

BOTSWANA-BAYLOR CHILDREN'S CLINICAL CENTRE OF EXCELLENCE

ANNUAL REPORT







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A future where all children are living longer and healthier lives.

To provide high-quality, comprehensive, family-centred health care, education, and clinical research.

Letter from the EXECUTIVE DIRECTOR



Dear Botswana-Baylor Friends,

This is my second 'Letter from the Executive Director'. It has been a privilege and honour to serve with such a group of passionate and hard-working people. Every year has its ups and downs but I am happy to report that we are ending this one on a high note. Here are a few highlights:

1. Government Support

The government of the Republic of Botswana, through the Ministry of Health and Wellness, continues to be our most important partner. We are pleased to announce that we received more resources to tackle paediatric cancer and blood disorders through a grant subvention we received recently. This grant will allow us to offer unparalleled paediatric care in Botswana while training different cadres of staff and engaging the community. The government continues to fund the infectious disease clinic, training, and capacity building for HIV with the necessary mentoring.

2. High-Level Site Visits

This year was filled with many site visits by dignitaries from several countries who we hope will become our advocates and further spread our message of and triumph over adversity. Some who passed by our clinics are:

- President Mokgweetsi Masisi paid Baylor College of Medicine and Texas Children's Hospital a visit. He was accompanied by his wife and daughter
- The First Ladies of Botswana and Germany visited the centre
- The First Ladies of Botswana and Rwanda paid a visit to the centre
- The President of Rutgers University, Dr. Robert L. Barchi, visited the centre
- The Ambassador of Germany to Botswana paid a courtesy call

3. Contribution to Science

We published one study that we believe will change how we do things:

• Revealing a safer sex option to reduce HIV risk: a cluster-randomized trial in Botswana that reveals the issues facing young women in Botswana and offers a potential solution

4. Changes in Governance Structure

Our Board of Trustees is in the process of being fully indigenised, with Baylor College of Medicine and Texas Children's Hospital now taking more of a technical assistance role.

On behalf of the Board of Trustees, Botswana-Baylor Management and staff, I would once again like to take this opportunity to thank you for your unwavering support. Without you, we would not be celebrating these successes.

Pula!

Mogomotsi Matshaba Executive Director PAGE | 03



Botswana-Baylor Children's Clinical Centre of Excellence (Botswana-Baylor) is a national general care and treatment facility that provides services in Gaborone, Botswana. We serve children, adolescents, and young adults and their families from around the country. Our services include treatment for HIV and associated infections and now extend to oncology care and treatment for patients nationally. In addition, we act as a major research hub contributing valuable information to the international HIV and oncology communities. Botswana-Baylor is a public-private partnership between the government of Botswana and Baylor College of Medicine's Baylor International Paediatric AIDS Initiative, which was launched in June 2003. Botswana-Baylor is registered under the laws of Botswana as a Trust. It is located on the campus of the Princess Marina Hospital, the largest tertiary care referral hospital in Botswana.

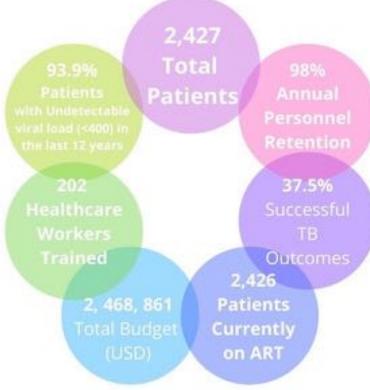
Botswana-Baylor provides free-of-charge, state-of-the-art paediatric HIV, oncology, and blood disorder care, treatment, and support to children, adolescents, and their families at the main clinic in Gaborone and through decentralised outreach services across the country. Botswana-Baylor is a leader in the field of paediatric HIV and cancer care in Botswana, the Southern Africa region and beyond.

The Global HOPE (Haematology-Oncology Paediatric Excellence) initiative, a partnership between several institutions, including the Texas Children's Cancer and Haematology Centre and the Botswana-Baylor Children's Centre of Excellence Trust, has improved the care of children with cancer and blood disorders in Botswana since 2007. The Paediatric Haematology Oncology (PHO) programme is located at Princess Marina Hospital, offering comprehensive PHO services. In June 2016, the Botswana Ministry of Health and Wellness formalised its partnership with Texas Children's Hospital to construct the Botswana Children's Cancer and Haematology Centre of Excellence. Texas Children's Hospital and the government of Botswana will cooperate on scientific, technical, and medical initiatives to dramatically improve paediatric cancer and haematology care throughout the country. Plans are underway to build the PHO COE adjacent to Sir Ketumile Masire Teaching Hospital at the University of Botswana. Because the construction is expected to take over three years, haematology and oncology services will be relocated to Sir Ketumile Masire Teaching Hospital during 2020. These services are currently provided at Princess Marina Hospital Paediatric Ward.



Malwelwe Village Chief Kgosi Bokau (centre, in the black jacket) dances with his fellow dance troupe members at the end of the World Haemophilia Day Outreach event.

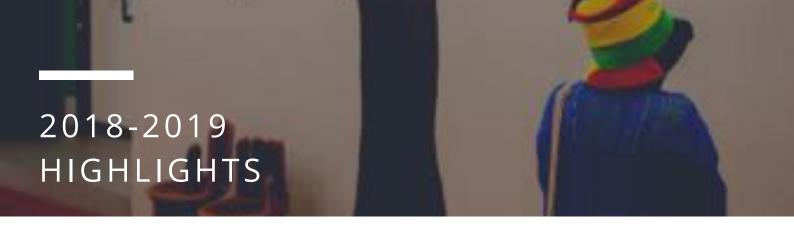
WHERE WE ARE TODAY



Botswana-Baylor Children's Clinical Centre of Excellence 2018-2019 Staff Overview		
Doctors	10	5 HIV and 5 Oncology
Nurses	10	9 COE and 1 PMH
Social Worker	1	
Clinical Psychologist	1	
Lab Technician	1	
Other Staff	62	Project Staff: 45 Finance, Administration and Others: 27
Long Term Volunteers and Interns	4	
Total Staff	90	

Key Programmes

- Paediatric Infectious Diseases Clinic (PIDC)
- Botswana Paediatric
 Haematology and Oncology
 Programme
- Paediatric KITSO Training
- Outreach Mentorship Programme
- Visiting Scholars Programme
- Advancing Partners and Community (APC) Project
- Collaborative African Genomics Network (CAfGEN)
- Public Health Evaluation (PHE)Ba Nana Study
- Adolescent Programmes
- Botswana Comprehensive Care and Support for Orphans and Vulnerable Children Project



President Masisi's Visit to Texas Children's Hospital and Baylor College of Medicine

His Excellency, President of the Republic of Botswana Mokgweetsi Masisi, together with senior government officials, visited Texas Children's Hospital and Baylor College of Medicine in Houston, Texas on September 21, 2018. The purpose of this visit was threefold: 1. For HE to appreciate the level of care and service envisioned in the Botswana Paediatric Oncology Project; 2. To meet with the Houston-based leadership and business community to help fundraise for this regional project; and 3. To look at potential areas where the Ministry of Health and Wellness may need support. HE was met by TCH senior leadership led by TCH President and CEO Mark Wallace, BIPAI President Dr. Mark Kline, Global Hope Director Dr. David Poplack, BIPAI COO Mike Mizwa, Botswana-Baylor Executive Director Dr. Mogomotsi Matshaba, and their teams. They toured the outpatient clinic tower and TCH facilities. They also visited the new, state-of-the-art Legacy Tower. HE Mrs. Masisi and the first daughter, Atsile, visited with the children admitted for cancer care and participated in an art therapy session.

Impact Evaluation of an Intervention Package for Adolescents Living with HIV in Botswana

In January 2018, Botswana-Baylor and UNICEF signed a contract to conduct an impact evaluation of an intervention package for adolescents living with HIV (ALHIV) in Botswana. The research is a partnership between the Ministry of Health and Wellness (MoHW)/District Health Management Teams (DHMTs), Botswana-Baylor, UNICEF and NGOs and Community-Based Organisations. The mixed methods evaluation will measure the effectiveness of a multi-pronged intervention package on clinical, psychosocial, and behavioural outcomes of a cohort of ALHIV on ART (10-24 years old) living in four DHMTs in Botswana (Selibe-Phikwe, Boteti, Tutume, Serowe and Kweneng East) for a 24-month follow-up period. Both quantitative and qualitative evidence will be collected to evaluate the intervention package. Botswana-Baylor and MoHW will design and implement the interventions. UNICEF will provide the funding and hire a consultant to conduct the evaluation and budgeting.



President Masisi at TCH

International Visits

On May 28, 2019, United States Congressman and Chairman of the Foreign Affairs Committee Ed Royce, United States Ambassador to Botswana Earl Miller, and several other distinguished guests visited the Botswana-Baylor and Global HOPE Botswana programmes. The group discussed topics related to diagnosing and treating Botswana children with HIV, cancer, and blood disorders and the key role of international partnerships.

2018-2019 HIGHLIGHTS

Global HOPE

Global HOPE — Haematology-Oncology Paediatric Excellence — is an initiative to address the lack of diagnosis, treatment, and care in paediatric cancer and blood disorders in southern and east Africa.

Lion's Club

The Global HOPE Botswana programme continued to strengthen the relationship with the Lion's Clubs across the country. This was realised through collaborating on various community activities and the multi-district Health Care Worker outreach training on awareness of paediatric cancer and blood disorders. This collaboration will go a long way in establishing and harnessing areas for potential partnership, both locally and regionally.

September - Childhood Cancer Awareness Month

As part of commemorating Childhood Cancer Awareness Month, we hosted this year's Childhood Cancer Survivor party on September 14 at Northside Primary School. The survivor party is among our most important annual events as we celebrate the lives of our brave survivors together with their families. It is a wonderful chance for some survivors to reconnect after having undergone treatment together and to meet new patients and families with shared experiences. Fifty-one survivors attended, each with at least one family member, marking the highest number of attendees to date! There were many activities, including art, a bounce castle, nail and face painting, sports, piñatas, and cupcake decorating.

Collaboration

The CAfGEN study is a member of the Human Heredity and Health in Africa (H3Africa) group, a collaboration of African scientists conducting genetic and genomic studies. As part of this consortium, there are several Working Groups, such as a Steering Committee to which Dr. Mogomotsi Matshaba, the Executive Director of Botswana-Baylor and Lead Principal Investigator of CAfGEN, has been elected to be the Co-Chair.



Representatives from BIHL and the PHO who attended the hand-over ceremony

International Childhood Cancer Day

In February 2019, our Global HOPE Botswana team hosted a day of games, art, and sports for children and adolescents who are either currently receiving treatment for cancer or have received therapy in the past. Patients attended, accompanied by siblings, parents, and grandparents, to enjoy a bounce castle, hula hoops, football, badminton, painting/drawing, face painting, and of course, food! Highlights of the day included a hula hoop contest between two of our staff doctors and several mothers and aunts, seeing several young patients use a badminton racket for the first time, and seeing several patients with recent bouts of illness now feeling well enough to run and play. We anticipate seeing this event continue to grow each year!

PROGRAMMES

Paediatric Infectious Disease Clinic (PIDC)

PIDC continues to provide unsurpassed care and treatment to our clientele thanks to our loyal and dedicated staff. The staff assists in mentoring visiting scholars, nurse prescribers while on training, and other cadres such as social workers, psychologists, and nutritionists. We average 90 patients daily including patients who come for medication refills.

Achievements

- Improved communication with adolescents, making it easier for them to open up to staff about their problems and challenges
- Tracked LTFU through home visits by the Inreach team
- Low mortality rates
- Reduced hospitalisations
- Challenge patients now achieving viral suppression rates

Challenges

- Adolescents' poor adherence to their medications
- Pregnancies among adolescents and young adults
- Patients who are refusing to come to the clinic
- Poor family support for adolescents and young adults
- Patients in need of transportation money
- Child neglect cases
- Depression and suicidal ideation

Total Rapid Test Done

VOE	NEGATIVE	POSITIVE	BTARTED ON MAART	TO LOCAL IDCC	TOTAL
ears	,	1	1	0	1
-13 -13	1	4	4	0	5
4-19 vara	2	5	3	9	7
0 and bove	4	8	3	1	10
OTAL	14	16			30

Negative: 66 Positive: 33



ARV regiment

DNA PCR- An HIV Test for Infants

BABIES TESTED (Post weaning): 3
BABIES WITH HIV NEGATIVE RESULTS: 3
BABIES WITH HIV POSITIVE RESULTS: 0
STARTED ON HAART: 0

Total HIV Tests Done

Total number of infants tested for DNA HIV from 1st July 2018 to 30st June 2019	33
Total number of infants tested HIV negative	31
Total number of infants tested HIV positive	2
Total number of infants already on HAART	2
Total number of infants tested but results still pending	0

Nurse Practitioners

The nurse prescribers have been the backbone of the clinic particularly since the departure of some doctors and considering that the remaining few have been very involved in other projects. The clinic currently has eight nurses trained in the provision of paediatric HIV/AIDS screening, care and treatment who see more than half of our stable patients. Nurse prescribers are also involved in other projects such as Outreach, Inreach, and PCI Caregivers classes as well as various research projects. They give health talks at schools, government ministries, and during boot camps.

Cervical Cancer Screening

Cervical screening makes it possible to find and treat early stage cervical cancer. Botswana-Baylor began the screening programme in November 2016, targeting sexually active young women and girls older than 15 years. Cervical cancer screening was integrated into routine clinical services offered at the Botswana-Baylor clinic. When the programme started, the Botswana national cervical cancer screening guidelines recommended screening only for women aged 30-49 years, but now after screening and reviewing results from different sites the national guidelines have been reduced to 25 years of age.

From July 2018 to June 2019, we screened 60 patients using Pap smear and Visual Inspection with Acetic Acid methods. Of these, seven were positive for human papilloma virus, a cause of cervical cancer. In addition, there were those diagnosed and treated for sexually transmitted infections, including genital warts and candida. Future plans are to screen all sexually active girls and young women for the timely identification and prevention of cervical cancer.

TB Report: July 2018 – June 2019

TB Report: July 2018 - June 2019		
Total Number of Patients Diagnosed with TB	16	
Total Number of Patients Who completed ATT	13	
Total Number of Patients on ATT	5	
Total Number of Patients who Died while on ATT	9	
Total Number of Patients with resistance	1	
Total Number of Patients Admitted	0	

Cervical Cancer Data

<00ym	>30yrs	
VIA - Negative = 32	VIA Negative = 7	
VIA-Positive =4	VIA-Positive 1	
	Defened 1	
PapSmear 6	Pap Smear 9	
Negative- 1	Negative- 7	
Ascus - 1	Ascus = 1	
ASC-H- 1	HSIL- 1	
LSIL - 2	Pending 0	
HSIL 0	5550	
Pending - 1	Control Version Control	
Genital Warts: 5	Genital Warts: 2	
PID: 1	PID: 0	
Candida: 3	Candida: 2	
PV Discharge (STI)	PV Discharge (STI): 1	



Baylor Staff At Work

PAEDIATRIC HIV/TB

Total number of patients diagnosed with TB: 16
Total number of patients who completed ATT: 13
Total number of patients on ATT: 3
Total number of patients who died while on ATT: 0
Total number of patients with resistance: 1
Total number of patients admitted: 0
Pulmonary TB: 16

Clinical Psychology

The year ending June 2019 came with another exciting new development for the Psychology department. We implemented our quality improvement initiative, the mental health screening programme, in December 2018 after we realised there was a high prevalence of mental health problems among HIV positive adolescents. Through daily mental health screenings, the clinical psychology department manages an average of five cases with suicide ideation, delusions, depression, anxiety, and substance abuse. Adolescents aged 13 to 24 years are offered to repeat the screening at regular quarterly visits to the clinic. Patients are also made aware that they have an option to use either the Setswana or English version of screening questionnaires for depression (PHQ-9), anxiety (GAD7), substance use (RAB and Audit), and general psychological disease (SSQ) on a pre-loaded tablet computer. Those flagged for severe results are immediately send to the clinical psychologist either as an emergency or an urgent case.

The following procedure indicates management of the cases:

Psychological emergency as indicated above means that a client is showing signs of psychosis or indicates suicidal ideation, thus answering yes to one or both of these questions:

- 1. I have thought about killing myself
- 2. I see or hear things others don't see or hear

Psychological urgency is defined as the scores below without the red flags:

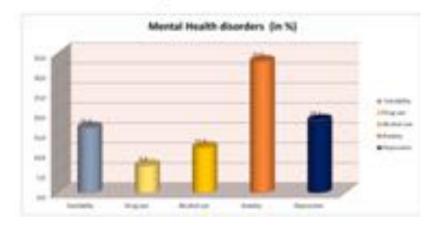
- 1. Scoring above 20 on the PHQ9
- 2. Scoring above 15 on the GAD7
- 3. Scoring above 12 on the SSQ
- 4. Scoring above 20 on Audit If mild to moderate score other members of the psychosocial team.

Outreach Mentorship Programme

The Botswana-Baylor Outreach programme aims to improve the capacity of peripheral hospitals and clinics across Botswana to optimise treatment and care services for HIV-infected children, adolescents, and young adults through mentorship of healthcare providers. The Botswana-Baylor team, composed of a nurse prescriber and physician, visits the outreach sites once per month. During the visits, the team consults and supports patients with virological failure; attends to other patients who require specialist care in the IDCC and on wards; and conducts side-by-side mentoring of medical officers, nurse prescribers, nurses, socialworkers, and other professionals. In addition, they provide didactic sessions that are structured around the fundamentals of paediatric and adolescent HIV treatment and care.

A total of 1,513 patient consultations were completed at 17 ART sites. Of these, 674 were for failing patients and 839 not failing. A total of 182 healthcare workers were mentored, including nurses, doctors, social workers, pharmacists, and other professionals.

The results for the first quarter of Mental Health Screening



Family Weekend Camp

We marked another landmark year in the partnership between Botswana-Baylor and SeriousFun, the youth camp network founded by Paul Newman for kids with medical conditions. During the weekend of 13-15 July 2018, we implemented the second family weekend camp, jointly planning, funding, and conducting the event alongside SeriousFun. The camp hosted 29 Botswana-Baylor patients with their 29 primary caregivers. The camp took place at Oasis Motel, which is situated almost 2 kilometres from the centre of Gaborone. The weekend camp afforded our campers who had adherence, disclosure, low self-esteem and other psycho-social challenges to reflect on them, share them with their caregivers in a safe environment, and learn new life skills. The caregivers had the opportunity to interact with and form friendships with other caregivers and have open discussion of ideas and opinions on how to care for children with chronic illness. The caregivers had the opportunity to also understand their children's experiences and challenges and work to help solve them during camp.



Crafts made by young Baylor patients at Camp

Social Work

The social work department continues to provide counselling, care and support services to Botswana-Baylor patients and their families. Supportive counselling and adherence counselling continue to be the main services provided by the social worker, Ms. Tapiwa Tembwe. Supportive counselling involves mostly follow-up of patients at their homes and the provision of family based social support services. Over the reporting period, Ms. Tembwe, with the support of a trained intern, multitasked in different spheres of work, including assisting clients referred through the APC and PCI projects and also acting as the director of the Family Weekend and Annual Camp Hope 2018. Other services that Ms. Tembwe provided included conducting counselling sessions, home visits, caregiver trainings, and coordinating the annual children's Christmas Party. The social work office also liaises with relevant community-based stakeholders to identify and refer families with atrisk children for HIV testing and enrolment in care. Ms. Tembwe also collaborated with relevant community-based stakeholders (social workers, clinics, police, and social services) to address the needs of children and families living in difficult circumstances and also engage all family members, including children, in adherence counselling sessions at home. She participated in training activities, such as training for other stakeholders and APC parents/caregiver trainings around Gaborone and other districts. Donations from the community to our patients include toys, clothes, and toiletries. Since June 2019, Ms. Tembwe also attends to patients referred from the Botswana-Baylor Mental Health screening study (known as the Friendship Bench).

Botswana Comprehensive Care and Support for Orphan and Vulnerable Children (OVC) Project

Botswana has a growing population of orphans, estimated at 6.28% of its entire population, according to the 2011 National Population Census. Children who are categorised as vulnerable in Botswana include those who are orphaned, living in abusive environments, living with a sick parent or guardian, living with HIV, living with a disability, or living outside of family care. These cumulative risk factors may result in illness; withdrawal from services, including schooling and health care; emotional distress; trauma; abuse; neglect; and exploitation. Other challenges facing orphans and vulnerable children with HIV infection include adherence to medication and a lack of emotional support.

The Botswana Comprehensive Care and Support project is implemented by various partners in seven PEPFAR priority districts (Kweneng East, Gaborone, South East, Mahalapye, Kgatleng, Southern, and Kanye) with the health PCI organisation serving the main as implementer. The project aims to improve the health, wellbeing, and safety of these children and their families through direct service delivery, referral and networking, and through capacity building for OVC service providers. Botswana-Baylor's role in this project is to provide care and support services to OVC living with HIV, from birth to 17 years old, and to their families.

Thirty community health workers travel to these children's homes to deliver a range of services that support them in almost every aspect of their lives. They link them to HIV and social protection programmes and provide counselling and psychosocial support. They asses the children's nutrition and help parents learn effective communication skills. The health workers even monitor their school attendance and progress, while preparing them for the workforce with vocational training support and referral. Each client receives a home visit every three months.

We have identified common challenges in all of the districts where the project is implemented. These include children without birth certificates, low rates of referral completion, and parents unable to supervise their children's adherence to medication. In order to address these challenges, Botswana-Baylor continually crafts quality improvement initiatives.



Gifts on display at the Children's Christmas Party



Adolescent Programmes

Teen Club

Teen Club is a monthly peer support group established in 2005 for HIV-positive adolescents who are between 13-19 years old. Teen Club empowers youths to build positive relationships, improve their self-esteem, and acquire life skills through peer mentorship, adult role-models, and structured activities. Teen Club creates a safe space for the teenagers to form friendships with peers with similar life experiences, while learning and acquiring important skills. Teen Club members are all HIV positive and know their HIV status. They meet once a month to socialise, share experiences, learn, and have fun. Teen Club sessions are guided by an 11-month, standardised curriculum with broad themes such as medication adherence, health and nutrition, career development, human rights, HIV status disclosure, and talent development. Botswana-Baylor staff review the curriculum annually with input from the Teen Club members.

The main Teen Club site is the Baylor Bristol-Myers Squibb Phatsimong Adolescent Centre in Gaborone, which hosts about 185 teens every fourth Saturday of each month. The COE also supported Teen Clubs at 12 satellite sites: Thamaga, Mahalapye Mother's Union, Molepolole, Goodhope, Kanye Main Clinic, Sefhare, Mookane, Mahalapye Airstrip, Moshupa, Ramotswa, Mochudi, and Kanye. Active Teen Club attendance stood at just below 500 across the 13 sites in the past year. The programmes that Teen Club offers would not be possible without the teen leaders and over 100 adult volunteers who participate in each monthly Teen Club event.



Teens working together at a training

Tutoring

The tutoring programme was established in 2008 to support school-age patients with learning difficulties and/or poor academic performance. Through the Adolescent Center tutoring sessions, over 200 children and adolescents have received this free academic assistance. COE patients often miss, at a minimum, one day of school every month in order to attend appointments necessary for treatment. The academic consequences of consistent absences are undoubtedly compounded over time. In addition, there are difficult psychosocial implications: a vast number of these youths are unable to disclose their HIV status due to widespread societal stigma. Peers' frequent questioning of inconsistent attendance or the burden associated with asking permission from teachers for time away from school complicate a young person's academic experience. Additionally, research suggests an increased risk of impaired neurological and psychiatric development in youth who acquired HIV perinatally.

COE clinicians, community health workers, psychologists, and social workers assess patients' academic performance during consultations and those with grades of 'C' or below are referred to the programme. The programme enrols youth in Standard 1 - Form 5 and averages 15-25 attendees per session on various subjects, with students often focused on Math, Agriculture, Sciences, or English. The tutoring sessions are led by dedicated volunteers who have either completed undergraduate studies, are still studying in surrounding universities and colleges, or are retired teachers.

Finding the Leader Within

The COE continued its partnership with Stepping Stones International (SSI) to implement Finding the Leader Within programme. This programme targets out-of-school and unemployed youths between the ages of 16 and 25. The eight-month curriculum was reviewed and adjusted to be six months-long and focuses on leadership development, career and vocational guidance, healthy and productive lifestyles, financial literacy, and information and communications technology skills. Guest speakers often visit to share their experience and knowledge in fields of work that are part of the curriculum. The sessions run four days a week (Tuesday through Friday) and are facilitated by COE staff and volunteers. Sixty-seven youths accessed the Leadership programme sessions and were further trained on Ready To Work modules: entrepreneurship and employability pathways that empower them with skills and knowledge to approach the world of work with confidence. Most of the youths were placed in jobs, which afforded them the opportunity to experience the workplace.

Young Adults Support Group

The number of young adults between 19-25 years old at the COE has been growing drastically. By mid-2017 there were about 750 young adults enrolled in treatment at the COE. These young adults are transitioning from a supportive paediatric and adolescent setting to adult care and require specific targeted support.

Modeled after Teen Club, Young Adults Support Group follows a structured curriculum that includes job readiness skills, personal finance training, emotional and mental health, sexual and reproductive health information, and self-care. During 2017-2018, an average of 35 youths attended the programme each month.



Clients doing some educational activities

Camp Hope

The Camp Hope residential camp was held in December 2018 and brought together 117 children. It was held at Mokolodi Nature Reserve and, as usual, comprised social activities, such as a campfire where campers roasted marshmallows and shared stories about the struggles of living with HIV/AIDS. That set the tone for the rest of the camp as the teens were prepared to learn more about taking care of themselves physically, mentally, and psychosocially — all whilst having fun. Camp Hope Botswana also introduced a new session called "Kgotlhatso" whereby campers share experiences living with HIV, challenges and coping mechanisms as well as reflect on their emotions and fears.

Other camp activities included arts and crafts, designing friendship bracelets and photo frames. There was a game drive, pillow case game and egg drop. Children also participated in life skills sessions on nutrition, hygiene, and confidence. On the final night, we celebrated everything the children achieved during camp with a dance and a talent show.

GLOBAL HOPE BOTSWANA

World Haemophilia Day Outreach to Malwelwe Village

April 17 is designated as World Haemophilia Day across the globe and this year our team celebrated it in Malwelwe village, where several of our haemophilia patients live. We commemorated WHD on Wednesday, April 24, in collaboration with the village chief ("kgosi" in Setswana), the nurses at the local Malwelwe Health Post, nurses from the regional leadership close to the village, staff and administration from Princess Marina Hospital, haemophilia advocacy groups, and of course our Global HOPE Botswana team. It was a fantastic day!



Villagers gather in the "kgotla" (meeting area found in each village) prior to the event start.

Health Care Worker Outreach Training

In June 2019, we launched a Health Care Worker Outreach Training, starting with Scottish Livingstone Hospital (SLH) in Molepolole, Botswana. We aim to train healthcare workers around the country on how to recognise, stabilise, and refer children with suspected cancer or blood disorders to our programme in Gaborone, since it is the only programme in the country that treats these diseases. The training will hopefully help reduce delays in diagnosis and treatment. In 2014-2015, Dr. Jeremy Slone spearheaded a similar campaign at 14 hospitals in Botswana, all of which we will revisit through our current outreach. We have thus far conducted training sessions at four of the 24 health facilities planned.

Thrive Volunteer Programme

In November 2018, the Global HOPE Botswana programme established a volunteer programme named THRIVE. THRIVE was pioneered by Dr. Maria Dunn, a paediatrician from Global HOPE; Ms. Peggie Savage, a community member with a long history of volunteering with the oncology programme; and Ms. Caroline Gartland, a child psychologist in Gaborone whose company SensoBaby works to promote healthy child development. The aim of THRIVE is to develop a pool of skilled and knowledgeable community volunteers to provide play and art therapy for children admitted to the paediatric oncology ward. THRIVE volunteers also participate in community activities and Global HOPE events such as the Survivor Party. As of June 2019, we have conducted two training workshops to equip volunteers with the necessary skills knowledge to work with this special population of children. Since the programme's inception, volunteers have spent time at the ward every Tuesday, Wednesday, and Thursday from 2-4pm and every Friday from 10am to noon.



Patient receiving treatment

EDUCATION

Paediatric KITSO Training Programme

Paediatric KITSO (Knowledge, Innovation, and Training Shall Overcome) trainings are five-day workshops funded by the Ministry of Health and Wellness for physicians, nurses, pharmacists, social workers, and other health professionals. We conducted four paediatric KITSO courses over the past year, reaching 118 professionals drawn from Palapye, Francistown, and the Greater Gaborone District Health Management Teams and the Institutes of Health Sciences.

Botswana-Baylor continued to adjust the paediatric KITSO curriculum content to match changes in national treatment guidelines and the evolving needs of children as they grow into adolescence and young adulthood. Future trainings will continue to highlight the role health care workers play in achieving the UNAIDS 90-90-90 global HIV campaign. We will also introduce new approaches and interventions in HIV prevention and care, such as the pre-exposure prophylaxis, and will include content to promote youth friendly sexual reproductive health services.

Visiting Scholars Programme

During this report year, 94 scholars, including medical students, residents, fellows, nurse prescribers, and other health professionals visited Botswana-Baylor from various training programmes in Botswana and from around the globe. The mission of the Botswana-Baylor visiting scholars' programme is to increase understanding of paediatric HIV and cancer treatment and care globally. The majority of the scholars were from the University of Botswana Medical School in Gaborone and from Baylor College of Medicine in Houston, Texas. The visiting scholars spent most of their time in the COE and with the Paediatric Oncology and Hematology ward at Princess Marina Hospital, shadowing and working alongside experienced clinicians and researchers. Some of the scholars also spent time with the outreach teams at other ART sites.

Visiting Scholars' Testimonies

"The opportunity to work in Botswana-Baylor's Children's Clinical Centre of Excellence, the most established paediatric HIV clinic in Africa, was an incredible experience for medical students. The clinic allows students to develop their scope of medical knowledge, knowledge of resources available in a middle income country, and independent clinical skills. The clinic does an excellent job of incorporating students into the workflow of patient care, and learners are given autonomy that accelerates their growth and contributions to medical care. I would highly recommend this opportunity to any students interested in global health due to its principal place in the shifting landscape of medical care in developing countries with unique demographics."

-Sriharsha Kambala, 2019 Visiting Scholar Baylor College of Medicine "I chose to participate in the Global HOPE programme through Botswana-Baylor's Children's Clinical Centre of Excellence because it is the first paediatric haematology-oncology programme established in Africa. The programme does an excellent job of incorporating visiting scholars into the medical care team so that we are not merely observers. I was participating on rounds, signing orders, teaching medical students, and learning so much from my patients and colleagues. I was also impressed by the diverse pathology I saw during my time at Botswana-Baylor. As a paediatric resident who is interested in haematology-oncology in lowresource settings, this programme provided me the opportunity to get hands-on experience — I highly recommend it!"

- Shilpa Thaivalappil, MD, MPH University of Virginia School of Medicine

SPECIAL FEATURE TELLING THE BAYLOR STORY

Depression, Acceptance and Academics

A young adult reflects on the role that Botswana-Baylor has played in his life.

Baylor has played a major role in my life. The first time I came here I was 12 years old. The first few times they were drawing blood. Then I came for a check-up one time and it was not a normal check-up. Check-ups are usually quick: go get weight, temperature, pill-count, see the doctor or nurse, and then go home. But this day we went to see the doctor and stayed for a while. They spoke to my aunt in private and then invited me into a pool of doctors and nurses. That is when they told me that I had HIV. I was 12 and I had heard of HIV. I burst into tears and cried for a while because my whole world had collapsed and I was very hurt.

However, a lady came in afterwards and she took me to a room filled with books and gave me a book I could draw in. I did that while we talked until time passed. I still remember waking up the next morning

"To me, Baylor is like a second home." in shock. I was hoping it was a dream, but when I realised it was not I decided that life must go on. Since then, I have come to grips with the fact of what is going on inside me. Ever since I was a child the way I thought about it was that I'm like a robot which always has to take its batteries (pills) for recharging and when I think of it like that it doesn't seem so sad anymore.

To me, Baylor is like a second home. It is filled with all these people who care about me, love me, and only want what is best for me. There was a time when I was 17 when my grades weren't good. It was the year before I went into form 5. I was really scared because in my family you have to have good grades in order to be respected. I don't know if that is an African thing or what?

They always want to know if you are performing well in school because they think that is the highlight of who you are, and regardless of what else is happening in life, that is the most important thing you should be focusing on. So I started thinking that if my grades were bad, then I wasn't good at anything in life. I felt empty and sad. I didn't know how to solve it because I was honestly trying my best; some subjects were just so difficult. That is when I started to have suicidal thoughts and took a few attempts at ending my life.

The emptiness was still there. During the first few months of my form 5, though, I met a gentleman at Baylor when I was sitting in the waiting room reading before my check-up. He asked if we could talk and we had a discussion about a tutoring program at Baylor. He asked me if I wanted to join and I did right away. From there on out, I came here every single weekend to try and further my studies. Baylor is a loving place, a wonderful place where they do their best to make sure that each patient is well taken care of, is healthy, and can keep going on with their life.

I expect and want Baylor to play a huge role in my life going forward. I want nothing to change. I want to come here even when I'm working. I will be in a suit and tie and say, "Hey could you please hurry up because my boss wants to see me right away." I think that Baylor is the closest thing to heaven.



Baylor client working on a craft at Camp Hope

The COE has continued to carry out research in several aspects of HIV care and treatment in order to inform practice and policies in Botswana and other countries.

Currently there are four studies that are ongoing:

- The Collaborative African Genomic Networks (CAfGEN) Study and IFGeneRA
- Medical Audit of Patients Registered at the Botswana-Baylor Children's Clinical Centre of Excellence
- PNCB Study
- Friendship Bench

Collaborative African Genomics Network (CAfGEN)

The CAfGEN study is still continuing since it started in 2014, and its mission is to create, as part of the H3Africa Consortium, a collaborative, multi-disciplinary, multi-institutional, inter- and intra-country network of African scientists, clinicians, and researchers to use genomics approaches to study gene/pathogen interactions for HIV/AIDS, its co-morbidities, and other diseases among diverse paediatric African populations.

The CAfGEN study has accomplished most of its aims during the first phase of funding, and that has led to the approval of awarding the second phase of funding from National Institutes of Health (NIH).

Community Advisory Board (CAB)

The CAfGEN Study has been embracing the important role the Community Advisory Board plays in the running of genetic and genomic studies, that it should be viewed as an assert for researchers and communities. The role of the CAB is to act as mediator between the research team and the community where the research is carried out. CAB has been meeting every month to get study progress updates, provide advice, and formulate policies and manuals. Most importantly, they received training facilitated by study researchers on CAB expectations, roles, and responsibilities.

RESEARCH AND PUBLICATIONS

Study Recruitment

Recruitment for the second phase started in May 2018. So far 503 participants for the retrospective cohort have been recruited, and of those, 365 participants were in CAfGEN 1, there were 138 new participants, three TB cases, and three TB Controls for CAfGEN 2

Training

CAfGEN supports the training of African Genomic scientists. So far for Botswana there are six trainees, five PhD trainees are doing bioinformatic, and one trainee is doing bioethics. Three others had completed their training in 2017 and have returned, and the other two trainees had already started the training programme in Houston at the beginning of the year. The other bioethics trainee is based at the University of Cape Town, South Africa.

CAfGEN Sites Visits

The Botswana-Baylor COE is the coordinating site for CAfGEN and one of its responsibilities is to visit other sites, to train, and to oversee study activities. The Baylor-Uganda COE, Makerere University, and the Eswathini COE were visited, and in Eswathini, the Lead PI, Dr. Mogomotsi Matshaba, and country PI organised and witnessed a scholarship ceremony of two MSC trainees in bioinformatics, which was also attended by the US Ambassador.

RESEARCH AND PUBLICATIONS

Publications

- The Collaborative African Genomics Network (CAfGEN): Applying Genomic technologies to probe host factors important to the progression of HIV and HIV-tuberculosis infection in Sub-Saharan Africa [version 1; peer review: 2 approved], Gerald Mboowa,
- A locus on chromosome 5 shows African ancestry-limited association with all immunization in sickle cell disease

H3Afica Consortium Meetings

CAfGEN Study as part of H3Africa Consortium, is required to attend the bi-annual consortium meetings and study team from the 6 various sites (Botswana COE, University of Botswana, Eswathini COE, Uganda COE, Makerere University and Baylor College of Medicine) do send delegates to attend.



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Naomi Mochabo – Executive Secretary – Secretary

FINANCIALS

Consolidated Financials – BWP

For the fiscal year ending 30 June 2019

Grants and Donations

During 2018-2019, almost all Botswana-Baylor activities were funded through continuing grants and donations. We received financial support as follows:

INCOME

Gross Income	26,806,702
Expenses	26,806,702
Surplus	0

BALANCE SHEET

Assets

Non-current	10,638,046
Current	16,178,344
Total	26,816,390

Donor	Amount	Activity	
	(BWP)		
Ministry of Health and Wellness	17 212 455	Core Activities, Outreach, KITSO, Clinical	
NIH	7 468 999	CAFGEN	
снор		PHE Study	
FHI360	436 472	APC Project	
PCI	3 204 699	OVC Project	
Texas Children's Hospital	2547119	PHO	
SeriousFun	901 080	Camp Hope	
		Family Weekend Camp	
University of Cape Town	924 759	(Research)	
PCNB Philadephia	232 821	- C. S. C. S. C. C. C. S. S.	
Friendship Bench- Philadephia	34 023		
UNICEF-Botswana	948 597	Adolescent Programmes	
YFFF	25 647	Oncology	
Novo Nordisk Haemophilia	307 436	Camp Hope	
Foundation		Family Weekend Camp	
Jannah Hodges and Rachel Bowers	P19 047.62	Children's Christmas Party	



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