“The SickKids-Caribbean Initiative provides a beacon of hope for improving care for children within the Caribbean region, through skills twinning with SickKids and the use of innovative technologies”.

Dr. Curt Bodkyn
Paediatric Oncologist and Lecturer in Child Health
University of the West Indies,
Trinidad and Tobago
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SCI Executive Summary

Improving Outcomes Together

SickKids-Caribbean Initiative (SCI) is a not-for-profit collaboration between the Hospital for Sick Children (SickKids), Toronto, Canada, and seven Caribbean institutions across six countries that strive to improve the outcomes and quality of life for children with cancer and blood disorders. The Initiative establishes partnerships between health-care specialists, building upon strong and ongoing collaborations and through training and education to support the early identification and treatment of children living with these devastating diseases in the Caribbean. The partners will work together to develop a comprehensive strategy to strengthen the diagnosis and treatment of children with cancer and blood disorders in the Caribbean.

SickKids Foundation is providing funding of $8,000,000 CDN through private donors and corporations. The estimated budget will be leveraged over the course of five years, to support program implementation for activities including telemedicine equipment enhancements, training and education, and the establishment of regularly occurring Case Consultation Review Rounds.

In the inaugural operational year, SCI has achieved many significant milestones and established a solid foundation upon which to build. It will be important to maintain this momentum in the coming years and we are confident that by working together we can achieve our collective goal: to enhance capacity for care and improve the outcomes and quality of life for children living with cancer and blood disorders in the Caribbean.

SCI Partners and Stakeholders

SickKids is working in partnership with the University of the West Indies (UWI), Ministries of Health and key hospitals from six participating Caribbean countries: Jamaica; Barbados; The Bahamas; Trinidad and Tobago; St. Vincent and the Grenadines; and St. Lucia.

University Hospital of the West Indies
Bustamante Hospital for Children
Queen Elizabeth Hospital
Princess Margaret Hospital
JAMAICA
BARBADOS
THE BAHAMAS

Eric Williams Medical Sciences
Milton Cato Memorial Hospital
Victoria Hospital
TRINIDAD & TOBAGO
ST. VINCENT & THE GRENADINES
ST. LUCIA

SCI Areas of Focus

1. Diagnostic Services
2. Clinical Care
3. Local Oncology Databases
4. Nursing
5. Sickle Cell Disease
6. Research and Evaluation
SCI Objectives

The goal of SCI is to build capacity among paediatric primary care providers and allied health-care professionals through:

1. Improving the clinical management and treatment of paediatric cancer and blood disorders.
2. Providing opportunities for training and education in the areas of nursing, pharmacy, diagnostic services, pathology and clinical care.
3. Establishing best practices and improving health outcomes through the development of local hospital-based oncology databases.
4. Establishing an integrated and sustainable communication structure for bidirectional education amongst local partners.

SCI Impact

- SCI will enable improved local access to services for children in the Caribbean with cancer and blood disorders.
- SCI will help to build long-term and sustainable capacity for Caribbean partners; from diagnosis to follow-up care.
- SCI supports SickKids’ vision of Healthier Children. A Better World.™ through knowledge transfer and exchange with partners.

SCI Timeline
**Areas of Focus**

Six areas of focus have been established as opportunities for SCI to improve clinical practice and patient care. These six areas of focus were identified through an initial needs assessment, supported by evidence and comprehensive consultation. Through collaboration within and across each of these focus areas, and the establishment of cross-partner working groups, SCI sets out to enhance international collaboration with SickKids and also strengthen cooperation within and between participating local institutions. Together the SCI partners seek to enhance capacity for care and improve the outcomes and quality of life for children living with cancer and blood disorders in the Caribbean.

**Diagnostic Services**

An accurate and timely diagnosis is the foundation for all subsequent patient management, but can prove challenging in low and middle income country settings, due to access, availability and quality of pathology services and limited diagnostic capabilities. SCI sets out to build the capacity for diagnostic services in participating countries across the region. By focusing on leveraging and enhancing existing local services, SCI enables a sustainable model for the timely and effective diagnosis and management of childhood cancers and serious blood disorders.

**Clinical Care**

Clinical care providers in the Caribbean are currently faced with challenges to effectively managing paediatric patients. A clinical care working group has been established in order to develop locally adapted treatment protocols and ensure best practices across the region. Monthly Case Consultation Review Rounds centred on interprofessional education delivered through telemedicine technology were launched in September 2013. These sessions provide a forum for clinical collaboration, knowledge exchange and real-time discourse on locally-appropriate treatment recommendations. Telemedicine uses live interactive videoconferencing technology to facilitate consultations and connect health-care professionals from across the Caribbean and from SickKids.

**Local Oncology Databases**

The initial needs assessment and further consultation identified the need to capture an accurate picture of the paediatric oncology patients presenting at participating treatment centres. The collection and validation of data on the demographics, disease characteristics and treatment outcomes, can inform the design of future interventions. SCI is establishing local hospital-based oncology databases for ongoing prospective data collection, allowing for the evaluation of implemented changes in therapy or supportive care. This treatment and outcome data from participating institutions will help to improve the clinical management of children in participating countries who are diagnosed with cancer.

**Nursing**

Interprofessional health-care teams have complementary roles in caring for children with cancer and blood disorders. Nurses have a critical role in these teams, often managing the delivery of patient care and in many cases leading implementation of best practices and protocols. Through engaging nurses SCI strives to increase the recognition of their integral role in the care of children. By focusing on interprofessional collaboration and family-centred care, SCI works together to advance paediatric nursing practice, build local nursing capacity through continuing education and ultimately achieve positive outcomes for children and their families.

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**Sickle Cell Disease**

Sickle cell disease is an hereditary blood disorder due to an abnormal haemoglobin - the protein that carries oxygen to cells. Recent years have seen significant management advances in high-income countries, effectively reducing mortality rates.\(^2\) Through training and cooperation, SCI is working collectively to improve the capacity for diagnosis and clinical care of children with this blood disorder in the Caribbean. The goal of the sickle cell disease working group is to enhance capacity at comprehensive care centres at which positively diagnosed patients will receive appropriate treatment. SCI will also work to build diagnostic competencies within designated laboratories and enable the effective and sustainable development of universal newborn screening programs.

**Research and Evaluation**

By including a focus in the areas of research and evaluation SCI will investigate the impact of paediatric cancer and blood disorders within the region. Capturing relevant baseline data will enable the evaluation of short, medium and long-term outcomes of the SickKids-Caribbean Initiative - to ensure SCI is reaching our collective goal to improve outcomes and care for children with cancer and blood disorders. Through the collection of key data SCI will be better equipped to define the risk of specific disorders within each country. The evidence collected will inform the development and implementation of interventional studies aimed at improving the delivery of care and outcomes for children.

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SCI Summary of Achievements

Funding Achievements

With the support of our generous donors, SCI has reached $7 million of its $8 million fundraising goal. Donations have been made from individuals, corporations, foundations, and events held in Canada and across the Caribbean.

Operational Achievements

Telemedicine Sites Launch in The Bahamas and Barbados

To mark the celebrations of The Bahamas 40th Anniversary of Independence, the BTC Telemedicine Room official opening took place July 15, 2013 at the Princess Margaret Hospital, The Bahamas, with the support of The Bahamas Telecommunications Company and the University of the West Indies (UWI). The telemedicine set-up and training was facilitated by the team from UWI Telehealth, Trinidad and Tobago – the telemedicine hub for the SickKids-Caribbean Initiative.

In November 2013 the Shaw Family Telemedicine Room, located at the UWI Cave Hill Campus, Barbados, supported by SCI Telemedicine Partner, Scotiabank, and the Leslois Shaw Foundation, officially opened. The Hon. John Boyce MP, Minister of Health, Government of Barbados, gave the feature address and the event was well attended by senior leadership from across SCI partner institutions, academic leaders, the media and key funding partners.

Three telemedicine site builds are scheduled in 2014 for: Victoria Hospital, St. Lucia; Milton Cato Memorial Hospital, St. Vincent and the Grenadines; and Bustamante Hospital for Children, Jamaica. An upgrade to existing telemedicine equipment is also scheduled for the Eric Williams Science Complex, Trinidad.

The official opening of the Shaw Family Telemedicine Room, Barbados, November 2013.
**Legal and Funding Sub-Agreements**

A master agreement covering the flow of funds was signed in June 2013, allowing project funds to flow from The Hospital for Sick Children (SickKids) to UWI, Jamaica; a Canada Revenue Agency qualified donee. Sub-agreements for the flow of funds from UWI to participating hospitals and health-care institutions have now been completed with The Bahamas, Barbados, Trinidad and Tobago and UWI, Jamaica, with further sub-agreements with St. Lucia, St. Vincent and the Grenadines and Bustamante Children’s Hospital, Jamaica, due to be ratified in the coming weeks.

Telemedicine Memorandums of Understanding (MoUs) have now been completed for The Bahamas, Barbados, Jamaica, St. Lucia and St. Vincent and the Grenadines, with a further MoU with Trinidad and Tobago, due to be ratified in the coming weeks.

**Establishing the Case Consultation Review Rounds**

Case Consultation Review Rounds launched in September 2013, centred on multidisciplinary clinical education delivered through telemedicine technology and providing a forum for clinical collaboration, knowledge sharing and treatment recommendations. As of April 2014, six Case Consultation Review Rounds sessions have been held, with two additional ad hoc consultations, reviewing a broad range of cases from five referring countries across the region. Eight supplementary Educational Rounds sessions were also led by the teams at SickKids. The educational and consultation review rounds series have been well attended, with participation from all partner institutions, and representation from across disciplines, including: Haematology/Oncology and Stem Cell Transplantation; Laboratory and Diagnostic Services; Radiation Therapy; Surgery and Support Services.

SCI has further partnered with the University of the West Indies Distance Education Centre (UWIDEC), co-presenting a series of educational lectures and case review rounds in the 2012/2013 and 2013/2014 academic years.

**Establishing the Focus Area Working Groups**

Six cross-partner working groups have been established, covering each thematic area of focus, in order to develop and lead implementation strategies, deliver on the objectives of the six identified focus areas, and establish and track relevant indicators to measure progress.
The Year Ahead – 2014 Goals

Diagnostic Services
- Conduct assessments to determine diagnostic support and training requirements.
- Assess capacity gaps and support immunophenotyping across sites.
- Build capacity within pathology and improved communication amongst pathologists.
- Develop an educational training video for laboratory technicians.
- Provide training, coordination, quality management and resource support where needed.

Clinical Care
- Telemedicine infrastructure is in place to conduct and facilitate Case Consultation Review Rounds.
- Capacity building through education via monthly series of Case Consultation Review Rounds.
- Develop best-practice standard of care protocols, in the areas of: supportive care; infection control; pain; blood products; and chemotherapy, among others, to support the management of leukemia; lymphoma, renal tumors; brain tumors; and sickle cell disease diagnosis.

Local Oncology Databases
- Establish local hospital-based oncology databases to collect data to inform evaluations; and to guide clinical management within the sites.
- Database architecture, parameters and user access specifications in place.
- Hire local data managers, where applicable, and begin data collection.
- Establish benchmark with regards to prevalence, survival rate and treatment outcomes for the participating sites.

Nursing
- Assess and identify requirements across the seven sites in order to determine tailored training, and nursing leadership priorities.
- Establish and foster a community of practice for nursing, leveraging telemedicine to connect nurses from across the region and provide a platform for education, knowledge sharing and increased collaboration.
- Develop a nursing educational curriculum, with a focus on paediatric oncology and blood disorders, in collaboration with SickKids and regional partners.
- Create patient education materials, in collaboration with SickKids.
Sickle Cell Disease

- Assess and identify requirements and current gaps in comprehensive care programming, advocacy and education across the seven sites.
- Build diagnostic competencies in designated laboratories - develop and undertake a pilot diagnostics screening program, with the Tropical Medicine Research Institute, University of the West Indies, Kingston, Jamaica, established as the North East regional hub.
- Undertake laboratory and equipment enhancement for the Tropical Medicine Research Institute as diagnostic hub for the North East region.

Research and Evaluation

- Put in place a regional Oncology and Blood Disorders Study Group to foster collaboration and to provide guidance in the areas of research and evaluation.
- Establish success indicators and baseline data to inform the assessment of short, medium and long-term outcomes of the Initiative.
- Capture relevant data, in conjunction with the local oncology databases established, to help further define the risk of specific disorders in each participating country.
“The SickKids-Caribbean Initiative is an important endeavour in pooling resources and working together to improve the quality of care in cancer and blood diseases for children in our region”.

Dr. Corinne Sin Quee  
Paediatric Haematologist-Oncologist and Lecturer in Child Health  
University of the West Indies, The Bahamas
Contact Us:
Paul Mihelcic, Senior Project Manager, SickKids-Caribbean Initiative
Email: paul.mihelcic@sickkids.ca
Phone: +1-416-813-7654 x 228922
Web: www.sickkids.ca/globalchildhealth/capacity-building/Caribbean-SickKids/Caribbean-SickKids.html
Twitter: @SickKidsGlobal