

# TAG-ICW TB/HIV Advocacy Project

## Battling the Dual Epidemic through Community Action

AUGUST 2008

### TB/HIV: What Every HIV/AIDS Activist Should Know by Nelson Juma Otwoma

I have always wanted to make a difference. My activism took root in my home province, Nyanza. My activism has always been focused on alleviating the burden of poverty and promoting health. I have always had an intense inner feeling that something needed to change; in fact, I was probably born an activist!

In 2001, I helped to found the Multifaceted Development and Research Centre (MDRC) with the mission of building local capacity to identify problems and seek suitable solutions in the areas of health and development. In the early days of activism at MDRC, my role was to say the things that no one else was saying...poor people were suffering with disease, poverty, and ignorance. MDRC was well aware of the burden caused by HIV and TB and when the opportunity presented itself, MDRC sought funding to address the burden of TB in the Suba district of Western Kenya. The intention of MDRC was to get people talking about TB and poverty in the hope that TB service delivery would improve in Suba. As the lead researcher of MDRC's TB/HIV Advocacy project, I was able to prioritize TB/HIV as an area of interest for the organization, and this continues to be a cornerstone of my own advocacy agenda.



Through my work with TAG, ICW and other organizations supporting TB/HIV work, I have had the opportunity to learn more about advocacy. I gained knowledge about research, the skills and steps of advocacy and the lessons learned from the work done by other activists. This has helped me redefine my own TB/HIV advocacy agenda. The WHO interim policy on collaborative TB/HIV activities recommends mechanisms to coordinate planning and resource mobilization between TB and HIV programs and strategies to reduce the burden of TB among persons with HIV, and the burden of HIV amongst people with TB. This policy has provided me with a framework for my TB/HIV activism. Understanding the science and policy aspects of TB/HIV has been vital in my advocacy to make civil society a stronger partner in allocating resources, as well as making sure that government programs meet our needs. Marrying the understanding of policy, science, and research with my understanding of my community has made the advocacy of MDRC more focused and powerful.

The unique challenges presented by TB/HIV coinfection should be a focus for HIV activists worldwide. Even though TB is curable,

- TB kills nearly 1.5 million people a year, of which 250,000 are people with HIV
- TB is a disease of poverty with 98% of TB deaths occurring in developing countries
- Africa has 80% of the world's TB/HIV burden despite being only 13% of the world's population
- TB is the leading cause of death among people with HIV (15% of deaths due to TB globally and up to 50% in some parts of sub-Saharan Africa)

For all the above reasons, as an activist, and especially as a HIV activist I engage in TB/HIV advocacy so that we don't continue dying of a curable disease while on HIV treatment. This advocacy is vital to raise the profile of TB among persons with HIV and stimulate response and resource allocation to TB and TB/HIV interventions. Resources for how you can become engaged in TB/HIV advocacy can be found on the back page of this newsletter. You can contact me at [otwomatom@yahoo.com](mailto:otwomatom@yahoo.com)

# TAG

Treatment Action Group

The Treatment Action Group (TAG) is a U.S.-based independent AIDS research and policy think tank fighting for better treatment, a vaccine, and a cure for AIDS. International Community of Women Living With HIV-East Africa (ICW) is based in Kampala, Uganda and is the only international network run for and by HIV positive women. It was founded in response to the desperate lack of support, information and services available to positive women worldwide and their need for influence and input on policy development.



The TB/HIV Advocacy Project strengthens the capacity of communities affected by HIV/AIDS to understand, mobilize, and respond effectively to the challenges posed by the intersecting TB and HIV epidemics. Through advocacy workshops and by coordinating and supporting activists' advocacy efforts, TAG and ICW work together to increase community understanding of TB/HIV coinfection and enhance research, treatment, and resources to combat the two epidemics.

For more information, please contact Claire Wingfield at [claire.wingfield@treatmentactiongroup.org](mailto:claire.wingfield@treatmentactiongroup.org) or Dorothy Namutamba at [dnamutamba@icw.org](mailto:dnamutamba@icw.org).



### HEPS-Uganda: Aaron Muhinda and Prima Kazoora, Uganda

HEPS is a health consumers' organization advocating for health rights and responsibilities. Through their involvement with the Advocacy Project, Aaron and Prima have had great success in integrating TB advocacy into HEPS's HIV work. Using resources and knowledge gained from TAG-ICW trainings combined with strong organizational support from HEPS (under the umbrella of the Uganda Coalition for Access to Essential Medicines), they have developed and implemented a TB and HIV medicine and diagnostics monitoring tool. They are using the data on availability and accessibility of TB and HIV medications and diagnostics to lobby policy makers to improve treatment access. This monitoring effort was originally focused on HIV, but participation in the Advocacy Project enabled Aaron and Prima to advocate for the inclusion of TB. HEPS has been able to build strong support for their work by involving diverse stakeholders such as the Ministry of Health, the WHO, and the Uganda AIDS Commission as well as fellow TB/HIV activists and community members. For more information, please visit [www.heps.org](http://www.heps.org) or e-mail Aaron at [muhindaaron@yahoo.com](mailto:muhindaaron@yahoo.com) or Prima at [pmkazoora@yahoo.com](mailto:pmkazoora@yahoo.com).



### Treatment Advocacy and Literacy Campaign (TALC): Carol Nawina Nyirenda, Zambia

Carol has lived with HIV for many years and has also survived TB treatment. She has been able to transform this personal experience into a political campaign to address TB/HIV, and has incorporated TB advocacy into her national and global HIV activism. Participating in the TAG-ICW advocacy trainings gave Carol a knowledge base of TB science, diagnostics, and treatment that has enabled her to train other activists on TB and TB/HIV coinfection and, along with fellow Zambian activists, to advocate for the Zambian government to implement WHO recommendations for collaborative TB/HIV activities. Carol has received global recognition for her activism and served as a panelist at the April 2008 meeting in Thailand of the UNAIDS Program Coordinating Board (PCB), addressing the issue of multidrug-resistant TB among people living with HIV. In part, her advocacy led the UNAIDS PCB to decide to monitor TB/HIV mortality numbers as a measure of the impact of the implementation of the collaborative activities recommended by the WHO policy to reduce the burden of TB/HIV. Carol was also invited to be part of the International Treatment Preparedness Coalition's World CAB meeting to discuss treatment access issues with the pharmaceutical industry. She is a community representative on the Stop TB Partnership's New Diagnostics Working Group, and is a board member representing communities of people living with TB, HIV, and malaria for UNITAID, where she has successfully lobbied for the provision of resources for diagnostics for TB drug resistance testing. For more information, please visit [www.talczambia.org](http://www.talczambia.org) or e-mail Carol at [carolnawina@yahoo.com](mailto:carolnawina@yahoo.com).



### Bouake Eveil: Coulibaly Gaoussou, Cote d'Ivoire

Coulibaly has been very active in advocating for the implementation of TB/HIV collaborative activities in his country. Through his work with Bouake Eveil, Coulibaly has provided support and education to people living with HIV and those who are coinfecting, with a particular focus on the importance of TB preventive therapy among people living with HIV. His organization has successfully advocated for a more collaborative approach to fighting TB and HIV in Bouake district and Coulibaly has also participated in some national HIV policy discussions and pushed for the inclusion of TB/HIV. Coulibaly has developed a comprehensive TB/HIV program in his organization that includes infection control measures and community TB/HIV sensitization. He has also created an association of people living with HIV and TB and their families. Because Bouake is affected by rebel activity, public health services are unstable, so Coulibaly also makes home visits to persons with HIV and TB to ensure that people have access to needed services. For more information, please e-mail Coulibaly at [c\\_gaoussou@yahoo.fr](mailto:c_gaoussou@yahoo.fr).



**Stop TB Partnership-Nigeria: Mayowa Joel, Treatment Access Movement (TAM) and Obatunde Oladapo, Positive Life Association of Nigeria (PLAN), Nigeria**

In November 2007, Joel and Oba traveled to the Union World Conference on Lung Health in Cape Town, South Africa, as part of their participation in the Advocacy Project. At the conference they met with other Nigerian stakeholders who were dismayed by their country's dismal level of participation in the conference as well as the lack of a coordinated response to address the TB burden in Nigeria. As community representatives to the Stop TB Partnership Working Groups on TB/HIV (Oba) and Advocacy, Communication, and Social Mobilization (Joel), they advocated for the creation of the Stop TB Partnership–Nigeria. This goal was achieved in May 2008 when over 90 national stakeholders gathered for the group's inaugural meeting. Joel and Oba are helping to plan the first Nigerian National TB Conference to increase awareness of persons with HIV about the importance of TB/HIV. They have also done capacity building on TB/HIV treatment literacy and advocacy for different stakeholders in the country, including government, NGOs, and people infected and affected by either or both TB and HIV. Both Joel and Oba have stated that the TAG-ICW Advocacy Project, which provided them with treatment and policy literacy and advocacy workshops, has helped them be more effective TB/HIV activists. For more information, please e-mail Joel at [mayowajoel@yahoo.com](mailto:mayowajoel@yahoo.com) or Oba at [obatunde65@gmail.com](mailto:obatunde65@gmail.com).



**European AIDS Treatment Group (EATG): Wim Vandavelde, Portugal**

Before participating in the Advocacy Project, Wim's main focus was HIV/HCV treatment advocacy for countries in the WHO European region. TAG-ICW training and support provided Wim with the tools to understand why TB is of concern for persons with HIV and strengthened his capacity to incorporate TB into his advocacy work. Wim was invited to be part of the Advocacy Project because of his role as a community representative to the Stop TB Partnership's New Drugs Working Group. He has also helped to set up a civil society network of Lusophone countries where he successfully advocated for the inclusion of TB/HIV into the network's priorities as well as into the Community of Portuguese Language Countries' health agenda. Wim gave a keynote address on community input in the regulatory process at the Global Alliance for TB Drug Development's Open Forum meeting in New Delhi in May 2008, ensured the inclusion of community perspectives in a scientific paper on priorities for new TB drug development, and provided the community perspective to the Portugal Ministry of Health on World TB Day. As chairperson of the EATG, Wim often meets with the private sector to monitor and advocate for a drug research agenda that responds to community priorities, and since his involvement with TAG and ICW Wim has incorporated TB drug development concerns in his meetings with pharmaceutical companies. For more information, please visit [www.eatg.org](http://www.eatg.org) or email Wim at [wim@eatg.org](mailto:wim@eatg.org).



**Swaziland National Network of People Living with HIV/AIDS (SWANNEPHA): Thembi Nkambule, Swaziland**

As an HIV treatment activist in a country with high TB/HIV prevalence, Thembi welcomed the opportunity to learn more about TB and to incorporate this knowledge into her activism. After attending advocacy workshops Thembi, through SWANNEPHA, has provided training on TB/HIV to 38 support groups and a core group of activists, and has improved SWANNEPHA's capacity to do TB/HIV advocacy and outreach. She has also helped develop a community training manual on TB/HIV and has already seen more comfort on the part of people with HIV to discuss TB within their network. Thembi has also been working on national policy advocacy to get people with HIV meaningfully integrated into TB and HIV programming and service delivery. Her national work was shared with global activists and TB/HIV implementers when she presented findings from her own and other activists' work at the 2008 PEPFAR HIV/AIDS Implementers Meeting in Uganda in June 2008. For more information, e-mail Thembi at [tnkambule@swannepha.org.sz](mailto:tnkambule@swannepha.org.sz).



## About the TAG-ICW Advocacy Project

The TAG-ICW Advocacy Project is part of TAG's broader TB/HIV Project, which has the following objectives:

- strengthening the advocacy efforts of Africa-based HIV organizations to improve access to TB/HIV collaborative services in partnership with ICW-East Africa
- working with global TB/HIV advocates to ensure that global program and funding efforts are informed by and reflect the priorities of persons living with TB/HIV
- creating awareness of TB/HIV issues among the U.S. political leadership to increase national support for TB threefold
- engaging with TB research and development initiatives, both public and private, to ensure that they are well resourced and working with community input to develop tools that are critical to address the TB/HIV epidemic

As part of their joint effort to support and coordinate increased TB/HIV advocacy, TAG and ICW have worked closely with over 40 activists from 25 different countries.

Since September 2007, TAG and ICW have provided three multiday advocacy workshops and sponsored a daylong satellite session at the Union Conference on Lung Health for selected TB/HIV activists. The first two workshops, held in Kampala and Abidjan, focused on providing essential TB/HIV knowledge in the areas of basic science, diagnostics, treatment, research, and advocacy to Anglophone and Francophone activists, respectively. The third workshop, in Addis Ababa, brought together all of these activists and provided updated technical and policy information as well as skills-building sessions based on advocacy targets prioritized by the activists (TB/HIV implementation, research, media, and Africa Union/UNGASS).

The activists who have participated in this project have shown that advocacy capacity can be increased through the TAG-ICW training curriculum. Pre- and post-training surveys have shown statistically significant increases in knowledge in each of the focus areas: a clearer understanding of the impact of TB and HIV and the consequences of coinfection; increased comfort with research- and evidence-based advocacy; and understanding of the WHO's collaborative activities and how to support implementation. Besides the focus on science and policy, these workshops have created an important space in which advocates may share successful TB/HIV strategies with each other and strategize on how best to achieve greater impact of their national and regional work. Activists have taken this body of knowledge to their organizations and integrated TB/HIV more prominently into their advocacy work.

Based on the data collected from the activists through surveys and interviews, we have learned that they feel better prepared to engage in dialogue with researchers, policy makers, government officials, and the media about TB and TB/HIV, and are gaining exposure locally, nationally, and globally for their advocacy work. The workshops have created opportunities for the activists to support each other and gain a broader perspective of the global struggle to fight TB and HIV.

## Global Resources for TB/HIV Advocacy:

### Treatment Activist and Policy Information

**International Treatment Preparedness Coalition Listserv:** Ed Ngoksin Attapon, e-mail: [attapon@apnplus.org](mailto:attapon@apnplus.org)

**TAG TB/HIV Listserv:** Joe McConnell, email: [tag@treatmentactiongroup.org](mailto:tag@treatmentactiongroup.org)

**Stop TB Partnerships TB/HIV Working Group:** [www.stoptb.org/wg/tb\\_hiv](http://www.stoptb.org/wg/tb_hiv)

**UNAIDS:** [www.unaids.org/en](http://www.unaids.org/en)

### Funders of TB/HIV Advocacy

**Tides/ITPC Collaborative Fund:** [www.hivcollaborativefund.org](http://www.hivcollaborativefund.org)

**Open Society Institute:** [www.soros.org/initiatives/health](http://www.soros.org/initiatives/health)

**Challenge Facility for Civil Society:** [www.stoptb.org/bi/cfcs/announcements.asp](http://www.stoptb.org/bi/cfcs/announcements.asp)

### Product Development Partners:

**Aeras (vaccines):** [www.aeras.org/home/home.php](http://www.aeras.org/home/home.php)

**TB Alliance (drug development):** [www.tballiance.org/home/home.php](http://www.tballiance.org/home/home.php)

**FIND (diagnostics):** [www.finddiagnostics.org](http://www.finddiagnostics.org)