Children and HIV: Closing the Gap Symposium
Ending Vertical Transmission through Community Action

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Elizabeth Glaser Pediatric AIDS Foundation
In 1981, Elizabeth Glaser unknowingly contracted HIV through a blood transfusion. Five years later, Elizabeth learned she had passed the virus to her daughter, Ariel, and her son, Jake. Following Ariel’s death in 1988, Elizabeth and her two best friends created the Foundation with a single mission:

**to eliminate pediatric AIDS.**

After Elizabeth passed away in 1994, the Foundation was named in her memory. Her legacy lives on in those who are fighting for children and families affected by HIV and AIDS worldwide.
A Trusted Leader

THE FIRST DECADE:
The Fight At Home

• Advocated for children affected by HIV/AIDS in the US
• Advocated for pediatric drug research and treatment
• Funded pediatric HIV/AIDS research.

THE SECOND DECADE:
The Fight for Children and Families Around the World

• With private donor support, we initiated Call to Action project in 1999 to implement PMTCT programs in Cameroon, Kenya, Rwanda, South Africa, Thailand, and Uganda.
• Through public-private partnership, we initiated Project Heart in 2003 to expand access to HIV care and treatment programs in Cote d’Ivoire, South Africa, Tanzania and Zambia.
• We are one of the largest implementation partners of the President’s Emergency Plan for AIDS Relief to provide prevention, care and treatment programs in countries most severely impacted by the HIV/AIDS pandemic.
Major Areas of Work

International Programs

Global Advocacy

Global Research
Global Impact

Working with governments and partners in 17 countries, Foundation supported programs have:

- Supported 5,400 sites
- Provided nearly 14.2 million women with the services to prevent the transmission of HIV from mothers to babies
- Tested more than 12.4 million women for HIV
- Enrolled more than 1.6 million individuals in to care and support programs, including 125,000 children under the age of 15
- Since enrollment began, more than 850,000 individuals have begun life-prolonging antiretroviral treatment - and more than 70,000 are children under the age of 15

* All data as of December 31, 2011
Eliminating Pediatric AIDS: What Will It Take

R.J. Simonds and Laura Guay

EGPAF

AIDSTAR-One Spotlight on Prevention
Sequence of PMTCT of HIV Services in Community and Facilities

**Community**

**Home and community**
- Learn of and seek services at antenatal clinic
- Take ARVs, other medications during pregnancy and breastfeeding
- Go to facility for safe delivery
- Go to maternal and child health facility in follow up
- Engage with ongoing community-based services for counseling, retention and adherence support, and social services.

**Facilities**

**Antenatal care site**
- Receive routine antenatal care services
- Receive health and HIV education
- Test for HIV and learn results
- Receive services for HIV+ women:
  - Evaluate for ART eligibility
  - Starts ART if eligible
  - ARV for PMTCT
  - Counseling for infant feeding options
  - HIV medical/psychosocial care
  - Test partner and children for HIV.

**Delivery site**
- Test for HIV if not already done
- Take intrapartum ARV
- Have safe delivery
- Receive support for infant feeding.

**Maternal-child health site**
- Receive nutritional support
- Receive family planning services
- Receive postpartum and well child care
- Obtain early infant HIV diagnosis
- Receive HIV evaluation and treatment
- Receive tuberculosis prevention services.

Pregnancy: 12-18 months postpartum
Optimal Interventions: WHO Recommendations

• New Prevention Tools
• Women who are eligible for ART receive it to maintain their health
• Duration of ARV use
• ARV prophylaxis regimen
• Infant feeding guidelines
High Coverage and Retention

Barker, Mphatswe, and Rollins 2011
Strong Health Systems

• A national plan to eliminate pediatric AIDS
• Strong management systems
• Financial systems
• Supply chain systems for reliable access to test kits, drugs, other commodities
• QI systems
• Information systems
• Human Resources
  – Create new job roles and positions, include community lay counselors
  – Task shifting, task sharing
  – Training for all roles

• Favorable policies-that promote
  – Integration of HIV and MCH services
  – Routine HIV testing
  – Task shifting/sharing

• Leadership and coordination at various levels
• Adequate financial resources
• Research and innovation
• Surveillance and measurement
Engaged Communities

• Knowledgeable
• Included in the generation of ideas to address stigma, discrimination, empowerment of women, male involvement
• Community-based psychosocial support and HIV testing and counseling
• Links between communities and facilities
Engaging community-based organisations in HIV care and treatment: the case of King’s Hope Development Foundation, South Africa
Description

- King’s Hope Development Foundation (KHDF) and the Olievenhoutbosch Clinic applied for and were granted the authority from the Department of Health (DoH) to down refer clients on ART in 2008 and follow-up enrolled patients.
- Foundation staff trained a KHDF retired nurse and social worker on HIV management and counselling.
- The nurse was trained using the Nurse Initiation Management of ART training (NIMART) and also attended a training on HIV/TB.
- KHDF expanded its structures to accommodate patients.
Impact

• KHDF down referred nine ART clients in January 2008 and, by the end of January 2011, had a total of 222 eligible clients collecting ART medications through KHDF offices.

• Through the KHDF partnership, the rate of clients lost to follow-up at Olievenhoutbosch Clinic decreased from 12% in January 2008 to 7% in January 2011.

• The defaulter rate decreased from 20% in 2008 to 8% in 2011.

• Clients are now able to access treatment in their community, rather than having to travel long distances.
# Number of Clients Down Referred from 2008-2011

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
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<tbody>
<tr>
<td>Number of patients down referred (followed up at a local facility after stabilized on ART)</td>
<td>9</td>
<td>120</td>
<td>213</td>
<td>300</td>
</tr>
<tr>
<td>Number of patients that are still collecting their medication</td>
<td>9</td>
<td>112</td>
<td>199</td>
<td>222</td>
</tr>
<tr>
<td>Loss to follow-up rate (%)</td>
<td>12%</td>
<td>10%</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>Defaulter rate (%)</td>
<td>20%</td>
<td>15%</td>
<td>11%</td>
<td>8%</td>
</tr>
</tbody>
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Lessons Learned

• CBOs can help facilitate easier access to medication and reduce the number of patients who default because of transport issues

• CBOs with trained or retired nurses can be assisted in the down referral and follow-up, care of clients on ART through training and mentorship

• Recommend the use of CBOs to provide HIV treatment and follow-up to eligible clients in communities with limited access to prescribing health sites
Using Community Focal Persons to Improve Retention of HIV-Infected Individuals in Care and Treatment in Rural Settings of Lesotho
To improve client retention and clinical outcomes, EGPAF collaborated with LENASO.

Community focal persons (CFPs), volunteer lay workers who serve as links between facilities and communities, are identified by facility nurses and district health teams, trained and mentored by LENASO program officers and LENASO district community coordinators.

Health centre nurses and counselors record the client’s physical address, phone number, and obtain client consent, which allows CFPs to follow up.

A list of client contact information is compiled every week using the health facility appointment books and registers.

The list is given to the CFPs who follow up with each client through home visits and offer supportive counseling and referral back to care (The HIV status of clients tracked are not disclosed to the CFPs to maintain confidentiality).
Results

- Review of site data from Machabeng Hospital, a district hospital serving a rural population of 69,749, was done in April 2011 by the Defaulters Tracking Team in the district composed of MOHSW, EGPAG, BAYLOR, and LENASO.
- A CFP based in this hospital was able to follow 125 clients over the course of five months (from November 2010 to March 2011).
- Of the 194 clients LTFU, 125 (64%) were traced and brought back into the facility for treatment from November 2010 to March 2011.

Figure 1. Trend of LTFU and retention in HIV care and treatment indicators since inception of CFP outreach

![Bar chart showing trend of LTFU and retention in HIV care and treatment indicators]
Lessons Learned

• The use of CFPs has demonstrated improved retention in HIV care and treatment in one rural district hospital in Lesotho; this intervention has been rolled out to other districts.
Male involvement in PMTCT through invitation letters: an experience from Olievenhoutbosch Clinic in Tshwane District, South Africa
The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) sensitized members of the Olievenhoutbosch Health Forum, which consists of 10 community based organizations (CBOs) and clinic staff about the importance of male involvement in PMTCT by using letters to invite men into the clinic to accompany partners.

In February 2010, nurses issued letters to the partners of all pregnant women visiting ANC.

On arrival at the clinic, all women accompanied by their male partners were counseled first by a nurse or a counselor and given health education on PMTCT, infant feeding, dual protection, HIV counseling, testing and treatment issues.

Male partners were tested for HIV by a nurse and referred for treatment when HIV-positive.
Results

• 900 HIV-positive pregnant women were given invitation letters between February and December 2010.

• 356 (40%) of these women returned with their male partners and received health education on HIV/AIDS, PMTCT, and HIV counseling and testing.

• During the time period the invitation letters were used, an increase in the total number of men receiving HIV counseling and testing was observed, from 1,002 in October-December 2009 to 1,340 in October-December, 2010.

• 32 male partners who were on ART joined a local support group run by Kings Hope, a community-based organization.

• The data collected at the ANC indicated an increase in male involvement in PMTCT
Proportion of women who came for testing and counseling with their male partners after receiving an invitation slip at Olievenhoutbosch Clinic
Uptake of male HIV testing at Olievenhoutbosch Clinic (2009-2010)
Lessons Learned

• Men may be more likely to participate in PMTCT when invited to engage at an early stage of antenatal care.

• Invitations to male partners in ANC can encourage men to receive HIV testing and treatment, and can also promote reproductive and family health.
Success is Possible

We have the science. We have the medicines.
We can eliminate pediatric AIDS.

Photo: James Pursey

www.pedaids.org