

# Botswana-Baylor Children's Clinical Centre of Excellence



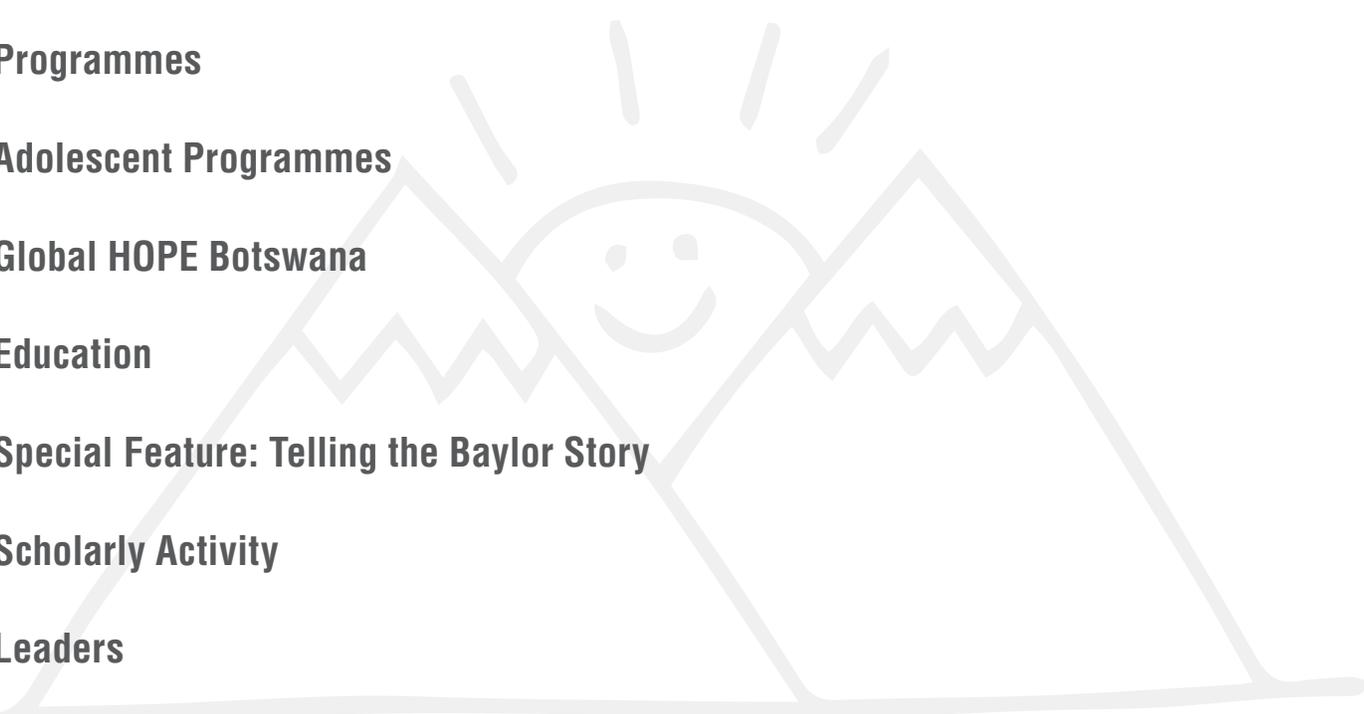
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# **Botswana-Baylor** **Children's Clinical** **Centre of Excellence**



- **Letter from the Executive Director**
- **Who We Are**
- **At a Glance**
- **2017-2018 Highlights**
- **Programmes**
- **Adolescent Programmes**
- **Global HOPE Botswana**
- **Education**
- **Special Feature: Telling the Baylor Story**
- **Scholarly Activity**
- **Leaders**
- **Financials**





# Botswana-Baylor Children's Clinical Centre of Excellence

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*Photography is generously provided by Smiley N. Pool.*



## EXECUTIVE DIRECTOR'S LETTER

Dear Botswana-Baylor Friends,

On behalf of the Board of Trustees and Staff of the Botswana-Baylor Children's Clinical Centre of Excellence, thank you for your continued support. The centre continues to inspire individuals, families, organisations, and businesses to create permanent charitable funds to help our community meet the challenges of changing times. We seek to find ways to increase our impact on improving the quality of life of our clients and their families.

As the fight against HIV is slowly won, one small victory after another, it has become clear that children and young adults across our beautiful country are not doing as well as they should be. We therefore have increased our efforts for this vulnerable group. As the Setswana adage goes, '**wa yo esi ga o ele**' — loosely translated to mean that '**one cannot succeed without the help of others**'. We continue to forge new relationships. We continue to work with our steadfast partners led by the Ministry of Health and Wellness in this noble endeavour. We celebrate new and invigorated relationships with old and new partners like Baylor College of Medicine/Texas Children's Hospital, Bristol-Meyers Squibb Foundation, UNICEF, ACHAP, Botswana-UPenn, NNH Trust, University of Botswana, University of Cape Town, and Serious-Fun, amongst others. Our most valued assets, our dedicated staff, have continued to go above and beyond the call of duty to meet these needs with your support.

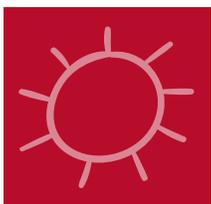
As we move forward, we are embarking on a new journey, dealing with even more maladies that affect our population. At the forefront is our support for the fight against **cancer and blood disorders**. Our impact can be measured by the number of lives touched directly or indirectly in this area. **We continue to strive for excellence through unsurpassed clinical care, education, research, and continuous quality improvement efforts that serve the whole country, not just our direct clients.** We define ourselves by taking a more active role in our community, supporting our government, educational institutions, and civil society.

Through collaborations, we have helped other institutions to achieve their mandates this past year, as illustrated by the following few examples:

- We are working with the **Bristol-Meyers Squibb Foundation** to construct the first children's cancer and blood disorder centre in the region, thanks to their \$50 million grant. Hundreds of health workers have already been trained to staff the programme.
- Through a grant from the **Collaborative African Genomics Network (CAfGEN)**, we supported **six PhD candidates in Genetics** for the University of Botswana. This is the first cohort to be trained to this level, boosting the number of expert geneticists in Botswana and helping our government move closer to the desired 'knowledge-based society'. Through the same grant, we will start to build the bioinformatics infrastructure at the university.
- A grant from the **IFgeneRA** project has allowed us to start training **one more PhD candidate** for the University of Botswana in Bioethics, boosting capacity in the Office of Research.
- The **Novo Nordisk Haemophilia Fund** grant allows us to support the efforts of the Ministry of Health and Wellness to provide services for patients afflicted with haemophilia.
- Through the **Computerized Neurocognitive Battery** grant, we are developing a digital tool that will help speed up the assessment of cognitive deficits in school children for the Ministry of Basic Education.

Once again, I would like thank you for your support. With your help, now and in the future, we are improving the lives of our fellow Batswana.

**Pula!**  
**Mogomotsi Matshaba**  
Executive Director



## OUR MISSION

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



## OUR VISION – BOTSWANA-BAYLOR

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

# BOTSWANA

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 HIV-infected children, adolescents, and young adults and their families from around the country. Our services extend to oncology care and treatment for patients around Botswana. 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, a tertiary care referral hospital.

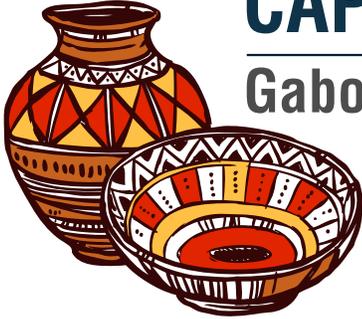
Botswana-Baylor provides free-of-charge, state-of-the-art paediatric HIV care, treatment, and support to children, adolescents, and their families at the main clinic in Gaborone and through decentralised outreach services across the country. Botswana-Baylor is a leader in the field of paediatric HIV 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. Since this will take some time, it is envisaged that the haematology and oncology services will be relocated to Sir Ketumile Masire Teaching Hospital during the year 2019. These services are currently provided at Princess Marina Hospital Paediatric Ward.

# BOTSWANA

## CAPITAL

Gaborone



## Official languages

English  
Setswana

## Demonym(s)

Batswana (plural)  
Motswana (singular)

Nation of  
**2.250.260**



in habitants



**320.000**

People living with HIV

**23.8%**

adult HIV prevalence (ages 15-49)

**74%**

adults on antiretroviral treatment\*

**60%**

children on antiretroviral treatments\*

\*All adults/children living with HIV  
Source: UNAIDS Data 2018



Officially the  
**REPUBLIC OF  
BOTSWANA**

# AT A GLANCE

## COE Programmes and Services



**Paediatric Infectious Diseases Clinic (PIDC)**



**Adolescents Programmes**



**Botswana Paediatric Haematology and Oncology Programme**



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



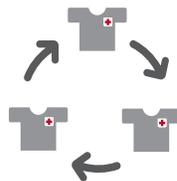
**Paediatric KITSO Training**



**Advancing Partners and Community (APC) Project**



**Outreach Mentorship Programme**



**Collaborative African Genomics Network (CAfGEN)**



**Visiting Scholars Programme**



**Public Health Evaluation (PHE) – Ba Nana Study**

# OPERATIONAL OVERVIEW



## Botswana-Baylor Children's Clinical Centre of Excellence 2017-2018 Staff Overview

|                                 |    |   |
|---------------------------------|----|---|
| Doctors                         | 9  | 4 HIV and 5 Oncology  |
| Nurses                          | 10 | 9 COE and 1 PMH   |
| Social Worker                   | 1  |   |
| Clinical Psychologist           | 1  |   |
| Lab Technician                  | 1  |   |
| Other Staff                     | 64 | Project Staff: 45<br>Finance, Administration and Others: 29 |
| Long Term Volunteers and Intern | 4  |   |
| Total Staff                     | 90 |   |

# 2017-2018 Highlights

## 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, Letlhakane, Tutume, Ghanzi) for a 24-month follow-up period. Both quantitative and qualitative evidence will be collected to evaluate the intervention package. Botswana-Baylor, in partnership with MoHW, will be responsible for designing and implementing the interventions. UNICEF will provide the funding and hire a consultant to conduct the evaluation and costing.

## CAfGEN Study Updates What is CAfGEN?

The Collaborative African Genomics Network's (CAfGEN) primary objective is to create a collaborative, multi-disciplinary, multi-institutional, inter- and intra-country network of African scientists, clinicians, and researchers using genomics approaches to study gene/environment interactions for HIV/AIDS, its co-morbidities, and other diseases among diverse paediatric African populations.

## Why CAfGEN?

Advanced genetic and genomic technologies promise to transform our understanding and approach to human health and disease. Such genomic analyses are now common in Western populations of European descent. Studies of host genetic factors underlying long-term non-progressors of HIV infection have led to new therapies through the identification of loci that are important to in vivo control of virus pathogenicity. Similar studies of host genetic factors influencing active TB infection have also identified important loci that could significantly impact the future development of more effective therapeutic and prophylactic strategies.

Most of the studies were undertaken in non-African, adult populations; yet there are more than two million new cases of HIV and HIV-TB in Sub-Saharan Africa every year, including more than half a million in children. Moreover, HIV-infected children — who differ from their adult counterparts in their route of acquisition, clinical course, and pathophysiology — have been conspicuously absent, although they potentially have more to ultimately contribute and gain from therapeutic advances.



Above: The CAfGEN team gathered in Kigali, Rwanda, with other members of H3Africa during the first cycle of the 12th H3Africa Consortium.

In sum, the specific aim of CAfGEN is to redress this scientific imbalance by integrating genetic and genomics technologies to probe host factors that are important to the progression of HIV and HIV-TB infection in Sub-Saharan African children.

## Site Visits

Amongst other activities, the CAfGEN team has been visiting other facilities in the Baylor network to train, support, and mentor CAfGEN sites, such as Eswatini COE, Uganda COE, and Makerere University. **One of the most important achievements is the implementation of the REDCap as a way of improving data capture and access by all stakeholders in H3Africa, a genetic research consortium.**

Botswana-Baylor's CAfGEN team has benefitted from increased collaboration with other CAfGEN sites. Working alongside these sites, we've been able to draw upon the extensive clinical and research experience of other researchers to further develop the genetic and genomic capabilities of the network. This will further cement our ability to provide the mentorship, training, and genomics expertise needed to fully establish state-of-the-art technologies in CAfGEN.

The duties of Botswana COE, Eswatini COE, and Uganda COE are recruiting sites, enrolling participants, and collecting and forwarding samples to respective universities. The University of Botswana and Makerere University have molecular genetics expertise. They are responsible for processing, aliquoting, and transferring samples to BCM.

## Collaboration

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



Above: The Botswana COE team travelled to Royal Villas, Eswatini, where Executive Director Dr. Mogomotsi Matshaba (centre) updated CAfGEN stakeholders. Pictured left is Finance and Administration Manager, Olekantse Molathegi, and right is Research Coordinator, Keofentse Mathuba.

## International Visits

On May 28, 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.



Above: From left, Dr. Slone, Dr. Matshaba, Mr. Ed Royce, and Mr. Earl Miller

# PROGRAMMES



## Paediatric Infectious Disease Clinic (PIDC)

The PIDC at Botswana-Baylor provides 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 2,416 active patients, most of whom receive follow-up care every three months as recommended. On average, the clinic sees 90 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 case load of 15 adult patients daily. Even with an increasing adolescent and young adult population,

clinical care outcomes continue to be exemplary. The rates of lost-to-follow-up, viral load suppression, and mortality are unsurpassed in Botswana at 1.25%, 91.85%, 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 minimising long-term treatment toxicities and monitoring for non-communicable diseases.

| <b>TB Report: July 2017 – June 2018</b>        |   |
|--|---|
| Total Number of Patients Diagnosed with TB     | 6 |
| Total Number of Patients on ATT                | 8 |
| Total Number of Patients who Died while on ATT | 1 |

Note: All patients had Pulmonary TB.

## Screening Clinic

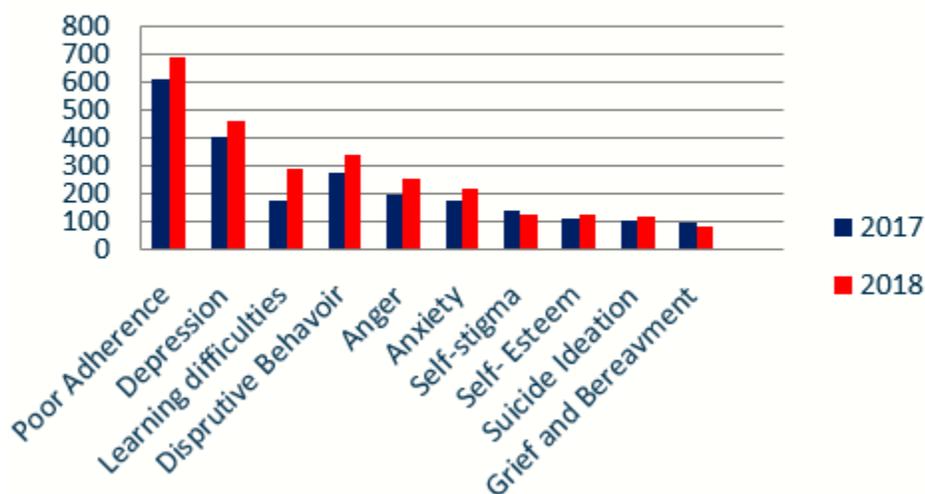
The national Prevention of Mother-to-Child Transmission (PMTCT) programme makes referrals to Botswana-Baylor for postnatal HIV screening at six weeks. In the report period, our staff tested 43 infants. The three who tested positive were initiated on treatment and care services. According to the Botswana 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). We suspect the others were 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 71 Double Rapid Tests, and 33 had positive results. Twenty-six of these individuals were initiated on ART at Botswana-Baylor.

## Clinical Psychology

This year marks 10 years of success in addressing mental health cases in the Clinical Psychology Department. Among 3,313 cases seen for the year ending 2018, we have achieved a success rate of over 90%, with improvements in behaviour, ART adherence, school performance, and the achievement of self-reported desired outcomes. We also monitor viral load suppression, increases of CD4, and overall good quality of life as indicators of success for both counselling and psychotherapy services provided by the psychology department. Unsurprisingly, as more and more perinatally HIV-infected children reach adolescence, the number of psychological problems related to this age group also increases. The graph shows the increases in the kinds of cases presented to the Psychology Department from 2017 to 2018.

**Top 10 Psychological Issues for the Year 2017 and 2018**



## Social Work

The social work department provided social welfare counselling services to all COE patients and their caregivers. Supportive counselling and adherence counselling remain the core services offered by our social worker, Ms. Tapiwa Tembwe. Supportive counselling involves mostly family care intervention and home visit follow-ups. Home visits are done on monthly basis. These include visits for patients failing treatment, defaulting, or lost to follow-up (LTFU). Ms. Tembwe conducts emergency home visits for patients with social issues at home. She also completes home visits accompanied by a nurse to assist patients LTFU or those who have defaulted treatment so that they can re-initiate HAART or receive adherence counselling.

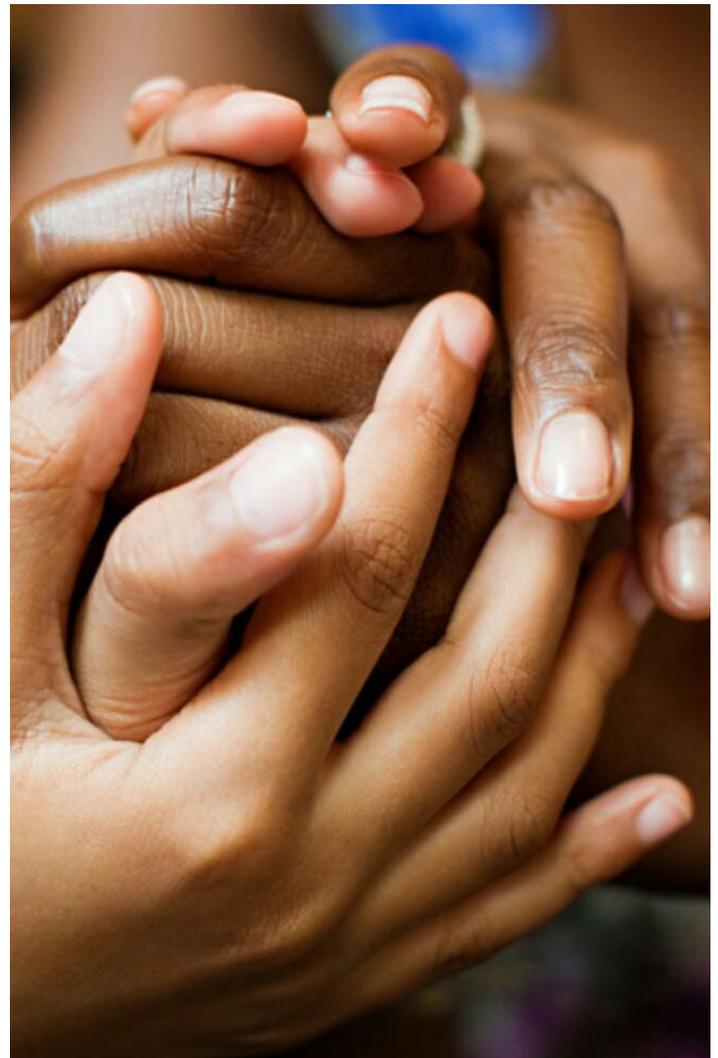
### The Top 5 Types of Cases Presented to the Social Work Department

- Supportive counselling
- Adherence counselling
- Child negligence and/or abuse
- Food and financial insecurity
- Transport funding

### 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. In 2017, we implemented the first ever family weekend camp, jointly planning, funding, and conducting the event alongside SeriousFun. The camp took place at Oasis Motel, which is situated almost 2 kilometres from the centre of Gaborone. This inaugural weekend

camp, taking place 6-8 October, 2017, welcomed 30 campers with medical challenges and their 30 caregivers. In 2018, we held another family weekend camp from 13-15 July again at Oasis Motel. The weekend camp affords our campers who have adherence, disclosure, and other psychosocial challenges to reflect on them, share them with their caregivers in a safe environment, and learn new life skills. The caregivers have the opportunity to also understand their children's experiences and challenges and work to help solve them during camp.



## Cervical Cancer Screening

Beginning in November 2016, Botswana-Baylor integrated cervical cancer screening and management into our routine clinical services, targeting sexually active girls and young women older than 15. Though the Botswana national cervical cancer screening guidelines recommend screening for women aged 30-49, our physicians have identified increasing numbers of cervical cancer cases among younger women and girls served at Botswana-Baylor. Between June 2017 and July 2018, we screened 73 patients aged 18-49 years. Of these, eight patients were positive for human papillomavirus, a cause of cervical cancer. In addition, seven patients were diagnosed and referred for treatment for sexually transmitted infections, including genital warts, pelvic inflammatory disease, 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 paediatrician or medical officer and a nurse prescriber provide clinical care services to patients alongside the local medical staff. The outreach team also conducts didactic educational sessions structured around the fundamentals of paediatric and adolescent HIV treatment and care.

Over the reporting period, the outreach programme covered 13 large ARV sites, mentoring 202 healthcare workers and seeing 1,403 patients. Of these, 594 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 transition from some ART sites where staff have been well mentored and are able to handle challenging paediatric and adolescent cases independently and expand its outreach to more ART sites nationally.

## Advancing Partners and Communities (APC) Project



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

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. Because of budgetary limitations in the past year, the number of Botswana-Baylor community health workers reduced from 33 to 30. Their main mandate was to conduct quarterly follow-ups with clients (for some clients, follow-ups are done monthly depending on their needs), 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 Botswana-Baylor provides under the APC project include Teen Clubs and caregiver education sessions.

The focus of the third year of the APC project (between 2017 and 2018) was to follow up with 2,640 children and adolescents who were enrolled in community care during the previous year. By June 2018, month nine of the project year, the community health workers conducted follow-ups for 83% (2,187 out of 2,640) of clients.

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

More and more children are leaving the project because of age restrictions, while fewer clients are enrolling: Fewer children are vertically infected thanks to the high success rate of the Botswana PMTCT programme.

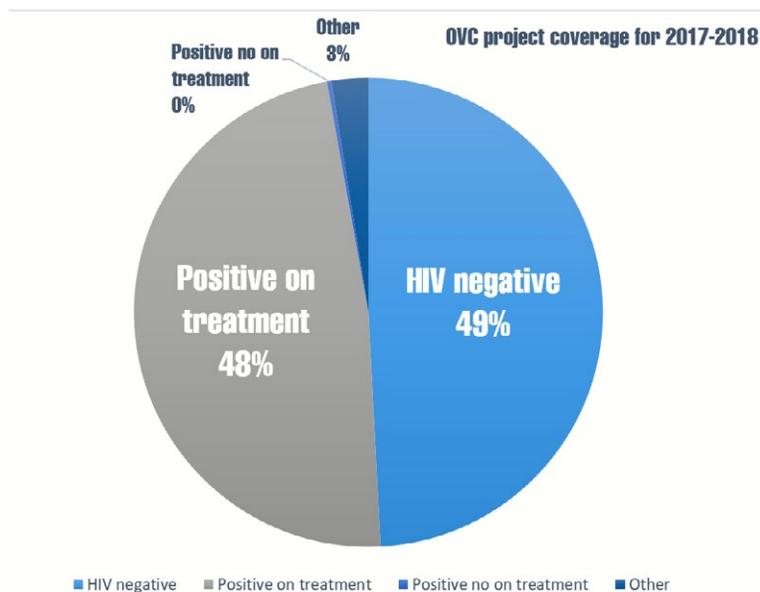
# Botswana Comprehensive Care and Support for Orphan and Vulnerable Children (OVC) Project

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 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 organisation 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 programmes and provide counselling 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 home visit every three months.

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



# ADOLESCENT PROGRAMMES

Above: The Teen Club Talent Show, held at the Phatsimong Adolescent Centre, empowers teens to showcase their talents and celebrate their peers.



## 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, 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 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 who attend sessions at the satellite sites continue to advocate for annual camps, but limited funding has so far prevented this.



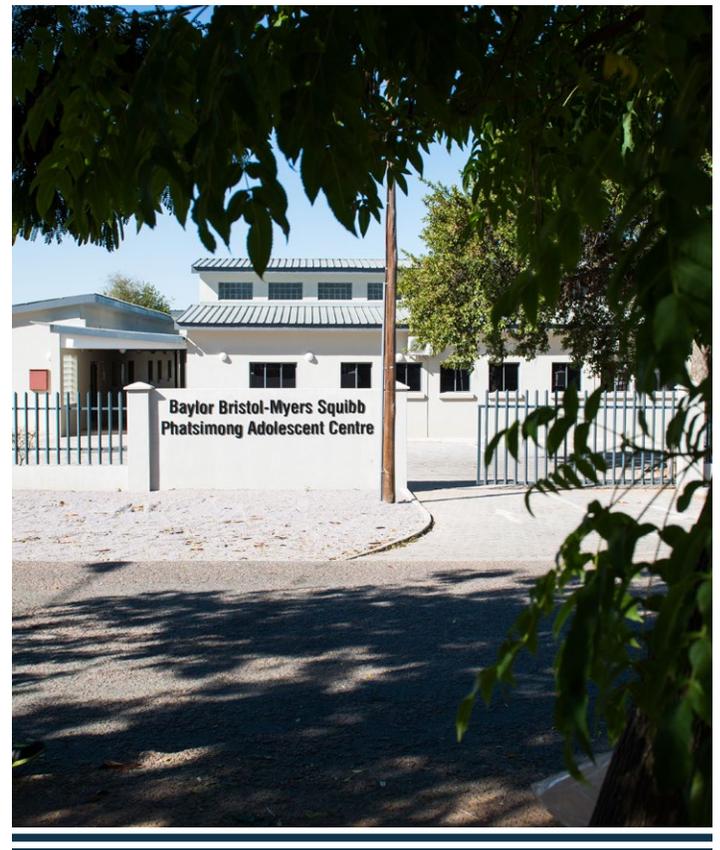
## Young Adults Support Group

The number of young adults between 18-25 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.

## 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 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.

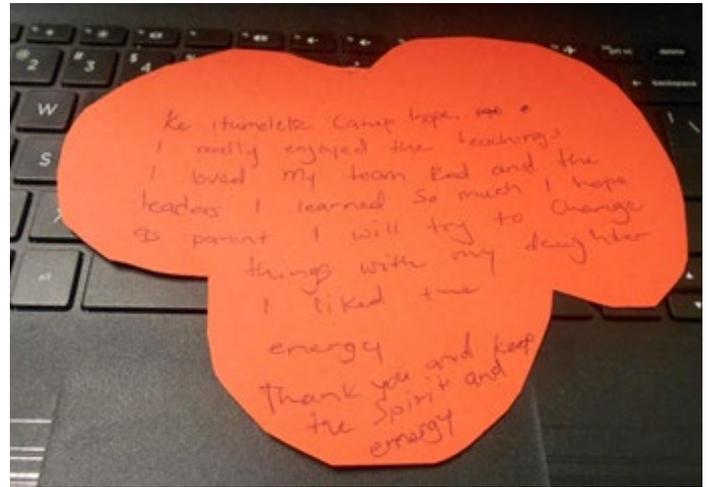


## Camp Hope

Botswana-Baylor's partnership with SeriousFun Children's Network inaugurated a Family Weekend camp in October 2017. Many participants saw this type of camp, which brings together adolescents with medical and psychosocial challenges and their caregivers, as a step in the right direction. For caregivers, it was a moment to spend time together with their children, understand their children's perspectives, and collaborate on solving challenges. A total of 30 adolescents and 30 caregivers attended the camp, which was held at Oasis Motel.

The Camp Hope residential camp was held in December and brought together 117 children. It was held at Big Five Lodge 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.

Other 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.



\*English translation of "ke itumeletse:" thank you

Camp Hope Botswana successfully completed the requirements for the December 2016 SeriousFun criteria assessment, meaning Botswana-Baylor's Camp Hope is in good standing with SeriousFun Children's Network and will continue to be eligible for funding and other SeriousFun benefits.

***"Ke itumeletse Camp Hope. I really enjoyed the teachings. I loved team Red and the leaders. I learned so much. I hope as parent I will try to change things with my daughter. I liked the energy. Thank you and the keep spirit and energy."***

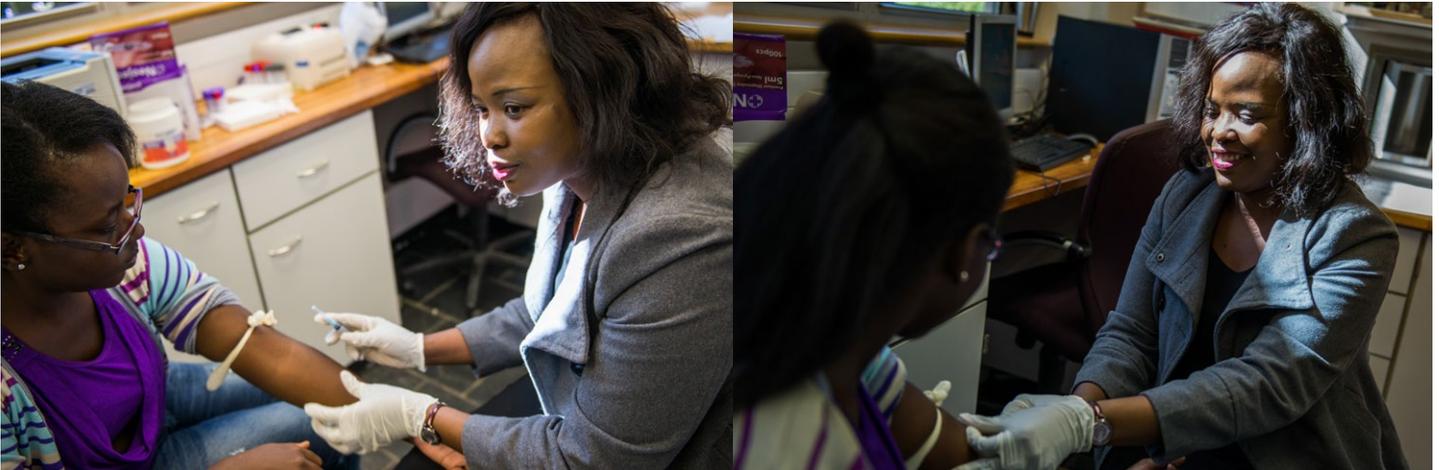
## Tutoring

The tutoring programme was established in 2008 to support school-age patients with learning difficulties and/or poor academic performance. Through weekly tutoring sessions, over 200 children and adolescents have received this free academic assistance. COE patients often miss, at 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 enrolls youth in Standard 1 - Form 5 and averages 15-25 attendees per session. 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.



# GLOBAL HOPE BOTSWANA



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. Funded through a \$100 million start-up grant from the Bristol-Myers Squibb Foundation, Texas Children's Hospital, and BIPAI, a key focus of Global HOPE is to expand local capacity that will serve as a foundation for long-term sustainable excellence in managing paediatric cancer and blood disorders. Botswana Paediatric Hematology-Oncology (PHO) programme, located at Princess Marina Hospital, has been offering comprehensive PHO services since 2007 and provides the starting point for Global HOPE in Botswana. The number of patients being diagnosed every year is increasing and many patients are still presenting at an advanced stage.

## TRAINING & EDUCATION

From November 2017 to September 2018, Global HOPE trained 202 healthcare workers in a wide range of functions, including medical officers, faculty, residents, intern medical officers, laboratory technicians, and visiting scholars.

## COMMUNITY ACTIVITIES

### Community Stakeholder Meetings

No single initiative can tackle the enormous burden of paediatric cancer and blood disorders in Botswana. So, as Global HOPE lays the foundation for its activities, one of the first steps was to initiate the Global HOPE Botswana Community Stakeholder Forum. This group comprises various local organisations involved in cancer and related illnesses. The goal of this initiative is to create a platform where partners jointly plan, share progress on activities, minimise duplication, and share resources. The Community Stakeholder Forum also seeks to unite individuals and groups assisting patients and families affected by cancer and blood disorders.

## September - Childhood Cancer Month

The Botswana Survivor Party has been an annual event since 2015. It has traditionally been held in September, in honour of Childhood Cancer Awareness Month. This event is one of the most important that we host every year, as we celebrate the lives of our brave survivors and their families.

Since 2016, it has been held at Northside Primary School, in partnership with their Standard 7 students (equivalent to Grade 6 in the US school system). The goal of the event is to invite all our patients, both on therapy and now off therapy, for a day of fun to celebrate overcoming the challenges and stress of their treatment.

This year we held the Childhood Cancer Survivor party on 14 September. The event provided a wonderful chance for some of our children and families to see each other again and share experiences, after having been through treatment together. A total of 51 survivors attended, each with at least one family member.

## **PAEDIATRIC PALLIATIVE CARE**

The first dedicated Paediatric Palliative Care (PPC) unit in Botswana was established in partnership between Princess Marina Hospital Palliative Care Services and the PHO programme in November 2017. The PPC programme has two main goals: to increase awareness among primary care providers to recognise when a child needs palliative services, and to assess the emotional and spiritual needs of the child and their family.

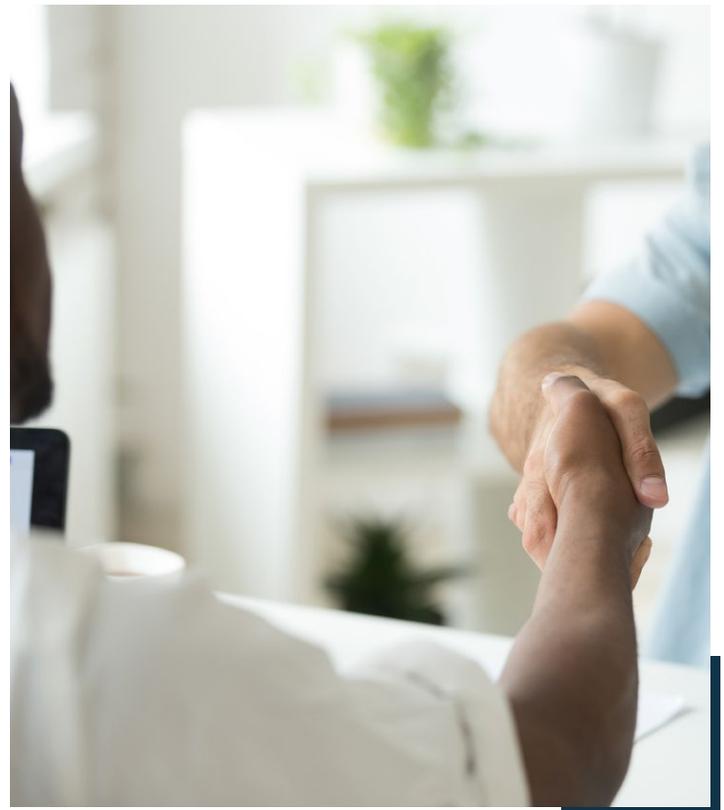
The team consists of Dr. Kamusisi Chinyundo, a Global HOPE paediatrician; an adult Palliative Care Specialist; and a specialist palliative care nurse. Services are provided in accordance with

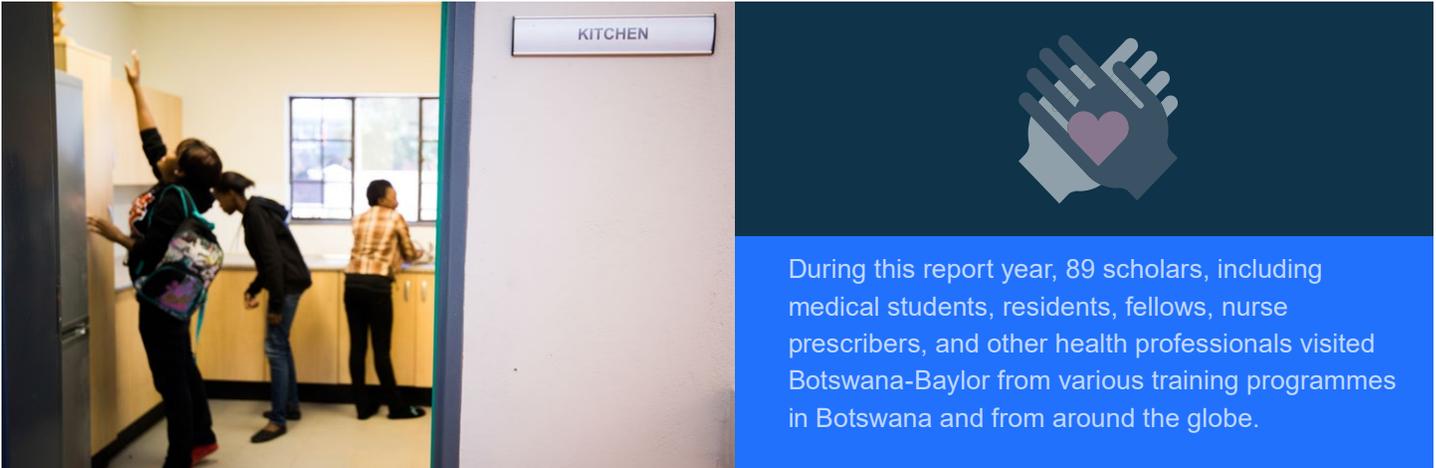
the Botswana National Palliative Care Strategy and Pain Management Guidelines. The PHO team identifies patients and refers them to the PPC service, which offers weekly rounding for inpatients and monthly outpatient clinics.

## **ACKNOWLEDGEMENTS**

We would like to extend our heartfelt gratitude to our partners for supporting our different activities throughout the year. Your assistance is highly valued and we wish to continue collaborating with you:

Bristol-Myers Squibb Foundation, Novo Nordisk Haemophilia Foundation, Lions Club of Gaborone, Lions Club of Phakalane, Botswana Life Insurance, Ladies Circle Botswana, Young Fighters Foundation (USA based NGO), De Beers, SensoBaby, Maruapula Secondary School, and Northside Primary School.





During this report year, 89 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.

## Paediatric KITSO AIDS Programme

Paediatric KITSO (Knowledge, Innovation, and Training Shall Overcome) AIDS 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 126 professionals drawn from Mahalapye, Palapye, Tutume, Kasane, Selibe-Phikwe, Bobonong, Mmadinare Letlhakane, 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 highlight the role health workers play in achieving the UNAIDS 90-90-90 global treatment target to end the AIDS epidemic by 2020. We will also introduce new approaches and interventions in HIV prevention and care, such as the pre-exposure prophylaxis.

## Visiting Scholars Programme

During this report year, 89 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 the Baylor College of Medicine in Houston, Texas. The visiting scholars spent most of their time in the COE and with the Paediatric Oncology and Haematology ward at Princess Marina Hospital, shadowing and working alongside experienced clinicians and researchers. Some of the scholars spent time with the outreach teams at other ART sites.

## Visiting Scholars' Testimonies

“Baylor College of Medicine is an esteemed and world-renowned academic health centre, and this is what convinced me to apply to their winter elective programme. As a medical student, I wanted to make my school holiday exciting but also informative, and Botswana-Baylor did not disappoint me. I spent four weeks working alongside the fantastic staff and incredibly knowledgeable doctors at the Botswana-Baylor Children’s Clinical Centre of Excellence. This centre is well equipped and specialises in paediatric HIV care, working alongside other government-appointed facilities in combating the HIV epidemic in Botswana. I was offered a well-rounded experience, from taking patient histories to performing physical examinations and investigating lab tests and drug interactions. I also conducted follow-up appointments and accompanied doctors on outreach visits. Botswana-Baylor far exceeded my expectations.”

- Yaseera Koya, MBBS  
Shanghai Medical College of Fudan University



Above: Yaseera visited a safari in the Okavango Delta in northern Botswana during her time as a Visiting Scholar.

“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 low-resource settings, this programme provided me the opportunity to get hands-on experience — I highly recommend it!”

- Shilpa Thaivalappil, MD, MPH



Above: Shilpa travelled to the Elephant Sands near Nata, Botswana, during her time as a Visiting Scholar

# Special Feature: Telling the Baylor Story

## Founding Support

### A Teen Club founder reflects on his role in Teen Club's development through the years.

I'm the only child of my late parents. I lost my mom at the age of 4, and four years later my dad passed away. I was adopted by my mom's sister, who later passed away after 10 years. Between 2000 and 2004, I used to get really sick. Then, finally, a private doctor suggested that I get an HIV test and that was in 2004 when I was 12 years old. I remember the night my aunt told me that the doctor had proposed I take an HIV test. I couldn't help but wonder how that could even be possible since I wasn't sexually active. At that point I didn't know that HIV could be spread in other ways. For two weeks, I refused to take the test.

Finally, she took me to a doctor who explained why it was important that I take the test. When we returned later for the results, he told me that I was positive. I didn't know what that meant or how I was going to deal with it. But the doctor who performed the test referred us to Baylor.

As soon as I got to Baylor and started treatment, it didn't take long for the staff to recognise how engaged and happy I was to be there. The following year, in May 2005, I became one of the founding members of Teen Club. With Teen Club I was able to say, "Oh, okay, I'm not the only person in this condition. There are all these people I can talk to, share information, and exchange advice here and there." I was able to see different children, with different issues, living in different places and conditions so it was very interesting for me.

When we started Teen Club it was only two boys and three girls. Nonetheless, it was a community that helped us learn "you are not going through this alone. There are more people in the same situation. We need to get to know each other." So we started having casual activities that allowed us to start in-

teracting and connecting. We would paint, draw, go to Mokolodi Nature Reserve for camps, and a lot of other fun activities. In the beginning, it was just for fun. A year later we decided to start bringing education to Teen Club. We talked about how HIV is contracted, how to protect yourself and others, and teenage pregnancy issues. It was everything in one.

From being a Teen Club member and founder, I became a Teen Leader. Being a Teen Leader played a major role in my life because it came with responsibility. They picked Teen Leaders based on how they performed with adherence so I would always make sure that I was adhering to my medication.

Because of this my adherence has always been good and allowed me to interact with the other Teen Club kids with confidence. Additionally, the work I did as a Teen Leader greatly impacted my current career. I was offered an internship with Positive Innovation for the Next Generation (PING) because of my experiences founding and leading Teen Club. I worked for PING from 2011 to 2013, at which point I started my own business.

Baylor has become my second home. I have nurses and doctors who care for me like I am their own child. Most importantly, they don't make it difficult to talk to them. They ask me, "Are you having sex?" When I was young I would just laugh but they still ask me now. That's how open they have been with me since day one. This openness allowed me to realise that if I passed it on to someone, I would blame myself in the end so it encouraged me to keep away from girls until I understood the importance of safe sex. That openness, that openness allows me to say, "Hey I'm thinking of doing this. What do you think?" These are things I can't say to an adult at home. These are just some of the things that make Baylor a great place to be.

# SCHOLARLY ACTIVITY



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**

Begun in 2014, the CAfGEN study continues in its mission 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 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 by the National Health Institute (NIH). Recruitment for the second phase started in May 2018; so far, 240 participants for the retrospective cohort have been recruited, and of those 131 participants were in CAfGEN 1, 18 are new participants, and there is one TB case. The study recruitment process was suspended since September 2018, while still processing FWA renewal.

CAfGEN supports training of African genomic scientist, and two PhD trainees have been identified and recruited into the CAfGEN trainee programme through the University of Botswana. They start their training in January 2019 in Houston, Texas.

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

The Medical Audit Protocol produced nine abstracts, of which four were oral and five were posters presented at BIPAI meeting in 2017.

1. Psychological Reactance Is a Novel Risk Factor for Adolescent HIV Treatment Failure
2. The Impact of Camp on Adherence Challenges in Adolescents at Botswana-Baylor Children's Clinical Centre Of Excellence
3. Outcomes of Adolescents and Young Adults with Virological Failure at 10 Botswana-Baylor Children's Clinical Centre of Excellence (BBCCOE) Outreach Sites in Botswana
4. Distinctive Barriers to Antiretroviral Therapy Adherence Among Non-Adherent Adolescents Living with HIV in Botswana.
5. Factors Surrounding HIV Positive Adolescents and Young Adults Who Attempt Suicide at an HIV Clinic in Botswana
6. Adolescent Motherhood: The Risk Factors for Second Generation Vertically HIV Infected Children
7. Implementation of Comprehensive Community Care and Support for Orphaned and Vulnerable Children
8. Integrating Cervical Cancer Screening into Routine Clinical Services at Botswana-Baylor COE
9. The Role of Community Health Workers in Paediatric and Adolescent HIV/TB Care: The Experience of Botswana-Baylor Children's Clinical Centre of Excellence (BBCCOE)



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

Adolescents and young people living with HIV are at higher risk of being lost to follow-up as well as experiencing worse clinical and psychosocial outcomes compared with adults. This is commonly because of a variety of barriers that prevent HIV-positive youths from accessing appropriate treatment and care services, inadequate social support by caregivers and/or peers, and stigma and discrimination.

Despite this, there are not many studies that examine an integrated package of care for these young people. Evidence on the effectiveness of a package of care in the Botswana context is required to inform the design and delivery of services aimed to improve their health and wellbeing. In addition, implementation costs should be determined in order to establish if it is feasible for government and other partners to scale up and sustain those intervention packages.

To address the gap, the Botswana-Baylor Children's Clinical Centre of Excellence has designed an impact evaluation in partnership with the Ministry of Health and Wellness, District Health Management Teams, UNICEF, and local civil society partners. The mixed methods evaluation will measure the effectiveness of a multi-pronged intervention package on clinical, psychosocial, and behavioural outcomes of a cohort of HIV-infected 10- to 24-year-olds on ART living in Selibe-Phikwe, Letlhakane, Tutume, and Ghanzi for a 24-month follow-up period. The study will recruit 400 youths to participate in the study. Both quantitative and qualitative evidence will be collected to evaluate the intervention package.

Botswana-Baylor and the District Health Management Teams will be responsible for designing and implementing the intervention package. UNICEF will provide the funding and also contract an independent consultant to evaluate and estimate the cost of the interventions. The Ministry of Health and Wellness will provide oversight and support to the project.

## Publications

1. Mboowa G, Mwesigwa S, Katagiryra E, Retshabile G, Mlotshwa BC, Williams L, Kekitiinwa A, Kateete D, Wampande E, Wayengera M, Kintu BN, Kisitu GP, Kyobe S, Brown CW, Hanchard NA, Mardon G, Joloba M, Anabwani G, Pettitt E, Tsimako-Johnstone M, Kasvosve I, Maplanka K, Mpoloka SW, Hlatshwayo M, Matshaba M. 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; referees: 2 approved]. *AAS Open Res* 2018, 1:3 (doi: 10.12688/aasopenres.12832.1)

2. Retshabile G, Mlotshwa BC, Williams L, Mwesigwa S, Mboowa G, Huang Z, Rustagi N, Swaminathan S, Katagiryra E, Kyobe S, Wayengera M, Kisitu GP, Kateete DP, Wampande EM, Maplanka K, Kasvosve I, Pettitt ED, Matshaba M, Nsangi B, Marape M, Tsimako-Johnstone M, Brown CW, Yu F, Kekitiinwa A, Joloba M, Mpoloka SW, Mardon G, Anabwani G, Hanchard NA; Collaborative African Genomics Network (CAfGEN) of the H3Africa Consortium. Whole-Exome Sequencing Reveals Uncaptured Variation and Distinct Ancestry in the Southern African Population of Botswana. *Am J Hum Genet*. 2018 May 3;102(5):731-743. doi: 10.1016/j.ajhg.2018.03.010. Epub 2018 Apr 26.

# OUR PARTNERS & DONORS

## Grants and Donations

During 2017-2018, 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 and Wellness | 7,777,500    | Core Activities, Outreach, KITSO  |
| NIH                             | 4,958,795    | CAfGEN                            |
| CHOP                            | 30,619       | PHE Study                         |
| FHI360                          | 2,861,012    | APC Project                       |
| PCI                             | 2,202,330    | OVC Project                       |
| Texas Children's Hospital       | 1,9449,623   | PHO                               |
| SeriousFun                      | 379,813      | Camp Hope/<br>Family Weekend Camp |
| University of Cape Town         | 218,720      | IFgenRA                           |
| UNICEF                          | 801,449      | Adolescent Programmes             |

| Other Donations            |                      | Activity                        |
|----------------------------|----------------------|---------------------------------|
| Hodges Partners (US)       | 2,500 USD            | 2017 Children's Christmas Party |
| Furman University          | 1,000 BWP            |                                 |
| Avukile Zoya GoFundMe      | 6,104.21 BWP         |                                 |
| KFC                        | Food                 | Adolescent Programmes           |
| Broadhurst Primary School  | 150 Presents         | 2018 Children's Christmas Party |
| Pie City                   | Pies                 |                                 |
| Oasis Motel                | Ice cream & cupcakes |                                 |
| Chicken Licken             | 500 meals            |                                 |
| Nicholas Hastings GoFundMe | 14,153.56 BWP        |                                 |
| Doug Ford                  | 2,000 BWP            |                                 |

## Consolidated Financials – BWP

(Fiscal year ending 30 June, 2018)

### 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



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**BIPAI** Baylor International  
Pediatric AIDS Initiative  
*at Texas Children's Hospital*



  
**Texas Children's  
Hospital**

**Baylor**  
College of  
Medicine