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THE COMMUNITY EDITION BUILDING A TB/HIV ACTIVIST MOVEMENT IN AFRICA

On September 14-19, 2008 in Entebbe, Uganda the International Community of Women Living with HIV/AIDS (ICW)- East Africa and the Treatment Action Group (TAG) held a training workshop to develop the capacity of HIV activists to integrate TB into their advocacy work.

Fifteen activists were selected (400 applications were received) representing Swaziland, South Africa, Zimbabwe, Ghana, Senegal, Ethiopia, Kenya, Malawi and Uganda. Participants were from 14 Africa-based HIV/AIDS advocacy organizations and also included representatives from three partner organizations, the Consortium to Respond Effectively to AIDS/TB Epidemic (CREATE), World Health Organization (WHO), and the Open Society Institute (OSI). The participation of CREATE, WHO and OSI provided perspectives from TB/HIV researchers, policymakers, and funders, respectively.

The training was divided into presentations and group work about the WHO policy on collaborative activities for TB/HIV, the science of TB and HIV, the huge unmet research needs for TB/HIV and the overall context of universal access and global targets. These topics provided for lively and engaging discussions by all participants. There was also emphasis placed on the Three Is of

the WHO 12 collaborative TB/HIV activities (intensified case finding, isoniazid preventive therapy (IPT) and infection control for TB).

To date, HIV activists have been in the forefront of advocacy efforts for research, resources, and scale up of HIV/AIDS prevention, care, and treatment compared with TB activism. There is a lot that can be learned from HIV activists' efforts in relation to what can be effective strategies to nurture a similar movement for TB, and as the leading cause of death among people with HIV in sub-Saharan Africa, there is a great role for HIV activists to play in addressing the crisis of TB/HIV co-infection. As a result the need to increase knowledge of TB science and policy literacy among HIV activists is crucial.

At the end of the workshop activists understood how they could call for the adoption and implementation of the Three Is, engage with policy bodies such as TB/HIV Joint Coordinating Boards and Global Fund country coordinating mechanisms to mobilize resources for TB/HIV advocacy work and programs; and understood the current situation in TB and TB/HIV research to ensure that community priorities are addressed and data is translated into policy and services on the ground.

Activists who are literate in the scientific as well as the policy and programmatic aspects of TB and



Participants working on advocacy plans for TB/HIV, Entebbe, Uganda, September 2008

TB/HIV co-infection are activists who are better able to advocate for universal access to effective TB diagnosis, care and treatment for people with HIV.

Contribution by Claire Wingfield, TAG and Dorothy Namutaba, ICW



Anglican Communion discuss global TB/HIV co-epidemic

On Monday July 28, 2008, RESULTS UK held a panel-led seminar on the co-epidemic of tuberculosis (TB) and HIV/AIDS at the Lambeth Conference in Canterbury, UK. The Lambeth Conference takes place once every ten years and provides a forum for debate on key issues affecting the Anglican Communion.

The session, "The Deadly Co-epidemic of Tuberculosis (TB) and HIV/AIDS", coincided with two major themes of the 2008 Lambeth Conference: HIV/AIDS and the Millennium Development Goals. It was chaired by the Most Reverend Thabo Makgoba, Archbishop of Cape Town, who called upon his colleagues to look at how churches can help halt the spread of these two diseases.

Those present included Anglican bishops from around the world involved in responses to AIDS, TB and malaria, as well as with the Church's wider development work.

Presentations on the state of the global TB/HIV co-epidemic and the role of faith-based organisations (FBOs) in tackling the epidemics were given by Dr. Hailyesus Getahun, TB/HIV Team Leader at the World Health Organisation, Kenyan TB/HIV activist Lucy Chesire and Dr. Kingsley Moghalu, Head of Global Partnerships at the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Based on recent data from WHO, Dr. Getahun explained that less than one per cent of people living with HIV worldwide are being screened for TB despite the fact that TB is a leading killer of people living

with HIV. Dr. Getahun suggested that there is an urgent need to further engage faith based organizations in the global TB/HIV response.

Lucy Chesire, who shared her personal experience of living with both diseases, called upon the Anglican Community and other churches to help reduce stigma and to provide integrated support for patients with HIV and TB.

Dr. Moghalu noted that only five per cent of Global Fund grants are being implemented by faith based organizations and that this figure should be much higher given the position of FBOs to influence change and to reach those in greatest need. The Global Fund's ninth funding round will be launched later in the year and provides an opportunity for the Anglican Community to submit proposals.

Several participants provided interesting inputs about their work, outlining their concerns as well as possibilities for capacity building and for integrating responses to TB and HIV.

Of particular note was the work of the Anglican AIDS and Healthcare Trust (AAHT) of the Anglican Church of Southern Africa (ACSA), presented by Bishop David Beetge,



(L-R): Dr. Kingsley Chiedu Moghalu (Global Fund); Lucy Chesire (Kenya); The Most Rev Thabo Makgoba (Archbishop of Cape Town); Dr. Haileyesus Getahun (WHO)

ACSA Liaison Bishop for HIV and AIDS. The AAHT is part of the Anglican Provinces in Africa HIV/AIDS, TB & Malaria Network, who have recently launched a strategic plan to integrate responses to these diseases in line with the Global Plan to Stop TB, 2006-2015.

Participants agreed that the session should be a starting point for further collaboration

between the Anglican Communion, civil society and international organizations to address these diseases of poverty.

Contribution by Philip Hadley, RESULTS UK

For further information see:

- » www.results-uk.org
- » <http://www.action.org>

Letter to the Editor:

A personal reflection of the Shack by the artist

The Shack was born out of a moment of fate, and it kept this momentum throughout its life, living for the moment, never knowing where it was going next but always ending up in the best places. A chance meeting with the Director of the Desmond Tutu TB Centre, Professor Nulda Beyers, who drew my attention to Tuberculosis led to a collaboration that saw The Shack first exhibited on World TB Day in 2006.

Over a period of 2 1/2 years The Shack was exhibited 8 times, in 5 countries on 4 continents. Primarily advocating to raise awareness about TB it also drew attention to the Millennium Development Goals, HIV/TB co-infection, and poverty.

The Shack was seen by thousands of people including affected communities, politicians, donors, academics and researchers in Cape Town, Paris, Amsterdam, The Hague, Sydney, Canberra and Mexico City.

Earlier this month a shipment arrived on my doorstep which contained fragments of The Shack which had been saved from the destruction of the exhibition in Mexico. One of the pictures I kept was a portrait of a little girl meeting Archbishop Desmond Tutu at the Tygerberg Hospital on World AIDS Day 2005. It used to sit on top of the shelves above the ghetto blaster by the bed in the Shack. The same day that I was told that I was going to have my first international exhibition at the UNION conference I was also told that this little girl had died of HIV. Driving home from that meeting I was torn between the euphoria of The Shack's success and



The Shack

the harsh reality of what The Shack represents: a way of living far beyond my comprehension and unjust to all who experience it. It was then that I realized the seriousness of my chosen subject matter, and the potential this work held to raise awareness of the issue.

When I opened my parcel and pulled out this photo I realized that the story of this little girl had just travelled a full circle around the globe advocating to stop what finally killed her. Her fight to survive has lived on through the power of photography.

This was the intimate nature of The Shack. It was a home and those who lived in it were a family of heroes. They face impossible challenges everyday that they make possible because they believe it is possible. In The Shack we were exposed to the atrocities of life as well as the beauty of human

compassion. From the smallest superhero Floyd who, by the age of eight had overcome more life threatening disease and abuse than most experience in a lifetime, to Mama Maposela and Jean Molenga who help children because they don't want them to go through what they did as children. These are all real stories about real people, and they had the courage to invite us into their home and share their lives with us.

There was far more to The Shack than just its stories and anyone who assisted in the building, organizing or manning of the exhibition will testify to this. In order to present these stories to the world there were countless hours of stress, cursing, and I lost count of the amount of times people swore to never be involved in the project again. But this tension always seemed to evaporate when the last sheet of plastic was placed on the roof and the first viewer would

puzzle over this mass of scrap metal and wood in the middle of a space-aged conference and read the introductory sign: POVERTY IS A WEAPON OF MASS DESTRUCTION. I am eternally thankful to all of you who swore, had sleepless nights, drafted countless emails for sponsorship, fought with officials and the odd viewer who disliked The Shack, and all of you who got bumped, bruised, dusty and smelly putting it up and taking it down. You – like Jean and Mama Maposela – have suffered to make someone else's life better.

Damien Schumann Artist, Photographer and Creator of The Shack

Read about the final exhibition of the Shack at the AIDS 2008 Conference in Mexico City:

» http://www.stoptb.org/wg/tb_hiv/assets/documents/IAS%202008%20Special%20Edition%20HIV%20TB%20Newsletter.pdf

COMMUNITY MOBILIZATION FOR TB/HIV IN SOUTHERN AFRICA



The Stop TB strategy calls for the empowerment of communities in the response to stop TB and TB/HIV. There are many places where involvement of community groups is still lacking. Communities are sometimes viewed as an add-on to the decision making process rather than a key stakeholder in a national response. There are however, some community groups who, having experienced the challenges posed by the TB/HIV co-epidemic in their own lives, have decided to take action.

In Southern Africa, the AIDS and Rights Alliance for Southern Africa (ARASA) works to empower groups around the SADC (Southern African Development Community) region. They train community groups about the science of HIV and TB and the WHO policy on the 12 collaborative TB/HIV activities, all of which need to be implemented in order to respond to the co-epidemic. They are helping community members become informed advocates for TB/HIV by increasing capacity to do advocacy and take an active role in the response to TB/HIV.

Within the 12 collaborative TB/HIV activities ARASA has also placed emphasis on the Three Is (intensified case finding, IPT and infection control). A campaign launched in April 2008 which calls for HIV services to actively identify TB cases, provide treatment and preventive therapy

where needed and ensure infection control measures to stop TB transmission are in place.

One example of the impact that the ARASA training has had are the activities of the Botswana Treatment Literacy Coalition (BTLC). After the training, BTLC identified as a key priority for their advocacy work the lack of education about infection control for TB in their communities, some of which have the highest prevalence rates of both TB and HIV in the world.

One of the activities BTLC undertook was to produce a public service announcement (PSA) which communicated simple messages about infection control in communities. The PSA was aired on prime-time television for 10 weeks.

The public response was overwhelming. Almost immediately BTLC – which is housed by the Botswana Network on Ethics, Law and HIV/AIDS (BONELA) – began to receive calls from people who had seen the PSA. People wanted to know more about what they could do, they wanted to know more about TB/HIV, and they wanted to know more about how to improve infection control measures in their own home. They also asked questions about symptoms - what to look for, what about side-effects, where to go and get tested for TB? They also raised ethical and legal questions such as whether it was legal for employers to dismiss them for having TB?

The activities of BTLC show how effective communities can be in the response to TB/HIV, in this case raising awareness and filling an information gap. BTLC got people on the street talking, they got civil society asking

what use are state-of-the-art diagnostics if people do not know when they should be tested, or how do we address infection control in health care facilities without looking at the places people live, work and play?

A proactive approach to community involvement in the TB/HIV response can help achieve national goals. There are many examples which show that empowered community members are well placed to help make this happen and BTLC is one of them.

WHAT NEXT?

BTLC will launch a national TB campaign in October. Using a wide variety of community-based platforms and communication tools, they will advertise key messages about TB/HIV around the country. Information about infection control, early and regular screening for TB, testing for HIV, isoniazid preventive therapy (IPT), adherence and support, and human rights will be disseminated. This is essential in order to establish an effective, sustainable and patient-centred approach response to TB/HIV.

Other community groups in the region are also taking action in response to TB/HIV. The Treatment Action Campaign (TAC) in South Africa conducts door-to-door TB campaigns, distributing educational material, referring people to treatment and care facilities, and supporting follow-up of patients in the community. The Collaborative Fund for HIV Treatment Preparedness has begun to support a pool of community organizations in SADC who are committed to integrating TB into their HIV work, for which ARASA will also be



Activists calling for action on TB/HIV in Botswana

providing technical assistance to build the capacity of informed TB/HIV community advocates across the region.

When empowered with information about TB/HIV, communities can and have assumed a more active role in the response to this co-epidemic. As governments around the world continue to make bold commitments to scaling up the 12 collaborative TB/HIV activities particularly the Three I's, they must also make meaningful commitments to working with communities – not merely as beneficiaries but as implementers, monitors and advocates.

Contribution by Paula Akugizibwe, ARASA

Battling the Dual Epidemic through Community Action

MEET THE ACTIVISTS

Multiface Development and Research Center: **Nelson Juma Otwoma**



Nelson Juma Otwoma is the Publicity and Communications Secretary for Multiface Development and Research Centre (MDRC), and the lead researcher for Public Health Watch's TB/HIV Monitoring and Advocacy project in the Suba district, Nyanza Province, Kenya. A graduate of Anthropology from the University of Nairobi, Mr. Otwoma is a Social Scientist with a deep interest

in advocacy, capacity building, and operations research focusing on HIV/AIDS/TB and associated crosscutting issues. As a person living with HIV, he is committed to promoting and advocating for meaningful involvement of PLWTB/HAS in TB/HIV/AIDS programs/activities.

"The WHO interim policy on collaborative TB/HIV activities 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."

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



Carol Nawina Nyirenda is the lead researcher for Public Health Watch's TB/HIV Monitoring and Advocacy project at the Treatment Advocacy & Literacy Campaign (TALC), monitoring the state of collaborative TB/HIV activities in Lusaka, Zambia. She sits on the TALC Board, edits the quarterly TALC Newsletter, and acts as international HIV/TB/Malaria Treatment Activist and

Alternate Board member on the UNITAID Board representing communities living with the three diseases. Ms. Nyirenda is a TB survivor, and a person living openly and positively with HIV.

"Along with fellow Zambian activists I called on the Zambian government to implement WHO recommendations for collaborative TB/HIV activities."

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



Thembi Nkambule is an HIV treatment activist in a country with one of the highest TB/HIV prevalence rates. She learned more about TB and incorporated this knowledge into her activism by providing training on TB/HIV to 38 support groups and a core group of activists. She has improved SWANNEPHA's capacity to do TB/HIV advocacy and outreach. Thembi has also been

working on national policy advocacy to get people living with HIV meaningfully integrated into TB and HIV programming and service delivery.

"I helped develop a community training manual on TB/HIV and have seen an increase in people living with HIV being willing to discuss TB within their networks."

Upcoming events

The Secretariat of the TB/HIV Working Group encourage members of the Working Group and other HIV and TB implementers and stakeholders to submit their abstracts on TB/HIV issues for these important meetings.

OCTOBER

IFIC CONGRESS 2008: 9TH CONGRESS OF THE INTERNATIONAL FEDERATION OF INFECTION CONTROL

When: **October 14-19, 2008**

Where: **Santiago, Chile**

For more information: www.ific2008.cl

39TH UNION WORLD CONFERENCE ON LUNG HEALTH OF THE INTERNATIONAL UNION AGAINST TUBERCULOSIS AND LUNG DISEASE (THE UNION)

When: **October 16-20, 2008**

Where: **Palais des Congrès, Paris, France**

The theme of the Conference is "Global threats to lung health: the importance of health system responses"

For more information:

<http://www.worldlunghealth.org/Conf2008/website/index.php>

» TB/HIV at the UNION - see the TB/HIV roadmap at the end of the newsletter

NAP AND NTP SPECIAL SESSION SUCCESSES AND CHALLENGES FOR COLLABORATION IN TB-HIV ACTIVITIES

When: **Friday 17th October 14:00-16:00**

Where: **Palais des Congrès, Room 351**

TB and HIV programme managers are invited to share experiences and discuss factors such as civil society participation, donor harmonization, and political leadership within the two programmes that have facilitated or impeded their partnership. This session recognizes the importance of facilitating dialogue between both groups of managers so as to document lessons learned and plan for the future. An output of this session will be to develop a list of action points which will be followed up in 2009 at the 40th Union Conference on Lung Health.

PATHOGENESIS AND CONTROL OF EMERGING INFECTIONS AND DRUG-RESISTANT ORGANISMS

When: **October 22-27, 2008**

Where: **Bangkok, Thailand**

For more information:

www.keystonesymposia.org/Meetings/ViewMeetings.cfm?MeetingID=995

Online registration deadline: **October 22, 2008**

JOINT MEETING OF THE AMERICAN SOCIETY FOR MICROBIOLOGY (ASM) AND THE INFECTIOUS DISEASES SOCIETY OF AMERICA (IDSA)

When: **October 25-28, 2008**

Where: **Washington, DC, USA**

For more information: Joint meeting of ICAAC and IDSA. <http://www.icaacidsa2008.org/>

NOVEMBER

GLOBAL FUND BOARD MEETING

When: **November 4 -7, 2008**

Where: **New Delhi, India**

For more information:

<http://www.theglobalfund.org/en/about/board>

TB/HIV CORE GROUP MEETING

When: **November 11-12, 2008**

Where: **Addis, Ethiopia**

TB/HIV WORKSHOP THREE IS

When: **November 13-14, 2008**

Where: **Addis, Ethiopia**

For more information: Email Eva Nathanson on nathansone@who.int

The objective of this planning workshop is to identify country specific critical action steps for nationwide expansion of collaborative HIV/TB activities and:

- Provide National AIDS and TB Program managers, or other relevant staff, with knowledge to enhance nationwide scale-up of collaborative HIV/TB activities and particularly the Three I's for HIV/TB.
- Identify action steps for TB prevention, screening and treatment for people living with HIV as a component of HIV treatment and care services.
- Identify action steps for nationwide expansion of TB infection control in health and congregate settings in the context of HIV/AIDS care and treatment.
- Identify action steps to ensure the implementation of revised recording and reporting formats and strengthen national HIV/TB monitoring systems.
- Develop country specific critical actions for nationwide scale up of collaborative HIV/TB activities, and particularly the Three I's for HIV/TB.

7TH LOUIS PASTEUR CONFERENCE ON INFECTIOUS DISEASES

When: **November 11-13**

Where: **Paris, France**

For more information:

www.pasteur.fr/infosci/conf/sb/clp7/

RESEARCH ON HIV/AIDS, MALARIA AND TUBERCULOSIS: CHALLENGES FOR THE FUTURE

When: **November 13-14, 2008**

Where: **Brussels, Belgium**

For more information:

http://ec.europa.eu/research/health/infectious-diseases/poverty-diseases/event-brussels-13nov_en.html

INTERNATIONAL COURSE ON HUMAN RESOURCES DEVELOPMENT AND MANAGEMENT FOR TB CONTROL

When: **November 17-28, 2008**

Where: **Bangkok, Thailand**

For more information:

www.iauatld.org/full_picture/en/frameset/frame-set.phtml?page=http://www.iauatld.org/full_picture/en/conf_courses/courses/liste_courses.phtml

DECEMBER

WORLD AIDS DAY

When: **December 1, 2008**

Where: **Global**

For more information:

<http://www.worldaidscampaign.org/>

15TH INTERNATIONAL CONFERENCE ON AIDS AND STIS IN AFRICA

When: **December 3-7, 2008**

Where: **Dakar, Senegal**

For more information:

www.icasadakar2008.org/en/index_8.php

GLOBAL FUND PARTNERS FORUM

When: **December 8-10, 2008**

Where: **Dakar, Senegal**

For more information:

<http://www.theglobalfund.org/EN/>

Roadmap HIV&TB/HIV Symposia



FRIDAY, 17th October 2008

Special Session 14:00 – 16:00 Location: Room 351

Successes and challenges for collaboration in TB-HIV activities

TB and HIV programme managers are invited to share experiences and discuss factors such as civil society participation, donor harmonization, and political leadership within the two programmes that have facilitated or impeded their partnership.

SATURDAY, 18 October 2008

Symposium No.3: 08:00 – 10:15 Location: Room 342AB

Highlights of the XVII International AIDS Conference, Mexico, August 2008

The International AIDS Conference in Mexico City presents the latest developments in many aspects of HIV/AIDS.

Symposium No.4: 08:00 – 10:15 Location: Room 352 B

HIV care and treatment: scale-up lessons for health systems strengthening

Highlights of recent findings and experiences that document various ways in which HIV-related prevention, care and treatment initiatives serve as an entry point to strengthen health systems.

Symposium No.10: 14:00 – 16:15 Location: Bordeaux Room

Immune reconstitution inflammatory syndrome and tuberculosis (IRIS)

State of the art lectures regarding TB IRIS (diagnosis, management, immunopathogenesis), followed by discussion about priorities and questions for research. Clinical case definitions for different types of TB IRIS that could be used in clinical and research settings will be discussed.

Symposium No.16: 14:00 – 16:15 Location: Room 343

Global initiatives to improve maternal and child health

Maternal and child health is an important focus of global initiatives for HIV, TB, malaria, safe water and immunisation; current focus of these efforts and opportunities for collaboration will be highlighted.

SUNDAY, 19 October 2008

Symposium No.21: 09:00 – 11:15 Location: 342 AB

The integration of food and nutritional support into the care and treatment of PLWHA

This symposium will summarise the science and the policy and programme experience to date with regard to how nutrition affects the progression of HIV/AIDS and TB, their treatment, clinical outcomes and disease management for patients with HIV and TB.

Symposium No.22: 09:00 – 11:15 Location: Room 352B

TB-HIV community activism: key components of a health systems response

Empowerment of the community is a key component of TB control strategies, yet the full scope has yet to be fully defined. The symposium will provide examples of how the work of empowered community activists can contribute to a health system response to address TB.

Symposium No.28: 14:00 – 16:15 Location: Bordeaux Room

Monitoring and evaluating the response to the HIV/AIDS epidemic at national and facility level in resource-poor countries



The Palais des Congrès in Paris, France, from 16 to 20 October 2008
<http://www.worldlunghealth.org>

Monitoring and evaluation (M&E) of HIV services at national and health facility level in low-income countries will be discussed; focusing on the differences between M&E systems for HIV testing and counselling, prevention of mother-to-child transmission, and antiretroviral therapy.

Symposium No.31: 14:00 – 16:15 Location: Room 352B

Male circumcision a success story for HIV prevention. Now what?

This symposium will review the scientific evidence supporting the effectiveness of circumcision to prevent HIV and outline the steps that are being taken toward implementation of circumcision, operations research around its implementation and issues around neonatal circumcision.

MONDAY, 20 October 2008

Symposium No.39: 09:00 – 11:15 Location: Room 342 AB

Promising HIV prevention interventions and strategies

The information covered in this session will help HIV and TB programmes enhance and coordinate their health system response to more effectively respond to the TB and HIV problem.

Symposium No.40: 09:00 – 11:15 Location: Room 352B

Innovative approaches to increasing HIV prevention, care and treatment among TB patients

In many countries, HIV, TB and other health services are delivered in vertical programmes. A health systems approach to integrate these services, maximize resources and provide continuity of care to patients will be discussed.

*Symposium No.42: 09:00 – 11:15 Location
Room: 341*

Treatment literacy: a vital weapon in battling TB-HIV

Several community-based organizations are now pioneering TB-HIV context-appropriate treatment literacy programmes so as to help empower people understand their own health needs. The symposium will provide insight from their experiences on how to use treatment literacy as part of a comprehensive strategy for controlling TB and HIV/AIDS in resource-poor settings.

Symposium No.49: 14:00 – 16:15 Location Room: 352B

Implementing the three I's: scaling up intensified case finding, isoniazid preventive therapy and infection control for TB for people living with HIV

This session will help HIV and TB programmes enhance and coordinate their health systems response to more effectively scale up the three I's.

Symposium No.53: 14:00 – 16:15 Location Room: 353

TB-HIV collaboration: how do health care systems manage to provide the needed care?

The co-management of HIV and TB presents a significant challenge for individual clinicians and health systems. Providing TB and HIV care in the same site has clear advantages to the patient (one-stop care) and the health system, but requires careful training, adequate human resources and close collaboration between district TB and HIV programme management teams.



GLOBAL THREATS TO LUNG HEALTH
THE IMPORTANCE OF HEALTH SYSTEM RESPONSES

39th Union World
Conference
on Lung Health

The Palais des Congrès in Paris, France, from 16 to 20 October 2008

<http://www.worldlunghealth.org>