



U.S. HIV/AIDS POLICY & THE FIGHT AGAINST TUBERCULOSIS

AN ADVOCACY CASE STUDY | MARCH '10

In 2003, the U.S. launched a new response to HIV/AIDS abroad called The U.S. President's Emergency Plan for AIDS Relief (PEPFAR). PEPFAR was the largest commitment in history by any individual nation to combat a single disease. While it signaled what would become an enormous achievement, at the outset, the plan failed to confront the number one infectious killer of people with HIV/AIDS: tuberculosis (TB). [more►](#)

This case study¹ tells the story of ACTION's strategies to increase PEPFAR's support for TB-HIV integration. In its advocacy work with PEPFAR, ACTION has contributed to:

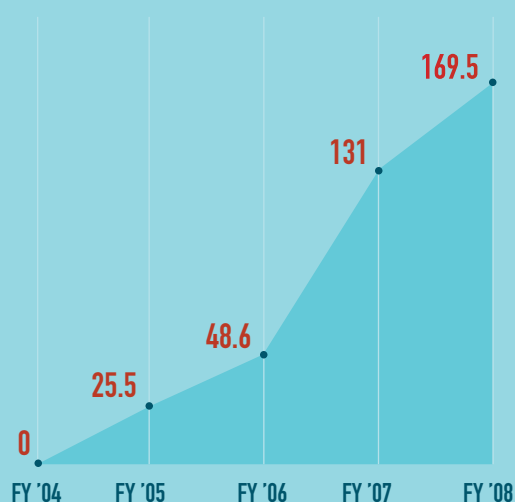
Securing Policy Change

In 2003, addressing TB-HIV co-infection was not part of PEPFAR's mandate. ACTION engaged and educated U.S. policymakers and civil society organizations,² motivating them to include TB in the fight against HIV/AIDS. PEPFAR now includes a significant commitment to "fully integrate HIV prevention, treatment, and care with TB services at the country level."³

Significantly Increasing PEPFAR Spending for TB-HIV

In 2003, PEPFAR allocated almost nothing for TB-HIV co-infection. By fiscal year 2008, the annual allocation for TB-HIV had increased to more than \$169 million (see graph).^{4,5} The 2008 reauthorization of PEPFAR included key TB-HIV policies and indicators within the HIV/AIDS program, as well as up to four billion dollars for global anti-TB efforts over five years.

PEPFAR TB-HIV Funding 2004 - 2008
US\$ (Millions)



QUICK FACTS ABOUT TB-HIV

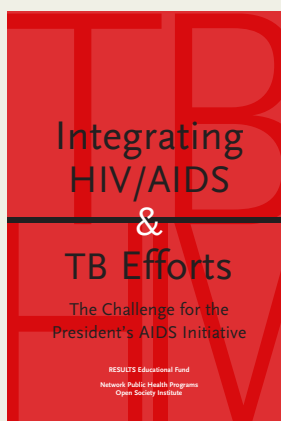
- At least one-third of the 33.2 million people living with HIV/AIDS (PLWHA) worldwide have a latent TB infection.
- PLWHA are 20-30 times more likely to become sick with active TB disease than those without HIV.
- 80% of those co-infected with TB and HIV/AIDS live in Africa.
- In 2007, only 2.2% of PLWHA world-wide were screened for TB.
- Unlike HIV/AIDS, TB is completely curable in the majority of cases, with drugs to treat a standard case costing as little as \$20 for a full course of treatment. Nevertheless, TB needlessly took 1.7 million lives in 2007, 1.37 million of which were PLWHA.

Source: World Health Organization



THE “WHAT”: ACTION’S ADVOCACY ACTIVITIES

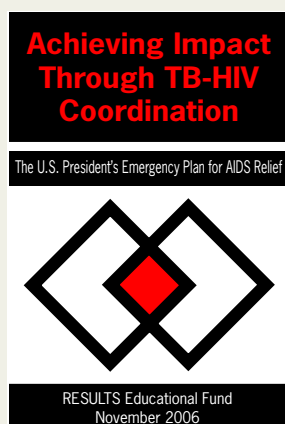
PEPFAR is administered by the federal Office of the U.S. Global AIDS Coordinator (OGAC). To make TB a PEPFAR priority, ACTION built relationships and worked directly with OGAC staff. ACTION met in person with high-level OGAC officials (including the Global AIDS Coordinator) attended OGAC briefings to pose questions on TB-HIV in public settings, and encouraged members of Congress to write to, and meet with, OGAC to highlight policy gaps identified in ACTION’s reports. ACTION also engaged the U.S. Centers for Disease Control and Prevention (CDC), which shared information regarding TB-HIV activities they were supporting in developing countries through PEPFAR. This information allowed ACTION to develop country case studies, profile successes within PEPFAR, and educate members of Congress about the important work the CDC, OGAC, and other U.S. government partners contribute to global TB and TB-HIV control.



ACTION's policy research helped to educate and build relationships with decision-makers, some of whom had influence over PEPFAR's budgets, policies, and programming. In February 2004, RESULTS Educational Fund⁶ released its first report on PEPFAR, *Integrating HIV/AIDS & TB Efforts: The Challenge for the President's AIDS Initiative*. The report praised PEPFAR broadly as an initiative that would begin to address HIV/AIDS at the scale needed, but at the same time warned that lack of attention to TB-HIV would undermine PEPFAR's success.

As an outcome of the report, ACTION began to develop a productive advocacy relationship with OGAC. By building a convincing, evidence-based case that PEPFAR should support TB-HIV integration, ACTION was successful in seeing the initiative develop TB-HIV policies and establish a specific budget line for TB-HIV activities.

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In 2007, ACTION released a second analysis of PEPFAR's efforts, *PEPFAR: Achieving Impact Through Scale-up of TB-HIV Activities*. By this time, PEPFAR had made TB-HIV one of its "priority program areas,"⁷ with goals to scale-up to universal access to TB-HIV coordinated services in each PEPFAR focus country. While the report identified gaps in PEPFAR's TB-HIV policies and offered recommendations for filling those gaps, ACTION also brought attention to areas of success that should be replicated and scaled-up, providing four case studies of countries where PEPFAR was making progress against TB-HIV. This report educated OGAC staff, contributing to an increase in anti-TB resources in PEPFAR. ACTION discussed the *Achieving Impact* report with OGAC in advance of its release, asking OGAC for feedback on the report before it was published. This approach garnered respect and fostered partnerships for addressing TB-HIV. As a former OGAC official explained:

"The report posed questions from a friendly group, and you started to think whether or not you can answer the questions they are asking. So we worked together to answer them. It was instrumental to the advocacy that got the addition to PEPFAR funds in 2007."

During the report's production and after its release, ACTION used the *Achieving Impact* report as a foundation for continued advocacy work.

THE “PUSH”: ACTION’S INTENSIFIED INVOLVEMENT

Successful advocacy requires that advocates constantly seek out and strengthen connections between their activities and the activities of other advocates in the field. ACTION made these connections between their country partners’ advocacy and with other TB and HIV/AIDS advocates in order to make TB a PEPFAR priority by:

LINKING THE FACTS► ACTION’s advocates are consistently ready with the latest data; international policy guidance; resource needs; and a persuasive, evidence-based rationale for its recommendations. As a former OGAC official stated about ACTION’s PEPFAR work: “[ACTION’s advocates] really brought technical knowledge about TB-HIV to the table.” ACTION shared that technical knowledge with colleagues in civil society and government institutions to use in formal discussions about PEPFAR.

MAKING THE ISSUE REAL► ACTION advocates spoke with high-level officials and members of Congress and their staff and arranged briefings to educate them about TB-HIV co-infection and possible solutions for the co-epidemic. For these briefings ACTION brought patient advocates and TB experts from affected countries to Washington to speak about issues related to TB-HIV within the context of PEPFAR. ACTION also sponsored policymaker delegations to PEPFAR target countries, including Kenya, Rwanda, and Tanzania. Face-to-face with health workers and patients, U.S. congressional staff saw the direct impact of TB-HIV on the lives of those patients and the obvious need for additional TB-HIV program support from the U.S. through PEPFAR. When these key staff returned from a delegation, they were inspired and often ready to become TB champions, sharing what they learned.

PARTNERING WITH THE HIV/AIDS COMMUNITY►

ACTION became involved in TB-HIV advocacy as soon as PEPFAR was launched in 2003. Many AIDS activists at the time were not fully aware of the deadly connections between HIV and TB. Recognizing the importance of providing TB services to PLWHA and providing TB patients with voluntary HIV testing and counseling, ACTION provided education and advocacy tools to AIDS activist allies,



WHO / TBP / GARY HAMPTON©

Congress, and OGAC. Since then, ACTION has helped connect TB activists and specialists with their counterparts in the HIV/AIDS community to share knowledge and experience. Facilitating this connection between the TB and HIV/AIDS communities has been crucial in ensuring that TB is addressed in PEPFAR programs. ACTION has been actively involved in the bi-annual International AIDS Conference (IAC) by conducting workshops, giving presentations, and reaching out to HIV/AIDS civil society organizations (CSOs) to build support for TB-HIV integration. At an ACTION press conference at the 2008 IAC in Mexico City, then UNAIDS Deputy Executive Director Michel Sidibe called for routine screening of PLWHA for TB. ACTION also helped to inspire a visible TB-HIV march of activists, coordinated with South Africa’s Treatment Action Campaign (TAC) and AIDS and Rights Alliance for Southern Africa (ARASA). These important achievements emboldened the international community of voices calling for PEPFAR to issue an improved response to TB-HIV.



Activists rally in Cape Town,
South Africa

CONNECTING ADVOCATES IN AFRICA ► ACTION is pushing for PEPFAR to incorporate collaborative TB-HIV services into all of the HIV/AIDS programs they support, but particularly in Sub-Saharan Africa where the burden of TB and TB-HIV are highest.⁸ As an ACTION ally from the WHO notes, “ACTION’s strength is having a presence in D.C. and in high TB burden countries.” ACTION has helped rally CSOs in Africa to call for treatment and prevention services. For example, ACTION’s partner in Kenya, KANCO (Kenya AIDS NGO Consortium), coordinated a letter writing campaign from people in Kenya to U.S. officials. In another campaign in 2008, ACTION delivered over 10,000 postcards signed by participants at the 2008 IAC to OGAC, other international policymakers, and key Ministries of Health stressing the importance of coordinated TB-HIV services. These campaigns made it difficult for decision-makers to ignore the demand for, and value of, TB-HIV services.

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Winstone Zulu

RAISING VOICES ► The stories of TB patient-advocates are powerful advocacy tools. ACTION often brings patient-advocates to the U.S. to educate decision-makers and community leaders, and to increase public awareness. One such champion is Winstone Zulu from Zambia. By sharing his experiences through international media, community events, and in-person meetings with policymakers, Winstone has put a human face on TB-HIV. In June 2008, ACTION invited Winstone to join the campaign to renew funding for PEPFAR, which took him to key locations including Los Angeles, Portland, New York, Cleveland, and Washington D.C. His meetings with grassroots advocates, congressional staff, and members of Congress ultimately helped to inspire action from all parties and motivate them to be more involved with the issue. In each city, Winstone stayed with ACTION supporters and met many grassroots advocates. When he arrived back home, he said, “People that hosted me wrote emails exclaiming: ‘We did it!’ That is one achievement that really sticks out.”

THE “HOW”: ACTION’S STRATEGIC CONTEXT

ACTION’s strategic advocacy was instrumental in dramatically increasing PEPFAR’s TB-HIV budget and making TB-HIV a policy priority. But how did these advocacy strategies actually work?

STAYING FOCUSED ▶ ACTION keeps its focus by maintaining a long-term objective. In its work with PEPFAR, ACTION had one over-riding goal: to see that PEPFAR became a world leader in providing integrated TB and HIV/AIDS services as a means of reducing the burden of both diseases. To accomplish this, ACTION has advocated that PEPFAR implement proper policies, steadily increase its TB-HIV budget (in turn scaling up its programming), and install monitoring and evaluating systems for its TB-HIV efforts and outcomes. ACTION and its networks use advocacy tools to ensure that PEPFAR’s decision-makers understand the complex relationship between TB and HIV/AIDS, prioritize TB-HIV co-infection within PEPFAR’s agenda, and provide adequate resources to carry this out. Much of ACTION’s work depends on reaching members of Congress, government officials, and other leaders in civil society with persuasive, evidence-based arguments for why PEPFAR should expand its TB-HIV efforts.

NURTURING THE NETWORK ▶ ACTION maintains strong, respectful relationships with decision-makers, issue experts, media, patient advocates, grassroots activists, other advocacy groups, and community leaders all over the world. This network helps to ensure that policy requests and recommendations are technically sound, backed by an informed constituency, and delivered effectively to policymakers. For example, when PEPFAR was being reauthorized in 2008, ACTION educated members of Congress about the need to address TB as part of a response to HIV/AIDS — and as a global priority in its own right — and empowered a highly trained grassroots network to present policy analysis based on WHO data to their members of Congress.

COMMUNICATING EFFECTIVELY ▶ Coordinating the various activities of many different people from all over the world is crucial to the effective operation of any international partnership. Frequent conference calls, keeping open lines of communication among partners, sharing

information strategically and efficiently, and holding in-person strategy meetings all play a role in harmonizing ACTION’s work across continents. Staying connected requires time and dedication.

WHAT COMES NEXT?

In 2009, ACTION released a report analyzing the efforts of four of the largest HIV/AIDS donors, including PEPFAR, in combating TB-HIV co-infection. The report emphasized PEPFAR’s strengths, but also highlighted major gaps in the scope and scale of its programming. Most importantly, ACTION’s 2009 report provided recommendations for how PEPFAR could improve its response to TB-HIV and act as a key component of the global effort to eradicate TB.

Securing policy change and creating an advocacy movement that led to a significant increase in PEPFAR spending for TB-HIV programs are major accomplishments, but there is still much more to be done. ACTION will continue working with OGAC to mobilize support for TB-HIV and to monitor PEPFAR’s TB-HIV funding and programming to ensure that each is taken to scale. This means ensuring that all TB patients, and those at risk for TB, are provided with voluntary HIV counseling and testing; that all PLWHA are screened for TB and provided appropriate treatment; and that PEPFAR implementers pursue other policies that reduce the risk of transmitting TB to PLWHA in healthcare facilities and other settings where people congregate. ACTION will also continue its broader advocacy work to educate decision-makers, build relationships with policymakers and allied organizations, and report on progress and gaps in the global effort to control TB.

THE “WHO” OF ACTION

ACTION (Advocacy to Control Tuberculosis Internationally) is an international partnership of civil society advocates working to mobilize resources to treat and prevent the spread of tuberculosis (TB), a global disease that kills one person every 20 seconds.

ACTION's mission is to build support for increased resources for effective TB control, especially among key policymakers and other opinion leaders in both high TB burden countries and donor countries. With effective policy advocacy and greater political will, rapid progress can be made against the global TB epidemic.

To learn more about ACTION's advocacy strategies and tactics, go to: <http://www.action.org/>

You can also access the ACTION Project's Best Practices for Advocacy at: http://www.action.org/best_practices

ACTION PARTNERS ▶

AIDES

Global Health Advocates

Global Health Advocates France

Global Health Advocates India

Indian Network for People Living with HIV/AIDS (INP+)

Kenya AIDS NGOs Consortium (KANCO)

RESULTS Australia

RESULTS Canada

RESULTS Educational Fund (US)

RESULTS Japan

RESULTS UK

ENDNOTES ▶

- ¹ This study is based on 33 interviews with stakeholders from ACTION, its partner organizations, and their colleagues working on TB and TB-HIV. Some interviewees asked to remain anonymous.
- ² “Civil society,” as the term is used in this study, is a term for organizations and associations (i.e., not government agencies or for-profit corporations) that work for the public good.
- ³ “Tuberculosis and HIV/AIDS,” <http://www.pepfar.gov/pepfar/press/81964.htm>.
- ⁴ This \$169 million includes \$139 million in core programmatic funding for TB-HIV and \$30 million in other field costs that were attributed to the TB-HIV program area.
- ⁵ ACTION. 2009. Living with HIV, Dying of TB: A Critique of the Response of Global AIDS Donors to the Co-epidemic. Washington, DC: RESULTS Educational Fund.
- ⁶ RESULTS Educational Fund hosts ACTION's secretariat, coordinating the international advocacy work.
- ⁷ PEPFAR. 2006. PEPFAR FY2007 Country Operational Plan Guidance. Washington, DC: OGAC.
- ⁸ Source: World Health Organization Media Centre Fact Sheet, “Tuberculosis”, <http://www.who.int/mediacentre/factsheets/fs104/en/>.



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