



# Bulletin 125

Medicus Mundi Schweiz

Netzwerk Gesundheit für alle  
Réseau Santé pour tous  
Network Health for All



SEPTEMBER 2012

## HIV, AIDS AND ADVOCACY

Reader of the [aidsfocus.ch](http://aidsfocus.ch) conference

## IMPRESSUM

**MEDICUS MUNDI SCHWEIZ**  
**Netzwerk Gesundheit für alle**  
**Réseau Santé pour tous**  
**Network Health for All**

Bulletin Nr. 125, September 2012  
**HIV, Aids und Advocacy**

### NETZWERK MEDICUS MUNDI SCHWEIZ

Die gemeinsame und verbindende Vision der Mitglieder des Netzwerks Medicus Mundi Schweiz ist Gesundheit für alle: ein grösstmögliches Mass an Gesundheit für alle Menschen, insbesondere auch für benachteiligte Bevölkerungen.

Medicus Mundi Schweiz vernetzt die Organisationen der internationalen Gesundheitszusammenarbeit, fördert den Austausch von Wissen und Erfahrungen, vermittelt ihnen Impulse für die Weiterentwicklung ihrer Tätigkeit und macht ihre Tätigkeit einem weiteren Publikum bekannt.

Das Bulletin von Medicus Mundi Schweiz erscheint viermal jährlich. Jede Ausgabe ist einem Schwerpunktthema gewidmet und enthält aktuelle Hinweise und Informationen.

Medicus Mundi Schweiz profitiert in seiner Arbeit von der langjährigen Partnerschaft mit der schweizerischen Direktion für Entwicklung und Zusammenarbeit DEZA, die auch die Herausgabe des vorliegenden Bulletins mit einem grosszügigen Beitrag unterstützt.

### GESCHÄFTSSTELLE UND REDAKTIONSSSEKRETARIAT:

Medicus Mundi Schweiz  
 Netzwerk Gesundheit für alle  
 Murbacherstrasse 34  
 Postfach, CH-4013 Basel  
 Tel (+41) 061 383 18 10  
 info@medicusmundi.ch  
 www.medicusmundi.ch

### REDAKTIONSKOMMISSION:

Martin Leschhorn Strebelt, Helena Zweifel  
**LAYOUT:** VischerVettiger Basel

### PRODUKTION:

Geschäftsstelle Medicus Mundi Schweiz,  
 Martin Leschhorn Strebelt

**DRUCK:** Südwestdruck Lörrach

**AUFLAGE DIESER NUMMER:** 1300 Ex.

**ERSCHEINUNGSWEISE:** Vier Nummern im Jahr

### NÄCHSTE NUMMER:

Gesundheitspersonalmanager  
**REDAKTIONSSCHLUSS:**

30. September 2012

**TITELBILD:** Washington, 24. Juli 2012,

© Helena Zweifel/aidsfocus.ch

## NETZWERK

Die 45 Mitgliedorganisationen von Medicus Mundi Schweiz:

Afro-European Medical and Research Network (AEMRN)

Aids und Kind

Aids-Hilfe Schweiz

Association Solidarité avec les Villages du Bénin

Basler Förderverein für medizinische Zusammenarbeit

Bethlehem Mission Immensee

Bündner Partnerschaft HAS Haiti

Calcutta Project

Christoffel Blindenmission (Schweiz)

CO-OPERAID

DM – Echange et Mission

Enfants du Monde

FAIRMED – Gesundheit für die Ärmsten

Fondation Sociale Suisse du Nord

Cameroun

Fondation Suisse pour la Santé Mondiale

Förderverein für Otorhinolaryngologie

Freunde Behindertenintegration

Kamerun

Gemeinschaft der St. Anna-Schwwestern

Graduate Institute of International and

Development Studies – Global Health Programme

GRUHU

Handicap International (Schweiz)

IAMANEH Schweiz

INTERTEAM

Jura-Afrique, Programme Santé

Kinderhilfe Bethlehem

Lungenliga Schweiz

Médecins du Monde-Suisse

medico international schweiz

medicCuba-Suisse

Mission 21

Novartis Stiftung für Nachhaltige

Entwicklung

Pharmaciens sans Frontières Suisse

Schweizerische Gesellschaft für

Tropenmedizin und Parasitologie

Schweizer Hilfsverein für das Albert

Schweitzer-Spital Lambarene

Schweizer Indianerhilfe

Schweizerisches Korps für humanitäre

Hilfe

Schweizerisches Rotes Kreuz

Schweizerisches Tropen- und Public-

Health Institut (Swiss TPH)

Secours Dentaire International

Service de médecine internationale

et humanitaire (SMIH)

SEXUELLE GESUNDHEIT Schweiz

SolidarMed

Stiftung Terre des Hommes

Verein Partnerschaft Kinderspitäler

Biel-Haiti

# INHALT

## EDITORIAL

Helena Zweifel

4

## INTRO

Mutter-Kind-Gesundheit muss verbessert werden

5

## HIV, AIDS AND ADVOCACY

### NO PROFITS BEFORE LIFE!

Nonkosi Khumalo

8

### ZIMBABWE: LOCAL LEVEL ADVOCACY IN HEALTH AND RIGHTS

Joshua Mavundu

14

### GLOBAL ADVOCACY IN AN ERA OF RESOURCE CONSTRAINTS AND SHIFTING GLOBAL PRIORITIES

Eduard Grebe

20

### BRINGING ABOUT CHANGE IN THE POLICIES AND PRACTICES IN TANZANIA

Paulina Alex

25

### CITIZEN VOICE AND ACTION – AN APPROACH TO SOCIAL ACCOUNTABILITY

Aashish Masih

31

### „ICH BIN MENSCHENRECHTSAKTIVISTIN“

Helena Zweifel

37

## RAISING AWARENESS AND INITIATING CHANGE

### “MAKE US THE LAST GENERATION TO BE BORN WITH HIV”

Nicola Willis and Andreas Keller

42

### ADVOCACY FOR IMPROVED MEDICAL CARE FOR HIV-POSITIVE PERSONS

Karolin Pfeiffer

44

### VON DER SELBSTHILFE ZUR EINFLUSSREICHEN BEWEGUNG

Albino Martín Portillo und Mirta Ruiz Díaz

47

## GLOBAL STRATEGIES

### TURNING THE TIDE TOGETHER: A DECLARATION TO END THE AIDS EPIDEMIC

The Washington D.C. Declaration

52

### EINE WENDE IST MÖGLICH, WENN JETZT GEHANDELT WIRD

aidsfocus.ch

54

### «WENN ES DEN GLOBAL FUND NICHT GÄBE, MÜSSTEN WIR IHN ERFINDEN»

Helena Zweifel

56

## DEBATTE

Thomas Schwarz

62

## MAGAZIN

65

Wir können Aids beenden! Die Stimmung an der Internationalen Aidskonferenz im Juli 2012 in Washington wirkte ansteckend und unterscheidet die diesjährige Konferenz von früheren.

Wir können Aids beenden, wenn wir alle mit vollen Engagement auf dieses Ziel hinarbeiten, die Regierungen im Globalen Süden und Osten und in Geberländern, WissenschaftlerInnen, NGO-VertreterInnen, AktivistInnen und Menschen, die mit HIV leben. Ein Schlüssel zur Beendigung von Aids ist die Versorgung aller Menschen mit wirksamen und kostengünstigen Aidsmedikamenten – zur Behandlung und zur Prävention weiterer Infektionen, insbes. auch der Verhinderung der Übertragung des Virus aufs Kind.

An der Aidskonferenz unterstrich die amerikanische Aussenministerin Hillary Clinton in einem engagierten Plädoyer das Engagement und Verpflichtung der USA, sich aktiv für eine aidsfreie Generation einzusetzen und versprach konkret zusätzliche 150 Millionen US\$ für drei Initiativen zugunsten von Gemeinschaften, die besonders gefährdet sind und diskriminiert werden. Frankreichs Präsident Hollande bestätigte per Videobotschaft die Verpflichtungen Frankreichs gegenüber dem Globalen Fonds zur Bekämpfung von Aids, Malaria und Tuberkulose und teilte mit, dass Frankreich eine Steuer auf finanziellen Transaktionen einführen wird um zusätzliche Gelder zu generieren. Die offizielle Schweiz glänzte durch Abwesenheit.

Die Schweiz hat sich letztes Jahr an der Generalversammlung der UNO zusammen mit anderen Regierungen in der politischen Erklärung zu HIV und Aids verpflichtet, «die Anstrengungen zu intensivieren, um HIV/Aids zu eliminieren». Was ist daraus geworden? Haben wir unsere Hausaufgaben nicht gemacht? Haben wir – die schweizerische Zivilgesellschaft – uns zu wenig anwaltschaftlich für die Millionen von der Aids-Epidemie direkt betroffenen Frauen, Männer und Kinder engagiert und die Schweizer Regierung zu wenig zur Rechenschaft gezogen?

Wir können von unseren Südpartnern aus Südafrika, Simbabwe, Tansania und Indien lernen: Sie setzen sich konkret und mutig mit HIV-positiven Menschen und lokalen Gemeinschaften dafür ein, dass ihr Recht auf Gesundheit umgesetzt wird, und sie ziehen ihre Regierungen zur Rechenschaft, wenn diese ihren Verpflichtungen nicht nachkommen.

Als schweizerische zivilgesellschaftliche Organisation ist es unsere Aufgabe, uns hier in unserem direkten Einflussbereich anwaltschaftlich zu engagieren, in Unterstützung und in Zusammenarbeit mit unsern SüdpartnerInnen. Dies heisst für uns, die Schweizer Regierung zur Rechenschaft zu ziehen, wenn sie den eingegangenen Verpflichtungen zur Intensivierung ihres Engagements in der internationalen HIV-Response und zu einer stärkeren Unterstützung des Global Fund nicht nachkommt. Es heisst auch, gegen Bestreben der pharmazeutischen Industrie zu verschärften Patentrechten anzukämpfen und dafür einzustehen, dass der Zugang aller Menschen zu lebensrettenden, kostengünstigen Medikamenten sichergestellt wird.

Die Fachtagung von aidsfocus.ch zu HIV, Aids und Advocacy im April 2012 war der Auftakt zu einem verstärkten Engagement in Advocacy für Gesundheit und soziale Gerechtigkeit für alle – Voraussetzung und Garant für eine Zukunft ohne Aids.

Helena Zweifel  
Geschäftsführerin Medicus Mundi Schweiz



## MUTTER-KIND-GESUNDHEIT MUSS VERBESSERT WERDEN

Das Netzwerk Medicus Mundi Schweiz wird an seinem diesjährigen Symposium die Mutter-Kind-Gesundheit debattieren. Trotz vieler Fortschritte in den vergangenen Jahren, handelt es sich um den Bereich, in welchem die globale Gesundheit am wenigsten vorangekommen ist. Es ist gut, dass das Thema in den kommenden Monaten verstärkt in den Fokus rückt.

**DIE BILL** and Melinda Gates' Foundation gibt dem Thema mit der Stossrichtung reproduktive Gesundheit verstärktes Gewicht. Im Vordergrund steht dabei, den Zugang zu Empfängnisverhütung zu verbessern. Melinda Gates sieht dies nicht als eine Wiederbelebung einer teilweise in Verruf geratenen Bevölkerungspolitik, sondern als eine Ausrichtung auf die Bedürfnisse von Frauen: «This is about empowering women to be educated and to make a choice that they want to make.» Melinda Gates hat sich als Katholikin mit diesem Engagement einige Kritik von religiösen Kreisen anhören müssen.

Im kommenden Juli findet in London der «Family Planning Summit» statt, der von der britischen Regierung gemeinsam mit der Bill & Melinda Gates Foundation getragen wird. Die Ziele dieses Gipfels sind ambitioniert: «The Summit will commit the global community to giving access to family planning to 120 million more women in the poorest countries by 2020.»

Auch die neue Gesundheitsaussenpolitik der Schweiz, welche der Bundesrat dieses Jahr verabschiedet hat, weist der Mutter-Kind-Gesundheit einiges Gewicht zu. Eine der zwanzig Zielsetzungen ist der Thematik gewidmet. Dabei soll die «medizinische und soziale Betreuung werdender Mütter in Ländern mit hoher Kin-

der- und Müttersterblichkeit verbessert» werden. Und: «Die Überlebenschancen für Kinder und Mütter werden durch Verbesserung des Zugangs verletzbarer Gruppen zu Gesundheitsdienstleistungen erhöht.»

Ausserdem wird es im Jahr 2014 zwanzig Jahre her sein, dass die Bevölkerungskonferenz von Kairo, die International Conference on Population and Development (ICPD), stattgefunden hat. Dann wird Bilanz über den damals verabschiedeten Aktionsplan gezogen.

Das MMS Symposium ermöglicht es zusammen mit relevanten Akteurinnen und Akteure hier in der Schweiz das brennende Thema der Mutter-Kind-Gesundheit zu debattieren, Handlungsmöglichkeiten zu evaluieren und den politischen Prozess zu stärken.

Martin Leschhorn Strebel

Beim vorliegenden Text handelt es sich um das Editorial für die MMS Nachrichten des Monats Juni.

Hintergründe zum Thema: <http://bit.ly/OTHe8h>

Wollen Sie die MMS Nachrichten regelmässig per Mail erhalten? Schreiben Sie ein Mail an: [info@medicus-mundi.ch](mailto:info@medicus-mundi.ch)



WWW.MEDICUMUNDI.CH

MMS SYMPOSIUM, 6. NOVEMBER 2012:

## Mutter-Kind-Gesundheit

Das Netzwerk Medicus Mundi Schweiz wird an seinem diesjährigen Symposium die Mutter-Kind-Gesundheit debattieren. Trotz vieler Fortschritte in den vergangenen Jahren, handelt es sich um den Bereich, in welchen die globale Gesundheit am wenigsten vorangekommen ist. Das MMS Symposium ermöglicht es zusammen mit relevanten Akteurinnen und Akteure hier in der Schweiz das brennende Thema der Mutter-Kind-Gesundheit zu debattieren, Handlungsmöglichkeiten zu evaluieren und den politischen Prozess zu stärken.

Ort: Basel, Hotel Hilton, Zeitraum: 9.00–16.45 Uhr

Programm: Das genauere Programm wird sobald wie möglich veröffentlicht.

<http://www.medicumundi.ch/mms/services/events/Symposium2012>

SYMPOSIUM MMS, 6 NOVEMBRE 2012

## Santé de la mère et de l'enfant

A l'occasion de son symposium annuel, le Réseau Medicus Mundi Suisse va débattre de la santé de la mère et de l'enfant. Malgré de nombreuses avancées ces dernières années, il s'agit d'un domaine au sein duquel la santé mondiale a fait le moins de progrès. Le Symposium MMS permet, conjointement avec des acteurs et des actrices pertinents, de discuter ici en Suisse du thème brûlant que constitue la santé de la mère et de l'enfant, d'évaluer les possibilités d'action et de renforcer le processus politique.

Lieu: Bâle, Hotel Hilton, Zeitraum: 9 heures à 16 heures 45

Programme: Le programme sera publié le plus tôt possible

<http://www.medicumundi.ch/mms-fr/services/events/Symposium2012>



Konferenzfotos: Daniel Rihs

Seiten 8–39

HIV/AIDS advocacy stories; Experiences, strategies, impact

**„However, it is a movement that faces serious challenges: instead of the increases in resources for AIDS programmes in developing countries that would be required to sustain progress, resources are declining.”** Eduard Grebe

# NO PROFITS BEFORE LIFE!

The Treatment Action Campaign (TAC) in South Africa has played a crucial role in the country's AIDS response, and is well known beyond the South African borders as a model of successful advocacy and activism. Since 1998, TAC has held government accountable for health care service delivery, campaigned against official AIDS denialism, challenged the world's leading pharmaceutical companies to make treatment more affordable and cultivated community leadership on HIV and AIDS.

By Nonkosi Khumalo\*

## THE TREATMENT

Action Campaign, TAC, was founded on the 10 December 1998, the International Human Rights Day. When TAC was launched, our agenda was to ensure that people living with HIV got access to safe and effective treatment, antiretroviral medicines in particular. These drugs were already available and widely used in developed countries. Sadly, it was not the case in South Africa. Antiretroviral treatment was so expensive that only a few and the rich could afford it. The majority of those living with HIV and in need of treatment were dying because they were too poor to access treatment.

But the problem of lack of access to treatment was not just about the price of drugs in South Africa. It was also about the lack of political leadership, starting from the top with ex-President Thabo Mbeki and the Ministry of Health under the late Minister of Health Dr Manto Tshabalala-Msimang, all the way down to provinces like the Eastern Cape, Mpumalanga and KwaZulu Natal. Consequently, this meant that no treatment plan was implemented until 2004. And there was no ambitious strategic plan until 2007, when the National Strategic Plan, or NSP as it is popularly called, was adopted by the Cabinet. There was almost no access to treatment and there were many unnecessary and avoidable deaths.

## BUILDING TAC

TAC has grown into a powerful independent force in South African politics. TAC grew from 15 members in 1998 to 15000 – 17000 at its best between 2000 – 2008. Some people joined because they were HIV-positive and wanted medication, and other people joined because they are socially aware and identify with people living with HIV and AIDS.

Most importantly for many of us in TAC, this organisation became a centre of learning and leading. It became a home where we learned about politics, leadership, democracy, law and social mobilisation. It became more than just about HIV, but also about access to health care and what section 27 of the Constitution means.

We have combined different tactics such as community mobilisation, the South African Constitution and law, education, research and use of the media to achieve our ends. This is why TAC has transformed many of us in ways we never thought would ever be possible. What built TAC and got the attention of the public was this t-shirt with the words "HIV-POSITIVE" printed boldly in front. The t-shirts were produced in 1999 as a tool to break down the secrecy, shame and stigma that surrounded HIV. HIV-positive and HIV-negative members of the new group began wearing the group's

now-famous T-shirts. We need to acknowledge that in this country people are living with HIV and that there is solidarity. TAC has spread the message that people with HIV can be treated and that poor people have a right to health care. Today the t-shirts have become an iconic symbol in South African society, representing the struggle for human rights.

Over the past decade the backbone of our work in TAC has been the treatment literacy programme. The focus of this programme is to teach the science of HIV and HIV treatment in communities across South Africa. The treatment literacy programme allows everyone to understand the science of HIV and how to manage the disease.

Teaching community members about HIV also helps to bridge the gap between doctors and patients. As patients learn, the programme empowers them to understand why they need treatment and why some people experience side effects. People became little doctors of HIV: They knew when what kind of drugs there are, when to start treatment, what kind of side effects there could be. It arms community members with the information they need in order to demand antiretroviral treatment from the public health service. It has changed the perception that 'AIDS equals DEATH' into the awareness that although you might have HIV, you can still lead a normal and productive life.

## LEGAL CAMPAIGNS

We also run workshops on the politics of governance for ourselves. We have to understand how our government works, what are the tools available and what are the priorities of the government are in regard to HIV. This allows us to identify strategies on how to engage with the government. We also had to learn what the provisions of the constitution are. We were told that the South African constitution is one of the best constitutions in the world. Section 27 of the constitution, which is the most important, accords the rights to health for every South African citizen. It says that everyone has the right to have access to health care services, including reproductive health care, to sufficient food and water, and to social security. It also says that the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights and that no one may be refused

emergency medical treatment. One of the tools and strategies we used the most was the courts.

An example is the campaign on prevention of mother-to-child-transmission (PMTCT). TAC filed a case against the government asking that the government be ordered to make nevirapine available to pregnant women with HIV who give birth in the public health sector, and to their babies. You cannot say that every citizen has the right to access to sexual and reproductive health and then not to provide mothers with ART in order to prevent the HIV-transmission to the baby. We won the case, and the PMTCT-programme has been rolled out to over 1'600 health facilities. For us, it was an entry point for campaigns for universal access to treatment, using provisions in the constitution for legal battles.

The new National Strategic Plan (NSP) 2012–2016 was launched on 1 December 2012. It is an ambitious scheme, which commits South Africa to the virtual elimination of mother-to-child transmission of HIV. Government aims to provide treatment to at least 80% of those who need it. Furthermore, it aims to halve the rate of new HIV infections by 2016. The NSP contains ambitious targets for dealing with the twin epidemics of HIV and TB, using early screening and testing, contact tracing, and better efforts to keep people on treatment for the required length of time.

Today, approximately 1.5 million people are on antiretroviral (ARV) treatment in South Africa. 2 million more need immediate access to ARVs. Even though the rate of new infections seems to be slowing down, it remains far too high. We must do more to prevent new infections – and this, too, begins with learning about the science of HIV.

We need government to draw on the treatment literacy expertise developed by organisations like TAC, and to use this knowledge to drive the new community health worker programme. We need a larger injection of financial and human resources into our health system and social services. And we need treatment-literate communities so that once and for all we can turn the tide of HIV.

## NEW "OLD" CHALLENGES

In South Africa 73% of people living with HIV are co-infected with TB. TB is an old disease, much older than AIDS and as dangerous, but



**“My challenge to international donors and international governments would be once more to say that lives of people living with HIV are still important lives.”**

it neither got as much attention and financial investment. In fact, TB is one of the leading causes of death among people infected with HIV globally. TB co-infections are for people living with HIV a leading cause of death. TB accounts for more than 1.5 million deaths a year globally.

In 2010 there were 7386 confirmed cases of Multidrug-resistant TB (MDR TB) in South Africa and 700 cases of extensively drug-resistant TB (XDR TB). Because XDR TB is resistant to the most potent TB drugs, patients are left with treatment options that are much less effective. XDR TB is of special concern for people with HIV infection or other conditions

that can weaken the immune system. These people are more likely to develop TB disease once they are infected, and also have a higher risk of death once they develop TB.

There is very little scientific development and investment in new drugs, diagnostics and technologies generally to deal with an old epidemic. With the current downturn in financial investments, getting proper diagnostics and new drugs remains only a pipedream. Currently the need to tackle TB globally requires an investment of \$1.3billion in 2012 and \$4.4 billion by 2014, however, through Global Fund, only \$362million is available to deal with TB this financial year.

We experience a diminishing political leadership globally on HIV and TB. The focus is shifting to other “major” global issues, such as climate change, economic growth or melt-down, etc.

#### **DIMINISHING FINANCIAL RESOURCES**

The devastating news came in November 2011 that the Global Fund to fight AIDS, Malaria and TB does not have enough money to put any one new on HIV treatment and cancelled Round 11. This effectively means no new grants until 2014. But effects will be devastating in Southern Africa, where millions are still awaiting lifesaving treatment. In some countries such as Swaziland, Mozambique and Zimbabwe, existing national treatment programmes are under threat of being severely curtailed, effectively reversing progress there. There is a Transitional Fund Mechanism put in place to cushion the programmes, but what this effectively does is to maintain what is already there without scaling up.

The U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) is scaling back in most countries — focusing on “health systems” instead. The US government in 2011 announced that its slogan will be “Turning the tide of HIV/AIDS” but this has not held true, especially in South Africa. Despite the promise to scale up, US government is actually cutting PEPFAR funding by 12% in its 2013 budget.

The Global Fund and PEPFAR combined account for 84% of the total HIV response in the developing countries. World Bank Multi-country HIV/AIDS programmes and UNITAIDS Paediatrics and second line ARV programmes are also shutting down or phasing out.

**\*NONKOSI KHUMALO** is a mother and an AIDS activist. She currently serves as the Chairperson of TAC. She began her tenure at TAC in 2001 as the organisation’s National Executive Secretary. Shortly after, she served as the National Women’s Health Programmes Coordinator where her focus was on evaluating Mother-to-Child Transmission Programmes, and the availability of Post-Exposure Prophylaxis for rape survivors in public health facilities. In 2004, Nonkosi was promoted to lead TAC’s Treatment Project. She is currently working on the implementation and research of the National Strategic Plan (2007-2011) for the South African National AIDS Council, serving as an Executive Member of the University of Natal for the Movement Against Women Abuse and as a board member of the AIDS Rights Alliance of Southern Africa. Contact: khumalo@section27.org.za;

Domestic purses are shrinking and health is compromised. Resources invested in wars rather than in lives... This crisis in global health could be the clearest example yet of how the world’s most vulnerable are being made to pay for the financial crisis that started in the banks and hedge funds.

#### **PROFITS MATTER MORE THAN LIVES**

Over the past decade, TAC has campaigned for affordable access to medicines, seeing a nearly 99% drop in the price of a standard triple drug combination, from roughly 9000 EUR per patient per year in 2000 to below 115 EUR per patient per year today. These prices came down primarily because of market competition among generic drug producers in India. Yet the battle for medicines access is not over, and many medicines, including cancer drugs and newer HIV medicines that people need after time, remain inaccessible to people in the developing world because of their high price.

European governments are pushing to limit our access to medicines through a Free Trade Agreement (FTA) that the EU is negotiating with India, which is the world’s largest producer of affordable generic medicines.

India is often called the “pharmacy of the developing world.” A study found that between 2003 and 2008, India supplied more than 80% of the HIV medicines used for the treatment of people living with HIV in developing countries. Beyond HIV, India is a vital supplier of affordable generic medicines to treat many other diseases.

But all this could change if the EU continues to pressure India to agree to more stringent intellectual property protection than that required by international trade rules. The United Nations, the World Health Organisation, the Global Fund to Fight AIDS, Tuberculosis and Malaria, and UNITAID have all warned against the adoption of these stringent measures that exceed India’s obligations. The adverse impact these excessive intellectual property provisions have on access to medicines is well documented.

The Swiss drug company Novartis took legal action against the government of India and filed for patent protection with the India’s Intellectual Property Appellate Board (IPAB) for a drug called Gleevec – a cancer drug for chronic leukaemia. Section 3(d) of the Indian Patent law states that new patents should not



TAC's iconic t-shirt

be given for routine improvements of existing medicines (“evergreening”). IPAB rejected the application, and in the meantime Novartis got exclusive marketing rights for Gleevec in India. It was selling it at \$2666 per patient per month. Generic companies on the other hand were selling it at \$177 per patient.

Should Novartis win the case, patents would be granted far more broadly on life-saving medicines in India, blocking the competition among multiple producers that drives prices down, and restricting access to affordable medicines for millions in India and across the developing world. A Novartis victory will also result in a negative precedent for countries like South Africa. South African law has no provision against evergreening and has issued patents for a number of previously registered medicines, including Gleevec. Civil society organizations such as MSF, TAC and the human rights NGO, SECTION27, are putting pressure on the government to revise existing legislation to include a provision preventing evergreening.

Ensuring that access to HIV medicines is protected is crucial to save lives and also reduce transmission of the virus. Last year, a landmark clinical trial showed that HIV treatment reduces by 96% the risk that the virus will

be passed on. It is imperative that medicines remain available and affordable so that we can begin to turn the epidemic around.

#### SOLIDARITY ACROSS BOARDERS

In the Political Declaration on AIDS 2011, world leaders have committed themselves to achieve universal access to HIV prevention, treatment, care and support by 2015. UNAIDS titles its strategy “Getting to Zero: Zero new HIV infections. Zero discrimination. Zero AIDS-related deaths.” I think that this strategy to getting to zero is an honourable principle as it was envisaged, but from the experience and what we see in terms of finances that are being available or not available and the responses of pharmaceutical companies, it will not be feasible to achieve zero principle by 2015. There are lesser resources invested in health and HIV generally. Pharmaceutical industries have started to reinforce the patents so that the new drugs that are most important especially for countries with high HIV epidemic will not be accessible for all. So much “getting to zero” is an honourable principle to get people behind, but I think that the international powers are not playing to the front in the moment and they need to be pushed once more.

My challenge to international donors and international governments would be once more to say that lives of people living with HIV are still important lives. We cannot talk about development without talking about health, and we need to rethink how much money we want to invest in wars and how much we invest in health.

The Swiss government has a huge responsibility that it has not risen to, especially with the fact that all the big international agencies are based in Switzerland. Global Fund was launched in Switzerland in 2002, and the Swiss contribution towards international drive on funding health has been very minimal compared to other countries who have the same GDP and are actually affected by the current Euro crisis.

My conclusion is that the voices of social movements and AIDS movements must be heard again – they have been too quiet for too long. Solidarity across borders North – South becomes vital one more time. We need to push for proper resourcing of the Global Fund, maybe with an expanded mandate on health. Once more shout: No profits before life!

## A timeline of TAC

- 1998** The TAC is launched on the steps of Cape Town’s St George’s Cathedral with its first campaign – calling for the provision of the antiretroviral (ARV) Zidovudine (AZT) for pregnant, HIV-positive mothers to prevent mother-to-child HIV transmission (PMTCT). The organization’s first statement also urges the government to develop a plan to provide affordable treatment for all HIV-positive South Africans;
- 1999 March** – After starting a petition for the introduction of PMTCT services, TAC members march on one of the country’s largest hospitals in Soweto. TAC protesters stage a lie-in at the hospital’s gate;
- 1999 June**, Thabo Mbeki is elected president and Manto Tshabalala-Msimang is appointed health minister, ushering in an era of “government-endorsed AIDS denialism”. Later, a Harvard University study will estimate that Mbeki’s delay in rolling out ARVs caused the death of 300’000 South Africans in the next five years;
- 2000** As the TAC imports the generic version of the antifungal medication, fluconazole, in defiance of pharmaceutical company Pfizer’s patent, Médecins Sans Frontières establishes the country’s first ARV treatment programme at a primary healthcare clinic in the Cape Town township of Khayelitsha;
- 2002** South Africa’s Constitutional Court rules in favour of the TAC, forcing the government to provide the ARV nevirapine to pregnant, HIV-positive mothers to prevent their unborn babies from contracting the virus. Later that year, Hazel Tau lodges a complaint regarding high ARV prices with the national regulatory body, the Competition Commission. She wins this complaint a year later;
- 2003** The TAC launches its civil disobedience campaign. Later that year, 21-year-old TAC member Lorna Mlofana is murdered after revealing her HIV-positive status. The man convicted of her murder served a few years in prison before being released;
- 2004** Government begins the slow roll-out of ARV treatment;
- 2006** The TAC wins a court case that establishes the right of prisoners to treatment. As of July 2011, about 9% of the country’s jails have ARV clinics on site;
- 2008** Government releases new PMTCT guidelines for administering more effective dual therapy instead of single ARV treatment; Mbeki is recalled from the presidency by the ruling African National Congress and Tshabalala-Msimang is replaced. Later that year, a moratorium on ARV treatment in South Africa’s Free State province commences due to financial mismanagement. The TAC launches protests at a local hospital in the province and parliament;
- 2008** November, TAC reveals it is experiencing a financial crisis that would force it to retrench 20% of its staff and cut back its treatment literacy programme;
- 2009** Jacob Zuma, the new President, signals an end to denialism and announces improved treatment guidelines, long lobbied for by the TAC and partners;
- 2010** South Africa has the biggest treatment programme in the world targeting at least one million people.
- 2011** 1 December, President Jacob Zuma unveiled the new National Strategic Plan (NSP) 2012–2016.

[www.irinnews.org/Report/93877/SOUTH-AFRICA-A-timeline-of-HIV-AIDS-activism](http://www.irinnews.org/Report/93877/SOUTH-AFRICA-A-timeline-of-HIV-AIDS-activism)

[www.tac.org.za/community/files/10yearbook/index.html](http://www.tac.org.za/community/files/10yearbook/index.html)

# ZIMBABWE: LOCAL LEVEL ADVOCACY IN HEALTH AND RIGHTS

Support groups in Zimbabwe are turning into advocacy groups with People living with HIV (PLHIV) successfully utilising advocacy methods in order to achieve better medical treatment and to reduce stigma in society. Success stories in Zimbabwe show the potential of HIV and AIDS related activism, linking local level activity with national campaigns.

By Joshua Mavundu\*

**THE CONCEPT** of local level advocacy initiatives in Zimbabwe began when Batanai HIV and AIDS Service Organisation (BHASO) in Masvingo, an NGO partner of fepa, trained the first core group of 30 advocates. Two people living with HIV (PLHIV) were chosen from each local support group and were trained to be advocates. BHASO provided them with systematic advocacy training which involves technical knowledge about the disease, treatment literacy and human rights, national and international networking as well as thorough preparation of campaigns.

## PLHIV AS DRIVERS OF ADVOCACY

Local level advocacy is spearheaded by PLHIV in the communities with knowledge on advocacy, human rights and law. The local advocacy committees in Masvingo involve all people in the community by holding consultation at all levels of the community. In most cases of HIV and health, consultations involve support group leaders, youth support groups, AIDS services organisations in Masvingo like Batanai, Zimbabwe AIDS Network, National AIDS Council, Red Cross, SolidarMed and many others. Local business people provide financial assistance during community meetings and are aware of

the work that the advocacy committee is doing. A diverse network of community participants are consulted and involved in the work of the provincial advocacy committee. This has enabled a shared vision with the community assisting in keeping the vision alive. For example, every time there are health rights violations in the community, e.g. drug stock-outs or discrimination, ordinary people in the community would generally ask if the advocacy committee knows about it and make every effort to bring the issue to the attention of the advocacy committee for action. This happens because everyone in Masvingo is aware of the shared vision of community health based on a human rights agenda.

The structure of local level advocacy creates a network of advocates from the community level up to the national level and operates at five levels: at the ward level, cluster level, the district level, the provincial level and the national committees. Almost all the provinces now have functional advocacy committees coordinated and run by PLHIV. Outside Masvingo the structure is coordinated by Zimbabwe Lawyers for Human Rights (ZLHR) in partnership with Zimbabwe Network PLVIH (ZNNP+). In 2009,

the national committee used to convene as a national roundtable, which is now the National Health and Rights Advocacy Forum.

The unique concept of advocacy committee is based on ownership by PLHIV who are supposed to drive the initiatives and function independent of anyone or any organisation. They are free to network and create partnerships in the communities as they deem fit in order to promote the shared vision of rights and health in the communities. Advocacy committees like support groups belong to the community and not to any institution or aids service organisation. Approaches have sought to dissociate the concept from the usual uneasy approach where people are owned by some person or institution. Advocacy committees therefore belong to the community and are there to hasten and behold to community needs and problems. They can operate independently because the concept is not expensive and is community driven.

## TAKING ACTION

Experiences in Masvingo have shown that advocacy is taking action and speaking out on a problem. Advocacy committee in Masvingo has undertaken action directed at changing the policy, practice, program, system, behaviours or environment in a manner that addressed the everyday problems faced by people in the community. Cases studies from Masvingo have

shown that advocacy action involves putting a problem on the agenda and drawing a community's attention to it and the need to solve the problem. Advocacy action herein highlighted involves a wide array of activities undertaken to achieve the desired change.

Throughout the narrative of advocacy diaries in Masvingo, it is apparent that advocacy action should first identify an advocacy objective. The advocacy committee or team has systematically set out what they intended to achieve before embarking on advocacy action. In most instances, initial research has been undertaken to provide relevant data to support advocacy arguments. Research has been carried out in various districts in the province on the thematic issues that have been raised in the districts as advocacy issues.

It is important to identify advocacy audiences. In the various districts in the province, advocacy targets have consisted of a cross section of government officials and key stakeholders who have contributed immensely to changes in policies, practices and programmes. The advocacy committee has systematically identified target audiences who make decisions or influence the decision making. In local level advocacy, it is important to identify who makes decisions in the local community and who can influence decision making.

Building partnerships and coalitions is important to strengthen the advocacy voice. The power of advocacy is found in the number of persons or organisations who support your objective. Non-governmental organisations, government health workers, business leaders, politicians and church leaders have all been part of the broader network of partners identified by the Masvingo advocacy committee for the work in the province. Besides facilitating political support, large numbers of people from diverse interests assist in amplifying the voice for the agreed cause.

The Masvingo advocacy committee has adopted innovative ways of framing advocacy content and presenting it. Formulating advocacy messages allows for the proper framing of issues using the appropriate language and data. This will also allow for persuasive presentations to be made to the appropriate audiences without wasting time. Usually policy makers do not have enough time to deal with many problems that are presented to them daily so it

\*JOSHUA MAVUNDU, the Advocacy and Gender officer of Batanai HIV and AIDS Service Organisation (BHASO) in Masvingo, Zimbabwe, has been the key driver of the local level advocacy program and the Meaningful Involvement of People living with HIV and AIDS (MIPA) in Masvingo Province. BHASO is a partner of fepa, partner of aidsfocus.ch. <http://www.bhaso.org/>, <http://www.fepafrika.ch/batanai>. Contact: [jmavundu@gmail.com](mailto:jmavundu@gmail.com); [scrutinize@bhaso.org](mailto:scrutinize@bhaso.org)

### References:

BHASO Advocacy Training Manual (2010). <http://bit.ly/T1DzpL>  
Local level Advocacy in Health and Rights: A case of Masvingo Province in Zimbabwe (2011), by Tinashe Mundawarara and Joshua Mavundu. <http://bit.ly/0h3x8h>



becomes critical to be able to package advocacy messages for efficiency and effectiveness within limited resources of time and limited opportunities to be heard.

Lastly, evaluation is crucial in advocacy because it enables you to see if the strategies being employed are working or not and to work on any improvements on current strategies in future actions. This is one area where serious effort is needed to effectively measure advocacy work in the province.

#### CASE 1: DRUG STOCK-OUTS

Coordinator (DAC) through a meeting where the committee highlighted the problem to the DAC, who later recommended a meeting between the advocacy committee and the Matron of Masvingo General Hospital. The meeting with the Matron did not yield much. The committee then engaged the Natpharm manager who highlighted that the Ministry of Health and Child Welfare (MoHCW) owed them a lot of money and the drugs were available but they could not be released owing to the debt.

The advocacy committee then had a meeting with the hospital pharmacist, who confirmed the information on condition of anonymity. From there the committee went to the Medical

Superintendent and demanded a meeting. During the meeting, the Medical Superintendent said there was no fuel to collect the drugs from Harare but the committee insisted that the drugs were there at the Natpharm pharmacy and that PLHIV should access those drugs immediately. Later on the Medical Superintendent (MS) went with members of the committee to Natpharm and met with the Natpharm manager who later agreed to release ten boxes of Cotrimoxazole.

#### Results of advocacy

Natpharm released 10 boxes of Cotrimoxazole to Masvingo General Hospital on the day and more supplies were subsequently released.

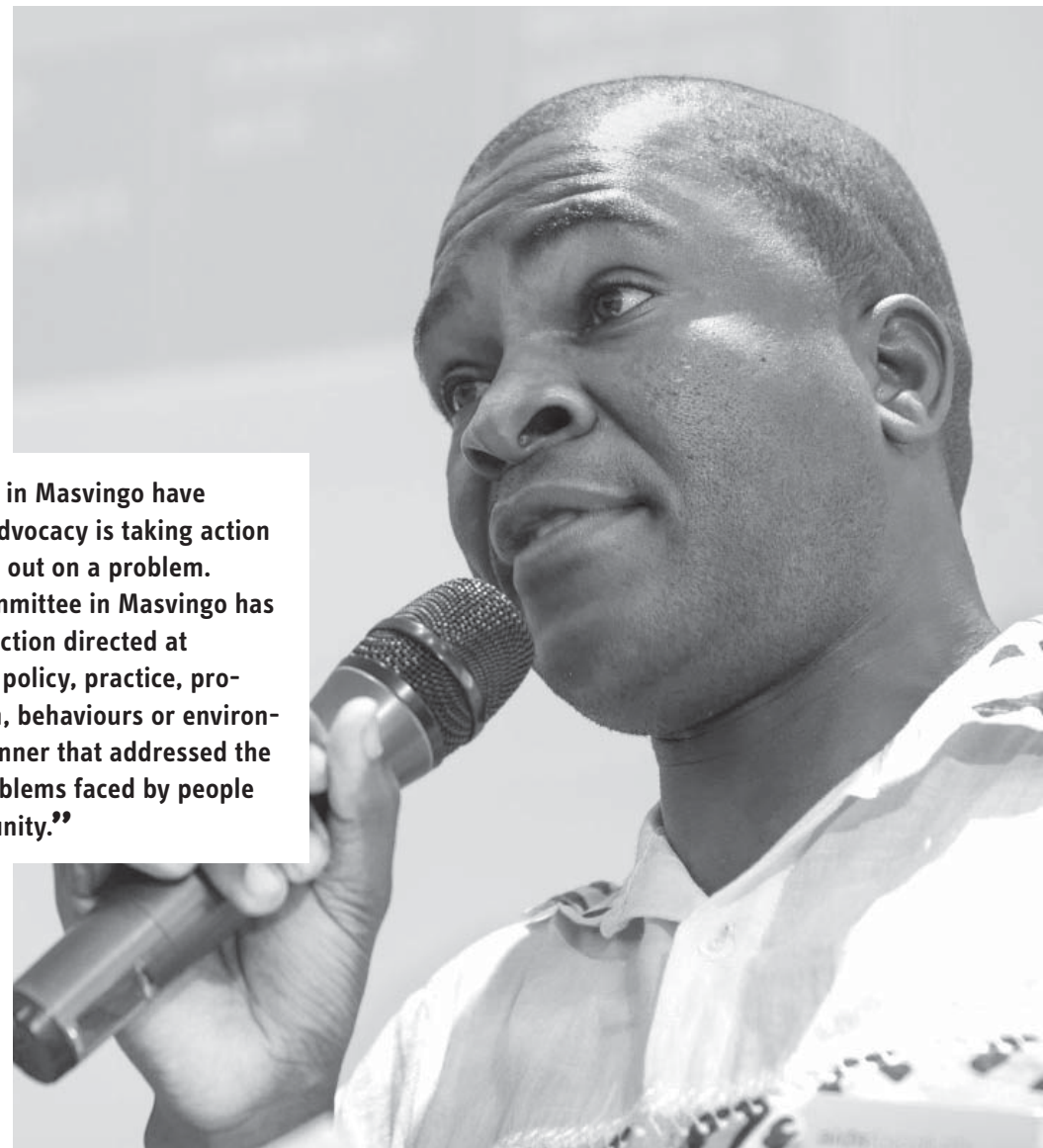
#### WORLD AIDS DAY ADVOCACY INITIATIVE

The year 2011 World AIDS Day commemoration was held in Mutare. The theme was, “Zero new infections, zero discrimination, zero HIV related deaths: Leaders make universal access a reality”. Basically the theme drives at leaders partaking and assuming influential roles in making universal access to treatment and human rights for PLHIV possible. It was also driving the issues of zeroing new infections, discrimination and new HIV related deaths. The commemorations were celebrated by a lot of stakeholders and partners from all over the country.

Batanai together with its strategic partners Zimbabwe Lawyers for Human Rights and Zimbabwe National Network for People living with HIV were also part of these commemorations with Batanai bringing in advocacy team members from all over the province to participate on this day.

In retrospect of the theme Batanai and its partners ZLHR and ZNNP+ facilitated a march initiated by PLHIV as a way of advocating for at least 15% of the national budget being routed to the health sector thereby increasing the funding that had already been allocated towards the sector. The health sector had been allocated 8.7% which is insufficient for health care in Zimbabwe especially with the issue of HIV where treatment is necessary and is on demand which drives our plight as Aids Service Organizations and various partners who work towards the betterment of the lives of PLHIV through positive living and treatment is part of it.

In this regard, a petition was prepared by PLHIV, which was delivered both orally and tangibly to the Minister H. Madzorere from the health department. This approach was effective because key government officials were present including Minister H Madzorere, Lucia Mativenga from the public service sector as well as Doctor Timothy Stamps who is the Health advisor to the president. From the civil society sector also were top officials from coordinating organizations like Zimbabwe AIDS Network who is vital for resource mobilization and advocacy in the health sector, the National AIDS Council which is the mother coordinating board, UNFPA representatives and other key partners. Thus these issues are considerably going to be deliberated due to the efforts and influence of these people. This anticipation



**“Experiences in Masvingo have shown that advocacy is taking action and speaking out on a problem. Advocacy committee in Masvingo has undertaken action directed at changing the policy, practice, program, system, behaviours or environment in a manner that addressed the everyday problems faced by people in the community.”**

was raised as the Minister Madzorere assured that he was going deliver and pursue the petition to the responsible authorities. PLHIV were happy as this has shown light that there is going to be a change.

The march was also supported by the Zimbabwe National Army, Zimbabwe Republic Police, youth and church groups and peer educators who vibrantly took part in efforts to make the goal of this initiative realized. This served as an indicator that even the state se-

curity agencies have the same cry towards the issues of universal access and human rights. Many groups (youth, children and church groups) have also engaged into these efforts and it has shown that people are realizing the intensity and the need that is there for the issue of access to be addressed fully or otherwise be redressed.



“It also results in PLHIV feeling that they have the ability to influence the agenda, to seek greater accountability from decision makers and to bring about change.”

#### CONCLUSION

In Masvingo advocacy team members are the voice of reason, the opinion leaders and drivers of social justice, speaking out on issues and being proactive. Key highlights of this local level advocacy effort include action for policy and programme change in Gutu ART services, which have been de-centralised to 14 local clinics and provided on a no-cost basis (including for OI infections, other essential medicines, diagnostics etc.).

#### Key results from local advocacy efforts on HIV and Human Rights in Masvingo include:

- The increase in ART sites from one site, charging user fees, in Gutu District in 2010 to one initiating site and 14 local clinics providing no-cost, comprehensive ART and opportunistic infection services in Gutu.
- 73 police and prison officers agreeing to undergo training on the rights of PLHIV and two support groups being established in established subsequently.

- User fees for ART services being done away with following a sit in, petitioning by 1000 PLHIV and a series of meetings at district and provincial level.
- An apology being printed in the local press and a HIV column being following stigmatizing coverage of the advocacy team's user fee action.

The result of this work is often qualitative, with PLHIV taking actions that advance the realisation of their right to prevention, treatment, care and support. It also results in PLHIV feeling that they have the ability to influence the agenda, to seek greater accountability from decision makers and to bring about change. When given the right support, these teams are a strong model for providing the space and structure for people living with HIV to create a shared vision for a rights-based community health agenda, to advance the Meaningful Involvement of People Living with HIV (MIPA) principles, and to advocate for the realisation of Universal Access in Zimbabwe.

#### Case 2: Decentralization of ART sites

Gutu as a district has a population of 31'715 PLHIV. There were 1700 PLHIV on ART in Gutu, and the target is that by the end of 2013 a total of 12'000 people will be able to access ART in the district. However the district had only one initiating site at Gutu Mission Hospital covering the whole district. All the services were being charged for and this forced PLHIV to travel long distances, furthest being 56km, to Buhera looking for ART services.

PLHIV were concerned with the distances they were travelling to collect ARVs, a fact they indicated was discouraging others to be tested. They didn't see it wise to know their status and then face challenges in accessing drugs due to the transport costs of travelling to Gutu Mission Hospital for diagnostic tests and monthly ARV supplies. PLHIV who accessed ARVs in Buhera were so also concerned about the ever flooding Nyazvidzi River since it was now into the rainy season.

In an advocacy stakeholder meeting the advocacy district team drummed up support of all stakeholders for this issue to be addressed once and for all. The advocacy committee led a consortium of community stakeholders, which included the Gutu Business Community Association, and approached MSF Belgium (who were assisting the majority of the PLHIV in Buhera) to come and operate in Gutu. The committee helped in mobilizing those who were accessing drugs outside Gutu to register at their local clinics. The registers were then used by the District Nursing Officer (DNO) as evidence to convince MSF to come into the district. MSF assessed the clinics and in-

dicated that there was need for renovation and to address security at the premises to secure the medical supplies. MSF gave a deadline of 30 December 2010.

The advocacy committee and the DNO tried to make health committees take responsibility but out of the targeted 15 health centers only one managed to put screen doors and window burglar bars. With the MSF deadline looming, BHA-SO had to take the responsibility of putting screen bars, ceilings, burglar bars, doors and window panes into the targeted 14 clinics to be used by MSF.

#### Challenges

The District Aids Coordinator and District Nursing Officer differed on which sites to be targeted. The team took a holistic approach of including both ideas.

#### Methods used

Stakeholder meetings, community meetings.

#### Results of advocacy

Since 1 Jan 2011 Gutu has one initiating site and mobile initiating clinics reaching 14 local clinics providing a no-cost (including for OI infections, other medications, diagnostics, etc). By May 2011, 600 PLHIV have been initiated on ARVs locally and 450 people who previously had to travel to Buhera (approx 45km) or Murambinda (56km) to receive their medication have been transferred to the local clinics.

## GLOBAL ADVOCACY IN AN ERA OF RESOURCE CONSTRAINTS AND SHIFTING GLOBAL PRIORITIES

The success of the global AIDS activist movement bringing about change in the global AIDS response is impressive. However, its time of greatest influence seems to be behind it, but the task ahead is still vast. It is critical that AIDS and global health activists revitalise their own movements and organisations.

By Eduard Grebe\*

**WHILE HIV/AIDS** remains one of the greatest challenges facing humanity – 2.7 million new HIV infections and 1.8 million AIDS deaths in 2010 – huge progress has been made, not least in rolling out antiretroviral treatment in sub-Saharan Africa. The global AIDS activist movement deserves substantial credit for these advances; in fact, it may be the most impressive example of health activism the world has seen.

However, it is a movement that faces serious challenges: instead of the increases in resources for AIDS programmes in developing countries that would be required to sustain progress, resources are declining. The Global Fund is in crisis, HIV/AIDS is no longer perceived in international policy fora as the major priority it once was (with attention shifting to other important questions like climate change), HIV/AIDS and public health advocates are fighting among themselves about whether disease-specific programmes are appropriate and leading activist organisations like the Treatment Action Campaign (TAC) are in decline. If the progress that has been made is not to turn into reverses, the global public health activist movement must be revitalised and a new partnership forged around a vision of universal access to integrated and effective healthcare systems.

### LOCAL AND GLOBAL ADVOCACY HAS CONTRIBUTED IMMENSELY TO ADVANCES IN AIDS TREATMENT

The transformation of HIV/AIDS from an automatically-deadly diagnosis to a manageable chronic disease through the advent of highly active antiretroviral treatment (HAART) in the mid-1990s was initially of little use to people living with HIV in the developing world. In 1997 a year's treatment cost about US\$16,000. But in the late 1990s an unprecedented global movement emerged, initially out of North American AIDS activism (itself drawing on the experiences of Stonewall-era gay rights activism). It comprised a network of activists spanning both the globe and social classes, bringing together people as diverse as gay activists from New York and Paris, women from poor villages in Africa and sex workers from South Asia. This movement forged a coalition that articulated access to healthcare and antiretroviral treatment as a human right and a moral imperative that could not be ignored. Together with a few visionary global leaders (Kofi Annan who drove the creation of the Global Fund to Fight AIDS, TB and Malaria, George W. Bush, who garnered support for the US President's Emergency Plan for AIDS Relief, Peter Piot, relentlessly working within the slow-moving UN system), sufficient momentum was at-



**“In this context, simply calling for increased funding for HIV/AIDS and/or for global health is unlikely to have much impact.”**

tained to significantly expand access to antiretroviral drugs. The prices of ARVs were driven down to as little as US\$143 per patient per year in 2010 (thanks largely to activist pressure for flexibility in intellectual property rights protection) and donor government disbursements increased from US\$1.2 billion in 2002 to US\$7.7 billion in 2008 (Kates et al 2011).

The Treatment Action Campaign in South Africa was one of many social movements to emerge in the developing world (if perhaps the most prominent) and played a critical role in both the establishment of global activist networks and domestic pressure for appropriate policy. TAC deserves a large part of the credit for the South African government's reversal of its AIDS denialism-inspired policy against the provision of antiretroviral treatment. It pro-

vides a model of poor and marginalised people effectively wielding social power against entrenched interests, including that of multinational pharmaceutical companies and a callous political class. It is particularly instructive for its use of both domestic civil society coalitions, meticulously built over time, and transnational activist networks in order to gain influence. Its influence even extended into the state and global institutions in what I have termed a “transnational network of influence”. (Grebe 2011)

But it is also a movement whose success can probably not be readily emulated. First, the political conditions within which it operated do not exist in most other African countries. South Africa was a new democracy with very strong protections of civil and political freedoms as well as independent courts who



Konzentrierte Zuhörerinnen und Zuhörer an der diesjährigen aidsfocus.ch Fachtagung

were willing to apply a progressive constitution (which includes an explicit right to access to healthcare) in judgments against the executive. Civil society movements in most other African countries do not have the freedom to pursue campaigns like TAC's without risking being crushed by powerful governments impeded by few checks and balances. Second, the South African HIV epidemic approached its peak at a time when global AIDS activism also approached its zenith (in part as a result of TAC's work), in a period of highly visible and effective campaigning.

TAC's time of greatest influence is therefore probably (and sadly) behind it. It is in the midst of a slow and incomplete leadership transition, from its founding generation of leaders to a new generation that is competent and committed, but has less experience and inherits a movement of tired activists. It is faced with a new set of challenges: ensuring continued progress in antiretroviral treatment delivery, revitalising a crumbling public healthcare system and improving HIV prevention. The end of

state-supported AIDS denialism has (paradoxically) weakened TAC by removing a source of public support and attention. Donors are turning to other projects. It is unlikely that TAC can rekindle the energy and the public support it had a decade ago.

#### THE DECLINE OF THE GLOBAL AIDS TREATMENT MOVEMENT

This malaise extends to the global AIDS activist movement. Many passionate activists and advocates for AIDS treatment continue to work tirelessly. But the level of attention, both from the media and from policy makers, has declined substantially. Increasingly, attention is focused on other problems, especially the continuing global economic crisis (particularly acute in Europe) and the long-term risks of climate change (which is, even with increased attention, not being addressed adequately).

With high-income countries battling recession and stagnation at home, bilateral and multilateral assistance for HIV/AIDS dropped off substantially after 2008: from US\$7.7 billion in

2008 to only US\$6.9 billion in 2010 (Kates et al 2011). In contrast to the substantial increases that would be required to increase access to antiretrovirals beyond the mere 35% of the 15 million people who require treatment currently receiving it. The Global Fund has had to cancel its eleventh round owing to funding shortfalls. We have a long way to go, and now little chance of getting to the destination.

To make matters worse, the global health architecture created to give effect to the universal access vision is not functioning optimally. Allegations of corruption and suspension or delays in disbursements are routine for Global Fund-funded projects. Even TAC – where financial management is beyond reproach – narrowly avoided the shuttering of several large projects and the retrenchment of most of its staff earlier this year owing to severe delays in the disbursement of Global Fund funds that had been allocated to it. It has still only received a portion of these funds -- and this is in a relatively well-resourced country with greater capacity at its CCM than is the case in many others.

Furthermore, the oppositional discourse that has emerged in the debates on global health priorities has harmed the cause of increased resources, not only for AIDS, but for health in general. While AIDS activists, global health advocates and development experts have bickered about whether we should be investing in disease-specific programmes or strengthening health systems, whether we should be focusing on malaria or diarrhoeal diseases, donors have started to look elsewhere. (For a discussion of the backlash against AIDS-specific funding, see Natrass and Gonsalves 2010). Instead of asking “what should we be spending on rather than AIDS?” we should have been asking “how can we best use the mechanisms and programmes we have built to ensure both increased delivery of AIDS treatment and stronger health systems?”

In this context, simply calling for increased funding for HIV/AIDS and/or for global health is unlikely to have much impact. This was brought home to me at the 2008 International AIDS Conference in Vienna, where the US Global AIDS Coordinator, Eric Goosby, was picketed by activists angry over the failure of the Obama administration to increase funding for PEPFAR. While I felt great sympathy with the cause of the protestors, it also appeared to me to be a campaign with no hope of success

given the extent of the economic crisis in the United States and the hostility of the Republican-dominated Congress to increased international aid. It was clear that something more would be required than repeating the calls of earlier campaigns increasingly loudly in the face of a hostile political climate.

#### WHAT IS NEEDED?

Reversing the declines in international AIDS assistance and building a new consensus on investment in global health requires that a new vision be articulated that can unite activists and policymakers in both donor and recipient countries. A good articulation of such a vision is provided by Mark Dybul (former US Global AIDS Coordinator and now with Georgetown University), Peter Piot (founding UNAIDS Executive Director and now Director of the London School of Hygiene & Tropical Medicine) and Julio Frenk (dean of the Harvard School of Public Health) in a recent article for the journal *Policy Review* (Dybul, Piot, Frenk 2012). They argue that while much of the progress achieved in the first ten years of this century has been thanks to newly-created disease-specific institutions and mechanisms (principally the Global Fund and PEPFAR and large philanthropic initiatives like the Bill and Melinda Gates Foundation), “the focus on specific diseases has exposed fault lines in delivering services in places where many suffer from multiple health issues at the same time or at varying points in their lives”. They propose instead an integrated approach focused on the health of individuals and communities to be driven through a new international health strategy and architecture comparable to the Bretton Woods agreement of 1944 and the institutions (like the World Bank) that gave effect to it.

A new international agreement to build a rational global health architecture is a very ambitious proposal indeed. But it is a vision that global health advocates – including those focused on HIV/AIDS – can unite around and that can become the foundation for a moral consensus and policy agenda to drive a new round of activism. Unless we are able to overcome what I have referred to as the “oppositional discourse” around conflicting international health priorities (HIV/AIDS programmes vs. health system strengthening, bed nets vs. sanitation programmes) it will not be possible to focus our limited advocacy resources and stand

a chance of building on the progress that we have already made in rolling out antiretroviral treatment in the poorest countries.

In pursuing this ambitious agenda, iterative and incremental advances can be achieved. While a new global health architecture is some way off (even in the best-case scenario), improvements can be made relatively quickly in the coordination and revitalisation of the architecture we already have.

It is also critical that building new partnerships on global health is not limited to mechanisms for transferring resources from high-income to low and middle-income countries. Significant assistance will undoubtedly remain necessary, but even the poorest countries can and must invest in the health of their populations. Not only is it unlikely – especially in the short to medium term – that sufficient resources will be mobilised from high-income countries to maintain the momentum towards universal access, but there are significant risks associated with dependency on external resources. Even now many treatment programmes are at risk because of reductions in funding to PEP-FAR and the Global Fund. Countries like Uganda cannot continue to depend on donor funds for more than 90% of health expenditure. Ac-

tivists, especially those who are based in low-income and African countries, must exert pressure on governments to increase health expenditure, at the very least to the 15% of national budgets that African Union members pledged to allocate to health in the Abuja Declaration of 2001. African countries have largely failed to implement this commitment, resulting in a lost decade of potential improvements in health systems, greater dependency on donors and a weaker moral voice when the leaders of the G8 and other rich countries are criticised for failing to implement commitments on international assistance.

It is also critical that AIDS and global health activists revitalise their own movements and organisations, in order to have a base from which to work. Organisations like TAC and the many similar movements across the developing world should be supported and assisted. They are our greatest asset and without them we cannot hope to succeed.

\***EDUARD GREBE** is a Researcher and PhD Candidate at the AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town, <http://cssr.uct.ac.za/>. Contact: [eduard.grebe@uct.ac.za](mailto:eduard.grebe@uct.ac.za)

#### References

- Kates, J. et al. (2011) "Financing the Response to AIDS in Low- and Middle-Income Countries: International Assistance from Donor Governments in 2010." Kaiser Family Foundation Report. Available at [www.kff.org/hiv/aids/upload/7347-07.pdf](http://www.kff.org/hiv/aids/upload/7347-07.pdf).
- Grebe, E. (2011) "The Treatment Action Campaign's Struggle for AIDS Treatment in South Africa: Coalition-building Through Networks." *Journal of Southern African Studies*, 37(4), 849-868. doi:10.1080/03057070.2011.608271
- Nattrass, N., & Gonsalves, G. (2010) "AIDS funds: undervalued." *Science*, 330(6001), 174-5. doi:10.1126/science.330.6001.174-b
- Dybul, M., Piot, P. & Frenk, J. (2012) "Reshaping Global Health", *Policy Review*, no. 173. Available at [www.hoover.org/publications/policy-review/article/118116](http://www.hoover.org/publications/policy-review/article/118116).

## BRINGING ABOUT CHANGE IN THE POLICIES AND PRACTICES IN TANZANIA

The Geita District in Northwestern Tanzania is one of the areas with the highest prevalence of HIV and AIDS. This influenced NELICO to take action in HIV, AIDS and advocacy, using a wide range of strategies in order to respond to the priority needs of orphans and most vulnerable resulting from the AIDS pandemic.

By Paulina Alex\*

**NELICO** started its operations in Geita District in March 2004 as a small non-governmental organization focusing on support to orphans and most vulnerable children. Starting of the organization was motivated with the desire to address the issues of HIV/AIDS and orphans in the District.

The government appeal for support from NGOs followed the official announcement by the Tanzania Government that Geita is the leading District for HIV Transmission in the Lake Victoria Regions of Tanzania and that the impact of HIV and AIDS has serious detrimental effects on the lives of women and children in Geita District.

Following this announcement and the diverse effects of HIV and AIDS on the lives of children in Geita District, in 2004, four committed women, specialized in sociology came up together with a motto of "Live to serve" and agreed to start the organization in the name of NELICO. Since inception to date NELICO is implementing programmes related to: Psycho-social support, legal aid and "Voices of youth" as part of its strategies in HIV, AIDS and advocacy.

As an active participating stakeholder in HIV/AIDS, NELICO works to mitigate the impact on an increasing number of orphans and most vulnerable children that are a consequence

of the AIDS epidemic and on people living with HIV, preferably youth groups. In order to help marginalized women and children and fill in the gap left by the government NELICO engages in HIV/AIDS advocacy to reduce the spread of HIV/AIDS, utilizing a wide spectrum of strategies.

#### COMMUNITY AWARENESS CREATION

NELICO engages the community to understand the preventive measures and get rid of practices, customs and traditions that speed up HIV/AIDS spread. The awareness creation is done through structured and unstructured community meetings where NELICO social workers knowledgeable on issues of HIV/AIDS discuss and share preventive measures that the community members have to take to reduce new HIV infections. This involves the issues of eliminating practices, customs and traditions that promulgate to the spread of HIV.

The practices that expose community members especially youth to new HIV infections are traced from both small and scale mining and in fishing places. The common features found in mining places and which can lead to new infections are excessive use of alcohol leading to unsafe sex. Many sex commercial workers do their business in mining places in consideration of substantial amount of money from the min-



**“NELICO has been working with people who do not want to disclose their status and do not want to start medication either for ignorance or shyness.”**

ers. The miners have a thinking of sex and alcohol as their primary leisure. The worse thing is a tendency of some miners, most of them young, bidding to take a lady for a date. They often ignore the use of condoms with the impression of fully utilization of money paid to the lady.

Similar features characterize fishing places. However, one notable difference in fishing places especially in islands is that the fishermen consider every woman belongs to every man in the island. The situation rarely accommodates the woman in terms of marital status – that is wife and husband or one to one relationship. So both men and women have multiple

sexual relationships in such places which multiply the possibilities of acquiring new HIV infections.

NELICO organizes awareness creation meetings, dialogues and campaigns and discusses with community members and other stakeholders like local community leaders and police force on how to get rid of such practices. The efforts are fruitful for local leaders and police forces do ban sex commercial workers in such areas. However, the challenge remains in the islands where the fishermen consider themselves as people with no government and rarely government initiative is observed.

In addition, NELICO has established HIV/AIDS youth clubs. The clubs involve young people, both male and female. The main goal of these clubs is to discuss preventive measures against HIV and AIDS. There is a tendency of adult male to get young girls as their sexual partners. And so many young girls have fallen prey to adults. Therefore, these groups in and out of schools give an opportunity to young people to decide their fate by suggesting solutions for themselves to prevent new infections.

The clubs hold individual and joint meetings in discussing these matters. In the beginning of this year (2012), NELICO conducted a joint dialogue involving youth on the effects of premarital sex of which the spread of new HIV infections is one of them.

#### **PSYCHOSOCIAL SUPPORT OF PEOPLE LIVING WITH HIV/AIDS**

Psychosocial support is an integral programme undertaken by NELICO for years now and has been used by NELICO in HIV/AIDS and advocacy in three parts. One is conducting trainings on memory book to people living with HIV (PLWH). The aim of the memory book trainings is to equip people living with HIV with the fundamental knowledge of preparing memory books on their life histories. This is a kind of therapy which enables people living with HIV even to disclose their status and to tell openly how they were infected. This is for their own benefit as well as for the benefit of their children and the community members at large. On this issue, NELICO was able to work closely with people living with HIV who formed a Vumilia Group.

The second part is psychological counselling of PLWH. A considerable number of people who are HIV positive approach the organization for support while not revealing their status. Psychological counselling has been provided so as to assist them to accept their situation, to consult a medical doctor for diagnosis and to start medication if possible. There many scenarios encountered, it suffices to note one:

A woman approached NELICO seeking support. She had two babies, one was two years old and the other almost eight months. However, before she could tell what kind of support she wanted, she was lamenting and feeling uncomfortable to the extent of saying that she wanted to commit suicide.

After a long discussion, the woman revealed that her husband died of AIDS a year before and she was unable to provide for the family. When she was asked to tell what she really wanted instead of committing suicide, she requested transport fare to visit a healing doctor, Pastor Amibilike Mwasapile who was thought to cure AIDS in Loliondo, near Arusha.

Having said so, she was asked first of all to visit the Geita District hospital before going to that healing doctor. This made her say openly that she was taking ARV but stopped. As a result of counseling, she agreed to go back to medication at the Geita District Hospital, HIV and AIDS Department.

Hence, NELICO has been working with people who do not want to disclose their status and do not want to start medication either for ignorance or shyness. The positive results that have been achieved to date is the involvement of some Vumilia group members to work with NELICO as community counselors.

The third part is the provision of a start capital to PLWH to establish income generating activities. A main challenge is that PLWH have an insufficient balanced diet in support of the ARVs they take. It is the policy of the country that ARVs are freely provided to PLWH but the issue of food remains to be an individual case.

Noting this gap, NELICO provides income to these people to start business. One good example is the support given to a Vumilia group to start a business of crushing gold ores.

#### **SOLUTION FOCUSED APPROACH**

This is a tool used to facilitate solutions to different problems that youth are faced within the society. One of the areas that solution focused approach is applied is HIV/AIDS Advocacy. The solution focused approach brings youth together and supports them to find solutions for themselves, how to deal with a HIV infection and how to handle their status. It appears that youth do not want to take the test and know their status. This is to the detriment of their health. Hence the solution focused approach gives them a chance to suggest solutions themselves towards stabilizing or keeping their health. However, those who test and happen to be HIV positive often travel away from their locality for medication just to hide their status. The solution focused approach has been used to discuss these issues and concerns.



Role play of a youth group to sensitize on the rights of children and youth.



Photos: © terre des hommes schweiz

#### LOBBYING GOVERNMENT AND POLITICIANS

NELICO takes part in the development issues of Geita Region and participates in many development meetings, workshops and seminars organized at the district and regional level. Such meetings are attended by politicians ranging from District commissioner, Councilors and Parliamentarians who have a say in law making processes. Having this platform, NELICO shares its experiences and contribute to the change of some of the practices and policies that involve HIV/AIDS.

One of the issues that NELICO has contributed and demanded the government to change is the employment of girl children as barmaids. The girl children working as barmaids fall prey to customers who sexually exploit them. These children are unable to bargain safe sex. Another area that NELICO is advocating is the elimination of employment of girl children in small scale mining activities. These places expose girl children to be used sexually by the miners. If left undone, these situation leads to new HIV infections.

With these efforts, the local government authority was able to pass a law banning young girls to work and unreasonably live in mining places. This is the response to the Child Development Policy of 2008, the Law of the Child Act No. 21 of 2009, National HIV/AIDS Policy of 2007 and the HIV/AIDS (Prevention and Control) Act of 2008. NELICO is armed with these policies and pieces of legislation in advocating for change with government and politicians in order to avoid new HIV/AIDS infections.

#### PROVISION OF LEGAL AID

Through its legal aid department, NELICO has been providing legal aid to people living with HIV/AIDS and other community members. The provision of legal aid involves awareness creation on legal literacy with particular focus to the Child Development Policy of 2008, the Law of the Child Act No. 21 of 2009, the National HIV/AIDS Policy of 2007 and the HIV/AIDS (Prevention and Control) Act of 2008.

People living with HIV/AIDS are sensitized to know their rights and obligations under the National HIV/AIDS Policy of 2007 and

the HIV/AIDS (Prevention and Control) Act of 2008. Both the policy and the law require that PLWH should not be discriminated and stigmatized. And under the Employment and Labour Relations Act of 2004, PLWH have equal employment opportunities regardless of their status. Therefore, when they feel that such rights are violated they have to demand and get redress.

However, the PLWH are also obliged by the policy and the law to make sure they value their health and avoid deliberate transmission of HIV to other community members.

Advocating the implementation of this policy and law comes from the fact that some employers do not offer job opportunities to people living with HIV due to their status. Meanwhile there are PLWH who are alleged to deliberate transmit HIV to other community members with the view have a long queue of people infected. This seems to be a matter of retribution. Retribution in the sense that some of the married women and men who exercise fidelity in the matrimonial relationship but at the end of the day they find themselves infected, knowing

that they are not the source. This creates hatred which sometimes leads to engaging heavily in unsafe extra marital relationships. In this situation, NELICO engages in awareness campaigns as noted before to alert the PLWH on the effects of having unsafe sex with another person while knowing that are their infected.

Another issue is that female spouses are thrown out of their family house for reason that they are HIV positive. The chase involves infringement of the spouse's property rights. Under these circumstances NELICO works to reconcile the situation so as to make the spouse not discriminated because of her status. When reconciliation and mediation fail, NELICO helps the client with court procedures that will assist in getting her rights.

#### CONSULTATIVE MEETINGS WITH KEY STAKEHOLDERS

In making sure it fully involves in HIV/AIDS advocacy, NELICO participates in and conducts consultative meetings with key stakeholders such as the government, non-governmental organizations, community based organization,

faith based organization, local leaders, activists, politicians, community members and elders.

The consultative meetings are organized by NELICO and others scheduled by ward development committees and district council. NELICO uses these meetings to share with these stakeholders issues pertaining to HIV/AIDS in the region. Thus they are responding to the government policy that in every meeting regardless of the planned agenda the issue of HIV/AIDS should be considered.

#### ENGAGEMENT OF MEDIA

NELICO engages media (radio and TV series) in awareness raising campaigns. The use of media is a reason that many people will get the information, including policy makers and law enforcers. NELICO has severally used the media in HIV/AIDS advocacy. One is the incidence of Kibaha Primary school of Coastal Region which labeled pupils who were infected by HIV by putting a red badge on their school shirts so as to make the rest of the students and teachers to identify them.

Considering that stigmatization and discrimination is against the national policies and laws, NELICO declared its position by condemning such situation which was alleged to be endorsed by some of the community members to media people. The story was covered by different newspapers.

#### IMPROVEMENT OF MONITORING AND EVALUATION PRACTICES

Since 2005 the NELICO has been implementing HIV/AIDS activities with different tools, techniques and approaches, including peer education and social agents at community level. The different stakeholders were not using the national adopted tool for monitoring and eval-

uation that was coordinated by the government and as being developed by the stakeholders and Tanzania Commission of Aids (TCAIDS).

The new tool which is in place and functional now is the Tanzania Output Monitoring and System for non-medical HIV and AIDS Interventions (TOMSHA). The tool is well detailed and clear to monitor HIV/AIDS interventions in the field. NELICO was engaged in the final stage of introduction of TOMSHA to the stakeholders. The tool was introduced to stakeholders in a workshop conducted in Mwanza for the Lake Zone Regions. NELICO was one of the stakeholders participating.

Before such a tool was developed it was quite difficult to capture the clear and reality outputs being achieved. NELICO has been appointed by TACAIDS as a national stakeholder to use the tool and train new organization. The appointment of NELICO was preceded by training NELICO staffs on this tool by TACAIDS. In addition, NELICO's appointment to report on issues of HIV/AIDS to TACAIDS was not a coincidence since NELICO has long experience and good track in managing HIV/AIDS projects and working with orphans and vulnerable children (OVC) and PLWH. Therefore, the tangible results that have been achieved by NELICO in implementing HIV/AIDS project activities are among the sources of its asset in networking and working with the government in Geita region and nation as well.

#### CONCLUSION

With the limited resources that NELICO has, it has managed to advocate for change in practices, customs, traditions as well as policies that impair the rights and obligations of PLWH. NELICO's advocacy strategies are formulated to respond to the priority needs of orphans and most vulnerable resulting from HIV/AIDS pandemic.

However, the challenges that need much more effort to eliminate include stigma and discrimination, which still exists in rural and hard to reach areas due to inadequate awareness on HIV/AIDS and social and cultural barriers that promote unsafe sex.

\*PAULINA ALEX is a sociologist (BA in Sociology) with more than eight years working experience in the area of HIV/AIDS and Advocacy in Tanzania. She is currently working with New Light Children Center Organization (NELICO) as an Executive Director. NELICO is a partner of terre des hommes Schweiz, partner of aidsfocus.ch, <http://nelicotz.org>. Contact: [newlightforchildren@yahoo.com](mailto:newlightforchildren@yahoo.com)

## CITIZEN VOICE AND ACTION – AN APPROACH TO SOCIAL ACCOUNTABILITY

Citizen Voice and Action is an approach that aims to increase dialogue between ordinary citizens and organizations that provide services to the public. It also aims to improve accountability from the administrative and political sections of government at local and national in order to improve the delivery of public services.

By Aashish Masih\*

**CITIZEN VOICE** and Action (CVA) aims to empower communities to influence the quality, efficiency and accountability of public services. Educated, empowered and mobilized citizens are encouraged to assess the performance of public services with the standards of service that government has committed. Citizens together with those providing services (service providers), government and local partners identify action to take to improve public services.

This approach is based on the view that individual and “community” are citizens of the country. Each citizen has the right to communicate with, and have a relationship with, their government. Active citizenship and engagement with government, helps governments to work effectively and to provide quality services.

#### HOW HIV-POSITIVE ACTIVISTS ARE TRANSFORMING PUBLIC SERVICES IN INDIA

For Suman, a young resident of a poor neighborhood in northern Delhi, it is not HIV that killed her husband Rajinder. No, it was a state bureaucracy that was unable to quickly and effectively provide him with the health services to which he was entitled. (Story compiled by Jeff Hall – CVA Global Coordinator World Vision International 2011)

Suman is one of approximately 2.2 million Indians living with HIV/AIDS. Now she is working with her fellow other AIDS activists to ensure that others do not suffer the fate of her husband. Together, they are using World Vision's “Citizen Voice and Action” approach to improve the health services that keep them alive. At a meeting of activists in northern Delhi, Suman sits at a small table and tells her story. In the year 2000, she and her husband Rajinder were diagnosed with HIV. With two children depending on them, Suman and Rajinder were devastated. But they began to take every measure possible to extend their lives, and signed up for a government programme that provided Anti-Retroviral treatments (“ART”). ARTs can greatly extend the life of those living with HIV and AIDS.

But then Rajinder had an allergic reaction to the treatment. His skin broke out in a horrible rash and he was forced to discontinue the treatment. The doctors were able to cure the rash. But in the absence of ARTs, the HIV in his body became much more lethal. Rajinder's doctor recommended him for “2nd-line” ARTs. These drugs are much stronger and are reserved for those with worsening cases of AIDS. Rajinder immediately applied to receive the drugs to which he was entitled under Indian law. But





**“All these stories of change stand out because changes were not brought from outside but from within.”**

because of government bureaucracy, the 2nd line ART drugs were not available to him for another 6 months.

By that time he was dead... “I’m sure he would have survived if he would have had the medicine sooner,” says Suman. She breaks into tears. The others comfort her.

It is in this context of systemic failure that World Vision’s “Citizen Voice and Action” approach works. Citizen Voice and Action is a community-led advocacy approach that empowers citizens to hold their governments accountable and improve the services on which

they depend. Using the Citizen Voice and Action tools, communities learn about local law and the services to which they are entitled. Next, together with government, they visit clinics, schools, and other government facilities to compare these commitments with reality. Finally, working collaboratively with government, communities create an action plan to improve services. Since 2005, World Vision has equipped hundreds of communities around the world with the Citizen Voice and Action approach.

In 2010, Suman and other HIV-positive activists in northern Delhi participated in a Citizen Voice and Action training. By leveraging India’s “Right to Information” law, they extensively researched the precise nature of the services to which they were entitled. When they measured those entitlements against reality, they found gaping holes. Working with the Delhi State AIDS Control Society (or “DSACS”, the government agency responsible for combating HIV and AIDS) the activists created an action plan. DSACS acted quickly on their behalf.

As a result of the Citizen Voice and Action exercise, the community of HIV positive people in northern Delhi has seen improvements in the services on which their lives depend. For example, after the exercise, clinics were equipped with scales so that they could monitor the critical weight changes in HIV patients.

Some ART centers also greatly improved their measures to protect the confidentiality of patients. Prior to the exercise, doctors and nurses would counsel HIV+ individuals behind a thin curtain. But after the Citizen Voice and Action exercise, consultations were moved to private rooms.

Likewise, Suman and her fellow activists were able to lower the costs of treatment. Prior to the exercise, Suman and others were forced to purchase their own test tubes for the frequent blood work that they must acquire. But Indian law guarantees that test tubes will be provided

by the clinics. After raising their voices, clinics began to provide these essential materials.

Ultimately, of course, it is the activists’ children who benefit from better health services. After Rajinder’s death, Suman was left to care for their 13 year old son named Shushil and an 8 year old daughter named Bhumika. Shushil escaped infection, but little Bhumika has tested positive for HIV. Every day, Bhumika takes her ART pills, once with her morning tea, and once at night before going to bed. Bhumika knows the schedule very well and reminds her mother if she forgets. Suman refers to the pills as “HIV” medicine. But Bhumika, not able to say “HIV” calls them her “A Chai” medicine. “Chai”, in Hindi, means “tea”. When asked how her work will help her Bhumika, Suman says “the improved services at the ART clinics will mean a lot to her.” But to Suman, it is just important that Bhumika benefit from an atmosphere free from stigma and discrimination. The group’s Citizen Voice and Action work has also helped to create this atmosphere.

Fighting stigma and discrimination has not been easy. Deepak, a member of the activist group, says “prior to the exercise, doctors and nurses treated us differently. They charged us more, provided us with poorer service, and treated us extremely rudely.” Kumar, another activist, concurs. “When we used to fill out forms, they used to have a separate pen that was only for HIV positive patients. I wanted to tell these people, ‘I am a human being, just like you.’” Bhumika felt this discrimination firsthand. Once, before the Citizen Voice and Action exercise, Suman took Bhumika to be treated for a horrible case of diarrhea. When the attending nurse realized that Bhumika was HIV+, her attitude changed and she became very unpleasant. Unlike other patients who were given beds, Bhumika was sent by the nurse to sleep on the concrete floor in a corner with only a sheet.

But now, following the Citizen Voice and Action exercise, the activists say that clinic staff have changed their attitudes. DSACS has educated clinic staff about the nature of HIV, raised awareness to counter the stigmatizing myths that surround HIV, and has given orders to clinics to change some of the most egregious procedures. Now, having changed some of the conditions at the clinics, Suman and her

**\*ASHISH MASIH** works as Community Based Performance Monitoring Manager with World Vision India, based in Faridkot, Punjab. He facilitates the “Citizen Voice and Action” program, working closely with the community. [www.worldvision.in/1452](http://www.worldvision.in/1452), Contact: [aashishmasih20011@gmail.com](mailto:aashishmasih20011@gmail.com), [Faridkot\\_india\\_adp@wvi.org](mailto:Faridkot_india_adp@wvi.org)

#### **Acknowledgement**

I thank World Vision India for providing me opportunity to present Citizen Voice and Action. I acknowledge and thank the contribution of Mike Nilson from World Vision Switzerland for opening opportunity to participate and his support. Thanks to Helena Zweifel for providing international platform for CVA presentation and article.



Young people are lead in a workshop, empowering them on what their rights are and how to ask for them from the government.

friends have set their sights higher. Working in coalition with other activist groups across India, they are fighting for quicker, easier access to 2nd-line ARTs – the same drugs that could have saved Suman’s husband Rajinder. .. But Suman does not dwell on what could have been – her sights are set on what can be. And she is passing along her passion for justice. She says Bhumika will make a good doctor and an activist. “Bhumika knows that her father died because he couldn’t take his medicine. That makes her passionate about good health. And I’m teaching her about our work [through Citizen Voice and Action]. If all our rights are not fulfilled, I will pass the struggle on to her, so she may continue it.”

This passion for justice, together with approaches like Citizen Voice and Action, offer a more hopeful future for Bhumika and others threatened by the pain of HIV and AIDS.

#### HEALTH CARE FOR PREGNANT WOMEN AND INFANTS

This success story is recently narrated by group of women who are resident of a village called Dingerhedi (alternatively known as Dingerheri) on how Citizen Voice and Action approach was used to improve the provision of health services particularly those pertaining to pregnant women, infants and children of the community. (Story compiled by Itunu O Kuku – Student of Institute of Development Studies Geneva March 2012) Dingerhedi is located approximately two and a half hours outside of New Delhi in the state of Haryana in northern India. World Vision conducts its community development work through Area Development Programs (ADPs) that target specific geographical regions of the country. Dingerhedi is geographically located in the Mewat region and was thus under World Vision’s Mewat ADP which was operational between 1998



A community leader speaks to participants on their right to health care at a local clinic in Sagar.

structured villagers on the rights and entitlements they had as citizens and the standards that they could expect from their government. This education of citizens included information on services available especially for pregnant women. Empowered by this knowledge, villagers then proceeded to demand these services as well as monitor their quality.

The group shared one concrete example to illustrate this. The government of India provides a free ambulance service to transport pregnant women from the village to the hospital to deliver safely. In addition to this, the government offers a sum of 1500 INR (29 USD) to all pregnant women who gave birth in the government birthing centers, in an attempt to encourage safe institutional deliveries in hospitals (as opposed to risky deliveries carried out traditionally).

Prior to Citizen Voice and Action initiative most of pregnant women were completely unaware of the monetary compensation available to them if they delivered institutionally. Some were aware of the ambulance service and availed of it but were unaware that it was free of charge and were made to pay exorbitant fees to the ambulance driver. It is because of their lack of knowledge most opted to simply stay at home and deliver their babies with the aid of traditional midwives who charged money for their services. These midwives charged money in a discriminatory manner in line with the traditional culture exist in village which values boys over girls, demanding 500 INR (10 USD) for delivering a boy and 300 INR (6 USD) for girls. Now that the villagers are aware of the existence of the free ambulance, they readily avail of it. Now not only do they no longer pay unnecessary fees for child birth but they are actually receiving compensation for having safe deliveries in government health centers.

#### CHANGES FROM WITHIN

All these stories of change stand out because changes were not brought from outside but from within, when people empowered with knowledge and demanded their rights. When people are educated on rights and motivated to fight their own fights, then change starts happening and it is sustainable. Today our development approach requires integration of rights based approach to allow people know their rights and ensure their responsibility to act. Cit-

and 2010. The Mewat Area Development Program was phased out in 2010 as per World Vision’s policy of limiting program interventions to 12-15 years to encourage sustainability in the communities. Though the project had been phased out the regular monitoring activities of Citizen Voice and Action are still carried out by the community.

The group narrated several examples emerged after citizen voice and action intervention in their village. Out of many good examples here is one.

The village group of women narrates that prior to citizen voice and action intervention, villagers were unaware of the various government programs and schemes targeted at ameliorating maternal and infant health. Their lack of awareness meant that they were unable to avail of these services that were within their reach and free of charge. The first training that the villagers undertook as part of Citizen Voice and Action was in 2008. The training in-

izen Voice and Action is a systematic approach having inbuilt tool for social accountability at the local level. World Vision India has success used this tool in many villages where people have story to tell. It is also true that all stories have flip side, where for every major change they have to go through difficult times and process. This means doing advocacy is not easy task and sometimes results are not immediate however the changes or results are sustainable.

Citizen Voice and Action emphasizes community development practices such as participation, inclusion, ownership and sustainability. The practical implementation of Citizen Voice and Action must be flexible and respond to local situations so it will look different in different situations. However, through practical experience in the pilot programs, we have found a number of linked core elements which should be included in all situations. These are information, voice, dialogue and accountability:

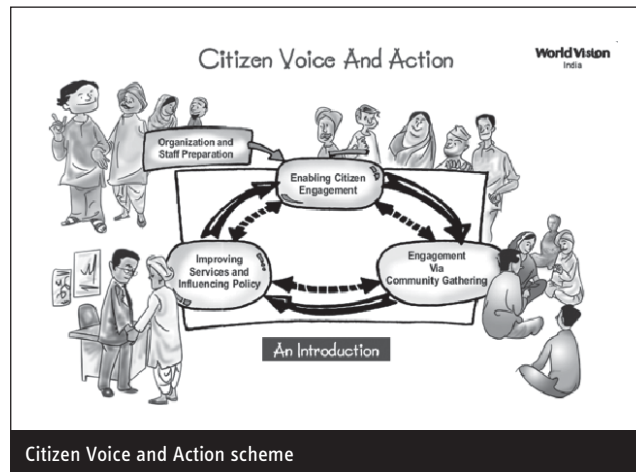
**Information** Increased access to, and use of, government information to inform citizens' choice and action.

Increased opportunity to share information and generate knowledge within the community about the performance and reform of public services.

**Voice** Increased opportunity for citizens to actively engage in and influence decisions that affect their lives. Increased capacity to engage in advocacy to demand answers from those in power.

**Dialogue** Increased dialogue; talking and listening with a view to reaching shared understanding, repairing and strengthening relationships and creating understanding and collaborative partnerships, particularly with those in power.

**Accountability** An increase in responsibility and responsiveness of power holders and duty bearers to those they serve, so they carry out and fulfill their roles and responsibilities to citizens.



Citizen Voice and Action scheme

## «ICH BIN MENSCHENRECHTS-AKTIVISTIN»

Welches sind die Rollen, Verantwortlichkeiten und Möglichkeiten von NGOs im Globalen Süden und Globalen Norden, Veränderungen herbeizuführen in Richtung des gemeinsamen Ziels, eine Zukunft ohne HIV und Aids? Welches ist die Verantwortung staatlicher Entscheidungsträger? Die Diskussionen in den Arbeitsgruppen und auf dem Plenum zu diesen Fragen waren sehr lebhaft und sind noch nicht zu Ende geführt.

Von Helena Zweifel\*

**DIE ERFOLGE** der letzten zehn Jahre in der globalen Aidsbekämpfung lassen sich sehen. Über acht Millionen HIV-positiver Menschen können heute weltweit und auch in Ländern mit niedrigem und mittlerem Einkommen mit antiretroviralen Medikamenten behandelt werden. Dies war vor zehn Jahren noch kaum vorstellbar gewesen. Die Zahl der Neuinfektionen hat in Afrika südlich der Sahara die Spitze überschritten und ist rückläufig. Diese Erfolge sind zum grossen Teil der unermüdlichen Advocacy von Menschen und Organisationen zu verdanken, AktivistInnen, WissenschaftlerInnen und PolitikerInnen, die sich zusammen mit Menschen, die mit HIV leben, für den Zugang aller Menschen zu umfassender HIV-Prävention und Behandlung, Pflege und Unterstützung einsetzen.

Über die weitreichenden Ziele der Advocacy zu HIV und Aids waren sich die TeilnehmerInnen der Fachtagung weitgehend einig, wenn auch unterschiedliche Konzepte und Begrifflichkeiten verwendet wurden. Ob das Erreichen der Millenniumsziele als Ziel anvisiert wird, ob für den Zugang aller zu umfassender Prävention, Behandlung und Pflege (universal access) plädiert wird, ob die Maxime von UNAIDS «auf Null kommen: Null Neuinfektionen, Null Sigma und Null Todesfälle in-

ge von Aids» heisst oder ob von einer «künftigen Generation ohne Aids» gesprochen wird, das langfristige Ziel ist für alle gleich: Gesundheit für alle. Die Rollen der verschiedenen Akteure sind unterschiedlich, im besten Fall sich ergänzend und gegenseitig unterstützend.

An der Fachtagung verwendete aidsfocus.ch einen sehr breiten Begriff zu «Advocacy», in Anlehnung an die Definition der HIV/AIDS Alliance in Simbabwe: «Advocacy is a process to bring about change in the policies, laws and practices of influential individuals, groups and institutions.»

### AIDS-ADVOCACY VON UNTEN

Lokale Gemeinschaften, NGOs und insbesondere Organisationen von Menschen, die mit HIV leben, sind die treibende Kraft in der nationalen und internationalen Aids-Advocacy. Sie sind nicht nur von den unmittelbaren Auswirkungen der Epidemie direkt betroffen, sie sind es auch, die die Erfahrungen und das Wissen haben, was verändert werden muss. Sie sind es, welche die Strategien entwickelt und an der Realität erprobt haben, und welche für die Advocacy-Arbeit das notwendige Feuer und den langen Atem haben.

Joshua Mavundu, Advocacy Officer von BHASO und selbst HIV-positiv, spricht sich klar dafür aus, dass HIV-positive Männer und Frauen Ausgangspunkt und Motor der Advocacy-Arbeit sein müssen. Die simbabwische NGO BHASO hatte Selbsthilfegruppen von Frauen, Männern und Jugendlichen, die mit HIV leben, initiiert. Diese Selbsthilfegruppen engagieren sich zunehmend in der Advocacy-Arbeit: sie wollen Einfluss nehmen auf Behörden und PolitikerInnen, um ihre Rechte und die Rechte aller aidsbetroffenen Menschen durchzusetzen. Eine anwendungsorientierte Ausbildung zu Advocacy und HIV hat die Jugendlichen fit gemacht für ihre Arbeit. Teams von Jugendlichen sind von Dorf zu Dorf gegangen, haben mit den Leuten geredet, deren Anliegen aufgenommen und nach Lösungen gesucht. Mit Informationen über Mängel und Argumenten ausgerüstet sind sie an die verantwortlichen Behörden und PolitikerInnen getreten, haben den Dialog gesucht und wo notwendig ihre Stimme lautstark mit Demonstrationen hörbar gemacht. Mit einigem Erfolg: die Medikamente und Nahrungspakete gelangen jetzt tatsächlich in die ländlichen Regionen zu den Leuten und die Medikamente werden tatsächlich auch gratis abgegeben.

Die südafrikanische «Treatment Action Campaign» (TAC), eine der wichtigsten und erfolgreichsten Aidsorganisationen weltweit, versteht sich primär als Advocacy-Organisation und kämpft seit Jahren dafür, dass alle Menschen, die mit HIV leben, Zugang zu qualitativ hochstehender, umfassender Prävention und Behandlung haben, um ein gesundes Leben zu führen. TAC war von HIV-Positiven und ihren Freunden gegründet worden und orientiert sich an den Rechten und Bedürfnissen aidsbetroffener Menschen. TAC hat selbst Pilotprojekte zu Prävention und Behandlung initiiert und gleichzeitig Druck auf die südafrikanische Regierung und die internationale Pharmaindustrie ausgeübt. Mit Kampagnen und Lobbyarbeit hat TAC

massgeblich dazu beigetragen, dass die Preise für Medikamente weltweit stark gesunken sind. «Die Sicherung des Zugangs zu HIV-Medikamenten und die Respektierung der Menschenrechte sind zentrale Elemente, um Leben zu retten und die HIV-Übertragung zu reduzieren», betonte Nonkosi Khumalo, die Präsidentin der TAC.

Diese Beispiele zu Advocacy zeigen, dass die Menschen im Globalen Süden sehr wohl bereit und fähig sind, sich für die eigenen Rechte einzusetzen, als HIV-Betroffene, vor allem aber als BürgerIn ihres Landes. «Was letztlich zählt ist, dass die Rechte der Leute verwirklicht werden und dass sie die Chance haben ihr Leben zu verbessern,» erklärte Joshua Mavundu.

Der Wirkungsbereich lokaler NGOs im Globalen Süden ist in ihrem direkten Umfeld und auf nationaler Ebene, für einige auch auf dem internationalen Parkett. Nochmals zum Beispiel aus Simbabwe: BHASO wird heute von nationalen Entscheidungsträgern auch auf Landesebene als ernstzunehmender Partner zu Advocacy und Aids respektiert. Das Advocacy-Konzept wurde auf nationaler Ebene übernommen und das Nationale Netzwerk für Menschen mit HIV und Aids hat in mehreren Provinzen bereits Advocacy-Teams nach dem Modell von BHASO eingesetzt. Joshua ist als NGO-Vertreter Mitglied des Country Coordination Mechanismus des Global Fund zur Bekämpfung von Aids, Malaria und Tuberkulose, einer Multi-Stakeholder-Partnerschaft auf Landesebene.

#### UNTERSCHIEDLICHE ROLLEN, GLEICHES ZIEL

In den Diskussionen zur Rolle von schweizerischen NGOs in Advocacy bestand der Konsens, dass Schweizer NGOs in der Advocacy auf lokaler Ebene im Globalen Süden oder Osten keine direkte Rolle zu spielen haben. Was sie jedoch tun können und müssen ist innovative und wirksame Ansätze von Südpartnern zu unterstützen, finanziell und wo notwendig und sinnvoll mit Beratung und Weiterbildung. Gerade in Abgrenzung zu staatlichen Geldgebern haben NGOs die Möglichkeit, innovative Ansätze und politische Kampagnen zu finanzieren. Die Advocacy-Arbeit von BHASO, die von fepa unterstützt wird, ist ein gutes Beispiel dafür. Das «Citizen Voice and Action»-Programm in Indien, mit welchem World Vision in Indien Menschen darin ausbildet und unterstützt, ih-

re Rechte als HIV-Positive, Mütter oder grundsätzlich als BürgerIn ihres Landes einzufordern und die entsprechenden Regierungsstellen zur Rechenschaft zu ziehen, zielt in dieselbe Richtung. Ebenso ist die Unterstützung der tansanische Organisation NELICO durch terre des hommes schweiz, welche sich unter anderem für die Rechte von Mädchen, die in Bars und in den Minen arbeiten und sexueller Gewalt und den Gefahren einer HIV-Infektion ausgesetzt sind, ein Beispiel für die Rolle einer Schweizer NGO.

Der Wirkungs- und Einflussbereich der Advocacy von schweizerischen Organisationen der internationalen Zusammenarbeit ist primär in der Schweiz auf nationaler Ebene und allenfalls in internationale Gremien wie UNAIDS, WHO oder dem Global Fund zur Bekämpfung von Aids, Malaria und Tuberkulose. So wirkt aidsfocus.ch mit seinen Partnerorganisationen auf schweizerischer Ebene, wobei aidsfocus.ch anwaltschaftlich die Anliegen und Interessen unserer Südpartner vertritt. Ansprechpartner sind schweizerische Entscheidungsträger zur internationalen Zusammenarbeit, insbesondere die DEZA, und je nach Thema weitere Bundesämter, ParlamentarierInnen und der Bundesrat.

Um wirksame Sensibilisierungsarbeit zu machen und glaubwürdig in den Policy-Dialog mit Entscheidungsträgern einzutreten ist aidsfocus.ch darauf angewiesen, den Puls zu fühlen und zu verstehen, was vor Ort in den Ländern Afrikas, Asiens, Lateinamerikas und Osteuropas wirklich geschieht und was die Anliegen unserer Partner sind. Die Förderung des Austausches und der Vernetzung von NGOs hier in der Schweiz wie auch über unsere Partner im Globalen Süden und Osten sind eine wichtige Aufgabe von aidsfocus.ch, Grundlage für die Advocacy-Arbeit. Zudem sollen Möglichkeiten der thematischen Zusammenarbeit ausgelotet werden, z.B. in Bezug auf den Globalen Fonds: Die Partnerorganisationen im Globalen Süden und Osten sind von den Kürzungen der Gelder direkt betroffen und haben Kenntnisse und konkrete Erfahrungen über die Folgen der finanziellen Engpässe, wenn z.B. Menschen, die mit HIV leben, vergeblich in den Kliniken Schlange stehen. aidsfocus.ch kann in Abstimmung mit südlichen und nördlichen NGOs versuchen, über den Schweizer Vertreter im Board des Global Fund Einfluss zu nehmen. Auch im Zeitalter von Internet, Facebook und Twit-

ter haben nördliche NGOs oft eher Zugang zu entsprechenden Informationen und Entscheidungsträgern. Genf, die globale Gesundheitshauptstadt, liegt in der Schweiz.

In den Diskussionen wurde auch die Rolle der Direktion für Entwicklung und Zusammenarbeit (DEZA) als Vertreterin der offiziellen Schweiz thematisiert. Diese liegt nicht nur im Policy-Dialog mit anderen Staaten im Rahmen internationaler Organisationen, sondern auch in der tatkräftigen Umsetzung der eingegangenen Verpflichtungen. Die Schweiz hat sich letztes Jahr anlässlich des High Level Meetings der Generalversammlung der UNO zusammen mit anderen Regierungen in der politischen Erklärung zu HIV und Aids erneut verpflichtet, «die Anstrengungen zu intensivieren, um HIV/Aids zu eliminieren». Dies würde auch ein verstärktes finanzielles Engagement in Sache internationaler Aids-Bekämpfung mit sich bringen. Dies ist bitter nötig. Im internationalen Vergleich hinkt die Schweiz punkto internationaler Gesundheitszusammenarbeit und Aids-Response hinten nach. Im Jahr 2011 gab die Schweiz bloss 0,027% des Bruttonationaleinkommens (BNE) für internationale Gesundheit und 0,007% für HIV-Programme aus. Damit liegt die wohlhabende, von der Wirtschaftskrise weitgehend verschonte Schweiz noch hinter Spanien und Deutschland und knapp vor Italien.

#### NEUE ALTE HERAUSFORDERUNGEN

Die TeilnehmerInnen der Fachtagung identifizierten mangelnde Finanzierung, schwindendes öffentliches Interesse am Thema und ungenügendes politisches Engagement als die grossen Herausforderungen in Hinblick auf eine Zukunft ohne Aids. Die «Aidsmüdigkeit» droht sich auszudehnen.

Die Streichung der 11. Finanzierungsrunde durch den Global Fund im November 2011 mit Konsequenzen auf Millionen von Menschenleben war an der Fachtagung ein viel diskutiertes Problem, welches Advocacy-Arbeit mit vereinten Kräften erfordert. Eine der Arbeitsgruppen forderte sehr konkret, dass aidsfocus.ch mit seinen Partnerorganisationen eine Strategie zur Stärkung des Global Funds und zur Rolle der Schweiz entwickelt. aidsfocus.ch hat bereits die Signale der Südpartner aufgegriffen, ist in Sache Global Fund aktiv geworden und hat den Policy Dialog mit Martin Dahinden,

\*HELENA ZWEIFEL ist Geschäftsführerin des Netzwerks Medicus Mundi Schweiz und koordiniert die Fachplattform aidsfocus.ch. Kontakt: hzweifel@medicusmundi.ch

dem Direktor der DEZA, und Marc de Santis, dem Schweizer Vertreter im Board des Global Fund aufgenommen. Der niedrige Beitrag der Schweiz an den Globalen Fund, dem zurzeit wirksamsten Instrument um Leben zu retten, ist beschämend. Die Schweiz zahlt gerade nur 8 Millionen Schweizer Franken und steht damit auch im Vergleich mit andern Ländern gemessen am Bruttoeinkommen so ziemlich am Schluss. Um den Global Fund zu stärken und wirksam Einfluss zu nehmen arbeitet aidsfocus.ch eng mit dem deutschen Aidsbündnis gegen Aids zusammen, u.a. weil die Schweiz zusammen mit Deutschland und Kanada einen Sitz im Board teilt. aidsfocus.ch ist Mitglied im Global Advocacy Network (GFAN) geworden, um den laufenden Reformprozess im Global Fund kritisch zu begleiten.

Zu den «neuen alten Herausforderungen», wie Nonkosi Khumalo sie bezeichnete, gehören die Bestreben pharmazeutischer Unternehmen, Patente auf Medikamente zu stärken, um ihre eigenen Profite zu sichern, auf Kosten der Menschen, die dringend bezahlbare Medikamente und Therapien brauchen. Ein aktueller Fall ist der Pharmakonzern Novartis, welcher die indische Regierung vor Gericht gebracht hat, um die Patentrechte zu verschärfen. Hier gilt es, dieses Ansinnen von Novartis bekämpfen, zusammen mit internationalen und indischen Netzwerken, Organisationen und Anwälten. Zugang zu Medikamenten und Patente sind wichtige Advocacy-Themen in der internationalen Advocacy. aidsfocus.ch hat daher den Aufruf von Act up Basel an Novartis – «Take the claws off our medicines» – mitunterzeichnet, wird aber mangels Kapazitäten in den Kampagnen nur eine kleine Rolle spielen können.

#### HIV, GESUNDHEIT FÜR ALLE ODER SOZIALE GERECHTIGKEIT?

Die Debatte um den Fokus Aids versus Gesundheit allgemein erwies sich auch an der Fachtagung als wenig fruchtbar. Die grossen Investitionen in die Bereitstellung von Aidsmedikamenten für Menschen, die mit HIV leben, können nicht isoliert gesehen werden. Vermehrte Testungen und Behandlungen haben gleichzeitig zur Stärkung örtlicher Gesundheitssysteme und so für die Behandlung anderer Krankheiten geführt. Die Kampagnen zur Verhinderung der HIV-Übertragung von der Mutter aufs

Kind sind begleitet von Bemühungen, die Mütter gesund zu erhalten, was nur mit der Bereitstellung von medizinischen Dienstleistungen für schwangere und gebärende Frauen bewirkt werden kann. aidsfocus.ch hat an der Fachtagung letztes Jahr die Notwendigkeit einer verbesserten und eine konsequente Verknüpfung von HIV mit sexueller und reproduktiver Gesundheit und Rechte gefordert. In der Aids-Advocacy geht es letztlich um nichts weniger als um Gesundheit für alle und um soziale Gerechtigkeit.

Nonkosi Khumalo bringt es auf den Punkt: «Ihr mögt mich als Aids-Aktivistin bezeichnen», meinte die Präsidentin TAC, «tatsächlich bin ich Menschenrechtsaktivistin, die über Aids spricht, aber auch über Informationsfreiheit, Pressefreiheit, Bewegungsfreiheit, etc.»

Das weltweite Engagement für das Recht auf universellen Zugang zu HIV-Prävention, Behandlung und Pflege muss unvermittelt weitergehen. aidsfocus.ch setzt sich dafür ein, dass das Recht auf Gesundheit für alle Menschen weltweit gilt, auch für HIV-positive und aidskranke Menschen. Für die 34 Millionen Menschen weltweit, die HIV-positiv oder aidskrank sind, bedeutet dies das Recht auf Behandlung, Gesundheitsversorgung und Nicht-Diskriminierung. Alle werdenden Mütter sollen die Chance haben, behandelt zu werden und so die Übertragung des Virus auf ihr Kind zu verhindern. Jochen Ehmer von SolidarMed zeichnet ein sehr treffendes Bild von einem Haus in Flammen: Mit vereinten Kräften ist es gelungen, einen Grossteil des Feuers zu löschen, nur in einem Zimmer lodert es noch. Wer würde jetzt das Löschen einstellen und den Wasserhahn zudrehen?



Seiten 42-50 Raising awareness and initiating change

**«Sie mussten den eigenen Serostatus anerkennen und mit der Krankheit leben lernen. Erst danach konnten sie sagen: «Jetzt sind wir stärker, jetzt haben wir die Kraft, an die Öffentlichkeit zu treten, um für unsere Rechte einzutreten und jenen eine Stimme zu geben, die sich nicht selbst äussern möchten.»** Albino Martín Portillo

## «MAKE US THE LAST GENERATION TO BE BORN WITH HIV»

HIV positive children and adolescents are at the heart of the “Zvandiri” programme, taking the lead as peer counsellors, trainers and advocates for the needs of their HIV positive peers, both locally and internationally. With innovative and colourful actions they are campaigning for the access of children anti-retroviral drugs and caring, supportive environments.

By Nicola Willis and Andreas Keller\*

**AFRICAID** is a community-based organisation based in Harare, Zimbabwe which is committed to helping HIV positive children and young people to develop the knowledge, skills and confidence to cope with their HIV status and to live happy, healthy, fulfilled lives. Africaid has been implementing its Zvandiri programme since 2004 at a time when access to medical care and treatment was increasing for HIV positive children and adolescents, yet gaps remained in understanding and addressing the psychological and social needs of this vulnerable group and how they impacted on clinical care and support.

Six HIV positive adolescents asked Africaid to help them establish a support group. They named their group “Zvandiri” as they wanted to say “I am a child with HIV, but accept me as I am”. This one support group has since evolved in to the “Zvandiri” model which provides holistic care for HIV positive children and young people through a combination of health services, psychosocial support and care, training and advocacy. These are provided through community-based services which are integrated within the clinical care provided by government and private clinics. This integration creates a robust continuum of care for

children and young people with HIV and their families and aims to promote their health and psychosocial outcomes.

### AN EXHIBITION, CAMPAIGN AND A MOCK GRAVEYARD

HIV positive children and adolescents are at the heart of the programme, taking the lead as peer counsellors, trainers and advocates for the needs of their HIV positive peers, both locally and internationally. They have embarked on a variety of different advocacy campaigns which they have designed and implemented themselves.

In 2012, in commemoration of World AIDS Day, they created their own art exhibition which was held at Zimbabwe’s national Art Gallery. The exhibition was named “The Audacity of Hope” and through their own artwork, including paintings, photos, sculptures, song and dance, the children from Zvandiri expressed their renewed hope for life as a result of access to treatment, care and support. They called on policy makers, donors, service providers, civil society and communities to ensure that children with HIV continue to receive anti-retroviral drugs and can grow up in caring, supportive environments.



The “mock graveyard” represents the thousands of children who have died in Zimbabwe as a result of HIV.

In 2011, the children from Zvandiri designed their own stigma campaign in response to the international campaign “Getting to Zero new infections, Zero HIV-related deaths and Zero stigma and discrimination”. They designed their “Bury Stigma, Resurrect Love” campaign which has involved HIV positive children and adolescents talking in schools and communities about their experiences. Their aim is that people have a better understanding of what it means to be living with HIV and that they can feel and be treated like any other child in their classrooms and communities.

Also in 2011, adolescents with HIV from Zvandiri joined together in an extremely moving, powerful campaign, launched at the Zimbabwe’s National HIV Conference. The focus of the conference was the Prevention of Mother to Child Transmission (PMTCT) and young people from Zvandiri used this platform to once again call on policy makers and donors. They constructed a ‘mock graveyard’, representing the thousands of children who have died in Zimbabwe as a result of HIV. This exhibit grew through the week long conference as conference delegates were invited to paint the name of a child they have known who died with HIV. The result was a thought-provoking reminder of the urgent need to prevent new HIV infections in children. The adolescents who created this exhibition led visitors around the graveyard, explaining that PMTCT programmes must be rolled out and that they must work. They summarised this by asking delegates to “Make us the last generation to be born with HIV”.

Through activities such as these described above, children and adolescents from Zvandiri are making brave decisions and taking bold steps to stand up and speak out about their experiences. They are determined to improve the lives of their peers, both now and in the future. With the appropriate support, so that they are not harmed in any way through these activities, they are impacting on individuals and society and changing the way Zimbabweans think about, feel and respond to HIV.

\***NICOLA WILLIS** is the founder and Director of Africaid and has been leading the development of Africaid’s “Zvandiri” programme. She is a paediatric HIV nurse from the UK but has been working in Africa since 2002. <http://www.africaid.com>; <http://africaid.co.uk/>

**ANDREAS KELLER** is a secondary school teacher from Switzerland employed through Bethlehem Mission Immensee and supports Africaid in training youth in computing and modern media as well as in creating teaching materials. Kontakt: [a.keller2@gmx.ch](mailto:a.keller2@gmx.ch)

The work of Andreas Keller at Africaid is supported by Bethlehem Mission Immensee, Switzerland, Member of the Network Medicus Mundi Switzerland

## ADVOCACY FOR IMPROVED MEDICAL CARE FOR HIV-POSITIVE PERSONS

SolidarMed, the Swiss Organisation for Health in Africa, considers advocacy for the poor in its programme areas as one task of the organization's projects. It contributes to the improvement of HIV services for the population in remote rural areas of Lesotho by using different platforms and levels.

By Karolin Pfeiffer\*

**SOLIDARMED** is working in rural remote regions within the national health systems of Mozambique, Tanzania, Zambia, Zimbabwe and Lesotho where people have only limited access to health care. Knowledge gained and lessons learnt in SolidarMed's programmes are shared at different levels aiming at initiating discussion and ultimately change towards improvement of access to good quality health services.

In Lesotho, SolidarMed has been supporting the Ministry of Health since 2005 in the establishment and decentralization of antiretroviral treatment (ART) for HIV-positive patients. With 23.6%, Lesotho has the third highest adult HIV prevalence worldwide (Demographic Health Survey 2009, MoHSW Lesotho). Despite massive national efforts in scaling-up ART-provision, only 57% of adults in need of treatment received ART in Lesotho by the end of 2009 (WHO/UNAIDS 2010). Lesotho therefore fell massively short of the UNGASS target of 80% treatment coverage by the end of 2010.

### EVIDENCE BASED ADVOCACY

Getting patients on treatment is, however, not the only challenge in HIV programmes. With increasing numbers of patients on lifelong ART, the disease has become a chronic condition with also rising numbers of treatment failures. Identifying patients failing on first-line treat-

ment and switching them to second line regimens is a question of life or death for these individuals – and a major challenge in ART programs in resource-limited settings. As a matter of fact, patients who are failing on a first-line regimen are often not or not timely switched to a second-line regimen. This leads to high mortality rates among patients who fail on first-line ART in resource limited countries (Keiser et al. *Trop Med Int Health* 2010, 15:251-258). The study on treatment failure, which is shortly described here, is an example of how SolidarMed achieved a change at national and local level for improved care of HIV positive patients.

Since SolidarMed started its HIV project SMART (SolidarMed antiretroviral treatment project) in Lesotho in 2005, more than 6100 patients have started ART in the catchment areas of the two long-lasting partner hospitals in the districts Butha Buthe and Thaba Tseka. 65% of these patients had still been under treatment by the end of 2011. These districts are rural and mountainous, and the majority of the population (about 132'000 persons) are poor subsistence farmers or migrant workers. Due to the decentralization of HIV services from hospitals to health centres and task shifting from physicians to nurses, the majority of patients are now able to access and continue HIV treatment at the nearest health centre. In this context, late detection of treatment fail-



Photo: N. Labhardt, February 2011

A nurse at a health centre in Lesotho explains to a patient how the ART-drug has to be taken

ure has been recognized as a major challenge. This judgement was based on both observation of nurses' performance during clinical consultations and on patient data: Since the beginning of the project, SolidarMed has monitored the clinical development of patients and progress of operations through routinely collected ART patient data.

To confirm treatment failure, a viral load measurement is required. Such viral load tests are relatively expensive (100 USD) and not available in Lesotho. In case of suspicion of treatment failure, the Ministry of Health in Lesotho provides funds for a limited number of viral load tests to be performed in a laboratory in South Africa. Having recognized the urgent need to identify patients who fail on first-line

ART and to switch them timely on second-line, SolidarMed decided to conduct a study to assess a simpler and alternative clinical score to predict treatment failure (compared to the National guidelines). During the study, conducted in 2010, all patients who had been identified as fulfilling WHO failure-criteria (same as those in the national guidelines) received a blood measurement for HIV viral load. In case of confirmed treatment failure, clinicians have to write a request to a second-line committee headed by the Ministry of Health and Social Welfare of Lesotho. With permission of this committee, those patients can then be switched to second-line ART.

The study revealed not only a high number of patients with treatment failure that had

not been detected and switched before. It also showed a high degree of uncertainty of WHO clinical or immunological criteria predicting "true" treatment failure as confirmed by viral load measurement (only 51% of suspects had confirmed treatment failure). Thus, the need for improved access to viral load testing to avoid delayed or unnecessary switch to 2nd line treatment became apparent. In addition, the study identified weaknesses in the process of switching patients, such as important time delays until the test result came back, and the lack of a standardized request forms for viral load testing.

#### RAISING AWARENESS AND INITIATING CHANGE

Results and lessons learnt of that study have been shared at facility and national level. At the hospitals, it has created awareness to more carefully assess patients for possible treatment failure and to develop routine procedures in requesting ARV 2nd line switches.

At national level, this issue has been discussed in meetings with the Christian Health Association of Lesotho (CHAL) and representatives of 8 out of 17 hospitals countrywide. The increased awareness has triggered a rise in viral load testing and of patients being switched to 2nd line regimens due to confirmed treatment failure. The study results have also been presented by the superintendent of one of the two partner hospitals in Lesotho at the International Conference on AIDS and sexually transmitted infections in Africa (ICASA) at Addis Abeba, Ethiopia.

In addition, SolidarMed and its partner CHAL organized a symposium in April 2012 with the participation of the Ministry of Health and main actors in HIV/AIDS in Lesotho (MSF, CHAI, Baylor, EGPAF, ICAP). It has resulted in an increased national awareness about the viral resistance problem, and in the development of standardized national procedures based on SolidarMed suggestions.

SolidarMed thus contributes to the improvement of HIV services for the population of Butha Buthe and Thaba Tseka districts in Lesotho by using different platforms and levels: Such as the here described study and symposium, but also through the collaboration within a research network (International Epidemiological Databases to Evaluate AIDS), through the presentation of its lessons learnt at ICASA and the World AIDS Conference, and, at least as important, the discussion of identified constraints and search for solutions together with its partners, national staff and patients at district, hospital and health centre level.

\*DR. KAROLIN PFEIFFER works as Desk Officer with SolidarMed in Lucerne, responsible for the Lesotho and Zimbabwe programme. [www.solidarmed.ch](http://www.solidarmed.ch), Contact: [k.pfeiffer@solidarmed.ch](mailto:k.pfeiffer@solidarmed.ch)

## VON DER SELBSTHILFE ZUR EINFLUSSREICHEN BEWEGUNG

In Paraguay wurde Aids lange Zeit verdrängt, Betroffene wurden diskriminiert und konnten ihr Recht auf Behandlung nicht einfordern. Aus dem Zusammenschluss Betroffener entstand im Laufe der Jahre eine gut organisierte Bewegung, die sich zunehmend öffentlich engagierte. Mit Unterstützung des Schweizerischen Roten Kreuzes konnte sich die Organisation Vencer etablieren. Sie ist zum wichtigen Akteur der nationalen Gesundheitspolitik avanciert.

Von Albino Martín Portillo und Mirta Ruiz Díaz\*

**CHRONIK** der Insel ohne Meer. Der Titel dieses Romans von Juan Rivarola Matto (Paraguayischer Autor, 1933–1991: *La isla sin mar*) eignet sich bestens, um Paraguay vorzustellen: ein warmes Land, das lange Zeit geografisch isoliert war, mit einer einzigartigen Kultur und in vielem ganz anders als seine Nachbarn. Im zweisprachigen Paraguay wird hauptsächlich Guaraní gesprochen, eine Indiosprache, die neben Spanisch offizielle Landessprache ist. Die Paraguayer sprechen, denken, fühlen und leben in Guaraní; Spanisch verwenden sie hauptsächlich als Kommunikationsmittel über die Landesgrenzen hinaus.

Paraguay liegt im Zentrum Südamerikas. Das wenig bekannte Land, das oft mit Uruguay verwechselt wird, hat 6,4 Millionen Einwohner, die hauptsächlich von Landwirtschaft und Viehzucht leben. Im Jahr 2011 feierte Paraguay 200 Jahre Unabhängigkeit. Diese zwei Jahrhunderte waren geprägt von permanenten politischen Unruhen, einer 60 Jahre dauernden Einparteiherrschaft und einer 35 Jahre währenden grausamen Diktatur. In diesen Jahren herrschten Autoritarismus, Korruption und eine skandalöse soziale Ungleichheit.

2008 zeichnete sich die erste friedliche politische Veränderung in der Regierung ab. Damals kam Fernando Lugo an die Macht, der

von den Parteien, von verschiedenen Organisationen und sozialen Bewegungen unterstützt wurde. Doch dieser Friede nahm ein jähes Ende, als im Juni 2012 ein politisches Erdbeben das Land erschütterte, das zum Sturz des Präsidenten führte.

#### HIV IN PARAGUAY

Der erste Aids-Fall wurde 1985 gemeldet. Im August 2011 waren 9701 Menschen mit HIV registriert. Nach offiziellen Daten betrug die HIV-Jahresinzidenz (Anzahl der Neuerkrankungen) in der Gesamtbevölkerung Ende 2010 17:100 000, was gegenüber 2004 einer Zunahme um mehr als 100% entspricht. Bei den Frauen ist die Inzidenz fast gleich hoch wie bei den Männern und bei den jungen Erwachsenen hat sie sich in den letzten zehn Jahren verdreifacht.

Das Gesundheitsministerium geht davon aus, dass die Zunahme der Neuinfektionen mit der Verbesserung des Meldesystems und dem besseren Zugang der Bevölkerung zu HIV-Tests zusammenhängt. Die Daten belegen jedoch, dass die Epidemie keineswegs unter Kontrolle ist und dass sich tendenziell mehr Heterosexuelle und immer jüngere Bevölkerungsschichten anstecken.



## DIE ANFÄNGE DER STIFTUNG VENCER

Die Organisation Vencer (Spanisch für besiegen) ging aus dem ersten Zusammenschluss von Menschen mit HIV/Aids in Paraguay hervor. Sie wurde 1996 als Selbsthilfegruppe gegründet, mit dem Ziel, untereinander Informationen auszutauschen und sich gegenseitig materiell und emotional zu unterstützen.

Die Betroffenen litten unter schwerwiegenden Mängeln und Ungerechtigkeiten: In vielen Gesundheitszentren wurden sie nicht behandelt, sie wurden gefürchtet und diskriminiert. Ihr Serostatus wurde ohne jegliche Kontrolle weitergegeben. Es gab weder Register noch aktuelle Informationen. Der Zugang zu Laboruntersuchungen und antiretroviralen Medikamenten war ungenügend und diskriminierend. Oftmals waren keine Medikamente verfügbar, was einen intensiven Handel auf dem Schwarzmarkt und Migration in Nachbarstaaten auslöste. Die Infizierten starben an der Krankheit, weil sie keinen Zugang zu einer angemessenen Versorgung hatten. Selbst nach ihrem Tod wurden sie noch diskriminiert: Sie wurden eiligst beerdigt, oftmals sogar ohne Sarg, nur in einem Abfallsack, und ohne den Verwandten eine Trauerzeit zu gewähren – in brutaler Missachtung menschlicher Würde.

Auf politischer Ebene wurde zu wenig für die Prävention und für die Behandlung und Betreuung von Menschen mit HIV/Aids getan. Daher versuchte Vencer, die schwierige Situation der Betroffenen zu lindern, indem Hilfe aus erster Hand geboten wurde: Ermöglichung von Laboruntersuchungen und medizinischer Beratung, Beschaffung von Mitteln für den Kauf von Medikamenten, internationale Hilfsaufrufe, aber auch Angebot von Rückzugsmöglichkeiten und gegenseitige emotionale Unterstützung.

## DER DURCHBRUCH

Vencer sah sich mit einem enormen Missverhältnis konfrontiert: Immense Not stand limitierten Möglichkeiten gegenüber. Deshalb wurde 1998 beschlossen, den Status der Selbsthilfegruppe aufzugeben und eine Organisation zu werden. Zunehmend bildete sich das Bewusstsein heraus, dass dem Staat Verantwortung zukommt, dass die Bevölkerung ein Recht auf Gesundheitsversorgung und Information hat. Da jedoch die Mängel und Schwächen weiterbestanden, musste ein umfassenderer Plan ins Auge gefasst werden. Dadurch entwickelte

Vencer eine ganzheitlichere, politischere Sichtweise. Ihre Mitglieder waren sich von Anfang an bewusst, dass diese Rechte in der Verfassung verankert waren; sie mussten nur eingefordert werden.

Während Jahren zeigten die Mitglieder von Vencer ihre Gesichter aus Angst vor Diskriminierung nicht und gingen ihren Aktivitäten im Verborgenen nach. Bis sie offen dazu stehen konnten, waren verschiedene Prozesse notwendig, zuallererst bei ihnen selbst: Sie mussten den eigenen Serostatus anerkennen und mit der Krankheit leben lernen. Erst danach konnten sie sagen: «Jetzt sind wir stärker, jetzt haben wir die Kraft, an die Öffentlichkeit zu treten, um für unsere Rechte einzutreten und jenen eine Stimme zu geben, die sich nicht selbst äussern möchten.»

## ENTSCHEIDENDE UNTERSTÜTZUNG

Zu Beginn, in der Phase Selbsthilfegruppe, war die Unterstützung der katholischen Kirche und eines Jesuitenpriesters sehr wichtig. Danach wurde versucht, die Ärzte zu gewinnen, die Menschen mit HIV/Aids betreuten, um an Informationen und Hilfe zu gelangen.

Es vergingen Jahre ohne Hilfe von aussen, mit kärglichen Mitteln: Freiwilligenarbeit, Sozialhilfegelder, Losverkäufe, Herstellung und Verkauf von Waschmitteln, einige Spenden und private Unterstützung, um die wichtigsten Kosten zu decken, um den Kampf zu unterstützen. Doch diese Erfahrungen waren auch sehr bereichernd und gaben den erreichten Zielen einen höheren Stellenwert. Im Jahr 2000 erhielt Vencer einige Mittel für Einzelaktionen: etwa 2000 Dollar von der Weltbank und ungefähr 5000 Dollar vom Canada Fund.

Die erste Zusammenarbeit zwischen Vencer und dem Schweizerischen Roten Kreuz kam 2004 im Rahmen eines Pilotprojekts zustande, für das ein Betrag von 11 000 Dollar zur Verfügung gestellt wurde. Die gemeinsame Ausarbeitung des Antrags erfolgte in einem zur Verfügung gestellten Haus, im Schatten eines Baumes. Die Unterstützung des SRK öffnete Vencer weitere Türen: Das niederländische Hilfswerk ICCO finanzierte den Kauf des Gebäudes für den Sitz der Organisation und ein weiteres Projekt, um die finanzielle Unabhängigkeit zu erhöhen. Mit einem zweijährigen, vom SRK finanzierten Projekt begann 2007 für Vencer eine neue Etappe, die sehr wichtige Im-



Präventions-Workshop zu HIV/Aids (von Vencer) für Jugendliche in Asunción.

pulse und Unterstützung brachte. Dabei handelt es sich um das erste grössere Projekt in Bezug auf den Umfang der Mittel und die Ausdauer.

## DIE STRATEGIEN VON VENCER

Die Entwicklung von einer Aktivistin- und Selbsthilfegruppe zu einer landesweit anerkannten Organisation erfolgte nicht einfach so. Tag für Tag wurde daran gearbeitet: Man lernte dazu, strauchelte, beschwerte sich, unterbreitete Vorschläge, machte seinen Einfluss geltend. Neben Fortschritten gab es auch ab und zu einen Rückschlag. Auf diesem Weg standen die folgenden Strategien im Vordergrund:

- Allianzen schmieden, Ängste und Neid überwinden, das Bewusstsein wecken, dass Veränderungen nicht alleine herbeigeführt werden können. Nicht nur mit anderen gemeinnützigen Organisationen, sondern auch mit dem Staat Allianzen eingehen. Dabei

die Rolle nicht aus den Augen verlieren, die der Zivilgesellschaft in Bezug auf die soziale Kontrolle zukommt.

- Präsent sein und die Mobilisation der Gesellschaft unterstützen, ob zur Durchsetzung von Lohn- oder Landansprüchen oder bei Protesten und Kundgebungen unabhängig vom Sektor. Präsenz markieren, die Öffentlichkeit für HIV sensibilisieren, das für viele unsichtbar ist.
- An Netzwerken, Debatten, Symposien, Kongressen auf nationaler und internationaler Ebene mitwirken, damit Vencer bekannt wird und sich zur massgebenden Organisation auf diesem Gebiet entwickeln kann.
- Durch wahrheitsgetreue, wissenschaftlich fundierte Informationen Barrieren überwinden, denn Unwissen erzeugt Ängste. Eine klare, verständliche Sprache und Terminologie verwenden. Grundlegende Informationen vermitteln, zum Beispiel dass HIV

nicht über die Luft, sondern auf anderem Weg übertragen wird, dass nicht von Aids-kranken, sondern von Menschen mit HIV/Aids gesprochen werden sollte, dass es weder schlecht noch gefährlich ist, mit ihnen zusammen zu sein. All dies vor allem gegenüber dem Pflegepersonal in den Gesundheitsdiensten betonen, damit es versteht, dass bei der Pflege von Menschen mit HIV/Aids keine unmittelbare Ansteckungsgefahr droht, dass die Übertragung anders verläuft. Dem Gesundheitspersonal aber auch aufzeigen, wie es sich schützen kann.

- Es sind kaum Register und verlässliche Informationen verfügbar. Deshalb Einzeldaten systematisch aufarbeiten, Informationen beschaffen, um gestützt auf Daten argumentieren zu können.
- Gesetze prüfen und das bereits Vorhandene nutzen, die Einhaltung bestehender Gesetze einfordern, Lücken und die Notwendigkeit neuer Gesetze und Vorschriften aufdecken.
- Politisch Einfluss nehmen, sich mit anderen Akteuren zusammenschließen, damit die Ziele in die staatliche Politik aufgenommen werden, um ihnen Nachhaltigkeit zu verleihen, um zu verhindern, dass es bei einem Regierungswechsel zu Rückschritten kommt.

#### AUSBLICK

Vencer ist in Paraguay die massgebende Organisation im Bereich HIV. In den letzten Jahren hat sie grosse Fortschritte erzielt, ohne die Bodenhaftung zu verlieren: Sie hat ihre Arbeit professionalisiert, ihre Leitung und Verwaltung optimiert und an Nachhaltigkeit gewonnen.

Durch Vernetzung, die Mobilisierung der Gesellschaft und das Schmieden von Allianzen hat sie das Vertrauen aller Sektoren gewonnen. Sie arbeitet seriös, kohärent, unter Berücksichtigung der Vielfalt, verantwortungsvoll und transparent. Neben der Koordination verschiedener Netzwerke übernimmt sie abwechselnd den Vorsitz in der Landeskoordination des

Global Fund und diskutiert offen mit den nationalen Behörden in den Bereichen Gesundheit, Erziehung, Justiz und Arbeit.

Die Situation der Menschen mit HIV/Aids hat sich verbessert. Die Mängel im Gesundheitswesen wurden etwas reduziert. Vencer spielte eine führende Rolle bei der Erarbeitung und Umsetzung eines neuen Gesetzes, das 2009 nach sechsjährigen Arbeiten in Kraft trat. Darin sind die Rechte und Pflichten sowie die präventiven Massnahmen im Zusammenhang mit HIV und Aids geregelt. Nun ist der Staat für die Prävention im ganzen Land zuständig. Alle Menschen mit HIV/Aids erhalten ohne Diskriminierung Zugang zur medizinischen Versorgung (frühzeitige Diagnose, Laboruntersuchungen, Medikamente gegen HIV und Begleiterkrankungen, medizinische Kontrollen, psychologische Unterstützung und eine qualitativ gute, einfühlsame Betreuung). Und nicht zuletzt konnte erreicht werden, dass all dies im Einklang mit den Menschenrechten garantiert wird.

Die grösste Herausforderung sind gegenwärtig die Stigmatisierung und Diskriminierung von Menschen mit HIV/Aids. Wichtige Aufgaben stellen sich zudem im Zusammenhang mit dem oben erwähnten Gesetz, was die Integration in der Gesellschaft, die Reglementierung und die Umsetzung anbelangt. Zudem muss der Kampf bei der Ausarbeitung der neuen Gesetze fortgeführt werden, die zurzeit in den Bereichen Antidiskriminierung, sexuelle und reproduktive Gesundheit und Bildung geplant sind.

HIV ist unterdessen auf allen Ebenen ein Thema. Dies macht deutlich, dass die Fokussierung auf den Menschenrechtsansatz und die politische Einflussnahme Wirkung zeigen. Das Thema HIV steht heute auf der politischen Agenda des Landes und hat Eingang in die staatliche Politik gefunden.

**«Turning the tide against the HIV/AIDS epidemic will take concerted leadership at all levels of government, health systems, academic and non-governmental organizations.»** The Washington D.C. Declaration



\*ALBINO MARTÍN PORTILLO ist Koordinator des Schweizerischen Roten Kreuzes in Paraguay  
MIRTA RUIZ DÍAZ, Direktorin Vencer

# TURNING THE TIDE TOGETHER: A DECLARATION TO END THE AIDS EPIDEMIC

We stand at a unique time in the history of the AIDS epidemic.

**THREE DECADES** of tenacious community advocacy, research, and service provision have brought the world to the brink of a scenario unthinkable a few short years ago: the possibility of beginning to end the AIDS epidemic in our lifetimes. The losses have been incalculable; the gains extraordinary. But now, through new scientific advances, and societal, political and human rights gains, we have discovered that it is possible to assemble and deliver a package of proven strategies, which, if taken to scale, can turn the tide on AIDS.

We still need a cure and a vaccine. But we must scale up our resources and efforts using the tools we have today to dramatically curb new infections and improve the health of tens of millions of people with HIV/AIDS. Millions of lives will be saved.

Turning the tide against the HIV/AIDS epidemic will take concerted leadership at all levels of government, health systems, academic and non-governmental organizations. We must strive for multi-disciplinary approaches that respect and uphold the human rights and dignity of all people affected by the epidemic. The goal of beginning to end the AIDS epidemic is ambitious, but achievable. It is within our grasp. To turn this tide together we must:

- 1 Increase targeted new investments.** We can save lives, avert infections and reduce the global price-tag of the epidemic with an immediate, strategic increase in investments now. Greater progress will require commensurate funding commitments from global and local donors, including from national governments worldwide.
- 2 Ensure evidence-based HIV prevention, treatment and care** in accord with the human rights of those at greatest risk and in greatest need. This includes men who have sex with men, transgender individuals, people who use drugs, vulnerable women, young people, pregnant women living with HIV, and sex workers, as well as other affected populations. No one can be excluded if we are to reach our goal.
- 3 End stigma, discrimination, legal sanctions and human rights abuses** against people living with HIV and those at risk. Stigma and discrimination hamper all our efforts and prevent delivery of essential services.
- 4 Markedly increase HIV testing, counseling and linkages to prevention, care and support services.** Every person has a right to know her/his HIV status and get the treatment, care and support they need.
- 5 Provide treatment for all pregnant and nursing women** living with HIV and end perinatal transmission: We can support women to stay alive and healthy and to end pediatric HIV infections
- 6 Expand access to antiretroviral treatment to all in need.** We cannot end AIDS until the promise of universal access is realized.
- 7 Identify, diagnose and treat TB.** Implement TB prevention programmes through integrated HIV and TB services. No more living with HIV but dying of TB.
- 8 Accelerate research** on new HIV prevention and treatment tools, including novel approaches such as pre-exposure prophylaxis (PrEP) and microbicides, and on optimal delivery of what we know works, from condoms to treatment as prevention. Expand research for a vaccine and a cure. Research is essential to leading us out of the epidemic.
- 9 Mobilization and meaningful involvement of affected communities** must be at the core of collective responses. The leadership of those directly affected is paramount to an effective HIV/AIDS response.

The challenges ahead are great, but the costs of failure will be greater. We call upon all concerned citizens of the global community, in the spirit of solidarity and joint action, and with the fullest engagement of the community of persons living with HIV, to seek renewed urgency to expand the global AIDS fight. We must act on what we know.

**We must start the end of AIDS – Together.**

<http://www.2endaids.org/read.html>

## EINE WENDE IST MÖGLICH, WENN JETZT GEHANDELT WIRD

Washington, 27. Juli 2012 – Die heute zu Ende gehende 19. Internationale Aids-Konferenz hat gezeigt, dass eine künftige Generation ohne Aids möglich ist. Wir stehen an einem einzigartigen Zeitpunkt in der Geschichte der Aids-Epidemie. Mit dem heutigen Stand der Wissenschaft können Millionen von Menschenleben gerettet werden, wenn wir alle Präventionsstrategien implementieren und Menschen möglichst frühzeitig mit lebensrettenden anti-retroviralen Medikamenten behandeln.

**EIN BREITES** Spektrum von Präventionsmethoden steht heute zur Verfügung. Bewährte Methoden sind Kondome sowie der Verhinderung der Übertragung des HI-Virus von der Mutter auf das Neugeborene durch antiretrovirale Medikamente. Zu den neueren Präventionsmethoden zählt die frühzeitige Behandlung von HIV-positiven Menschen mit Aids-Medikamenten, die die Behandelten deutlich weniger ansteckend macht. Spätestens seit der Konferenz in Washington ist klar, dass jede weitere Verzögerung in der Behandlung zu zusätzlichen HIV-Infizierten führt.

Ein Hindernis für erfolgreiche HIV-Präventionsmassnahmen stellt in vielen Teilen der Erde die gesellschaftliche Diskriminierung von Gruppen dar, die besonders von HIV betroffen sind: Männer, die Sex mit Männern haben, SexarbeiterInnen und Drogennutzende. Berichte von Betroffenen zeigten auf, dass jegliche Form der Diskriminierung beseitigt werden muss. Nur wenn die Menschenrechte aller respektiert werden und die gefährdete Gruppen selbst zu Wort kommen, können HIV-Präventionsmassnahmen wirksam umgesetzt werden.

Die Washingtoner Erklärung ruft dazu auf, das Blatt zu wenden. Helena Zweifel, Koordinatorin von aidsfocus.ch, der schweizerischen Fachplattform HIV/Aids und internationa-

le Zusammenarbeit.ch ist überzeugt, dass das Blatt gewendet werden kann in Richtung einer künftigen Generation ohne Aids. Dazu braucht es den politischen Willen aller Entscheidungsträger, globale Verantwortung zu übernehmen und Solidarität zu leben. Für die Schweiz bedeutet dies, ihren finanziellen Beitrag zur Bekämpfung der internationalen Aids-Epidemie substantiell zu erhöhen und sich dafür einzusetzen, dass Pharmapatente nicht den Zugang zu lebensnotwendigen und kostengünstigen Medikamenten verhindern.



## «WENN ES DEN GLOBAL FUND NICHT GÄBE, MÜSSTEN WIR IHN ERFINDEN»

Die Streichung der 11. Finanzierungsrunde, die Reaktion von Südpartnern sowie die Fachtagung im April 2012 haben aidsfocus.ch veranlasst, sich aktiv für die Stärkung des Globalen Fonds zur Bekämpfung von Aids, Tuberkulose und Malaria zu engagieren. aidsfocus.ch ist heute international gut vernetzt mit Advocacy-Organisationen und -Netzwerken und hat den Politikdialog mit Schweizer Entscheidungsträgern zum Globalen Fonds aufgenommen.

Von Helena Zweifel\*

**DER GLOBALE** Fonds zur Bekämpfung von AIDS, Tuberkulose und Malaria (GF) ist ein Kind der Advocacy der Zivilgesellschaft, welche sich lautstark für den Zugang aller zu Aidsmedikamenten einsetzte. «The internationally-recognized role that civil society played in launching the Global Fund's first funding round and in the conceptualization and design of the Global Fund led to a sense of ownership; the Global Fund was an initiative that they had helped to create, fund and govern», anerkennt der GF (An evolving partnership, GF). Der Beschluss über die Gründung des GF wurde auf der UNO-Sondergeneralversammlung zu HIV/AIDS in New York 2001 auf Antrag von Kofi Annan gefasst und in Zusammenarbeit mit zivilgesellschaftlichen VertreterInnen umgesetzt.

«Wenn es den Global Fund nicht gäbe, müssten wir ihn erfinden», erklärte Simon Bland, Präsident des Board des GF zu Beginn des Workshops des Global Fund Advocacy Networks (GFAN) am 21. Juli 2012 in Washington. Die VertreterInnen des Boards und des Sekretariats des GF waren am Workshop des GFAN und an der internationalen Aidskonferenz in Washington sehr präsent. Sie informierten, stellten sich Fragen und suchten die Dialog.

### DAS KERNGESCHÄFT: LEBEN RETTEN

Die Leistungen des GF lassen sich sehen: Er ist in den zehn Jahren seines Bestehens zum weltweit wichtigsten Finanzierungsinstrument im Gesundheitsbereich geworden. Von praktisch keiner Aidsbehandlung im Globalen Süden im Jahre 2002 sind bis heute 7 Millionen Menschen in den wenig entwickelten Ländern mit antiretroviralen Medikamenten behandelt worden, etwa die Hälfte von ihnen dank dem GF. Auch die HIV-Prävention konnte weltweit ausgedehnt werden. Heute erhalten etwa die Hälfte aller HIV-positiven, werdenden Mütter Medikamente, um die Übertragung des Virus auf ihr Baby zu verhindern. Die Mehrzahl dieser Dienstleistungen wurde durch die Finanzierung durch den GF ermöglicht. 9,3 Millionen Menschen konnten für Tuberkulose behandelt und 270 Millionen imprägnierte Bettnetze zur Prävention von Malaria verteilt werden. Gesundheitssysteme wurden gestärkt und das Leben einer signifikanten Zahl von ÄrztInnen und weiteren GesundheitsarbeiterInnen gerettet.

Die Crew des GF gibt sich zuversichtlich, dass der GF gestärkt aus der Krise erwächst, welche durch angebliche Veruntreuung von Geldern des GF, angeschlagenes Vertrauen von Geberländern in den GF und der Streichung der

11. Finanzierungsrunde im November 2011 hervorgerufen worden war. Der GF hat in diesem Jahr im Eiltempo einen tiefgreifenden Restrukturierungsprozess durchgemacht, um zielgerichteter arbeiten zu können. Vor allem das Management der Gelder wurde gestärkt und in Form gebracht. Das Vertrauen der Geber scheint zurückgewonnen worden zu sein. Statt der befürchteten finanziellen Engpässe, die zur Streichung der 11. Runde geführt hatten, stehen dem GF dieses Jahr 1,6 Milliarden Dollar zur Verfügung, sodass Lücken gefüllt und mit der Umsetzung der neuen Strategie 2012–2016 «Investing for Impact» begonnen werden kann. Der Vorwurf der Korruption und Veruntreuung von Geldern konnte gemildert werden. Eine vom Generalinspektorat in Auftrag gegebene Analyse von Audits und Untersuchungen zeigt, dass ein sehr kleiner Teil der Mittel – 3% – der zwischen 2005 und 2012 überprüften Mittel vergeudet, in betrügerischer Absicht missbraucht oder unzureichend in Rechnung gestellt worden waren. (GF 10/07/2012) Punkte Vorwürfen angeblicher Korruption scheint der GF Opfer einer seiner Stärken – der Transparenz – geworden zu sein.

### KNACKPUNKT: NEUE FINANZIERUNGSMECHANISMEN

Der GF ist im Prozess der Entwicklung eines neuen Finanzierungsmodells, das das Finanzierungssystem mit den Runden ersetzen soll. Die finanzielle Unterstützung des Fonds soll vor allem Ländern mit der höchsten Krankheitslast und armen Ländern mit der grössten Kluft zwischen Bedarf und vorhandenen Ressourcen zu gute kommen. Für Regierungen und Nichtregierungsorganisationen (NGO) im Globalen Süden und Osten ist es ein Anliegen, die sehr komplizierte Bürokratie des GF zu vereinfachen, damit sie sich ihren primären Aufgaben, der Umsetzung der Programme widmen können und nicht ein Grossteil ihrer Zeit für das Schreiben von Projektanträgen und Berichten und dem Verhandeln mit dem GF aufwenden müssen.

Das neue Finanzierungsmodell schlägt einen iterativen Prozess mit länderspezifischen Lösungen vor: Implementierende Länder und GF arbeiten zusammen die Finanzgesuche aus, basierend auf den Bedürfnissen und nationalen Strategien der jeweiligen Länder und Interventionsstrategien, deren Wirksamkeit als er-

wiesen gilt. Mit diesem für jedes Land massgeschneiderten partizipativen Prozess sollen die Länder «Ownership» gewinnen.

Viele NGOs in Süd und Nord begrüssen grundsätzlich das neue, auf partizipativen Prozessen beruhende Modell. Doch der Teufel sitzt im Detail, und die Details sind noch nicht ausgearbeitet worden. Wer sind die Gesprächs- und VerhandlungspartnerInnen? Wer sind die «Länder» und wie werden die Gelder festgelegt? Was geschieht mit den Country Coordinating Mechanisms, Multi-Stakeholder-Partnerschaften, in denen die Zivilgesellschaft vertreten ist, die aber nicht immer reibungslos funktionieren? Wie werden die Länder ausgewählt? Die Anliegen der Regierungen und die der Zivilgesellschaft sind nicht immer deckungsgleich oder auch nur aushandelbar. In Russland und der Ukraine z.B. werden Gruppen, in denen HIV stark verbreitet ist, wie DrogennutzerInnen und Männer, die Sex mit Männern haben (MSM), diskriminiert. Nur dank dem GF erhielten zivilgesellschaftliche Organisationen, die mit diesen Risikogruppen zusammenarbeiten, bisher die notwendige Unterstützung für zielgruppengerechte Prävention, Behandlung und Betreuung.

### PROTESTE

An der Internationalen Aidskonferenz in Washington unterbrach ein Gruppe von AktivistInnen die Podiumsdiskussion zur Zukunft des GF mit einer Protestaktion, um ihre Botschaft an die Leute zu bringen: Das neue Finanzierungsmodell muss nachfrageorientiert sein und darf den Anträgen von Ländern keine Obergrenze setzen («No caps»). Die AktivistInnen baten die PodiumsteilnehmerInnen, ein entsprechendes Versprechen zu unterzeichnen. Der CEO des Global Fund Gabriel Jaramillo was der erste, der seine Unterschrift unter das Dokument setzte.

Die Welt braucht einen voll finanzierten und starken GF um die Zahl der dringend notwendigen lebensrettenden Dienstleistungen massiv zu erhöhen, betonte die Sprecherin der Aktivistinnen, Rosemary Mburo, Koordinatorin der Africa Civil Society Platform bei der World AIDS Campaign. Sie hielt fest, dass «wir keine aidsfreie Generation verwirklichen können mit einem Global Fund, der für Länder und Regionen einen engen Rahmen und für Gesuche willkürliche Obergrenzen setzt, oder

der zufällige Listen mit den Interventionen aufstellt, die finanzierbar sind.»

Als einzige Vertreterin der Zivilgesellschaft fand die Marokkanerin Nadia Rafif, NGO-Vertreterin für die MENA-Länder im Board des GF, offiziell Platz auf dem Podium. Die Zivilgesellschaft sei besorgt, da viele Regierungen ein neues Modell vorschlagen, das dem GF-Prinzip der Nachfrageorientierung widerspricht und harte Obergrenzen für Summen («Caps») setzt für die Gelder, die ein Land oder eine Region erhalten würde. «Wir glauben, dass dies ein verhängnisvoller Fehler sein würde. Politiken, die die Nachfrage eingrenzen ermutigen weder Country Ownership noch Innovation, Kreativität und Flexibilität», erklärte sie.

#### DIALOGBEREITSCHAFT

In der Networking Zone des Global Fund Advocacy Networks (GFAN) im Global Village waren VertreterInnen des Global Fund sehr präsent und suchten das Gespräch, informierten, beantworteten Fragen und ermutigten zu Vorschlägen. Auf die besorgte Frage eines Teilnehmers, wie garantiert werden könne, dass die Beiträge nachfrageorientiert vergeben werden können, versicherte Shaun Mellors, Vertreter der Communities im Board des GF, dass jeder neue Finanzierungsmechanismus wie bisher auf die Anträge der Länder reagieren muss. Im neuen Modell wird mehr Interaktion zwischen Geldgebern und Empfängern stattfinden. Bisher wurden nur ca. 50% aller Anträge finanziert, ca. 50% zurückgewiesen – eine grosse Zeit- und Ressourcenverschwendung.

Wie kann sichergestellt werden, dass das Geld dahin fliesst, wo es gebraucht und am wirkungsvollsten eingesetzt werden kann, insbesondere für sogenannten «Key Populations» (Bevölkerungsgruppen, die besonderen Risiken ausgesetzt sind und stigmatisiert werden, wie MSM, SexarbeiterInnen und DrogennutzerInnen)? Todd Summers, Präsident des Strategy, Investment and Impact Committee des Global Fund (SICC) gab ein erklärendes Beispiel: Wenn ein Land mit einer konzentrierten Epidemie nur 9% für «Key Populations» wie Drogenabhängige, bei welchen die HIV-Prävalenz sehr hoch ist, budgetieren würde, müsste der Global Fund mit den LandesvertreterInnen darüber diskutieren. Die Ausrede eines Landes, sie hätten keine Studien zu den «Key Populati-

ons» gelte nicht. Der GF würde Gelder für eine entsprechende Studie zur Verfügung stellen, und darauf aufbauend kann ein Antrag mit wirksamen Interventionen für die besonders betroffene Gruppe formuliert werden.

Von allen Beteiligten wurde wiederholt betont, dass an dem festgehalten werden soll, was gut und spezifisch für den Global Fund ist, wie die Country Coordinating Mechanism mit aktiver Beteiligung der Zivilgesellschaft. Viele Fragen zur konkreten Trendwende im Global Fund blieben jedoch offen.

#### DAS LANGE WARTEN

Der Global Fund hat erklärt, dass Ende September neue Finanzierungsmöglichkeiten für Länder eröffnet werden und im April 2013 Entscheide zu den Gesuchen getroffen werden können. In der langen Wartezeit kämpfen Länder damit, die finanziellen Lücken zu füllen, die durch die Streichung der Beiträge des Global Fund entstanden sind. An einem Anlass des GFAN im Global Village stellten VertreterInnen von Médecins Sans Frontières (MSF), RESULTS, der HIV/AIDS Alliance, des Eurasian Harm Reduction Network und der Open Society Foundations ihre Studien zu den Auswirkungen finanzieller Löcher vor. Sie zeichneten ein erschütterndes Bild.

MSF dokumentierte im Bericht «Losing Ground: How funding shortfalls and the cancellation of the Global Fund's Round 11 are jeopardising the fight against HIV & TB» (MSF 2012) wie die Demokratische Republik Kongo und Guinea bereits die Zahl der Menschen, die antiretrovirale Behandlung (ART) bekommen sollte, beschränken musste, während Uganda nicht in der Lage war, die Zahl der Leute, die jedes Jahr mit einer Behandlung beginnen, zu erhöhen.

Der Bericht der Open Society Initiative zeigte auf, wie die Finanzierungskrise die Aktivitäten von zivilgesellschaftlichen Organisationen im südlichen Afrika ernsthaft untergraben hat. Die knapper werdenden Gelder wurden aus relevanten Unterstützungsprogrammen und von der Arbeit mit den von der Epidemie besonders betroffenen Gruppen genommen. (OSISA 2012) «Die Länder werden gezwungen, zwischen der Aufrechterhaltung von wichtigsten medizinischen Dienstleistungen und der Unterstützung von zivilgesellschaftlichen Initiativen, die diese unterstützen, zu entscheiden. Meist



haben diese Länder ihre Gelder von der Unterstützung zivilgesellschaftlicher Organisation, Menschenrechtsprogrammen, Basisarbeit und politisch sensiblen Programmen abgezogen», erklärte die Autorin des Berichts, Laura Lopez Gonzalez. Gerade diese Aktivitäten, die so zentral sind für den Erfolg nationaler HIV-Programme, sind die ersten, die gestrichen werden.

#### UNSERE VERANTWORTUNG WAHRNEHMEN

Die Reaktionen von Südpartnern auf die Streichung der 11. Finanzierungsrunde im November 2011 und ihre Appelle an aidsfocus.ch sowie die Diskussion an der Fachtagung im April 2012 zu HIV, Aids und Advocacy waren Auslöser für ein verstärktes Engagement von aidsfocus.ch für einen gestärkten Global Fund. aidsfocus.ch arbeitet heute eng mit dem deutschen Aktionsbündnis gegen Aids (www.aidskampagne.de) und ist Mitglied der deutschen zivilgesellschaftlichen Steuerungsgruppe zum Global Fund. aidsfocus.ch ist zudem gut vernetzt mit weiteren Organisationen und Netzwerken, insbesondere dem Global Fund Advo-

cacy Network (GFAN), um anstehende Fragen zu diskutieren, Positionen zu erarbeiten und Einfluss zu nehmen auf die Entwicklung und Entscheide des Global Fund.

Die Schweiz ist im Board des Global Fund als Mitglied der Interessensgruppe Deutschland-Kanada-Schweiz vertreten. So ist es naheliegend, dass auch zivilgesellschaftliche Organisationen der Schweiz, Deutschlands und Kanadas für den Policy-Dialog mit ihren Vertretern zusammenspannen. Im Herbst soll Deutschland einen eigenen Sitz im Board bekommen, die Schweiz wird sich nur noch zusammen mit Kanada einen Sitz teilen, womit Einflussbereich und Verantwortung der Schweiz steigt. aidsfocus will den Reformprozess im GF kritisch begleiten und den Policy-Dialog mit den Schweizer Entscheidungsträgern, insbesondere der Schweizer Vertretung im GF, Marc de Santis, intensivieren. Auf der Agenda sind aktuelle Geschäfte mit grossem Impact, die dieses Jahr noch besiegelt werden, wie die Verabschiedung des neuen Finanzierungsmodells und die Wahl des neuen CEO.

«Wenn der Globale Fonds jetzt seine Investitionen zurückfährt, wird das verheerende Konsequenzen haben, die in manchen Ländern schon ansatzweise zu sehen sind», sagte Farai Mahaso, Geschäftsführer der simbabwischen Aidsorganisation BHASO, in unserem abschliessenden Gespräch am Rande der Aidskonferenz in Washington. aidsfocus.ch nimmt die Befürchtungen seiner Südpartner ernst. VertreterInnen der schweizerischen Zivilgesellschaft wollen sich in internationalen Netzwerken nicht weiter schämen müssen für den völlig ungenügenden Schweizer Beitrag zum Global Fund. Im Jahr 2012 zahlte die Schweiz bescheidene 8,7 Millionen US\$ ein. Im europäischen Vergleich: Dänemark hat dem GF dieses Jahr 29,3 Millionen US\$ zugesprochen, Holland 31,4 Millionen US\$, Deutschland 254,9 Millionen US\$ und Frankreich 452,8 Millionen US\$ (GF, [www.theglobalfund.org/en/about/donors](http://www.theglobalfund.org/en/about/donors)).

In der neuen Botschaft zur internationalen Zusammenarbeit der Schweiz 2013 – 2016, welche die Schweizer Entwicklungs- und Aussenpolitik der nächsten Jahre prägen wird, ist der Globale Fonds zur Bekämpfung von Aids, Tuberkulose und Malaria als eine der 13 prioritären, multilateralen Organisationen aufgeführt, mit denen die DEZA zusammenarbeitet. «In Periode 2013–2016 ist eine substanzielle Erhöhung des Beitrages vorgesehen», steht im Anhang zum Botschaftstext.

aidsfocus.ch wird sich dafür einsetzen, dass die Schweiz in den nächsten Jahren ihren Beitrag mindestens verdoppelt. Mit Informations- und Öffentlichkeitsarbeit will aidsfocus.ch die Schweizer Öffentlichkeit, Politik und Verwaltung für die Notwendigkeit eines starken GF mit einer namhaften Unterstützung der Schweiz für globale Gesundheit und Gerechtigkeit sensibilisieren. aidsfocus.ch wird den Policy-Dialog mit den EntscheidungsträgerInnen pflegen, insbesondere der DEZA, und wenn notwendig mit weiteren Advocacy-Instrumenten die Schweizer Regierung zur Rechenschaft ziehen.

\* HELENA ZWEIFEL, Geschäftsführerin Medicus Mundi Schweiz und Koordinatorin von aidsfocus.ch, der Fachplattform HIV/Aids und internationale Zusammenarbeit, [www.aidsfocus.ch](http://www.aidsfocus.ch). Kontakt: [hzweifel@medicusmundi.ch](mailto:hzweifel@medicusmundi.ch).

#### Ressourcen

An evolving partnership. The Global Fund and civil society in the fight against AIDS, Tuberculosis and Malaria. [http://bit.ly/gf\\_partnership](http://bit.ly/gf_partnership)

Global Fund releases an analysis of audits and Investigations (GF 10/07/2012) [http://bit.ly/GF07\\_12](http://bit.ly/GF07_12)

Global Fund Advocacy Network (GFAN), [http://bit.ly/gf\\_advocates\\_network](http://bit.ly/gf_advocates_network)

MSF (2012): Losing Ground: How funding shortfalls and the cancellation of the Global Fund's Round 11 are jeopardising the fight against HIV & TB. [http://bit.ly/losing\\_ground](http://bit.ly/losing_ground)

OSISA: The First to Go: How communities are being affected by the Global Fund Crisis (2012) <http://bit.ly/osisa2012>

Aktionsbündnis gegen Aids, [www.aids-kampagne.de/](http://www.aids-kampagne.de/)

Global Fund: Geldgeber und Beiträge [www.theglobalfund.org/en/about/donors/](http://www.theglobalfund.org/en/about/donors/)

# DANKE!

Das Netzwerk Medicus Mundi Schweiz und aidsfocus.ch danken der Direktion für Entwicklung und Zusammenarbeit, der AIDS-Hilfe Schweiz, terre des hommes schweiz und World Vision Schweiz für die Unterstützung der Fachtagung und des vorliegenden Readers.



Schweizerische Eidgenossenschaft  
Confédération suisse  
Confederazione Svizzera  
Confederaziun svizra

**Direktion für Entwicklung  
und Zusammenarbeit DEZA**



AIDS-HILFE SCHWEIZ  
AIDE SUISSE CONTRE LE SIDA  
AIUTO AIDS SVIZZERO

**terre des hommes schweiz**



**World Vision**

Get involved in global health debates – and keep your mind open!

## UNIVERSAL HEALTH COVERAGE: A SHARED VISION BEYOND 2015?

The existing fragmentation of the global health advocacy community is worrying. To overcome this situation people of the health community should agree on an overall understanding on what they want. Universal Health Coverage could work as a common, holistic concept for integrating the global movement for health, writes **THOMAS SCHWARZ\***.



Why should nongovernmental organizations dealing with international health cooperation get involved in global health advocacy, in high politics, in debates on issues such as the reform of the World Health Organization or the development of a Framework Convention on Global Health?

As many other NGO representatives you might answer: “Good question. I do not know why I should. And now please let me continue my work.”

I do not mind. I even do not mind if you ask me: “And anyhow, what do you think that we can change at a global level?” I also agree with you that it makes sense to share tasks among people and institutions working in different ways towards the shared vision of health for all.

Nevertheless, I do not like to ask those academics specialized in global health issues or that couple of highly professional lobbyists working for those few highly professional international NGOs to represent my voice and my interests in the global arena.

Also in smaller NGOs and NGO networks there are people interested and able to get involved in global health issues. Not following all the “hot” issues, but some of them. Not knowing everything, but trying to learn and share. Not getting always involved, but sometimes at least. I will do this – join me, if you dare.

### FRAGMENTED GLOBAL HEALTH ADVOCACY

Social advocacy aims at changing the “what is” into a “what should be” – a more decent and more just society. In a globalized world, social change requires advocacy beyond countries’ borders: transnational advocacy and international advocacy, based on international networks and coalitions.

What really worries me is the existing fragmentation of the global health advocacy community: The HIV/AIDS people, the Mother and Child Health people, the Reproductive Health and Rights people, the Noncommunicable Diseases people, the Human Resources for Health people etc., all act as independent thematic lobbies on the global “market for attention”, mainly around events such as the recent World Health Assembly, the G20 summit and the Rio+20 conference, promoting and pushing particular interest only – and reporting back success stories such as “great, there is a sentence on ... in the ... declaration!”.

We can either accept this reality or only care for our niche in this market (let us say HIV/AIDS ...), or we can undertake steps to overcome the fragmentation. For this we need an overall understanding on what we want and who are our allies. For me, a key part of the identity of the *Medicus Mundi* Switzerland and International Networks is that we see health in an integrated, holistic and systemic way, therefore focusing our attention on health systems and social and political determinants of health rather than on particular topics.

### UNIVERSAL HEALTH COVERAGE

34 years after Alma Ata and its powerful call for “Primary Health Care” and “Health for All”, there might be a good opportunity today to create again an integrated global movement for health around the new slogan of “Universal Health Coverage”. With her speech at the World Health Assembly in May, WHO Director General Margaret Chan took herself the lead in the “UHC movement”:

“In my view, universal coverage is the single most powerful concept that public health has to offer. It is our ticket to greater efficiency and better quality. It is our saviour from the crushing weight of chronic noncommunicable diseases that now engulf the globe. Universal coverage is the umbrella concept that demands solutions to the biggest problems facing health systems. That is: rising health care costs yet poor access to essential medicines, especially affordable generic products; an emphasis on cure that leaves prevention by the wayside; costly private care for the privileged few, but second-rate care for everybody else; grossly inadequate numbers of staff, or the wrong mix of staff; weak or inappropriate information systems; weak regulatory control, and schemes for financing care that punish the poor. Universal coverage is the hallmark of a government’s commitment, its duty, to take care of its citizens, all of its citizens. Universal coverage is the ultimate expression of fairness.”

This is not only enthusiasm, but also strategic speaking: In order to save health as a key development issue after the “decade of global health” (2000-2010) it makes sense that the World Health Organization goes for incorporating health as “universal health coverage” into the post-MDG framework. And there is nothing wrong with this.



The members of the Medicus Mundi Network share the vision of access to health and health care as a fundamental human right. We know that keeping health care sustainable and affordable is a huge challenge, and we are convinced that a key strategy is to strengthen the health system as a whole. If “Universal Health Coverage” is the way our vision and an integrated strategy are promoted these days, let us be happy that things keep moving. Cooperation and partnership among the UN agencies. The novel UNAIDS structure, originally made up of six, later 10 UN agencies represented a radical restructuring of global architecture towards cooperation and partnership, now a hallmark of global health action.

\* **THOMAS SCHWARZ** is Executive Secretary of the Medicus Mundi International Network and a member of the team of Medicus Mundi Switzerland.  
contact: schwarz@medicusmundi.org, www.medicusmundi.org

#### Sources, references and entry points:

Get involved in Global Health! Thomas Schwarz, MMI Blog, September 2011,  
<http://getinvolvedinglobalhealth.blogspot.ch/2011/09/get-involved-in-global-health.html>  
Medicus Mundi International: Advocacy Policy (2009), <http://bit.ly/mmi-advocacypolicy>.  
Medicus Mundi Switzerland: Manifest «Gesundheit für alle – ein realistisches Ziel» (2004),  
<http://bit.ly/mms-manifest2004>  
MMI Thematic guide: Universal health coverage, [www.bit.ly/mmi-uhc](http://www.bit.ly/mmi-uhc)  
Medicus Mundi International: Global health policy and governance. Topic page with Network resources, Network program, thematic guide, <http://bit.ly/mmi-globalhealth>  
MMI global health updates on Twitter: News on international health policy, practice and cooperation, [https://twitter.com/#!/MMI\\_Updates](https://twitter.com/#!/MMI_Updates)

# MAGAZIN

MEDICO DEUTSCHLAND

## DIE GEHEIMEN ÄRZTE – WIE SYRISCHE MEDIZINER IM UNTERGRUND LEBEN RETTEN

Der Bürgerkrieg in Syrien geht mit unverminderter Härte weiter. Die medizinischen Einrichtungen und das medizinische Personal, das so dringend gebraucht würde, sind längst zu Zielen der Aufstandsbekämpfung geworden. Für medico Deutschland berichtet ein Arzt.

**DER BÜRGERKRIEG** in Syrien geht mit unverminderter Härte weiter. Die medizinischen Einrichtungen und das medizinische Personal, das so dringend gebraucht würde, sind längst zu Zielen der Aufstandsbekämpfung geworden. Für medico Deutschland berichtet ein Arzt.

Es ist der Februar dieses Jahres. Syrien ist in Aufruhr. Überall wird demonstriert, in manchen Städten wie Homs und Idlib finden regelrechte Strassenkämpfe statt. Wir haben uns in Beirut verabredet. Nach Tagen des Wartens steht er am Nachmittag einfach vor uns. Wir nennen ihn Doktor B. Seinen wirklichen Namen können wir nicht preisgeben, es wäre lebensgefährlich für ihn. Doktor B. ist etwa Mitte Dreissig, schwächling, blass und hat tiefe Ringe unter den Augen, die von vielen Nächten ohne Schlaf erzählen. Er ist Thorax-Chirurg und arbeitet in einem staatlichen Krankenhaus einer syrischen Grossstadt. Nach der täglichen Schicht beginnt sein zweites

Leben, dann ist er ein «Doktor al-Thaura», ein Arzt der Revolution. Er fährt an die Orte des Protests und besucht die Patienten in Privatwohnungen, Kellern oder in Hinterzimmern.

Die staatlichen Krankenhäuser sind längst nicht mehr sicher: «Ich habe gesehen, wie verletzte Demonstranten in der Notaufnahme vom Sicherheitsdienst geschlagen und gefoltert wurden.» Viele seiner Kollegen hätten sich darüber empört. Die Verletzten würden entweder nicht registriert, so dass sie nach einer Erstversorgung direkt verschleppt werden können, oder aber als «Verkehrsunfälle» geführt.

#### NETZ VON «ILLEGALEN» KLINIKEN

Doktor B. konnte das nicht mehr ertragen. Er begann mit einer kleinen OP-Tasche illegale Hausbesuche zu machen. «Einmal versorgte ich in meinem Auto sechs Stunden lang einen Studenten, der drei Schussverletzungen hatte. Als uns ein Privatkrankenhaus aufnehmen wollte, wurden wir vom Geheimdienst entdeckt, konnten aber in letzter Minute fliehen.» Zusammen mit anderen Ärzten gründete er eine medizinische Kommission, sie richteten ein Netz von illegalen Kliniken ein. Alles musste heimlich geschehen, denn werden diese sogenannten «Untergrundhospitäler» verraten oder vom Regime entdeckt, droht den Patienten und Ärzten mindestens eine Verhaftung mit anschliessender Folter, oftmals auch der Tod. Auch die Apotheken werden überwacht, so dass auch die Medikamente entweder ins Land geschmuggelt werden oder unter Le-



## Solidarität mit Syrien

Das MMS Bulletin publiziert diesen Beitrag mit freundlicher Genehmigung von medico international Deutschland – einer Schwesterorganisation von medico international schweiz. Der Bericht ist im medico rundschreiben 1/2012 erschienen.

Seit Beginn des Aufstands unterstützt medico unbewaffnete lokale Bürgerkomitees in ihrem mutigen Einsatz gegen das Assad-Regime. Von den Medien meist unbeachtet demonstrieren die vorwiegend jungen Aktivistinnen und Aktivisten noch immer für ihre Freiheitsrechte und ein Leben ohne Angst und Despotie. Darüber hinaus leisten sie unmittelbare Nothilfe für die ausgebombten und vertriebenen Bewohner aus zerstörten Dörfern oder umkämpften Stadtvierteln, schützen verfolgte Oppositionelle und versorgen durch ein Ärztenetzwerk in geheimen Notkliniken die Verletzten und Verwundeten, die in den staatlichen Krankenhäusern von Folter und Tod bedroht wären. Im Nachbarland Libanon hilft der medico-Partner AMEL, eine säkulare libanesische Hilfsorganisation, Flüchtlingsfamilien aus Syrien.

### Spendenstichwort: Syrien

Spendenkonto: 1800, Frankfurter Sparkasse, BLZ 500 502 01

### Online-Spenden:

[www.medico.de/spenden](http://www.medico.de/spenden)

bensgefahr aus den staatlichen Krankenhäusern mitgenommen werden müssen.

Der Doktor hat uns auf einem winzigen Chip Videofilme mitgebracht: Ärzte behandeln Schussverletzungen, es gibt einen Operationstisch, Licht, entsprechendes chirurgisches Gerät. Alle engagierten Mediziner leben gefährlich: Nach Angaben der Lokalen Koordinationskomitees in Syrien wurden seit dem Ausbruch der Demonstrationen am 14. März letzten Jahres mindestens 295 Ärzte verhaftet. Was passiert, wenn

er entdeckt wird? «Medizinische Hilfe wird behandelt wie Terrorismus oder Desertion», sagt er ernst und ergänzt ohne jedes Pathos: «Ich hoffe, sie töten mich schnell, wenn sie mich erwischen». Der Doktor muss zurück. Er quittiert uns eine Geldsumme, die wir ihm übergeben. Damit wird er später in Syrien auf dem grauen Markt dringend benötigtes medizinisches Gerät kaufen. Dann verschwindet er: «Morgen früh um 6 Uhr beginnt im Krankenhaus meine Schicht. Wenn ich fehle, stehe ich sofort unter Verdacht.»

## PERSPEKTIVEN FÜRS LEBEN SCHAFFEN CRÉER DES PERSPECTIVES DE VIE



Foto: © Elizabeth Deacon/IRIN

### MUTTER-KIND-GESUNDHEIT IN ENTWICKLUNGSLÄNDERN

Das Netzwerk Medicus Mundi Schweiz wird an seinem diesjährigen Symposium die Mutter-Kind-Gesundheit debattieren. Trotz vieler Fortschritte in den vergangenen Jahren, handelt es sich um den Bereich, in welchen die globale Gesundheit am wenigsten vorangekommen ist.

**Datum:** 6. November 2012, 9.00–16.45 Uhr

**Ort:** Basel, Hotel Hilton

#### Kontakt

Martin Leschhorn Strebel  
mleschhorn@medicumundi.ch

[www.medicusmundi.ch/mms/services/  
events/Symposium2012](http://www.medicusmundi.ch/mms/services/events/Symposium2012)

### LA SANTÉ MÈRE-ENFANT DANS LES PAYS EN DÉVELOPPEMENT

A l'occasion de son symposium annuel, le Réseau Medicus Mundi Suisse va débattre de la santé de la mère et de l'enfant. Malgré de nombreuses avancées ces dernières années, il s'agit d'un domaine au sein duquel la santé mondiale a fait le moins de progrès.

**Date:** 6 novembre 2012, 9.00–16.45 heures

**Lieu:** Bâle, Hotel Hilton

Le programme sera publié le plus tôt possible

#### Contact

Martin Leschhorn Strebel, mleschhorn@medicumundi.ch

[www.medicusmundi.ch/mms-fr/services/  
events/Symposium2012](http://www.medicusmundi.ch/mms-fr/services/events/Symposium2012)