

BOTSWANA-BAYLOR CHILDREN'S  
CLINICAL CENTRE OF EXCELLENCE

# BOTSWANA

2016 - 2017 ANNUAL REPORT



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## VISION

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

## MISSION

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

*The photography in this report was generously provided by Smiley Pool.*







## LETTER FROM THE EXECUTIVE DIRECTOR

Dear Supporters,

This last year has been remarkable. First and foremost, this is the year in which we saw our founding executive director, Professor Gabriel Anabwani, retiring after 15 years of exemplary dedication and service. Professor Anabwani was instrumental in the inception and development of our centre, growing from a staff of just three on the day we opened to 84 today. The centre achieved great success and we are grateful for his dedication and inspiring leadership. As we reflect on these achievements, we look forward to the future with great resolve and determination to carry on the legacy of excellence he has entrenched.

The change in leadership comes at a time when the haematology oncology service starts to grow into a full-fledged centre of excellence. We saw a new step in this growth when the president of the Republic of Botswana, Lieutenant General Dr. Seretse Khama Ian Khama, broke ground at the site of the upcoming Paediatric Haematology and Oncology Centre of Excellence. This centre will be a first in the region and will be part of the new Global HOPE programme. Plans are underway to set up a temporary structure that will allow us ramp up services while we await delivery of the final structure. We believe this programme will be the next step in the transformative change that we have embarked on to improve care of children with cancer on the sub-continent.

On the research front, we started the year with a notification from the National Institutes of Health (NIH) that our study, Collaborative African Genomics Network (CAfGEN) has been funded for a further five years. This is a result of the success of the first phase of the grant, in which we contributed significantly to science by examining the genetic composition of Botswana more than ever before. The history-making Genome Adventures comic books (available in eight languages) have been a highlight of the achievements of this study, celebrated in four countries (Botswana, Uganda, the United States, and Tanzania). We have also been awarded another NIH grant: Individual Findings in Genetic Research in Africa (IF-GENERA), led by our collaborators at the University of Cape Town, which seeks to study return to genomic results to participants. We continue to look at ways of increasing our research capacity by investing in people.

The centre continues to enjoy unwavering support from the Ministry of Health and Wellness and other government agencies, the Baylor College of Medicine and Texas Children's Hospital, the US government through the National Institutes of Health and USAID (PCI- Botswana, FHI360), Stepping Stones, SeriousFun, Botswana-UPenn Partnership, Botswana-Harvard Partnership, and the Bristol-Myers Squibb Foundation.



We could not have achieved all of this success had it not been for the support of our dedicated staff and their families, partner institutions, the Botswana government, and our clients and their families. We are grateful for all you have done so far and know that you will continue to support this centre in the next phase of development.

*Le ka moso!*

**Mogomotsi S. Matshaba, M.B.B.Ch.**  
Executive Director

*Right: More than 2,000 patients receive ART from Botswana-Baylor.*





## WHO WE ARE

Botswana-Baylor Children's Clinical Centre of Excellence (Botswana-Baylor) is a national HIV/AIDS care and treatment facility that provides services in Gaborone, Botswana, for HIV-infected children, adolescents, and young adults and their families from around the country. It is a public-private partnership between the government of Botswana and the Baylor College of Medicine - Baylor International Pediatric AIDS Initiative (BIPAI), 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, a tertiary care referral hospital.

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



## AT A GLANCE

*“We could not have achieved all of this success had it not been for the support of our dedicated staff and their families, partner institutions, the Botswana government, and our clients and their families..”*

*- Dr. Mogomotsi Matshaba*

**84**

Total staff

**2,381**  
Total patients

**87%**

Undetectable patients

**20,750,023**

Total Budget (BWP)

**127**

Health care workers trained

**2,380**  
Patients on ART

### Key Programmes:

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



# 2016-2017 HIGHLIGHTS

## **Paediatric Haematology-Oncology Centre of Excellence - Groundbreaking Ceremony**

On 21 February 2017, His Excellency the President Lieutenant General Dr. Seretse Khama Ian Khama of the Republic of Botswana; Honorable Minister Dorcas Makgato of the Ministry of Health and Wellness; representatives from the Bristol-Myers Squibb Foundation, Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI) and Texas Children's Cancer Center's Global HOPE programme; and other distinguished guests all gathered for the groundbreaking ceremony for the Paediatric Haematology-Oncology Centre of Excellence in Gaborone. The Global HOPE programme will bring to Botswana the latest bio-medical technologies and the potential to work with local institutions such as the Botswana Innovation Hub and University of Botswana to quickly increase the survival of children with cancer and life-threatening blood disorders in Botswana and the region," said President Khama.

## **Botswana-Baylor and Project Concern International (PCI)**

In October 2016, Botswana-Baylor signed a five-year sub-award agreement with PCI to implement the Botswana Comprehensive Care and Support for Orphan and Vulnerable Children project. The project aims to improve the health, wellbeing, and social outcomes for orphans and vulnerable children and their families. The funding is from USAID.

## **Establishment of Cervical Cancer Screening**

From November 2016, Botswana-Baylor COE integrated cervical cancer screening and management into the clinical services it offers. By implementing a simple "see and treat" programme, we have greatly expanded the prevention of cancer among youths enrolled in treatment at Botswana-Baylor.



## CAfGEN Study Receives a New Grant from NIH

By studying the genes of people with HIV and TB, scientists have developed new therapies to suppress or prevent infections. But the vast majority of genetic research takes place outside of Africa on non-African populations, and studies involving African children are completely absent. The Collaborative African Genomics Network (CAfGEN) aims to close this data gap. In 2014, the U.S. National Institutes of Health (NIH) gave Botswana-Baylor \$3.64 million to provide expertise and patient recruitment for the project. In addition to genomics research, the CAfGEN supports training of African genomic scientists and building scientific infrastructure in the participating countries, Botswana, Swaziland and Uganda. The first phase of the project ended in August 2017, and NIH awarded a second grant, totaling up to \$5 million to implement a five-year phase two, which began in September. Also collaborating on CAfGEN are Baylor College of Medicine, Baylor College of Medicine Children's Foundation - Swaziland, Baylor College of Medicine Children's Foundation - Uganda, the University of Botswana Department of Biological Sciences, and Makerere University in Uganda.

## Genomic Medicine for Nurses in Africa Training

As part of the CAfGEN project, the COE conducted the Genetic Medicine for Nurses in Africa training course, offered to all nurses working at Botswana-Baylor. This is a free, distance-learning course designed for nurses in Africa to increase knowledge in genetics of African health issues and to build skills in genetic counselling, community engagement, ethical conduct in research, and patient care. Thirteen nurses attended the training, which is accredited by the University of Cape Town.

## Tenth H3Africa Consortium Meeting

H3Africa has three main goals: increase the number of African scientists working on genomics, establish ways for them to collaborate, and expand the physical infrastructure for their work. The H3Africa Consortium is the vehicle for that second goal, tying together those working on H3Africa projects across the continent. The consortium holds two meetings a year, and the tenth H3Africa meeting took place in Gaborone from 12-15 May 2017. It was hosted by the Botswana-Baylor CAfGEN project and attended by delegates from over 27 countries.

*Right: Trainings at Botswana-Baylor include patients, family members and healthcare workers.*





Literary

Extracurricular

- Sport  
- Club  
- Comp

Out

- Concrete / Detail  
- Organics Seed

# PROGRAMS

## Pediatric Infectious Disease Clinic

The PIDC at Botswana-Baylor provides quality HIV testing, treatment, care, and support services to children, adolescents, and their families. Our current patient load is roughly the same as the previous report year, with 2,381 active patients, most of whom receive follow-up care every three months as recommended. The clinic sees 100 to 120 patients per day.

The COE also addresses the needs of caregivers with complex social situations through the Family Model Clinic (FMC). The FMC operates within the COE and serves the primary care needs of many of the HIV-infected adult caregivers of children and adolescents enrolled in treatment at Botswana-Baylor. The FMC also cares for a group of young adult patients who have transitioned from the PIDC. The FMC is staffed by an adult physician or medical officers on a rotational basis with a typical



Above: Delegates from 27 countries attended the H3 Africa Consortium Meeting held in Gaborone, Botswana hosted by Botswana-Baylor.



case load of 15 adult patients daily. Even with an increasing adolescent and young adult population, clinical care outcomes continue to be exemplary. The lost to follow up, viral load suppression and mortality rates are unsurpassed in Botswana at less than 1%, 87%, and less than 2%, respectively.

Our TB/HIV integration plan continues to develop cost-effective ways of dealing with TB/HIV over time. Screening rates for TB have improved. We continue to add more services aimed at keeping our adolescent population healthy, with a focus on minimizing long-term treatment toxicities and monitoring for non-communicable diseases.

## Screening Clinic

The national Prevention of Mother-to-Child Transmission (PMTCT) program makes referrals to Botswana-Baylor for postnatal HIV screening at six weeks. In the report period, 49 infants were tested. The six diagnosed with HIV were initiated on treatment and care services. According to the Botswana national HIV testing guidelines, newborns who test negative should be re-tested at 18 months to re-confirm the results. Only one infant who originally tested HIV negative at Botswana-Baylor was re-tested at 18 months (and was negative). The others are

suspected to have been re-tested at other health facilities, where rapid tests are widely available.

Botswana-Baylor uses DNA PCR testing, a highly sensitive method of HIV screening that can detect the virus using very small amounts of blood. The clinic also offers HIV screening using the Double Rapid Test, which produces much faster results. Over the reporting period, we conducted 48 Double Rapid Tests, and 15 had positive results. Fourteen patients were initiated on ART at Botswana-Baylor, and one person preferred to be initiated at their local clinic.

## Clinical Psychology

Since its inception in 2008, the Clinical Psychology Department has made significant contribution to the care of children, youths and their families by addressing their mental, emotional and behavioral needs. Patients are referred to the Clinical Psychologist by other clinicians at the COE or by Community Health Workers. Through observation, interviews and tests, the psychologist makes a diagnosis of any existing or potential disorders. Then, formulate a program of treatment according to the client's needs, and continue monitoring the client's progress on a regular basis to ensure that a desired behavior is met, e.g. good adherence.

Over the reporting period, the Clinical Psychologist Onkemetse Phoi broadened her scope of work to include children, adolescents and young adults referred by Community Health Workers through the Advancing Partners and Communities and the Orphans and Vulnerable Children Care and Support Projects. The clients referred from the community present with a host of

psychological issues, such as depression, sexual and physical abuse, education difficulties, and others.

Unsurprisingly, adherence to medication continues to be the biggest challenge stemming from other psychological factors, with depression being the highest cause.

### The Top Ten Psychological Issues Presented to the Psychology Department





## Social Work

The social work department continued to provide social welfare counselling services to patients and their caregivers. Supportive counselling and adherence counselling were the main services offered by our social worker, Ms. Tapiwa Tembwe.

Supportive counselling was offered mostly to families during home visits. Home visits were done on a monthly basis targeting mainly patients who were not returning regularly for treatment and those with poor adherence to medication.

### The Top Eight Problems Presented to the Social Work Department

Supportive Counseling: 37  
Negligence, Abuse, Custody, Placement: 22  
Death and Bereavement: 15  
Adherence Counseling: 81  
Family Conflicts: 11  
Food and Financial Security: 16  
Behavioral Issues: 10  
Transport Problems: 17

## Cervical Cancer Screening

Beginning in November 2016, cervical cancer screening and management was integrated into routine clinical services offered at Botswana-Baylor clinic, targeting sexually active girls and young women older than 15. The Botswana national cervical cancer screening guidelines recommend screening for women aged 30-49. However, increasing numbers of cervical cancer cases were being identified among younger women and girls served at Botswana-Baylor.

Between November 2016 and June 2017, we screened 53 patients aged 18-26 years. Of these, six were positive for human papillomavirus, a cause of cervical cancer. In addition, 16 patients were diagnosed and referred for treatment for sexually transmitted infections, including genital warts, genital herpes, and Candida.

## Outreach Mentorship Programme

The mission of the Botswana-Baylor outreach mentorship programme is to strengthen the capacity of non-Baylor healthcare facilities across Botswana to provide quality HIV treatment and care services to children, adolescents and young adults. During monthly visits, a Botswana-Baylor pediatri-

cian or medical officer and a nurse prescriber provide clinical care services to patients alongside the local medical staff. The also lead outreach team also conducts didactic educational sessions structured around the fundamentals of pediatric and adolescent HIV treatment and care.

Over the reporting period, the outreach programme covered 10 large ARV sites, mentoring 126 healthcare workers and seeing 712 patients. Of these, 288 patients were on treatment but their HIV viral loads were not suppressed. The majority of the patients who experienced virological failure (when ART fails to suppress and sustain a person's viral load below a certain threshold) at outreach sites achieved viral suppression within three months following interventions by the outreach team. Almost all those patients had been switched to a newly introduced drug, Dolutegravir, which is known to suppress the virus quickly. Botswana-Baylor plans to expand its outreach activities to more ART sites in an effort to further reduce failure rates among children, adolescents and young adults nationally.



## Advancing Partners and Communities Project

Community health workers can be extremely effective at improving outcomes for patients. They're not just patients — they're neighbors.

The Advancing Partners and Communities (APC) project aims to strengthen the local response to the HIV epidemic through community empowerment, community HIV testing and counselling, community care for tuberculosis (TB) and HIV, and HIV prevention. APC is funded by USAID with FHI360, a US nonprofit, acting as lead implementer, reaching eight PEPFAR priority districts: South East, Kgatleng, Gaborone, Mahalapye, Southern, Goodhope, Ghantsi, and Kweneng East.

The COE partnered with FHI360 in October 2015 and began enhancing community-based care for HIV-positive children and adolescents under 19. Through the project, Botswana-Baylor readied 33 community health workers to conduct monthly follow-ups with clients, track patients who are lost to follow-up and return them to

care, provide adherence and psychosocial support to clients and their family members, and link clients to other HIV- and TB-related health services. Other services provided by Botswana-Baylor under the APC project include Teen Clubs and caregiver education sessions.

The focus of the second year of the APC project (between 2016 and 2017) was to follow up with 3,000 children and adolescents who were enrolled in community care during the previous year. Community health workers met with most patients monthly, or more frequently for clients with more challenges. By June 2017, they conducted 2,775 follow-ups.

The APC project has played a major role in identifying HIV-exposed children and linking them to HIV counseling and testing services. It has supported medication adherence and has promoted retention in care.





FOR LONG TIME



## Comprehensive Care and Support for Orphan and Vulnerable Children 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 categorized 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 disability, or living outside of family care. These cumulative risk factors may result in illness; withdrawal from services, including schooling and healthcare; 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 organization PCI serving as the main 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 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 programs and provide counseling and psychosocial support. They assess 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 vocation training support and referral. Each client receives a household visit every three months.

In the course of the project, we've identified the lack of birth certificates as a problem among OVCs. Babies are often released from hospital before receiving a birth certificate, and their parents and caregivers are not able or are reluctant to follow up with the National Births and Deaths Office. Not having a birth certificate can affect Botswana's ability to access free government services.

*Left:* Challenges facing orphans and vulnerable children with HIV infection include adherence to medication and lack of emotional support.

A birth certificates and national identity card (Oman) acts as a proof that indeed one is a citizen, giving them access to government provided services such as medical care, social welfare and school.

In addition, project data show that many OVCs have not had an HIV test even when their biological parents are HIV positive. This is usually because parents and caregivers are afraid of the possible outcome of the HIV test or they don't understand the importance

of infant and child testing. Botswana-Baylor Community Health Workers have intensified risk assessment and referrals for HIV counseling and testing in all the OVC households they visit.

<b>OVC Care and Support Project Reach</b>	
HIV-positive youth enroled into care (0-17 years):	<b>1,047</b>
HIV-positive and -negative clients enroled into care (0-35 years):	<b>3,468</b>
Number of patients visited by Community Health Workers:	<b>2,785</b>
Number of caregivers and young mothers trained on vocational and personal finance skills:	<b>83</b>
Parents and caregivers trained on parent-child communication:	<b>297</b>
Number of social workers trained:	<b>47</b>
Number of young mothers trained:	<b>44</b>



# ADOLESCENT PROGRAMS

## 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, learn, and have fun. Teen Club sessions are guided by a 12-month, standardised curriculum with broad themes such as adherence, health and nutrition, and career development, human rights, HIV status disclosure, and talent development. Botswana-Baylor staff review the curriculum annually with input from the Teen Club members.

Here's what one 18-year-old Teen Club member has to say about his experience in the programme:

***"I would say Teen Club has played a major role in my life. When I came here I didn't know anyone. I started interacting with people, finding new friends in Baylor. I found a best friend at Teen Club. And with Teen Club I was able to say 'Oh, okay, I'm not the only person in this condition.' There are these people I can talk to, share information, exchange advice here and there. I was able to see different children with different issues living in different places and conditions. So it was quite an interesting path for me."***



The main Teen Club site is the Baylor Bristol-Myers Squibb Phatsimong Adolescent Centre in Gaborone, which hosts about 150 teens every fourth Saturday of every 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 just below 500 across the 13 sites in the past year. The programmes that Teen Club offers would not be possible without the continuous help and facilitation by Teen Leaders and over 100 adult volunteers who regularly participate in each monthly Teen Club event.



FTLW program attends a *Ready to Work* workshop session learning about people, money, entrepreneurship and employability skills.



## Young Adults Support Group

The number of young adults between 18-25 years old at the COE has been growing drastically. By June 2017 there were about 750 young adults enrolled in treatment at the COE. These young adults are transitioning from a supportive pediatric 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 2016-2017, an average of 35 youths attended the programme each month.

## Finding the Leader Within

The COE continued its partnership with Stepping Stones International (SSI) to implement Finding the Leader Within. This programme targets out-of-school and unemployed youths between the ages of 16 and 25. The eight-month curriculum focuses on leadership development, career and vocational guidance, healthy and productive lifestyles, financial literacy, and information and communications technology skills. The sessions run four days a week (Tuesday through Friday) and are facilitated by COE staff and volunteers. The 2017 class included 39 youths.



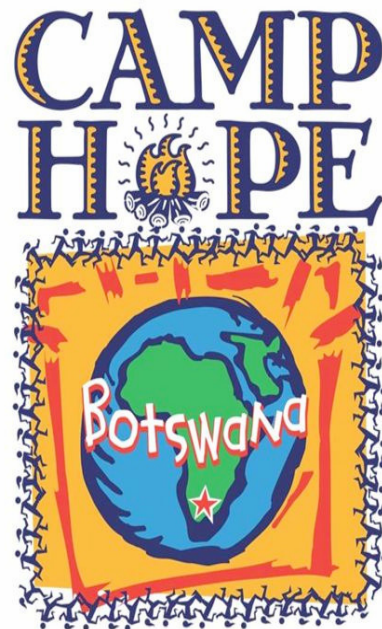
Adolescent participate in psychosocial support activities at the Phatsimong Adolescent Center at the Baylor COE.

## Camp Hope

A total of 96 campers aged 10-16 years attended Camp Hope 2016. The residential camp was held at Mokolodi Game Reserve. The campers arrived on 27 November 2016 with lots of excitement and energy. We began the festivities with a campfire at which the children, roasted marshmallows and told a story 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 activities included arts and crafts, where they made friendship bracelets and photo frames. There was a team treasure hunt and silly Olympics, complete with sack races, dizzy dancing, and paper plane throwing. They also participated in life skills sessions on nutrition, hygiene, and confidence. On the final night, we celebrated everything they achieved during camp with a dance and a talent show.

Camp Hope 2016 was made possible through a tripartite partnership between Baylor-Botswana, Serious Fun, and Sentebale. Serious Fun and Sentebale are international organizations that host camps dedicated to bettering the lives of vulnerable children.







# GLOBAL HOPE

*Botswana is set to be the hub of a \$100 million campaign to dramatically improve the prognosis of thousands of children with cancer and blood disorders in Sub-Saharan Africa.*

On 21 February 2017, the Bristol-Myers Squibb Foundation (BMSF) announced its transformational investment of \$50 million to support Texas Children's Cancer Center's Global HOPE initiative. Global HOPE — Hematology-Oncology Pediatric Excellence — has since launched a fundraising campaign to match BMSF's grant to help build long-term capacity of the initiative. Our role is central: The Botswana Paediatric Haematology-Oncology Centre of Excellence (PHO) will be among the most sophisticated children's cancer and blood disorder centres in the region.

## **Building the Botswana Children's Cancer Centre of Excellence**

Global HOPE has begun designing a state-of-the-art paediatric cancer and haematology centre for Botswana. In the interim, Global HOPE will build a temporary clinic using shipping containers, prefabricated modular parts, and limited on-site construction techniques. This approach will provide standards that can be adapted easily to each site (Botswana, Malawi, Uganda). Global Hope will deploy 4 pediatricians with oncology clinical expertise to manage the program and provide services.

## **Enhancing Pediatric Hematology - Saving Grace**

Grace Abraham, a Botswana native, was part of an exchange programme at the University of Nebraska when she was diagnosed with osteosarcoma, a type of malignant bone cancer, in early 2015. Since treatment in Omaha was not feasible, the United States Department of State contacted



When it is completed in 20XX, the Botswana Paediatric Haematology-Oncology Centre of Excellence will be the most advanced paediatric cancer center in Sub-Saharan Africa.

Dr. Jeremy Slone to see if he could provide the complex care she needed in Botswana.

Grace faced many challenges throughout her treatment, including the difficulty of undergoing chemotherapy. But Dr. Slone accompanied her through the journey. She even became a Motswana pioneer as the first paediatric osteosarcoma patient treated by Global HOPE who had a limb-salvage surgery (her tumor was removed but her leg was spared).

Grace is now two years out from finishing her treatment. She is doing quite well but remains at risk of recurrence and undergoes routine testing to make sure the cancer is not coming back. She has become a paediatric cancer advocate in Botswana, speaking to children with cancer and parents, urging them to fight the disease despite the challenges.



# EDUCATION



Training at the Botswana-Baylor COE.

## Paediatric KITSO Training

Paediatric KITSOAIDS trainings are five-day workshops funded by the Ministry of Health and Wellness for physicians, nurses, pharmacists, social workers, and other health professionals. (The acronym stands for Knowledge, Innovation, and Training Shall Overcome AIDS.)

We conducted three paediatric KITSO courses over the past year, reaching 105 professionals drawn from Greater Gaborone, Lobatse, Goodhope and Ngamiland District Health Management Teams.

Baylor-Botswana reviewed the curriculum content to match changes in national treatment guidelines and the evolving needs of children and adolescents living with HIV.

## Visiting Scholars Programme

During 2016-2017, 94 scholars, including medical students, residents, fellows, nurse prescribers, and other health professionals visited Botswana-Baylor from various training programs in Botswana and from around the globe. The visiting scholars spent most of their time in the COE shadowing and working alongside experienced clinicians and researchers.

What one visiting scholar said about his experience at the COE:

*"I decided to rotate at Baylor because this organisation represents one of the great partnerships in global health. I was eager to learn from their example and better understand what has led to this success. Since arriving in Botswana, I have not been disappointed. I feel very fortunate to have had the opportunity to spend a month working at a clinic under the supervision of this staff. Patients are eager to engage in the Teen Club, while the dietician, social worker, and psychologist services help ensure that all of the medical expertise translates into successful care plans." - Tim Visclosky*



Tim Visclosky, a second year postgraduate Pediatric Resident from University of Michigan, was among our visiting scholars.

## SPECIAL FEATURE

### Telling the Story of Botswana-Baylor

*A patient reflects on Baylor's role in shaping the young woman she is today.*

I lost my mother at a very young age; I was 5 years old when she passed away. She had AIDS and was unable to get medication soon enough due to the stigma surrounding HIV/AIDS.

Once she passed away my family decided to get me tested for HIV, and unfortunately I was positive. I started going to Princess Marina Hospital and switched to Baylor when the centre was built in 2003.

There are some traumatising things that have happened to me: People tried to take advantage of me from a young age, and I began having suicidal thoughts. Living in a home without my parents was hard because I don't think people understood me. I would sometimes get exhausted because of the side effects of my medication, but they wouldn't understand because they are not living with HIV. It was hard to see my cousins just enjoying life; they had their mother and father.



Training at Phatsimong Adolescent Centre.

Looking back, I can now say that everything that happened to me when I was a child built me and gave me a stepping stone to my future. I got to learn a lot of things that most people my age haven't experienced. Over time I have taken it upon myself to take my medication the way it was prescribed and always come for my monthly check-ups. I just decided to make it a part of my life. People don't tell you to go and bathe; it is just a part of you. So I made meds a part of me. It was hard at first, but once I started to understand HIV/AIDS I began realizing that I'm not that different from other children. Yes, I have HIV/AIDS, but it doesn't describe who I am.



Baylor has played a big role in that realization. It is a place of opportunities, and because of it I have achieved so many things. I have been particularly close with one doctor here, and I remember one time he was asking me about furthering my education. These are the types of questions that he would ask about my future. It is really nice to know that there is someone that I can trust and tell them my deepest concerns. A person you don't even know — we are not family, weren't friends before, but he actually cared about my life, my future, and where I want to be. That is a good example of the people at Baylor. They really do care about our life, future, and health. Just a few days ago a staff member asked me about the courses I want to take in university. All these people actually care about and want the best for me!

### ***'It is a place of opportunities'***

Teen Club has also been amazing for me. It opened a lot of doors. I can't even stop smiling when I talk about it. I started coming to Teen Club when I was 13 and ran for Teen Leader the following year. I wanted to be someone that kids could look up to. Once I was elected I started mentoring other kids. It was really wonderful because I got to acquaint myself with a lot of people. Everyone was able to see my transformation from a little girl starting junior high to the woman I am today.

At Teen Club we have sessions on a lot of topics. One topic we cover is sexuality. This is important because at that point hormones are raging, and it is just confusing. They make time for us to discuss these issues. I could not go to my aunt and say, "I have started having these kinds of feelings, and I am not sure what they are." So it is nice to have someone you could run to and say, "This is what has been happening to me. I have feelings for this person. How do I go about it?" I know now that if I was to get into a sexual relationship I would need to protect myself and the other person. I need to tell my partner that I am HIV positive so that we can build a relationship.

***"Yes, I have HIV/AIDS,  
but it doesn't  
describe who I am."***

Going forward, I think Baylor is still going to be a huge part of my life. I know whenever I'm in need, or in trouble, I can come here and seek help. It is not like other settings where you meet people you don't know each time. When I come to Baylor I know I will get to see the same faces. Baylor is my pride and joy, and when I am here I am always happy. Even when I have a bad day I know somebody is going to make me laugh.

## Field Experiences from our Community Health Workers

Botswana-Baylor Community Health Workers (CHWs) serve both the Advancing Partners and Communities project; and the Orphans and Vulnerable Children Care and Support project. They know every corner of the villages they cover, making it easy to visit their clients.

*“Some of the cases we handle are very distressful and we need counseling from the psychologist or social worker. We also need to meet regularly as CHWs to share our experiences and challenges...”*

*“There are challenges. You go to a home and the household members do not know about the child’s status. Some caregivers still prefer not to disclose their child’s status to people in their household. You struggle to find a place where to sit and talk in privacy. It make some home visits very difficult.”*

*“We need strong communication skills to help deal with all kinds of people.”*

*“Some families will be wondering how they will benefit from a CHW’s visit. They have great expectations of our visits. They expect immediate or material help such as money, jobs, food, etc. They become impatient when you have nothing to offer. Feeling unable to help people with their problems such as a lack of food is very distressing.”*

*"If you know the life in the community, you may understand at times why they don't take their medicines or why they miss their appointments or why they are unhappy and what resources within the community could help them. When my clients need help, I know where to go and who to talk to... For working people, I can see them late in the evening or at the weekend."*

*"I have learnt the value of confidentiality in life. It is the ability to keep confidentially that wins trust in the community..."*

*"Going out and facing a stranger in his or her own home has given me tremendous confidence to deal with people..."*

*"When you get into a home, you see what is really happening. If a child doesn't have enough food to eat or there is no space for privacy and there are nine people in a house with two moms or many adults in the home are not working, it's important for me to see that - not to be sympathetic, but it's to empower me to find sources of help to change the life of that child."*

*"We become more important in their lives than I think we can ever understand. In some homes we play the role of a peacemaker. We find adolescents who are violent and rebellious to their caregivers and they are not taking their meds or they have defaulted. We counsel the adolescents and refer difficult cases to the social worker. When the situation improves, we then provide services to the family. Such intentions bring us closer to the caregiver and the adolescent."*



# SCHOLARLY ACTIVITY

The Botswana-Baylor continued to carry out research in several aspects of HIV care and treatment to inform policy and practice in Botswana and internationally. We conducted four major studies during the reporting period as follows:

## **Collaborative African Genomics Network (CAfGEN) Study**

The CAfGEN study 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 specific aims of CAfGEN are as follows:

1. Recruit well-phenotyped paediatric HIV and HIV-TB infected patients and create a DNA and RNA biorepository from blood and sputum samples linked to a central clinical database.
2. Evaluate the roles of 'established' and novel HIV disease progression alleles in children by sequencing and Allelotyping candidate genes and by using whole-exome sequencing in case-control genetic studies of long-term non-progressors status.
3. Use integrated studies of clinical outcomes, DNA, and paired RNA analysis in HIV/TB co-infected children to identify genes that contribute to the progression to active TB.
4. Enhance undergraduate, graduate, and faculty education in genetics/genomics and provide opportunities for long- and short-term training of scientists and technicians from African universities.
5. Establish genetic and genomic technologies and supporting laboratory and physical infrastructure for large-scale analyses of common diseases.

In summary, we successfully completed recruitment of 500 participants for the retrospective cohort, 606 participants for the prospective cohort. There were no incident TB cases from the prospective cases so far, however we still managed to recruit 20 TB Cases and 20 Controls. The recruitment is still going on for the TB recruitment; the challenge is the low number of cases so far.

In addition, the study supported capacity building by training scientists in the areas of genetics/genomics. A total of seven PhD trainees (three from Botswana and four from Uganda) were sent to Houston, USA, for training, and they completed their studies at the end 2016. They are helping to oversee the newly established sequencing and bioinformatics initiatives and training more African scientists and technicians in genetics/genomics.

## **Medical Audit of Patients Registered at the Botswana-Baylor Children's Clinical Centre of Excellence**

Four abstracts from the Botswana-Baylor Medical Audit protocol were presented at the BIPAI Network meeting in November 2016 as follows:

1. Determination of the True Lost to Follow Up rate: the Botswana-Baylor Experience.
2. A case study of BCG immune reconstitution syndrome after Antiretroviral Therapy initiation in an HIV positive infant in Botswana
3. Mortality trends at the Botswana - Baylor Children's Clinical Centre of Excellence.
4. HIV DNA Polymerase Chain Reaction (DNA-PCR) trends at the Botswana-Baylor Children's Clinical Centre of Excellence

## **Public Health Evaluation (PHE) of Adherence to HAART among HIV-positive Adolescents – The Ba Nana Study**

The Ba Nana Study is a five-year longitudinal cohort study of 300 adolescents in care for HIV at the COE that completed data collection in July 2017. The study aimed to increase understanding of factors related to

HIV treatment adherence and how to better monitor adherence among adolescents. The study data analysis is ongoing; however, six papers have already been published based on the study findings.

So far, the key findings from the study include the following:

- High scores on the Paediatric Symptom Checklist, a brief psychosocial screening tool, predict HIV treatment failure in the subsequent six-month interval.
- Adolescents who come to clinic alone are more likely to have virologic failure than adolescents who come to clinic with a parent or guardian.
- Paradoxically, in a setting in which pills are routinely counted to assess adolescent adherence, adolescents who repeatedly come to clinic with fewer pills remaining than expected (“>100% adherence” when measured by pill count) are more likely to actually have worse adherence than those whose pill counts show that they did not take all of their pills. These adolescents may be discarding pills in an attempt to avoid detection.
- Psychological reactance in adolescents is associated with higher rates of virologic failure.
- Younger adolescents with high levels of HIV-related stigma have better treatment outcomes, but older adolescents with high levels of HIV-related stigma have worse treatment outcomes.

## The Impact of Providing Relatively High-Risk Information by Ages and Partnership Network on Sexual Behaviour of Botswana Youth

Starting 2014, Botswana-Baylor partnered with the Ministry of Education and Skills Development, the Jameel Poverty Action Lab, Evidence Action, and the local NGO Young 1ove, to evaluate a one-hour curriculum on the HIV risk of sexual relations with older partners, often called ‘sugar daddies’. The project was implemented in 343 schools across four education regions, including Kgatleng, Kweneng, South East, and Southern. When the project began, it reached 13,366 students directly through peer facilitators, and a further 13,000 students through 106 trained guidance and counselling teachers. The target age groups were Standard 6 in primary schools and Form 1 and Form 2 in junior schools. The project included a peer arm, guidance and counselling arm, and a pure control arm where no intervention was implemented to be able to compare the impact of the programme on youth’s attitudes, knowledge, behaviour, and teenage pregnancy.

In 2015, the COE and Young 1ove returned to all 343 schools a year later to determine the impact of the programme. Roughly 42,000 students in the same schools as the

baseline survey were re-assessed on their knowledge, attitudes, and self-reported sexual behaviours. All students were also assessed for the main outcome of pregnancy (used as a proxy measure for unprotected sex and HIV rates) through three measures: self-reported, school reports by teachers and students, and visual checks (‘tummy spotting’). While in schools, the surveyors collected attendance data, recording all girls who had dropped out, transferred schools, or missed school for at least two weeks. Twelve surveyors, called trackers, then received extra training to locate and interview girls absent from school. The tracking teams administered a written survey (comparable to the in-school survey) and oral interviews with both the girls and their caregivers. Similarly, pregnancy status of all the tracked girls was recorded. A total of 539 girls (representing a 92% tracking success rate) were found and interviewed across Botswana, providing a rich collection of qualitative and quantitative data on our main impact measure of pregnancy.

Highlights of the results of the study include:

- The study found that sexual behaviour changed based both on self-reported data as well as our measures of pregnancy and missing from school, although here the data were ambiguous.
- The study also found that the messenger matters. Peers as messengers of



sexual risk information seem to lead to better outcomes than teachers.

- The study assumed that sugar daddies were primarily men in their 40s. However, we found that the actual age of partners was concentrated on men in their early 20s.
- Knowledge attained about HIV risk was mostly forgotten a year later, though some was retained.

The study found that pregnancy is a poor proxy for unprotected sex and thus HIV risk. HIV transmission is influenced by a number of factors that pregnancy does not measure in any way (for instance, the number of partners a girl has, whether each partner is circumcised, etc.).

## Publications

Okatch H, Beiter K, Eby J, Chapman J, Marukutira T, Tshume O, Matshaba M, Anabwani GM, Gross R, Lowenthal E. 2016. Brief Report: Apparent Antiretroviral Overadherence by Pill Count is Associated With HIV Treatment Failure in Adolescents. *J Acquir Immune Defic Syndr.* 15;72(5):542-5.

Ioannides K.L.H., Chapman J, Marukutira T., Tshume O, Anabwani G, Gross R, Lowenthal E.D. 2017 Patterns of HIV Treatment Adherence do not Differ Between Male and Female Adolescents in Botswana. *AIDS Behavior.* 21(2):410-414.

Yang E, Mphele S, Moshashane N, Bula B, Chapman J, Okatch H, Pettitt E, Tshume O, Marukutira T, Anabwani G, Lowenthal E. 2017. Distinctive Barriers to Antiretroviral Therapy Adherence among non-adherent Adolescents Living with HIV in Botswana. *AIDS Care.*

# LEADERS

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Botswana-Baylor Children's Clinical Centre of Excellence

# FINANCIALS

## Consolidated Financials - BWP

(Fiscal year ending June 30 2017)

### INCOME

Gross Income	20,750,023
<u>Expenses</u>	<u>19,575,609</u>
Surplus	1,174,414

### BALANCE SHEET

#### Assets

Non-current	10,991,159
<u>Current</u>	<u>24,937,970</u>
Total	35,929,129

## Grants and Donations

During 2016-2017, almost all Botswana-Baylor activities were funded through

continuing grants and donations. We received financial support as follows:

Donor	Amount (BWP)	Activity
Ministry of Health & Wellness	11,669,731	Core Activities, Outreach, KITSO
NIH	2,371,606	CAfGEN
CHOP	192,379	PHE Study
FHI360	3,238,838	APC Project
PCI	915,692	OVC Project
Texas Children's Hospital	189,973 766,222	Facilities PHO
Serious Fun	20,475	Camp Hope

Other Donations		
Tinnietiny Worldbusiness	3,500	Children's Christmas Party
Broadhust Primary School	150 gifts	
Pie City	food	
Lion Park Resort	venue	
Twizza	drinks	
Shoprite / Bikers Association	food, dj, tent, chairs	
KFC	food	

*Back cover:* The Phatsimong Adolescent Centre: A mural painted by volunteers, community partners and youth who receive services at the Centre.



# BAYLOR-BOTSWANA

Botswana-Baylor Children's Clinical Centre of Excellence Trust

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