability and increasing drug costs. Support is needed to establish a childhood cancer program, increasing advocacy within the

region and establishing regional collaboration to set regional healthcare standards and drug procurement, with additional funding being welcomed. Survival rates have improved significantly over the last 2 decades from 34% to 60%. The advantages include having a registry, access to all to free health care, collaboration with SCI, and strong charity support.

Guyana

Dr. Sherilyn Stanton, presented on the situation in Guyana where there is no pediatric oncologist, and no pediatric ICU/ER, and children with leukemia/lymphoma receive treatment by pediatricians, and those with solid tumors receive treatment from medical oncologists. There is one consultant oncologist, 2 registrars, 2 general medical officers, 4 nurses and 1 social worker. Nursing standards require upgrading in areas such as improving nurse to patient ratio, formalized orientation program and evidence-based nursing policies.

Funding for the public health care system is covered through the government. Coverage includes all blood work and procedures (e.g. IV accesses, bone marrow aspirate, lumbar puncture, biopsies, debulking surgeries, echo, ECG, etc.) including referrals/transfers within the public system. Medications, including chemotherapy, are provided for free (government funded) at Georgetown Public Hospital based on availability. There are delays in care as reading of bone marrow aspirates are conducted only once weekly. Blood product availability is limited, and the country is moving toward voluntary donations. Drug availability is also limited.

Peru

Dr. Monika Metzger, from St. Jude's presented in lieu of Dr. Liliana Vásquez on the Peru demonstration project, established in 2019 as the Americas region index country for the Global Initiative for Childhood Cancer. A situation assessment was completed and showed that overall mean diagnosis latency of childhood cancer in Peru is 107 days (more than threefold than developed countries). Sixty nine percent of childhood cancer cases present in advanced stages.

There are geographic, financial and cultural barriers to improve childhood cancer care. Four out of the five main cancer centers are in the capital, Lima. Therefore, people living in remote areas such as the Amazon have difficulty getting to treatment. Peru experiences an 18% of treatment abandonment, which is higher than the rates reported from other countries. This is largely due to low level of parental education, low socioeconomic status, radical surgery, late presentation, and beliefs of cancer as incurable. To address the situation, the Ministry of Health has established work groups with medical and public health personnel to examine and address issues to improve care, in the following areas:

Workgroups

- Early detection
- Abandonment
- Building Capacity
- Education
- Registry
- Nursing
- Psychological
- Infection control and support
- Surgery
- Palliative Care

Clinical Work Groups

- Retinoblastoma
- LGG
- ALL
- HL
- Wilms tumor
- Burkitt lymphoma

Central America

Dr. Monika Metzger, St. Jude's presented on the Central America sub regional project to improve childhood cancer care, which was established with the leading local pediatric oncologists, COMISCA and PAHO in 2019. A rapid situation assessment has been completed in each country and a national pediatric cancer control plan is currently in development in each country of Central America, including Haiti & Dominican Republic.

In addition, standardized protocols for the treatment of childhood cancer and a program for early detection of cancer are being developed as part of this initiative. Continued medical education for health personnel, early integration of childhood cancer curriculum in medical school and general pediatric residence are also areas of work.

Psychosocial support to the patient, family and the community is a vital component of pediatric cancer care. Therefore, educational campaigns are being developed and disseminated widely for early detection of cancer throughout this subregion.

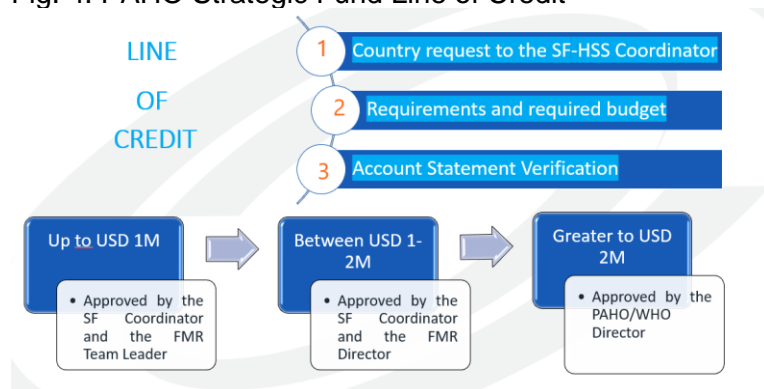
Session 3: Pediatric Cancer Medicines: Access, Availability, Quality and Rationale Use

This session was moderated by Dr. Charlie Preston, PAHO and it began with a presentation on drug availability, need, and access dynamics in the Caribbean, by Dr. Avram Denburg, The Hospital for Sick Children. He reported on a mixed methods study conducted through the SCI to assess issues related to access, availability and cost of essential pediatric medications. A total of 50 key informants from leading hospitals in the Caribbean participated in the study. The main challenges identified were in reliability of drug supply, price volatility, and delays in receiving medications. Price differences were noted between countries, where Jamaica had lower prices compared to Barbados and the Bahamas. Procurement agencies expressed interest in using PAHO's Strategic Fund. However, there are major drawbacks, including the fact that the countries cannot meet minimum order quantity, there are large upfront costs and central warehousing is critical. The study noted the need to improve data collection on drug inventory, use, price, stockouts; and to address the barriers to utilizing the PAHO Strategic Fund for pediatric cancer drugs.

Dr. Charlie Preston, then presented on the opportunities to improve drug access and quality for pediatric medicines. He noted that there is little drug regulatory capacity in this subregion, and that information on pediatric cancer drug availability, cost and quality are limited. He highlighted the Caribbean Regulatory System, which has been established by PAHO and CARPHA as the regional drug regulatory mechanism, and also includes post market surveillance, called VigiCarib as well as a regional drug testing lab, called MQCSD. Through this system >75 essential medicines, including cancer medicines have been qualified and a public list of recommended products is available: <http://carpha.org/What-We-Do/Laboratory-Services-and-Networks/CRS>.

Juliana Vallini, PAHO presented on the PAHO Strategic Fund, as an opportunity to increase access to essential medicines. This is a pooled procurement mechanism for essential drugs that offers Member States one unique price regardless of purchase size, along with reduction of transactional and operating costs, financial support through a line of credit and cross fiscal year allocation, and assured quality of drugs.

Fig. 4: PAHO Strategic Fund Line of Credit



There are various opportunities for the Caribbean to leverage the Strategic Fund including maximizing the use of long-term agreements, implement regional demand planning, consolidating and joint purchasing (where/when possible), exploring new opportunities, and making use of the line of credit.

Session 4: Health Human Resources Strengthening for Pediatric Cancer Care

This session was moderated by Dr. Curt Bodkyn, Trinidad & Tobago and began with an overview of the SCI and the capacity building initiatives. Margaret Manley, The Hospital for Sick Children described how SCI is working to share resources, tools and knowledge to build capacity for care and, through interprofessional education, ultimately improve the quality of care for Caribbean children living with cancer and blood disorders. During SCI Phase I (2013-2017), collaborative working groups were established to focus on areas of importance to the diagnosis, treatment and management of childhood cancers and serious blood disorders. The following selected outcomes, divided into four sectors of activity, demonstrate SCI's success:

Education and Quality Improvement	Case Consultations
<ul style="list-style-type: none"> • 4 Caribbean pediatricians trained in hematology/oncology through Sick KIds Fellowship Training Program, with one fellow about to start his final year and a new fellow starting the fellowship in July • 27 nurses from SCI partner countries completed the SCI-Uwison Pediatric Hematology/Oncology nursing program (PHONEP) at the University of the West Indies School of Nursing in Trinidad and Tobago • 22 lab trainings conducted • SDC patient education toolkit has been created and distributed 	<ul style="list-style-type: none"> • 418 case consultations provided by more than 40 SCI consultants at SickKids • 7 telemedicine facilities completed • 259 Specialized Diagnostic Tests completed for patients diagnosed with leukemia • Immunophenotyping is now available to all children in the SCI partner countries • Community of practice, including the formal formation of a regional hematology/oncology pediatric body

Local Oncology Databases	Research, Policy and Advocacy
<ul style="list-style-type: none"> • 616 patients registered in local oncology databases • 7 local data managers hired and trained across SCI partner countries • 7 custom-build local databases established and maintained in SCI partner hospitals to record and track pediatric patients diagnosed with cancer 	<ul style="list-style-type: none"> • 28 Invited lectures on the work of SCI • Study on availability and access to pediatric cancer drugs will be complete and evidence will be available to support country and regional policy recommendations and change • Enhanced ability of key advocacy groups to work collaboratively and effectively under the guidance of The Just Because Foundation

During Phase II (2018 – 2021), SCI will continue building on the successes of Phase I with a focus on sustainability, this will include elevating clinical care through continued support for case consultations and building a network of physicians in the region to consult on cases; leveraging patient data collected in the local oncology databases to implement quality improvement for life-saving care; continued specialized training for physicians and nurses with targeted education opportunities in pediatric hematology/oncology; and collaborating with government and academic institutions on research to lead to the development of an evidence-based regional strategy for pediatric cancer and blood disorders.

Dr. Corrine Sinqee-Brown, The Bahamas, then presented on the health human resource analysis conducted through SCI, noting that there are only 6 hematologists/oncologists plus one in training in the region, whereas there is a need for 13 oncologists and 5 hematologists to adequately manage the number of children diagnosed each year. SCI has expanded capacity through medical fellowships, nursing education program, facility-based initiatives, continuing education and telemedicine education sessions. A total of 4 physicians have received training formal training at SickKids through medical fellowships, additional fellow will begin training in 2020. To date, there has been a 100% retention rate of physicians in home countries at their onset facilities. A full-time 40 credit competency based, post registration program has been developed for nurses in partnership with the University of the West Indies School of Nursing in Trinidad and Tobago. A total of 38 nurses have been trained through this program, leading to 96% retention in home countries, and 92% of graduates still working at their 'onset' facility. A total of 38% changed clinical areas based on administrative request.

Dr. Ramon Yacab, Belize provided a commentary, noting the challenges in their country with no pediatric oncologists, and patients are sent to Mexico or Guatemala for treatment, subsidized by the government. The future looks brighter as Belize will open an adult oncology clinic soon, a medical oncologist has been hired, nurses and pharmacists trained and capacity is expected to improve for adult cancer care. Access to medications within the country continues to be a major challenge.

Dr. Els Dams, Suriname also provided a commentary on the situation in Suriname which too lacks pediatric oncology capacity and sends their children to Colombia for treatment (previously to The Netherlands). There are abandonment issues due to distance and fear that the children will not come back. There is one pathologist and two pediatric oncology nurses. With regards to diagnostics, there is no flow cytometry, no cytogenetics and no MTX/metanephrines measurement available. In reference to treatment, medicines are available; however, they have limited reimbursement, \$600 a year, and there is no separate pediatric oncology unit.

Session 5: Financing and Quality of Care for Pediatric Cancer

This session was moderated by Dr. Sumit Gupta, The Hospital for Sick Children, who led with a presentation on the cost-effectiveness of childhood cancer care. He noted the lack of data on the cost and cost-effectiveness of delivering childhood cancer care which led to a group of researchers to conduct a cost effectiveness study in El Salvador, Ghana and Mexico. The study results illustrated how highly cost effective childhood cancer treatment is across these settings.

Although this study demonstrated that childhood cancer treatment units were cost effective, cost effectiveness does not necessarily equal affordable. Overall outlays for childhood cancer are small compared to overall health system or even cancer care budgets. It's imperative that financing discussions be undertaken by health care providers, decision makers and related stakeholders regarding funding for childhood cancer care in the Caribbean.

Dr. Jonas Gonseth-Garcia, PAHO presented a tool that measures quality of care in the hospital setting, that has potential to be applied to pediatric cancer care. The tool, called Assessment of Essential Conditions (AEC) in Health Services Quality of Care tool is an on-line platform where health administrators can enter data across several quality domains to identify opportunities for improvement in health care. AEC provides elements to facilitate the analysis of relevance, quality of care, control of results and management agreements. During the presentation, participants learned about how AEC was applied to improve maternal health services, as a case example and to illustrate the potential use for pediatric cancer care.

DAY TWO

Session 6: Strategies to Improve Pediatric Cancer

Moderated by Dr. Betzabe Butron, PAHO she led the session with a presentation on leveraging child health initiatives to improve pediatric cancer care. She noted that the field of pediatrics has evolved over the past few years from individualized care to a more comprehensive and multidisciplinary approach. The focus has shifted from survival to thriving, from having a fragmented approach to having a comprehensive medical approach from pregnancy to adolescence with the first years being fundamental to the healthy development of a child. Long are the days of focusing on the child only. At present, the emphasis is on a child and his/her environment and the reciprocal interaction between the child and his/her parents/caregivers and other community systems surrounding that child. Pediatric medicine used to be curative and preventative. However, more than ever pediatrics is more concerned with the healthy growth and development of every child, including their physical health and socio-emotional health. The focus has also gone from meeting the immediate medical needs of the child to meeting the larger needs of the child and family.

Following the presentation, a group discussion was held to identify strategies to improve pediatric cancer care across the domains of organization and delivery of pediatric cancer care, access to essential medicines, health human resources, and financing

A rich discussion took place including topics such as continued cancer care during disasters, access to high quality medications and conducting a study to test the quality of current medications in use, discharging patients without a socioeconomic safety net, blood bank needs,

addressing the needs of pediatric patients, their families, and communities, and addressing palliative care for pediatric patients including education of health care professionals.

It was suggested that a study would be valuable on essential pediatric medications and to better understand how the products are regulated, their availability and access in this subregion. Palliative care for childhood cancer was also noted as a need to be addressed. Many health care professionals do not feel comfortable administering morphine to children. At times, morphine escalation is needed, and education of healthcare providers is lacking in this area.

Blood banking is a topic that was also noted as needing attention, especially platelet transfusion. In the Bahamas, certain American blood banking related guidelines were adopted, but there is confusion among blood banking specialists and health care providers. It would be helpful to revisit blood banking guidelines and platelet transfusion.

Conversations regarding the topic of staying motivated as a health care professional while serving the needs of children with cancer, their families and communities took place. Participants agreed that childhood cancer does not just affect the child with cancer, but it also impacts the family and the entire community. Therefore, interventions should be geared at all levels.

Session 7: Country and Regional Initiative Planning

Meeting participants worked in small groups, organized by country and by regional level to identify the needs and gaps and possible actions to fill the needs for improving childhood cancer care. For each of the main areas of organization and delivery of pediatric cancer care, access to essential medicines, health human resources, and financing, participants identified the main gaps and opportunities to improve the situation. Break out groups completed initial documents that will serve as the foundation to develop the 2020-2025 Pediatric Cancer Control Plans for each country and for the region. Following is a brief summary on the needs and preliminary plans to address such needs for each of the countries:

Bahamas

Standardized and formalized treatment protocols is a priority, as is training of pharmacists and blood bank technicians. There are issues related to blood banking, especially with regards to donation habits – moving away from on demand to voluntary donation. Moreover, female/male donors for platelet transfusion needs to be addressed and could use WHO guidance. There's an issue with CMD testing. Timeliness of pathology reports and the availability of second opinions need to be strengthened. A site scanner is needed for pathology reviews. The Bahamas plans to draft an MOU to establish a regional network to review pathology cases. A planning and forecasting tool for medications would be extremely helpful to have. Access to a reliable list of approved, and non-compliant, drugs is needed. Porta Cath supplies, needles and catheters are needed. A succession plan for pediatric oncologists is required as current pediatric oncologist hopes to step out/retire in the near future. The Bahamas has 'free health care for children' in theory; however, the country officials need to strategize on how to finance it. Family psychosocial support services also need strengthening.

Barbados

Issues in primary care provider referral delays and pathology delays in diagnosis are two of the main issues being faced. Barbados is collaborating with primary care providers to set a pathway to expedite referrals. There is no pediatric pathologist, there is a pathologist who has gotten

training in pediatrics. Cancer registration is solid, and a data manager is willing to continue working pro bono. Training is needed for flow cytometry and cytogenetics as equipment is available. Barbados plans to engage in conversations with the region and SCI to identify training opportunities for staff. There is no hematologist. Barbados has a national formulary committee that provides a list of drug providers and the ability to tender. The hospital pharmacy also has the flexibility to do its own procurement if the vendors do not have the drugs or if there are special drugs needed. PAHO's Strategic Fund is not working effectively in Barbados. The 60-day line of credit is still a barrier. Healthcare providers will engage in talks with stakeholders and PAHO to find a solution, a potential regional purchasing approach may be the solution. Radiation oncology is an area that needs improvement. Palliative care is on the agenda, currently palliative care is only available in the private sector.

Belize

Belize is making great strides to strengthen its adult oncology health system. Belize does not have a pediatric oncologist in the country and children with a suspicion of cancer are sent to Mexico for care. Training primary care providers and front-line individuals, such as community health workers, for early detection of childhood cancer symptoms is essential for the prompt referral to Mexico. There's only one government funded pathology lab; however, it is rather limited. The national cancer registry only includes public institutions, and it is more than a registry, it also serves as a patient follow up/tracking system. Registry is being revised to include children. Like other countries, there are blood banking issues and most patients bring their own blood. Hospital is opening an adult outpatient chemotherapy unit next month. However, there are no chemotherapy drugs in country. Health Ministry allows patients to purchase their own medications, which becomes an out of pocket expense. Belize plans to explore its options for affordable medications through PAHO's Strategic Fund and COMISCA. Hospital has a low budget; therefore, financing at all levels is a major issue. Collaborations are essential to strengthening Belize's pediatric oncology health system.

Guyana

Cancer patients are referred to Guyana's region 4 for treatment, with referral pathways well established. There are not enough pathologists, which leads to delay in samples being read. There are no standardized treatment protocols in Guyana, which is a major challenge. Guyana is interested in collaborating with SCI and other regional partners to formalize protocols, tailored to its setting. The cancer registry is not current, and it is not electronic. There is no in country specialist for palliative care. Additional palliative training is needed, and would like to collaborate with PAHO, SCI and regional countries to establish a more formalized training. Blood banking, like other regional countries, is based on need rather than voluntary ongoing donation. Access to essential medications is a major challenge as drugs do not arrive on time. The procurement department could act more swiftly to stock the appropriate quantity of drugs needed and monitor expiration dates more closely. The pharmacy needs an electronic system to monitor drugs and provide alerts when certain drugs need to be reordered. When medications are not available, patients must pay out of pocket. Continuous training of oncology nurses is needed as previously trained nurses have been reallocated within the hospital.

Jamaica

Increased training for primary care healthcare providers for early detection of childhood cancer symptoms is needed. A continued problem for Jamaica is the inconsistent supply of reagents for timely diagnosis, especially with IHC. Jamaica plans to lobby for expansion of diagnostic capacity, locally and regionally. There is a gap in treatment based on age limits. Having island-wide protocols would be a great way to establishing standardized care. There is a national cancer registry, which has been collecting data since 2018. There is also a hospital-based

registry through SCI. Continuation of data manager's salary is needed. A pediatric oncology unit is needed with isolation. Jamaica would like to have a centralized system for importing hard to get drugs. There is an adult palliative care service at home; however, there is no palliative care service for children. Palliative training is needed as providers do not feel comfortable with administering escalated amounts of morphine to kids. There is a need for surgical oncologists, pharmacists, psychologists and social workers. There is no chemotherapy hood in the public system. The cancer strategic plan expired in 2018. This is an excellent time to revisit it and include pediatric cancer.

St. Lucia

Like other small countries in the Caribbean, St. Lucia triages pediatric oncology patients out of the country. More specifically, pediatric patients are sent to Martinique. St. Lucia has a role in maintenance treatment – in agreement with SCI's protocols - once they come back from treatment. St. Lucia is interested in developing national guidelines on early childhood cancer diagnosis and a protocol to support families. St. Lucia has 2-4 pediatric cancer cases each year and the Sick Kids database is utilized. There is timely and reliable histopathological diagnosing locally. However, flowcytometry, cytogenetics, and IHC are also sent overseas, which is funded by private groups. Patients are sent to France for induction, an initial cost is covered by the cancer center and the patients' family and the rest is absorbed by the French government. Confirmatory tests are done by Sick Kids. Patients have also been sent to Trinidad and Tobago and at present, there are options to collaborate with Barbados for treatment. St. Lucia will be exploring the possibility of sending pediatric patients to Barbados. A data manager is needed as the SCI trained data manager moved. There is a national cancer registry, which resides at the Ministry of Health. St. Lucia needs a case manager for pediatric cancer care who can manage patient referrals, guidelines, family support, communication, etc. There are no palliative care protocols. Palliative care training is needed, especially for nurses, doctors and for parents. St. Lucia may not need a full pediatric oncologist given the low volume of cases. However, it does need a pediatrician who is willing to undergo pediatric oncology training. Another weakness is the absence of radiotherapy on the island; therefore, Guyana provides some support. There is no proper financing for pediatric cancer care. NGOs provide aid; however, it is unpredictable. An organized and sustainable stream of funding is needed. Increased psychosocial support from local advocacy groups is needed.

St. Vincent & the Grenadines

There is no specific pediatric cancer unit in St. Vincent & the Grenadines. The pediatric oncology is managed by the pediatric team, which consists of three pediatricians, two registrars, two health officers and four interns. There is an adult oncologist who provides support, however she may be relocating soon. There are 2-4 pediatric cases per year, and while some of the cases are treated within St. Vincent & the Grenadines, a few cases are sent to Trinidad and Tobago or Barbados for treatment. Medications are available to a certain extent. There are long waits for medications, and this creates challenges. Continued training of nurses is needed as the nursing heads tend to move trained nurses within the hospital based on need. Treatment is not done at the main hospital, it is conducted at the Diagnostic Center, where two pharmacists mix the chemotherapy drugs. Special accommodations at the hospital are made if patients come from far away to avoid abandonment of treatment. There is no formal palliative care unit. Pediatric cancer care is subsidized. However, families are responsible for travel expenses. The government and certain organizations provide some assistance with additional expenses; however, it is inconsistent. St. Vincent & the Grenadines needs to look for different and more sustainable revenues. National cancer registry needs to be updated. Plans are underway to train a couple of individuals to assist with the cancer registry. Education on cultural issues and treatment is needed for families to dispel myths.

Suriname

There is no pediatric oncologist in Suriname, and most pediatric oncology cases are treated in Colombia. Increased awareness of general physicians about childhood cancer symptoms is needed, causing referral delays. There is only one pathologist in Suriname and limited IHC. Treatment protocols from the Netherlands are available and have been adapted; however, adaptations have been made but these have not been formalized yet. One of the main issues at the moment is the high cost involved in sending kids to Colombia (costing ~ \$100K -175K USD per child). There is no cancer registry yet. Suriname is optimistic to establish a cancer registry with technical support from PAHO and other collaborators. There is no official palliative care unit, training for health care professionals is needed in this area. There is a need to strengthen the psychosocial support for families to decrease abandonment of treatment. Shortage of blood supply is also another issue, leading to lack of platelets. Suriname has an EML in alignment with WHO's EML. Suriname also has a central procurement through its government. There have been some supply issues, but these can be remedied with better planning with regards to estimating needs. Suriname needs a pediatric oncologist. A hematologist is joining the team soon. There is a formal 2-year pediatric oncology nurse training available with a new cohort starting this year. A national insurance system is in place, and most of the Suriname population has medical insurance, but there is a cap for oncology care.

Trinidad & Tobago

In 2017 a National Cancer Control Coordinating Committee (NCCCC) was established with six focal areas including lung, breast, prostate, colorectal, cervical and childhood cancer. Quarterly meetings were progressing well; however, they slowed down in 2019 due to lack of coordination. Pediatric oncology cases are referred for treatment to Eric Williams Medical Sciences Complex, which is financed by the government. There is a pediatric oncologist and another one completing training. TTO uses Sick Kids treatment protocols. The main challenge is how to get the resources to update the protocols and stay current once the SCI initiative comes to an end. A national cancer registry has been in existence since the late 90s and it is currently being reactivated. There is a research nurse who serves as a patient coordinator. Medications could be better coordinated, although, the hospital is good at doing adhoc purchases as needed. Most patients who leave the country go to Sick Kids for treatment, especially for bone marrow transplantation. There is a National Procurement System and most essential medicines are generally available, with a few exceptions due to low volumes needed and are purchased on an adhoc basis. There is a cadre of nurses, having at least one pediatric oncology trained nurse always present during every shift. Pharmacy mixes the chemotherapy. There is a pharmacy school, and pharmacists are trained as clinical pharmacists but do not function as clinical pharmacists. TTO has a dedicated social worker assigned to JBF and would like to recruit a play therapist and a schoolteacher for long stay patients at the ward. There is no pediatric oncologist fellowship, there is a post graduate program in pediatrics. The SCI initiative has been instrumental in providing training opportunities for nurses and physicians.

In addition to the country specific needs, the following region-wide activities were identified from the small group work:

- conduct a comprehensive Caribbean landscape analysis
- collect informational data for patient monitoring and quality of care
- develop standardized treatment guidelines
- conduct a drug quality study
- address blood bank needs
- develop a region-wide and multi-level advocacy and communication campaign
- develop a civil society network in the Caribbean for patient and family support initiatives

CONCLUSIONS

The meeting identified priority areas of action as earlier detection and diagnosis of childhood cancer in primary care, with timely referral for specialized treatment; increased access to essential medicines for childhood cancer; training and continuing multi-disciplinary medical education for specialists and primary care providers; improved continuity of care, including for children who live far from treatment centers to prevent abandonment of treatment; and the production and sharing of evidence for public health use to mobility political and financial support.

Moving forward will require strong political leadership and commitment from multiple partners. All participants considered critical the role of WHO/PAHO, SCI, and St. Jude's in providing the tools, guidance and technical support needed to assist countries in effectively developing and implementing their National Pediatric Cancer Plans to reach higher survival rates for children in the Caribbean. Next steps following this meeting is for each of the countries to complete their respective national pediatric cancer plans and implement priorities, and for PAHO to lead the implementation of the region-wide activities.

