The Stephen Lewis Foundation’s Work on HIV/AIDS in Africa

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I T’S CRUNCH TIME for the AIDS pandemic. Despite all the scientific holocausts about the numbers of people in treatment who are thereby staying alive — six million at last count — there are ten million who require treatment now but aren’t getting it, and for every person we put into treatment, there are two new infections.

The virus continues to outstrip our capacity to respond, and the carnage is most deeply felt in Africa. What is most galling about this state of affairs is the recognition that we’re actually on the verge of a breakthrough against the pandemic.

We have the capacity to roll out treatment as health systems improve and health professionals grow in number; antiretroviral drugs are increasingly available at low cost (and in the new parliament there is a real possibility that the Canadian generic drug legislation will actually pass both House of Commons and Senate); we appear to have a real possibility that the Canadian government will change its stance on imprisoning people who do not have HIV/AIDS; and in the new parliament there is even a chance that the United States (known as PEPFAR) will cut the leveraging which enables it to use anti-retroviral drugs to provide drugs for millions, but to posture as a leader.

It’s worth recalling that when the Stephen Lewis Foundation started out, our call was “Erasing the pain of HIV/AIDS in Africa.” And then, recently it was changed to “Turning the Tide against the pandemic.” It’s frustrating to those of us who have been engaged and passionate about this issue for so many years.

But in the midst of the malaise and the despair of today — or perhaps because of it — something extraordinary has happened. At the grassroots, people are coming together to bond, defiantly, in the struggle against the pandemic.

Even more, those same grandmothers who five years ago lived in a disintegrated, crumbling, run-down shack now have solid homes of brick with sturdy, impermeable roofing. Women who are living with AIDS as a result of sexual violence have access to counselling and home-based care. The home-based care workers, who were always cagily referred to as “volunteers,” in a life and death situation, are now being paid. And now, women who five years ago lived desolate, are today nurturing community gardens and have a sense of purpose. In the words of Jeanne, “That’s what turns the tide.”

The slogan of City of Joy is “turning pain into power.” Women’s pain turns to power. Community gardens bring new revenues and the community thrives. There is a sense of purpose and a sense of hope.

The reason the grandmothers of the DRC are so successful in their support of the grandmothers of Africa is not only because of the Canadian government, but also because of this short message, this fact of human nature — that without purpose, life is empty. The community thrives because people are coming together to bond, defiantly, in the struggle against the pandemic.

We actually see it happening. Canadians who have worked with the grandmothers of the DRC, for example, have been amazed at the extraordinary level of determination and resolve. The grandmothers are responsible for this change. They are angry, and they know that they need to have the skills to achieve it, and only the resources to execute their vision.

A young woman named Jeanne will be amongst the first group of residents. Here’s how she describes what has happened to her:

"When I came out to the Panzi Hospital, I had been raped twice. I was tied to a tree and gang raped. For weeks. I escaped, I got to the Panzi Hospital, had extensive surgery, recovered, and went home. Then she was raped again.

She walked out of the bed and into the Panzi Hospital for a second time. Fast-forward to February 2011 and the opening of the City of Joy. More than a thousand people are gathered in the middle heat under a huge tent. Groups of women are singing and dancing — the ones who have worked on the construction are building on their heads as they dance.

The front rows are packed with dignitaries: The governor of South Kivu province. A representative of President Joseph Kabila. A delegation from UNAIDS. The high-profile actors who are supporters of V-Day. A Ugandan congressman and President Obama’s Ambassador-at-Large for Global Women’s Issues.

Jeanne steps up to the podium, a small but resolute figure. A laptop is projected high above her of powerful faces. Her voice is clear, unemotional, "When you look at me, what do you see?" She asks. "Do I look like an animal? Because you are letting violence happen in your country, would you end it?"

As the translator has sanitized Jeanne’s words, afraid to convey the fullness of the rage, the foreign philosophy giving her strength and support to her question in the midst of the malaise, the translator asks. "Can you see me as an animal? Because you are letting violence happen in your country?"

"Do you see me as an animal? Because you are letting violence happen in your country, would you end it?"

This was no exercise in hyperbole — a return to normalcy. It is a much more radical — and more radical — goal than just survival, or than a return to normalcy. It's a return to normalcy as a leader.

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MALL CHILDREN who are heartbeat-free by the birth of their mother or father, or who are them-
selves suffering from AIDS, are often lost in a place of
grief beyond words.

Thabo, aged 4, was brought to the hospital shortly
after his mother's death. Teachers told that he wouldn't
stop kicking, screaming and crying.

Two music therapists sat beside him and weaved the
touch of his crying into their songs.

Still tearful, he finally allowed himself to be carried
into a music therapy session where he tentatively banged
at a drum. When the therapists demonstrated their
philosophy by picking up his beat on their guitars, Thabo's
face lit up with delight. Months later, he was "well-inte-

rated by looking at the unique rhythm of their speech.

Patients, tenderly, the therapists joined their voices to
his babyish outbursts. By the fourth session, Caylem

suddenly acted out the scene of his father's death.

Patiently, tenderly, the therapists joined their voices to

their status. As a widow, she stood her ground
and sold her home and changed her world.

"Being a field representative has taught me a lot—it has humbled me and strengthened
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younger, and the road ended.

"Most of our work now focuses on grief," explained
one of the therapists. “Music contains all emotions that
need to be expressed, and it is usually safer to express
ourselves through music.”

The emotional, physical and economic burden might well have crushed any one of us.
But Sylvia, being a supportive member of her community, discovered and linking with
so many African sisters, and connecting with her Canadian counterparts, went back
home and changed her world.

"It can and will save Africa," she can certainly be
heard to say.

The treatment of HIV-positive patients is not always an easy one. As a result of the
virus, a number of patients experience chronic health problems.

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As a home-based care worker for Keep a Child
Alive South Africa, a Blue Riband Welfare Centre,
Patricia is passionate about her work. To watch the
suffering and respect with which she does it is heart-warming.

She works with children who have been left behind
due to the AIDS pandemic. She helps them to
feel secure and build up their self-esteem.

She says, "I need to give them love and care so that they can live long, happy, healthy lives."
I.T’S STUNNING how quickly a once-sturdy community can spiral downward into isolation and misery in the wake of a natural disaster, especially when stunning is the reverse spiral how a community can begin to climb back out of the depths, slowly and step by step, using tools and support in a way that ensures momentum.

HIV/AIDS stepped through Uganda and swept away an entire generation of young adults: a whole cohort of productive workers, parents and teachers and family-support units. Left behind, like shipwreck survivors in the remote southern hills of Uganda were a tidal-wreck of old women and orphaned children, in hundreds of tiny villages that were left to crumble in the torrential seasonal rains.

When Kenneth Mugayehwenkyi came home to these hills after studying at South Scotia’s Coady International Institute and earning his MA in public health in the United States, he went to visit one of those grandmothers. Encouraged by her visit, he had been sending money to this hometown grandmother who was raising two prodigal grandchildren. Now that Jaja saw her living conditions—a half-tumbled mud shack, a half-collapsed roof grass open to the rains and a nicotine trail that had been washed away in floods—the utter misery of her impoverishment struck him forcibly.

He began to visit her, and then another of her friends. Soon he had a roster of a dozen grandmothers, most of them grieving, heeding the call to come and find themselves through their difficult days, often with the aid of home-brew liquor.

Kenneth encouraged the women to come together to form a group—what he termed “family” meetings.

Then, observing their starvation and fragile health, he arranged to provide their food for their grandchildren. It was the little plastic bowls they quickly brought with them that alerted Kenneth to the next step he could take, the step that would change all their lives.

The grandmothers’ bowls, he learned, were intended to take home part of the children’s bowl and a wellspring of African ingenuity, creativity and determination that can turn the tide of AIDS in Africa. It can be done.

HIV/AIDS: THE STATISTICS

In the 30 years since the first AIDS diagnosis, more than 25 million people have died and more than 60 million people have become infected with HIV worldwide.

Each day, more than 3,000 people are newly infected with HIV worldwide, including 1,000 children.

For every person starting treatment, two are newly infected.

Of the 33.3 million people living with HIV worldwide, 22.5 million (68%) are in sub-Saharan Africa.

Sub-Saharan Africa accounts for 63% of new HIV infections and 72% of global AIDS deaths.

Of the 16.6 million children (age 0-17) who have lost one or both parents to AIDS, 14.8 million of them are in sub-Saharan Africa.

Of people living with HIV were aware that they were infected in 2009.

Although HIV testing has increased throughout Africa in recent years, less than 40% of people living with HIV were aware that they were infected in 2009.

Of the 15 million Africans who are eligible for treatment, 12.5 million (83%) are not receiving it.

Of people living with HIV with an AIDS diagnosis, 20% of whom are children, are particularly vulnerable; they are several times more likely to be living with HIV than ranks of the same age.

The prevalence of gender-based violence is as high as 95% in some countries, with one in four women in sub-Saharan Africa reporting that their first sexual experience was coerced.

WHAT WE DO

The Stephen Lewis Foundation supports community-based organizations working on the frontlines of the HIV/AIDS crisis. These organizations support children orphaned by AIDS and the grandmothers who have stepped in to care for them, and sustain associations of people living with HIV/AIDS, who are working to address stigma, educate their communities and press for change.

As of 2010, the Lewis Family has funded more than 700 initiatives with 300 community-based organizations in 15 countries. To learn more, visit www.stephenlewisfoundation.org
Kelvin was left to support his younger siblings, including (inset) Gertrude, 13 and Luckson, 11, work with his one battery, which he quickly
simply walked away with everything they could
in the face of almost unbearable loss and hard
too familiar. The other half, less known, is the
HIV and nearly 700,000 children have lost one
Zambia, where one in seven adults is living with
shabby two-room mud huts—headed by orphan
How dogged perseverance and help from the
form CASA, Central Action on HIV/AIDS Zambia, to try to prevent the spread of HIV/
AIDS and to help the afflicted like the Mulenga
difficult and hard time. The mentors are crucial to
K’naan performs ‘Waving Flag’ with four audience members
little packet of energy can light a wider, brighter
themselves, for example, choose
to walk and swimming in the huge lagoons.
without parents
without hope
The Stephen Lewis Foundation
The Stephen Lewis Foundation supports community-based organizations to turn the tide of AIDS in Africa

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THE LUKANGA SHAMPS are a vast and
remote wetland in central Zambia,
home to such remarkable creatures
as the Sichimba, an endemically adapted
to walking and swimming in the huge lagoons.
They are also home to at least 100 households—
slightly two-room mud houses—headed by orphan
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ircraft. That’s a staggering number, even for
Zambia, where one in seven adults is living with
HIV and nearly 700,000 children have lost one
or both parents to HIV/AIDS.

This is one half of a story that has become too
familiar. The other half, less known, is the
extraordinary resilience and creativity of African
communities in the face of staggering devastation.
Kelvin, now 15, is one example of perseverance
in the face of almost unbearable loss and hardship.
Kelvin and his four younger siblings were orphaned four years ago when their father, and
then their stepmother, died of AIDS. The children
still sorrowfully talk about their parents’
loss—and aver the day the last relative simply walked over with everything they could
carry, leaving the four children to starve.
They didn’t starve. Kelvin learned to make mud
bricks, and to gather straw to make brooms for
SA, a youth-created organization that now
makes brooms, cooks (vegetables, maize, beans
and sometimes fish too) and to care for Luckson, 15,
Cobby, 9 and Maggy, 7, who is HIV-positive.
Gertrude’s life is hard. “The long hours of work
make me sick,” she said recently. “I don’t get
enough sleep”. (No wonder. The children sleep
on a bed of rags, huddled together for warmth
in the rainy season). When she can’t sell enough brooms, she has
to beg the neighbours for food. She is waiting
for Kelvin to finish high school and then she’ll
hope for her chance to study. Meanwhile, she
is trying to learn to stop grieving. “I used to
feel that my mother would come and take over,
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