# Baylor International Pediatric AIDS Initiative

2011-2012 Annual Report

The Promise: Long, Healthy Lives

#### Our Vision

A healthy and fulfilled life for every HIV-infected and -affected child and their family.

#### Our Mission

To provide high-quality, high-impact, highly ethical pediatric and family-centered health care, health professional training and clinical research, focused on HIV/AIDS, tuberculosis, malaria, malnutrition and other conditions impacting the health and well-being of children worldwide.

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"I can't believe that my son looks this good! I once narrowly escaped being published in the newspapers because of my child's appearance. The child was very thin that I even felt ashamed of people looking at him. I would keep him covered and kept out of sight as much as possible. I now move freely with him. Thank you for changing our lives."

Letter from the President

When we first began treating children with HIV in 1986, our only option was to use adult formulations in child-sized quantities. That early experience led to research that paved the way for development of child-specific medicines.

As we worked with more and more HIV-positive children, their families, their physicians and other health workers, so too did our efforts to treat the whole child. The relationship between HIV and the United Nation's Millennium Development Goals reflects an understanding that the AIDS response is inseparable from broader health and human development efforts.

HIV infection is a systemic disease and therefore so must our response to it. That is why BIPAI's work includes prevention, education, research and care and treatment for not just HIV/AIDS, but those diseases and conditions often concomitant with it, such as tuberculosis, malaria, malnutrition, sickle cell and cancer.

BIPAI centers of excellence and clinics continue to be the leading pediatric health center in each of their respective countries. Our staff members frequently serve as mentors to other health facilities across the African continent and serve leading roles in the development of guidelines and training of providers for the care and management of HIV in each country where we operate.

BIPAI has saved thousands of lives, reduced stigma and discrimination and restored hope to whole communities. We invite you to join us on our journey.

Very best wishes,

#### Mark W. Kline, M.D.

J.S. Abercrombie Professor and Chairman

Department of Pediatrics, Baylor College of Medicine

Physician-in-Chief, Texas Children's Hospital

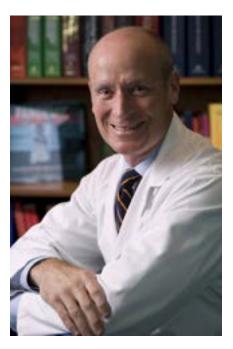
President, Baylor College of Medicine International Pediatric **AIDS** Initiative

A Mother in Uganda

#### **BIPAI at a Glance**

BIPAI is the world's largest university-based care and treatment program for HIV-infected and –affected children.

Budget	<sup>\$</sup> 36.4 million
Patients in care	100,000+
Centers	8
Satellites	4
Offices	8



## About Our Program

BIPAI impacts the lives of the most vulnerable victims of HIV/AIDS – women and children.

Headquartered in Houston, Texas, Baylor College of Medicine International Pediatric AIDS Initiative (BIPAI) at Texas Children's Hospital offers care and treatment to children and their families for HIV/AIDS, malnutrition, malaria, tuberculosis, pneumonia and other concurrent diseases; health professional education and clinical research in resource-limited settings. More than 100,000+ children and adults have received BIPAI services in the last 16 years, making it the world's largest university–based care and treatment program for HIV-infected and –affected children.

The COEs are state-of the-art pediatric and family-centered primary care centers and are, in many cases, the only pediatric-specific infrastructure in the countries where they are present.

BIPAI operates in the U.S., Romania and 10 countries in Africa. It also provides specialized training and technical assistance to numerous partner programs in countries such as Equatorial Guinea and Mozambique.



#### Where We Work

BIPAI specializes in extending life-saving health care to children and families in some of the countries hit hardest by HIV/AIDS. Because effective HIV-treatment requires treatment of the whole child and often family members, BIPAI incorporates into its programs the treatment and study of other pediatric diseases and health conditions including tuberculosis, malaria, malnutrition, hepatitis, cancer and sickle cell disease.

As of June 30, 2012, BIPAI has invested more than \$36 million in pediatric health care infrastructure; \$32.5 million in capacity building by hiring doctors to work and teach where health professionals are in critically short supply; and \$6.1 million in operational support.

You can find BIPAI in these countries:

- 1 Luanda, Angola (IPO)\*New
- 2 Gaborone, Botswana (COE)
- 3 Gondar, Ethiopia (IPO)
- 4 Maseru, Lesotho (COE)
- 5 Monrovia, Liberia (IPO)
- 6 Benghazi, Libya (IPO)
- 7 Lilongwe, Malawi (COE)
- 8 Maputo, Mozambique (IPO)
- 9 Constanta, Romania (COE)
- 10 Mbabane, Swaziland (COE
- 11 Mbeya, Tanzania (COE) Mwanza, Tanzania (COE)
- 12 Kampala, Uganda (COE)
- 13 Houston, Texas USA, Headquarters (IPO) (not shown at right)

COE = Center of Excellence IPO = International Project Office



## Operational Highlights

BIPAI services are provided free-of-charge and delivered by a multidisciplinary team, including pediatricians, nurses, counselors and other health personnel working together to directly care for more than 100,000+ HIV-infected and -affected children and adolescents and their families. Operational accomplishments during 2011-2012 include:

- Transitioned care to local physicians as Pediatric AIDS Corps program ended in some countries
- Expanded income generating activities for patients and family members, especially adolescents
- Continued growth of teen clubs and adolescent-specific services to meet rapid growth of aging patient population
- Established or expanded oncology services throughout network to combat cancers common to HIV patients
- Secured commitment from Texas Children's Hospital to strengthen COE facilities management systems and improve infrastructure throughout the BIPAI Network
- Expanded sickle cell screening program in Angola to Cabinda
- · Placed the first Global Health Corps obstetrician/gynecologist and pediatrician in Liberia
- Serves as a role model for other programs through BIPAI's Teen Club International, with representatives of the Swaziland Teen Club attending the AIDS 2012: XIX International AIDS Conference in Geneva, Switzerland
- Expanded a teach and train project in Serengema, Tanzania, to include the first Global Health Corps surgeon



- Completed third year of medical education program at Gondar University Hospital in Ethiopia which included clinical care and outreach
- Continued expansion of work in Tanzania and Uganda to cover areas previously unserved or underserved by BIPAI
- · Launched the first BIPAI maternal health program "Saving Mothers, Giving Life" in Uganda
- Doubled local funding in Romania to 1,000 separate donations
- Established demonstration gardens at COEs in Tanzania and Uganda to combat food insecurity and teach teens gardening skills

# Testing & Prevention

Testing is the first step toward successful prevention of transmission of HIV from mother to child. That is why BIPAI devotes considerable resources to public awareness campaigns, education and community-wide testing that help identify HIVinfected people and help reduce stigma.

Once identified, HIV-positive people are directed to a BIPAI clinic or a health center partner to receive free counseling, support and treatment, HIV transmission prevention education.

Early identification encourages earlier treatment and thus better outcomes. If BIPAI can get to a child early in the progression of the disease, that child tends to stay healthy, in school and on the path to becoming an adult. If a mother or father receives HIV care and treatment it increases the likelihood of their survival of their children.

BIPAI hosts or participates in hundreds of Know Your Status testing and education events in the



each year.

In Uganda, a pioneer Safe Male Circumcision camp was organized for high school students. During the camp 1,045 males were circumcised in five days. The camps were rolled out to other areas and by June 2012, 16,664 circumcisions had been performed.

services.

countries where it operates. One of its largest partnerships in testing and education occurs in Malawi through the popular Grassroots Soccer program. These large public events succeed in testing and educating thousands of football fans

BIPAI also concentrates on prevention efforts such as male circumcision programs.

Other prevention services include risk reduction counseling, prevention of mother-to-child transmission of HIV and early infant diagnosis and sexual reproductive health education and

## Spotlight: Prevention in a Rural Setting

Herd boys represent a unique facet of life in the highlands of Lesotho. Boys and young men spend months away from home shepherding their livestock – cattle, sheep, and goats. Few interventions have previously addressed this migratory portion of the population working in the most remote areas of Lesotho.

Together with local and international partners, BIPAI Lesotho hosted a special event for the herd boys in Mokhotlong District. The event focused on HIV and sexually transmitted infections (STI) education providing information on safer sexual practices, STI screening and treatment, HIV

counseling and testing, and referral to adolescent-friendly health centers. Over 200 herd boys received age-appropriate health education and over 150 accepted screening and prevention services.

The initiative was extremely well received by the local community and the participating herd boys. Following the success of the pilot in Mokhotlong, the Ministry of Health of Lesotho adopted the model and has organized additional events. BIPAI Lesotho continues to support these testing and prevention efforts.



# (PMTCT)

One of society's best opportunities to make progress in the fight against HIV/AIDS lies in preventing mothers from passing HIV on to their children. That is why BIPAI devotes considerable resources to Prevention of Mother-to-Child Transmission (PMTCT) programs. All programs are geared to helping mothers deliver healthy babies.

Throughout the network, exposed infants (those born to HIV-positive mothers) are supported with services that include:

 Nutrition counseling, such as breastfeeding education and complementary feeding counseling and support

• A call-back program in which all newly-diagnosed HIV-positive infant caregivers are contacted by a counselor to ensure earlier antiretroviral treatment (ART) initiation

country

• The Peer/Expert Mothers program which trains HIV in the basics of PMTCT, infant feeding and exposed infant care and work with nurses at local hospitals. The trained mothers then visit the homes of new or expecting mothers to provide advice, care and education.

• Immunizations, as recommended by each

#### Adolescent Care

Teen Clubs - monthly peer support meetings for adolescents receiving care at BIPAI COEs - continues to grow rapidly as healthy patients become teens. These clubs educate young people on their disease, general health, and leadership and job skills. The goal is to help guide participants toward maintaining healthy lifestyles as they gain independence and transition to adulthood.

Thousands of youth between ages 11 and 21 participate in BIPAI Teen Club activities across Africa. Further, members of one of the Swaziland Teen Clubs were invited to attend the AIDS 2012: XIX International AIDS Conference in Geneva, Switzerland.

Teen Club meetings address relevant yet sensitive topics, primarily those related to HIV

infection and sexual and reproductive health. Topics include adherence to ART, overcoming stigma and discrimination, puberty, sexually transmitted infections, decision-making skills and building healthy relationships.

In Lesotho, an active peer support group for fathers (Caring Fathers) provides emotional and practical support. Recent meetings have focused on food preservation and income-generating activities. Botswana hosts a teen mother club for its young mothers. Several Teen Clubs also help their members through income-generating activities such as gardening and sewing.

Thanks to recognition by UNAIDS as a cuttingedge program in helping transition to adult care, Teen Clubs have been launched in non-BIPAI countries, including Namibia.





#### Spotlight: A Teen Named Mary

Mary is a 17-year old girl living in Tanzania. Her mother passed away while giving birth in 2002. When her father passed away from tuberculosis several months later Mary and her siblings were sent to live with different family members.

Mary became very ill and was taken to the hospital. Test results were given to her family but she was only told to take her medications for a chest cold.

It wasn't until she went to visit the doctor alone that she found out that she was living with HIV. She wanted to cry but did not. She had many questions but no answers.

Believing she had little hope for a future, she began to stigmatize herself and became very depressed. Her medication adherence was poor.

One day she learned about the BIPAI clinic where they treat children for HIV. She met other teens living with HIV. She joined Teen Club and helped start a sewing group, an income-generating activity.

Improving her health and her outlook has taken hard work, but now Mary is calmer, happier and looking forward to becoming self-supporting through her sewing.

"I am so grateful to BIPAI for their help and inviting me here. You all help us so much. If I had not joined, I don't know where I might be. I am very grateful and I love you all very much," said Mary.

#### Satellite Services & Outreach

When BIPAI is establishing itself in a new country, it works with the Ministry of Health to match its services to that country's health care priorities. If a center of excellence (COE) is needed, the country chooses a location with the highest needs. The COE then serves as that country's hub for pediatric HIV/AIDS care. Over time, BIPAI decentralizes by building satellite clinics in smaller cities in order to reach those rural areas.

BIPAI also works to ensure equity and quality care in peripheral geographic settings by mentoring medical professionals in outlying areas using a variety of methods. These include:

 Home visits for patients with adherence problems

• Toll-free telephone lines for outlying physicians to call with questions about patient care

• Focused education for health care professionals who are caring for HIV-positive children • Peer education for patient advocates and key community members

• Training for school teachers and community members who may be called upon to care for HIV infected children

BIPAI Botswana's pioneering efforts in homebased intervention were recognized as a best practice by UNICEF in May 2012. The Botswana outreach program continues to be widely duplicated worldwide.

The goal of outreach is simple: To ensure that children and caregivers have all the support needed not only at the clinic level but at family and community level too.

Taking services into the home encourages testing of all family members, lessens the stigma associated with visiting an HIV clinic, and reduces the financial burden families face when traveling to the center.





#### Expansion & Task-Shifting

In addition to expanding geographically, BIPAI officially announced that it would serve as a medical home for its patients' complete health care in 2011-2012.

Diseases such as tuberculosis, sickle cell, malaria, cancer and conditions like malnutrition and maternal mortality necessitated that BIPAI move beyond treatment of just pediatric HIV/ AIDS to treat all conditions that impact HIVinfected children.

BIPAI also expanded its ability to care for patients through task-shifting – the movement of responsibility for simple tasks from doctor to nurse or from nurse to health assistant. In Botswana, a nurse prescriber (equivalent to a nurse practioner) program has trained several nurses in the care of stable HIV-infected patients.

These nurse prescribers (NP) expand BIPAI Botswana's ability to care for patients by seeing 50 percent of the patients, doubling the number of those seen in 2011. Even better, patient satisfaction remains very high.

In fact, the nurse prescriber program has worked so well, the national government is considering extending the role of NPs to include treatment initiation in other areas of the country.

#### Education

Since antiretroviral medicines for children were first approved by the U.S. Food and Drug Administration in 1990, BIPAI's doctors have worked to address a key component in successfully caring for HIV-infected children – the shortage of health care professionals who know how to treat and manage their unique needs.

Professional development of the local health workforce is crucial to the sustainability of BIPAI efforts in each country in the Network. For this reason, BIPAI is dedicated to recruiting, training and retaining high-caliber local health professionals, finance and adminstrative staff, and monitoring and evaluation staff.

Local personnel, with the exception of the Global Health Corps and assigned administrative leadership from BIPAI, primarily staff the Foundations. Ultimately, these Foundations become integrated into the local NGO landscape just as the COEs become integrated into the MoH systems of care.

The ongoing construction and implementation of BIPAI's COEs represents a substantial investment of capital and resources.

This investment, coupled with an equally substantial investment in human capital and resources, allows for the provision of care and treatment to more than 100,000 children, adolescents, and adults who are currently treated at 7 primary centers in Africa and more than 4 satellite outreach centers.

Other countries and organizations seek out BIPAI for its intensive, well-rounded education for health care professionals working in resource-limited settings.





## Research & Publications

Since the opening of the first Center of Excellence (COE) in June 2003 in Gaborone, Botswana, BIPAI has initiated 106 research studies and 35 publications in medical journals.

Data collected through research activities is used to highlight successful interventions such as drug therapy or behavioral change, model practices that can be replicated, and inform others about lessons learned.

Information is also used to determine if planned program objectives are achieved, if target populations have been reached, and the quality of services provided has improved.

This research is usually conceived and conducted by BIPAI personnel, sometimes in collaboration with local partners who are usually based at other healthcare facilities. Some research has been sponsored by external stakeholders such as Bristol-Myers Squibb, Boeringer Ingelheim

All personnel involved in the conduct of BIPAI research complete training in Good Clinical Practice and obtain certification of such training. Over the last four years, many BIPAI personnel have also followed training in research methodology and this course is repeated intermittently if required as a refresher course or for new recruits.

For external research sponsors possibly the greatest attraction for partnering with BIPAI is the ability to enroll large numbers of HIV-infected children rapidly, especially since patients are now relatively rare in developed countries.



and the Medical Research Council of the United Kingdom. The COEs in Botswana and Uganda are the most experienced in the conduct of research, but studies have been performed by all the other centers in Romania, Swaziland, Lesotho, Malawi, and very recently in Tanzania, the newest of BIPAI's centers in Africa.



# Glossary

AIDS	Acquired immunodeficiency syndrome	
ARV	Antiretroviral drug	
BIPAI	Baylor College of Medicine Internation	
COE	Center of Excellence	
HAART	Highly active antiretroviral therapy	
HIV	Human immunodeficiency virus	
МоН	Ministry of Health <b>PIDC</b> Pediatric Infe	
NGO	Non-governmental organization	
РМТСТ	Prevention of mother-to-child transmis	
ТВ	Tuberculosis	
WHO	World Health Organization	

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