



**Keep the Promise!**  
**Access for All!**



Aktionsbündnis gegen AIDS

Leben ist ein Menschenrecht!  
[www.aids-kampagne.de](http://www.aids-kampagne.de)

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The work carried on daily in organisations such as the Treatment Action Campaign (TAC), the Ndlovu Care Group and People of Hope is truly remarkable and we would also like to express our thanks to them for having given us insight into the wonderful work they do.

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## Action Against AIDS Germany

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services (...).”

Article 25 of the Universal Declaration of Human Rights of the United Nations, 1948

With its campaign, Action against AIDS Germany wants to break the silence on HIV/AIDS and is committed to a world without AIDS and poverty. HIV/AIDS impacts on all aspects of lives of people living with the disease. The HIV/AIDS epidemic threatens prospects for development globally and increases the risk of further impoverishment. The HIV/AIDS epidemic calls worldwide for social rethinking.

The demands of Action against AIDS Germany refer to the HIV/AIDS specific targets of the United Nations set in June 2001 and are specifically addressing the German government and the pharmaceutical industry. Core demands focus on support for human right to life and health, additional funding for global AIDS prevention and treatment by the German government and price cuts for essential medicines by the pharmaceutical industry. Through national campaigning and political dialogue Action against AIDS Germany reminds all relevant stakeholders of the international commitments and promises of UN Member States' governments and the G8. It demands urgent implementation as political decision-makers, pharmaceutical companies and the general public have to take on responsibility in the global fight against HIV/AIDS. The lives of millions of people depend on keeping these promises.

Action against AIDS Germany is a German nationwide network of more than 100 non-governmental organizations and more than 280 grassroots groups working on AIDS and development cooperation. In order to coordinate the network's lobbying activities and public relations a campaign bureau has operated out of the German Institute for Medical Mission (DIFÄM) in Tübingen since 2002. The civil society network is exclusively funded by membership fees.

# Keep the Promise! Access for All!

## Do you know your HIV status?

Have you ever been tested for HIV? Or have you ever considered the possibility of having been infected with HIV? If so, you may possibly know the thoughts and questions that go through one's mind then: "How will it change my life if I my test results show I am HIV positive?" "How will the people around me react to my diagnosis?" "Will my parents, brothers and sisters, friends and partner stand by me?"

## Life is a human right!

In principle, thanks to the treatments developed since the middle of the nineties, the illness connected to the 'human immune-deficiency virus' (HIV) has changed into a treatable chronic disease. On the condition that treatment begins early and is carried out consistently, people can live for decades with HIV and can lead nearly normal lives. People need adequate healthcare services and support from those around them so that they will take their drugs regularly. This is how such an impressive decrease in the death toll has been achieved in the industrial countries. In the developing world, however, the situation is much more dramatic. Although the treatment programmes have expanded in recent years, by the end of 2007 only one third of those in need of treatment actually received it. In 2007 alone, two million people died due to inadequate access to treatment and many more millions of lives are under threat. Yet studies show that even under the difficult conditions that exist in the developing countries, it is possible to reduce the death rate by 95%!

Life is a human right! The lack of access to information on HIV prevention, to preventive measures, to care for those infected with HIV and those ill with AIDS, and to the best treatment available, robs millions of people of their basic right to life and good health.

**This booklet tells the life stories of five people from South Africa. It uses them as examples to show the tragedies that occur when there is inadequate access to HIV prevention and treatment measures. But it also shows how the effects can be eased through solidarity, self-help initiatives and medical care.**

## What is HIV? What is AIDS?

*HIV is a virus that weakens the human immune system. The term AIDS refers to all the symptoms and signs of various illnesses that appear as a result of this weakened immune system.*

*AIDS is characterised by a collapse of the immune system, whereby other illnesses (such as cancer or tuberculosis) can spread through the body unchecked. In the end, they are the cause of death. Without treatment one half of the infected adults die after about 11 years. Only half of the children infected during pregnancy or birth reach the age of two.*

*Infection can occur if a body fluid (such as blood, sperm, vaginal secretions or breast milk) with a sufficiently high concentration of HIV enters the body. This access may be through the bloodstream, the mucous membrane of the vagina, the glans/foreskin, the anus/intestines, the urethra, the mouth and the throat. Intact skin is an effective protective barrier against HIV infection.*

*That is why HIV is transmitted only by unprotected sex, the sharing of needles/syringes – usually by drug users for injection – blood transfusions or the infusion of blood products, and by a mother to her child during pregnancy, birth or breastfeeding.*

# Sheila



Sheila lives in Elandsdom in the province of Limpopo, north of Johannesburg. She is 45 and has two children. She has spent most of her life here. She has known for ten years that she is HIV positive. When she received her diagnosis, she was working as domestic help in Johannesburg, earning 660 South African rand (ZAR) a month (equivalent to about € 60).

In 1999 Sheila became ill. She felt very weak and often had to vomit. At the primary health care centre in Elandsdom she was found to have tuberculosis (TB). The doctor then suggested she should have an HIV test. She was totally surprised at the result. Even today she has no idea how she became infected.

Immediately after her diagnosis, tests were done to determine the condition of her immune system. It was so weak that an outbreak of AIDS could be expected at any time. At that time it was still up to the infected people themselves to pay the ZAR 3,000 per month (about €270) for the treatment. Fortunately, the family Sheila worked for was prepared to pay the costs for her. That was the only way to suppress the virus to below the detection level, where it still is today. Sheila has not been healed of HIV. She has to continue to take

her daily tablets, but she is doing well. Sheila noticed that many people around her denied that HIV and AIDS existed. That is why she joined the Ndlovu AIDS Awareness Program (NAAP). Together with the NAAP staff she went into schools to talk to the students about her status and her experiences as a person infected with HIV. For several years now she has been working with patients at the primary health care centre as a counsellor.

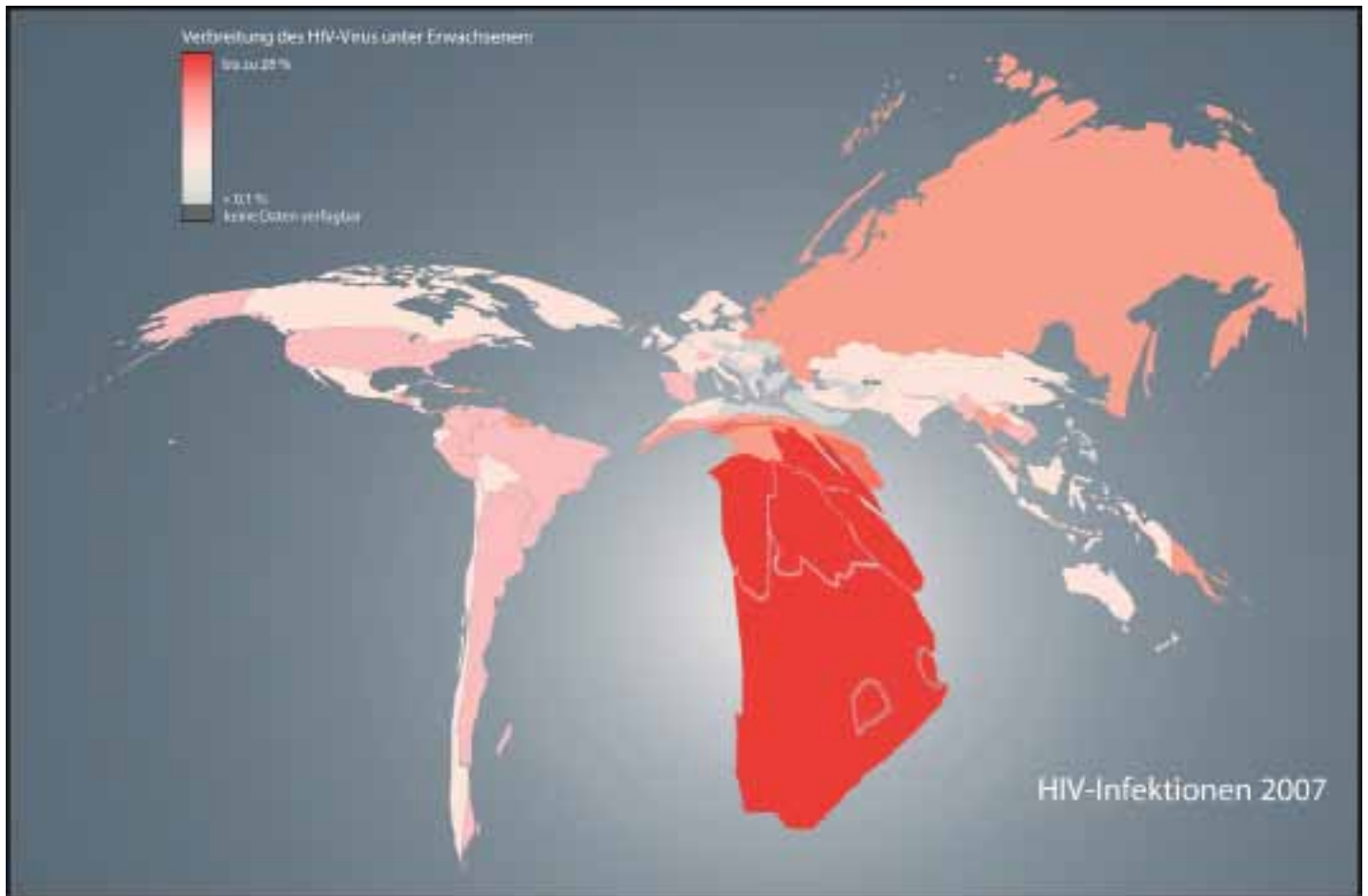
Her colleagues at NAAP and the experience she has gained through her work at the centre have encouraged her to overcome her fear of isolation and to talk openly about her status. Thanks to her example, many of the people around her have had themselves tested and have changed their attitudes to HIV. That makes her feel proud. Sheila lives positively. She pays careful attention to her nutrition and her health. She enjoys every minute of her life because she is happy to be alive. It only makes her sad not to know who will look after her children one day. She hopes that ever more people will look after their health and have themselves tested.

## Co-infections of HIV and tuberculosis

*Since HIV weakens the immune system, opportunistic illnesses are very likely to occur. One of the most common in sub-Saharan Africa is tuberculosis. According to the South African health ministry, 50 to 80% of the people infected with tuberculosis in southern Africa are also HIV positive. If anti-retroviral and TB treatment are not available, most AIDS patients die of TB.*

*This is a very important point to consider, because TB should be treated before anti-retroviral treatment begins. Furthermore, tuberculosis is a serious illness, which can also be deadly if it goes untreated, even for people whose immune systems are not weakened by HIV.*

# Fact sheet on the national and global HIV/AIDS epidemic in 2007/2008



## Globally

<b>People living with HIV/AIDS worldwide</b>	<b>33 million</b>
Adults	30.8 million
Women	15.5 million
Men	15.5 million
Children under 15 years of age	2 million
<b>Number of new HIV infections in 2007</b>	
Total new infections	2.7 million
Newly infected adults	2.3 million
Newly infected children under 15 years of age	370,000
<b>Deaths due to AIDS</b>	
Total deaths due to AIDS	2 million
Adults	1.8 million
Children under 15 years of age	270,000
<b>Africa is the continent hit the hardest.</b>	
Africa has 22 million people living with HIV/AIDS	
New infections	1.9 million
Deaths due to AIDS	1.5 million

# Fact sheet on the national and global HIV/AIDS epidemic in 2007/2008

## Many Latin American countries have a very high infection rate.

Today 1.7 million people in the region have HIV/AIDS	
New infections	140,000
Deaths due to AIDS	63,000

## The epidemic is spreading in Asia.

Today there are already 4.2 million people with HIV/AIDS	
New infections	330,000
Deaths due to AIDS	340,000

## The epidemic in Eastern Europe and Central Asia is sizable.

People living with HIV/AIDS	1.5 million
Newly infected adults	110,000
Deaths due to AIDS	58,000

Source: UNAIDS (2008), AIDS Epidemic Update

## Germany

<b>People living with HIV/AIDS</b>	<b>63,500</b>
Men	51,800
Women	11,700
Children	200

## Distribution according to the source of infection

Men having sex with men	38,700
Heterosexual sex	8,700
Living in high-prevalence regions	7,300
Intravenous drug use	8,200
Haemophilia, blood transfusions	600
Mother-to-child transmission	200

## Number of new HIV infections in 2008

Total new infections	3,000
Newly infected men	2,650
Newly infected women	350
Newly infected children	25

## Distribution according to the source of infection (an estimate)

Men having sex with men	72%
Heterosexual contacts	20%
Intravenous drug use	8%
Mother-to-child transmission	1%

<b>Total number infected since the epidemic began</b>	<b>ca.83,000</b>
Deaths in 2008	650
Total number of deaths since the epidemic began	27,500

Source: Robert-Koch-Institut (2008), HIV/AIDS in Deutschland – Eckdaten. Epidemiologische Kurzinformation

## Social reasons for the spread of HIV

Southern Africa is at the centre of the worldwide HIV epidemic. Almost 35% of all of those infected with HIV but less than 2% of the global population live there. The rate of infection among adults between 15 and 49 is over 10%. No other region in the world has a rate this high. The reasons for the rapid spread of HIV in this area lie mainly in the adverse living conditions.

From colonial times to the present day, southern Africa has been exploited by the politically and economically powerful in search of raw materials for Europe and North America. This requires an abundance of cheap labour. Land grabbing and other arbitrary measures have forced the local people to work in the mines and on the plantations. Compulsory relocation and expropriation created great waves of migrant workers in large parts of the region and these continue to this day.

The great majority of the labourers live in men's hostels, where sex for money is one of the few forms of recreation. Wives and other family members are not allowed to accompany the men. Moreover, the insecurity of these jobs forces many of the women to stay at home and farm for their own household consumption. Under these conditions, with the families split up, it is impossible to keep up stable sexual partnerships. The result is that migrant workers very quickly spread sexually transmitted diseases.

At the same time, this economic exploitation and oppression have created the most extreme income disparity in the world. The women are disadvantaged in several ways. Since there is a very high rate of unemployment among younger women, often the only source of income for them is sex with men who are better off financially and usually considerably older than they are. Their financial dependence and the great age difference make it difficult for them to insist on precautions against HIV infection, such as condoms.

### **The health system in South Africa**

*During apartheid a centralised health system was set up in South Africa. There were only a few large hospitals located in the cities and almost no doctors in private practice. The apartheid regime showed practically no concern for the health of the non-white population.*

*After the African National Congress (ANC) took over power in 1994, the system was gradually decentralised and expanded. In addition to large hospitals in the cities, they also created clinics and primary health care centres in towns and settlements. Basically, the medical care that is available in and near the cities in South Africa is good, but it is still unaffordable for many. In the countryside the situation is a lot worse and it is a fact of daily life that people have to travel long distances to receive medical care.*

*In addition, the health system in South Africa – as in many African countries – suffers from a lack of qualified personnel. There are not enough trained doctors and nurses. For that reason and because of the enormous number of patients, it is almost impossible for the medical staff to cope with the workload. Every day each doctor and nurse has to treat between 50 and 60 patients. The situation is made even worse because the developed countries actively lure away qualified medical staff by promising them much higher wages. The WHO estimates that there is a global deficit of 4.3 million qualified medical personnel to provide basic health care services.*

# The feminization of the epidemic

Whereas it was mainly men that were infected with HIV in the beginning, the proportion of women and men that are infected worldwide has meanwhile more or less balanced out. However, in sub-Saharan Africa, more than 60% of those infected with HIV are female. Especially among young people between 15 and 24 years of age in South Africa, the feminization of the epidemic is very obvious according to UNAIDS.

Prevalence (= the percentage infected with HIV) among young men of this age group is about 4% in South Africa. For young women of the same age group the percentage is more than four times that, about 17%.

This development can be attributed to two things: For one, due to physical conditions, women are more likely to become infected with HIV. In addition, there is social injustice based on gender, which must also be focussed on if the fight against HIV is to be effective. It is more difficult for women than for men to demand the use of condoms because, due to their social position, they have less bargaining power than their male counterparts. Moreover, men often regard the use of condoms as unmanly. The use of condoms also tends to be regarded as an admission of promiscuity or infidelity. Both women and men share this perception.

## Antiretroviral drugs (ARV)

*ART (antiretroviral therapy) or HAART (highly active antiretroviral therapy) refers to a form of therapy that consists of a combination of three different pharmaceutical substances. It has been in use since 1996 and has been improved continuously since then. The three substances prevent the HIV virus from reproducing.*

*Ideally the concentration of HIV in the blood can be reduced to below the detection level. However, due to the adaptability of the virus, the medication must be taken very regularly in order to avoid the development of resistance. If it does occur, the only solution is to choose a medication with a different active ingredient. A different set of drugs might mean that the patient must cope with stronger side effects. The fewer the drugs that are available to treat the particular strain of virus, the more difficult it is to consider the patient's tolerance of the treatment. Furthermore, alternative medication is generally much more expensive (See Generics).*

*Although there have been no long-term studies, it is expected that HIV-positive people who take their ART continuously and successfully will have an almost normal life expectancy. Nevertheless, an HIV-positive person who has begun taking ARVs will have to take them for the rest of his or her life. The virus cannot be completely vanquished by the medication available to date.*

## Antiretroviral treatment: a huge gap between access and need

*In 2007 about 1.7 million of the approximately 5.7 million HIV-positive people in South Africa needed treatment. Currently there are only about 560,000 people in South Africa receiving antiretrovirals; at the end of 2007 it was 460,000. At the moment, an average of just 20 – 40% of those in need of treatment is receiving it. That places South Africa in the middle range compared to other high-prevalence countries. These are small steps forward, but there are still 1,000 people dying of AIDS in South Africa every day.*

*According to the WHO, at the end of 2008 about four million people worldwide were receiving antiretroviral treatment. In spite of the enormous increase compared to previous years – it was barely two million in 2006 and three million in 2007 – more than three times as many, about ten million people worldwide, need antiretroviral treatment. In view of the 33 million people infected with HIV and the current rate of 2.7 million new infections every year, the need will rise drastically. The proportion of those newly infected to those newly receiving treatment is still 5 to 2.*

*That means that for every two persons who begin antiretroviral treatment there are five more people who have just been infected.*

## Susan



Susan's case was quite different from Sheila's. She is now in her early thirties. Before she got married in 2000, she had had only very few sexual contacts. She did not know much about her husband's history before her marriage. After a year, her husband became very ill and the two of them went to a primary health care centre together. Susan already had a suspicion that it could be HIV. The doctors advised the couple to have themselves tested but Susan was afraid and it took her some time to agree to the test. Both were HIV positive. In contrast to Sheila, Susan knows who infected her with the virus. At first she was furious with her husband, because he had known that he was bringing the virus into their relationship, but as time has passed she has resigned herself to the fact and accepted the situation.

Her husband's condition rapidly grew worse and he became ill with various other diseases. The couple was unable to afford treatment. In 2003 Susan's husband died of AIDS.

Two years later Susan met her present partner, who is HIV negative. Her son, who is three years old meanwhile, is not HIV positive either although Susan did not participate in a prevention programme (PMTCT/PPTCT) to protect him from HIV infection. They were lucky!

Susan has not taken any antiretroviral medicine herself up to now. Sometimes she feels well, sometimes not so well. She knows that she could take part in the national programme but she doesn't have the energy to comply and cope with the conditions of regular treatment. She would need to attend a two-week course informing her about the treatment but also requiring her to show she knows about the proper use of the medication. Only then do the participants receive their treatment. But Susan is a bit hesitant to start medical treatment that is to last a lifetime.

Only a few people know her HIV status. Although the few friends that she has told support her, she doesn't dare to make her status public.

Susan says that she is happy. In spite of her infection, she usually feels well. What makes her feel sad is the fates of the people she encounters nearly daily in her work with the HIV-positive. She would like to help HIV-positive people to accept their status as she herself has.

# The prevention of mother-to-child transmission (PMTCT)

When an HIV-positive woman gives birth to a child, she can pass on the infection to her baby. The likelihood of this happening is between 15 – 30%. We generally use the abbreviation PMTCT for the attempt to prevent this transmission. The method has several components. As a rule, mothers are given antiretroviral treatment before and during birth. This reduces the mother's viral load noticeably for a short time and reduces the probability of her passing the infection on to her child. After birth, the child is given ARVs as well to reduce the odds of it becoming infected. Breast milk also contains the virus and, accordingly, breast-feeding carries a considerable risk (5 to 20%). That is why most PMTCT programmes offer infant formula as an alternative to mothers and families wherever conditions allow. But the hygienic conditions in many developing countries are not good enough. Whenever this is the case, the World Health Organization recommends that the baby be breast-fed exclusively for the first six months of its life and then quickly weaned. The latest studies have shown that continuing antiretroviral prophylaxis during the breastfeeding period concretely reduces the risk of transmission. If PMTCT is carried out fully and correctly, the risk of transmitting the infection to the infant is reduced to 1 – 2%.

According to UNAIDS, South Africa is meanwhile one of the few developing or threshold countries that provide more than 50% of HIV-positive mothers with PMTCT treatment. It must be noted, however, that only a little more than half of the pregnant women are being tested for HIV at all. Women who go to a clinic or a hospital during their pregnancy do undergo obligatory testing, but many give birth without any medical help at all. Furthermore, South Africa uses a treatment consisting of two compounds, although the WHO now recommends using three different substances to reduce the likelihood of infection even further and to prevent the development of resistance.

In Africa over 80% of all HIV infections come about as a result of heterosexual intercourse. In order to reflect the responsibility men bear in transmitting the virus, the prevention method described above is now being referred to as the prevention of parent-to-child transmission (PPTCT).

## **The HIV test**

*A common HIV test looks for HIV antibodies in the blood. This kind of test can only provide a reliable result if at least three months have passed since exposure took place. This is because it takes some time for a detectable number of antibodies in the blood to be built up. The virus itself can usually be detected four to six weeks after infection.*

*However, the virus test is considerably more expensive than the normal HIV test and is therefore rarely performed. In any case, individual counselling is essential before and after the test.*

*If the test result is positive, it is very important to determine the levels of two substances in the blood, both at three-month intervals: the number of CD4 cells and the virus load. The number of CD4 cells reveals to what extent the immune system has been weakened by the HIV infection.*

*Normally, adults have more than 1,000 CD4 cells per microlitre of blood. The virus load refers to the amount of HIV present in an infected person's blood. The higher the level, the greater the risk the infectious disease will advance rapidly and the greater the danger of transmitting it to others. When the virus load is below 20 – 50 copies of the virus per micro litre of blood, it cannot be detected using the methods normally available.*

*However, this does not mean the person has been healed.*

## The effects of the epidemic

HIV infection has a disastrous effect on social and financial living conditions and development potential. It is particularly younger adults that become infected because the virus is mainly transmitted through sexual intercourse. When they become ill several years later, they are generally in the most productive period of their lives and carry responsibility in society and in their families. Often it is both of the parents and several children that are infected, which greatly increases the burden on the families. In many cases, social marginalisation makes their desperate situation even worse. In the final phases of the disease, those infected are usually confined to their beds most of the time and need someone to look after them.

The rate of infection is growing, particularly among groups of the population with little access to education and income. Those who are financially better off are more likely to have the information and the means to protect themselves from infection. Therefore the epidemic has a stronger effect on people without financial reserves to pay for coping with the disease and its after effects. Their chances of survival depend on the ability of the other members of the household to work.

Under these conditions, grave illness or death present serious problems that the families can barely cope with. Studies in South Africa have shown that the per capita income of families where one member is ill with AIDS is almost one third less than that of households that are not affected. As a result of government austerity programmes – usually due to pressure to pay back foreign debts – many developing countries have introduced user fees for public health services and require patients to contribute towards the cost of medication. That means that people with an advanced HIV infection must pay too high a cost for their treatment. This plight might force them to sell some of their modest property or belongings and take on loans.

Caring for the growing number of orphans is too much for the grandparents, who have in many cases reached the age where they really need help themselves. Traditional neighbourhood support is generally still functioning but ever more families are affected by HIV/AIDS themselves. Orphans often have no access to care, food, educational opportunities and health care. Where there is poverty, AIDS not only destroys millions of human lives, it also destroys the basis of life for those who have been left behind.

This process of impoverishment, with all its consequences on the social and political stability of the countries that have been hit hard, constitutes the most serious repercussions of the epidemic. Misery and despair in turn create a greater danger of HIV infection. The epidemic itself is creating the conditions for its continued spreading.

There are tragic individual stories behind the current figures. We must not accept this pain and the social consequences. Universal access to preventive measures, treatment, care and support for those affected or threatened by HIV and AIDS is essential. Everyone must have access to the necessary information and be free to act in such a way as to avoid HIV infection. Those who have already been infected must have access to the most effective treatment with the least possible side effects and to proper attention and care.

## Flora



Flora is in her late fifties, has been a widow for many years, and has known since 2006 that she is HIV positive. She works for People of Hope and looks after people who are HIV positive. Since her organization works with HIV positive people, those in charge encourage each of their staff members to have an HIV test. Without this policy, Flora would not have undergone a test.

She does not know how she was infected. Her first reaction to her diagnosis was great fear. Since then she has constantly been thinking about her situation. Her children were the first people she told about her status. They did not believe her at first, but later they accepted the situation. She has also told her team at work and her friends about it now.

Her HIV infection is already very advanced. She has lost a lot of weight lately and she is afraid she will die soon. She does not talk about whether she takes antiretroviral drugs or not or whether she would take them.

She is happy to be able to spend time with her children but it makes her sad to see that people often do not get antiretroviral treatment until they are already very ill and that then they have to suffer from the side effects, which are sometimes very strong. She would like other people to know that she works for People of Hope and has been helping others in spite of her own illness.

# The national ARV programme in South Africa

It was not until 2003 and under strong national and international pressure that the government decided to launch a national treatment programme. Everyone who is HIV positive and whose CD4 count falls below 200 per microlitre of blood is to be accepted into the programme and receives free antiretroviral treatment. Originally the programme was run in the large central hospitals and then it gradually expanded to include smaller clinics. That is the weak point in the programme because many patients end up on long waiting lists and die before they can receive treatment. In addition, the people often have to travel great distances and/or are confronted with very high transportation costs. The indispensable trip to the hospital when they begin their treatment often takes an entire day due to the distance and the waiting time involved.

Furthermore, the programme has some serious management problems. The consequence is that in some provinces a continuous supply of medication can no longer be guaranteed or the supply has even been disrupted. Because of the high likelihood that the virus will build up resistance to the ARVs, these supply deficits can be deadly.

## Drugs in use or available

The South African national programme has access to only 10 of a total of 23 known antiretroviral compounds. In industrial countries such as Germany the latest compounds, which tend to be more effective and have fewer side effects, are available as a matter of course. Because they are costly, they are normally not available in developing countries.

The standard treatment in South Africa consists of three compounds, one of which (Stavudine) can have a relatively large number of side effects, some of them very strong. For that reason this compound is hardly used in Germany any more. Its newer equivalent is still under patent but voluntary licences have been granted to South African drug producers. Nevertheless, it still remains considerably more expensive than the drug offered as part of the standard treatment. The higher price of the new compound can be explained by the lack of generic competition and the conditions imposed by the licensing contract.

All AIDS patients who begin antiretroviral treatment within the framework of the national programme are given the standard treatment and it is only when complications arise (such as strong side effects or very serious intolerance) that treatment with other ARVs is offered. Most changes in medication during treatment are due to intolerance of that particular compound (Stavudine). That makes its further use highly questionable.

## Pressure from those infected & affected

In 1998 ten HIVpositive people in South Africa founded the Treatment Action Campaign (TAC). Its objective was and is to gain access to HIV treatment and make it available to all who need it.

At that time the South African government, headed by President Thabo Mbeki, denied there was a connection between HIV infections and the illness known as AIDS. Furthermore, the government was of the opinion that not antiretroviral treatment but a combination of red beets, garlic and lemons would be effective in fighting HIV infections. Although this claim was never backed up by verifiable scientific findings, the government tenaciously held on to it for years. At the International AIDS Conference in Toronto in 2006, the South African government stood there alone with its thesis. It was this international isolation that slowly brought about a change of attitude on the issue.

TAC is to be thanked for its decisive efforts to increase national and international pressure on the South African government. In its relentless lobbying and advocacy for the right to antiretroviral treatment it presented its case with great credibility and received international recognition.

The campaign organised demonstrations in many South African cities and set up branches of TAC in all provinces. At the local level, TAC supports the fight against HIV by means of awareness campaigns and self-help groups in which those who are HIV-positive can talk to each other about their experiences. The organization did not even hesitate to take their government to court to sue for the right to treatment. As a result, the South African Constitutional Court decided in 2002 that the government was obligated to set up a programme to prevent the transmission of HIV from parent to child (PPTCT).

The combination of public pressure through the Treatment Action Campaign, the way the South African government was exposed at the International Conference on AIDS in Toronto in 2006, and a change of leadership in the health ministry led to the National Strategic Plan (NSP), a joint strategy paper by the government and civil society, in 2007. For the first time, this plan names concrete objectives to be reached within clearly specified time limits. With the high quality of the NSP and the obvious change in direction on the part of the South African government, the decisive factor is now the precise implementation of the plan. The problem now is that some of the drug prices are still too high. It will only be possible to reduce them further through additional strong, constant international pressure.

# Andile



Andile is 31 years old and has known for five years that he is HIV-positive. He lives in Khayelitsha, near Cape Town. He grew up in a rural area several hundred kilometres east of Cape Town.

Strong stomach aches and other complaints were why he went to see the doctor at the time. He had no suspicion at all of being infected with HIV. So the positive test result surprised him.

Andile felt very bad, emotionally, after his diagnosis. He did not know how to handle the situation and how to continue his life. After hesitating for a long time, he finally told his mother about his HIV status and discovered that his fears of rejection on her part were unfounded. Moreover, his mother convinced him to go for treatment immediately and encouraged him to take charge of his life again. So Andile went to the nearest hospital and had his immune system tested.

His immune system was almost completely destroyed. The immediate result of this diagnosis was that he was accepted for the national ARV treatment programme at once. His immune system is recovering slowly. Andile receives medication for three months in advance. It is only about a 15-minute walk to the nearest hospital. That makes it much easier for him to get his treatment. In the beginning the people around him reacted very negatively to him and his HIV infection. Most of the neighbours avoided him.

During one of his visits to the hospital Andile came into contact with the Treatment Action Campaign (TAC). Convinced by their objectives, he began working for the organization as a trainer in 2006. Meanwhile, he is passing on information about HIV to others in workshops. Spurred on by his own experiences and his work, he has decided to speak openly about his status. This openness has made it possible for Andile to convince many people around him to get tested.

Andile is happy when he can spend time with his family. He is not happy that so many people around him are still dying due to HIV, although access to the required life-saving medication is considerably better today than it was six years ago. He would like discrimination of those with HIV to stop.

## Taking on responsibility in your own country and internationally!

There has hardly been a topic that has motivated people to self-organisation in the way the HIV/AIDS crisis has. It has driven the infected and their families to respond to their problems collectively worldwide. Non-governmental organisations have joined ranks nationally and internationally to form alliances and networks to exert pressure on governments and pharmaceutical companies. These initiatives demand a rational, united, political approach to the problems and distress that have been revealed so sharply in the fates of suffering individuals. One of their achievements is a declaration that the members of the United Nations signed in 2001 committing themselves to intensifying their efforts to conduct a comprehensive campaign to stop the HIV epidemic. The UN acknowledged that the AIDS issue constituted a global emergency and was one of the greatest challenges to human life, human dignity and the effective upholding of human rights. They agreed to enforce laws and carry out other measures to end all forms of discrimination against people with HIV/AIDS and the members of vulnerable groups. Moreover, concrete time-bound targets were set. In the field of prevention, particularly the following should be mentioned:

- To reduce the spreading of HIV among young people between 15 and 24 years of age worldwide by 25% by 2010.
- At least 95% of this age group are to have access to HIV information and education by 2010.
- To reduce the proportion of infants infected with HIV by 50% by 2010. To achieve this, 80% of all women receiving antenatal care are to have antiretroviral treatment and any other services required to reduce the transmission from mother to child.

The UN recognizes that prevention, care, support and treatment for those infected with HIV are elements that reinforce each other and they must be effectively integrated to form an effective response to the epidemic. In order to put the right to health into practice, the UN wants to ensure access to the best treatment available for HIV/AIDS.

In the follow-up declaration in June 2006, the United Nations underscored these commitments and agreed to achieve its objective of universal access to comprehensive prevention programmes, treatment, care and support by the end of 2010. Each country was to set up its own targets for this. Significant progress has been made since then, although it is not nearly sufficient for the fulfilment of these promises. This delay in implementation is costing several thousand lives per day and leading to thousands of new HIV infections daily.

### **Stigmatisation because of HIV**

*The social stigma associated with HIV all over the world often keeps people from getting tested and from showing an interest in information about HIV. In absolute terms, stigmatisation and discrimination are more common in high-prevalence countries than in Germany, for example, but not in proportion to the number of people infected. Social stigmatisation means that people break off contact with the person infected with HIV, for instance. Many are afraid of being infected themselves just through contact with a person who has HIV. Some people believe that HIV infection is punishment for bad behaviour. Again and again stigmatisation takes on drastic forms, such as when those infected are abandoned by their families, or even stoned to death by their own neighbours.*

*But it also has other effects. In South Africa people sometimes go to the trouble of travelling to a different province to get tested. They want to avoid having anyone they know find out anything about their situation. Likewise, fear of stigma is also the reason that those involved are afraid to talk to their partners about the need of using condoms. The growing number of people in South Africa whose health is improving because of antiretroviral treatment plays an important role in reducing social stigmatisation. HIV is no longer regarded as the deadly disease it was only a few years ago. Moreover, people living with HIV today can more often join in community social life and also become actively involved in awareness programmes.*

# Imani



Imani was 25 when she found out that she was HIV positive. When she informed her family about her status shortly afterwards, their reaction was very drastic. They rejected Imani, left the township and moved to a city almost 300 kilometres away. Imani's family left her alone with her fate.

The People of Hope organisation heard of Imani's fate from the neighbours. When organisation members came to visit her, they found a very ill young woman. She had no income and had to look after herself. She was shunned by her neighbours. The People of Hope took care of Imani, but she had had herself tested very late and she had not received any treatment. Imani was 25 years old when she died of AIDS.

Imani's fate is by no means unusual. Even if access to treatment has clearly improved in recent years, many people still know too little about HIV and have themselves tested much too late. They do not go to the primary health care centres and hospitals until they are already very ill. Often, by the time they go for testing, their immune system is so weakened that the chances of successful ARV treatment are very small.

## A holistic understanding of universal access

The life stories we have told and the information we have gathered show that it is necessary to look at the problem holistically if an effective response to the HIV epidemic is to come about. That is why the goal of universal access must apply to all areas of activity and it demands comprehensive programmes. In the field of prevention these comprise:

- Scientifically sound information about HIV infection and the means of preventing it;
- The provision of means of prevention such as condoms, sterile needles, and opiate replacement therapy for injection-drug users;
- Provision of voluntary counselling and testing;
- Timely and effective treatment of sexually transmitted diseases;
- Sexual education for young people in schools and other places;
- Overcoming social conditions that make it difficult for people to avoid risky behaviour and to protect themselves from HIV;
- Improving educational opportunities to make it easier to get information and to increase people's freedom of action;
- Social, economic and legal gender equality and the curtailment of expectations related to gender-dictated roles, which hinder self-determination not only for women but also for men;
- Programmes targeted at key population groups that are especially vulnerable to HIV due to marginalisation and their particular circumstances;
- Comprehensive measures to prevent the transmission of HIV from parent to child;
- Blood-transfusion surveillance;
- Universal precautions in the health sector.

### **Efforts in the field of care, treatment and support comprise the following:**

- Combination therapy with the most effective and best-tolerated antiretroviral drugs;
- The prevention and treatment of opportunistic infections;
- Counselling and support on the basis of open dialogue between the patient and medical personnel to facilitate the continuous regular taking of medicine;
- Ensuring healthy nutrition, which is essential for recovery or maintaining a functioning immune system;
- Home-based care for the seriously ill by volunteers under the supervision of medical personnel, to relieve the burden on family members;
- Building up local health systems with a focus on overcoming the lack of qualified medical personnel and caregivers, and creating functioning supply systems to provide drugs consistently and reliably;
- The integration of HIV treatment programmes with tuberculosis-control measures and all other relevant health services.

### **Support and mitigation of the effects comprise the following measures:**

- The support of orphans and vulnerable children, no matter what the cause of their distress is;
- Material, psychosocial and spiritual assistance for families affected by HIV or particularly under strain due to the epidemic, in the form of social programmes that equally benefit all those in need.

## An interview with Heidemarie Wieczorek-Zeul

**An interview with former German Federal Minister for Development Cooperation, Heidemarie Wieczorek-Zeul, and Action against AIDS, Germany, who has been in charge from October 1998 until October 2009 (the interview has been conducted when the Minister was still in power).**

[Answers slightly condensed by Action against AIDS]

**What is your understanding of universal access? What is your paramount goal?**

We go along with the [...] agreed goal of full access to HIV and AIDS prevention measures and to treatment and care for people with HIV. That is what I understand as universal access. That is also our paramount goal. [...]

**How has this commitment of the federal ministry contributed towards achieving the goal of universal access and what is it doing to help now?**

This is important: The complexity of the pandemic and the variety of forms it has taken in different countries demand a comprehensive approach in the battle against HIV infection and its consequences. The German government's development cooperation policies, therefore, support its partners on several levels. We promote prevention, the creation and expansion of effective health and social security systems, and solidarity with those affected. In addition, in order to curb the spread of HIV, it is important to provide condoms and to promote their use. The development policies of the German government are helping to achieve

universal access to prevention, treatment and care in all of these areas. Particularly close to my heart is the promotion of access for disadvantaged groups. These include women, girls and sexual minority groups. Furthermore, the German government supports the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). [...] The German government has contributed a total of EUR 670 million to the GFATM since 2002. As a result, three million lives have been saved. In the period from 2008-2010 the German government is contributing EUR 200 million per year to support the work being done by the GFATM.



## An interview with Heidemarie Wieczorek-Zeul

**How far do you think we have come towards universal access?**

We have had considerable success in recent years: By the end of 2008 over 3 million people had received medication. That is an increase of 800% in only four years. That is a wonderful achievement! In the field of prevention, there is a positive trend as well, especially among the members of particularly vulnerable groups. Nevertheless, we must speed up our fight against HIV appreciably. Otherwise many countries will not fully reach the goal of universal access within the next few years. In spite of the increased supply of antiretroviral medication, only about one third of those in need of it are receiving it. We need to increase our efforts in the field of prevention, as well.

**What do you feel are the most important political (or perhaps technical or cultural) obstacles? Which of these could the German government help to eliminate?**

Inefficient health systems in poor countries make it difficult to achieve universal access. There is a lack of basic essentials: health-care personnel; preventive, diagnostic and therapeutic instruments and equipment. Another barrier to effective preventive measures is stigmatisation, discrimination and a disregard for the human rights of those living with HIV and those with an especially high risk of becoming infected. To meet these challenges, German development cooperation aims at promoting health systems in developing countries and the German BACKUP initiative, for example, supports self-help initiatives among groups of the disadvantaged to help fight stigmatisation and discrimination. I consider it very important to promote fair access to HIV services for women and girls as well as for men and boys. In order to exclude inequality of access due to gender, German development politics helped to establish the gender equality strategy of the GFATM.

**What is your assessment of the work of the Global Fund to Fight AIDS, Tuberculosis and Malaria to date? What is your reaction to the current funding deficit of the Global Fund?**

The GFATM is a unique funding instrument because it involves governments, civil society and private enterprise. It has meanwhile become the most important funding institution in the fight against HIV and AIDS, tuberculosis and malaria. The fund has been a clear success: the allocation of over US\$ 15 billion in 140 countries made it possible for 2 million people infected with HIV to receive life-saving treatment.

It is important to close the current GFATM funding gap. We must succeed in substantially increasing the funds for 2011 to 2013. Hopes are high for contributions not only from governments that have done very little for the Global Fund so far, but also from private enterprise and foundations. Naturally I, personally, intend to make a strong effort to convince the German government to increase its contribution to the GFATM. I am counting on support from civil society to this end as well.

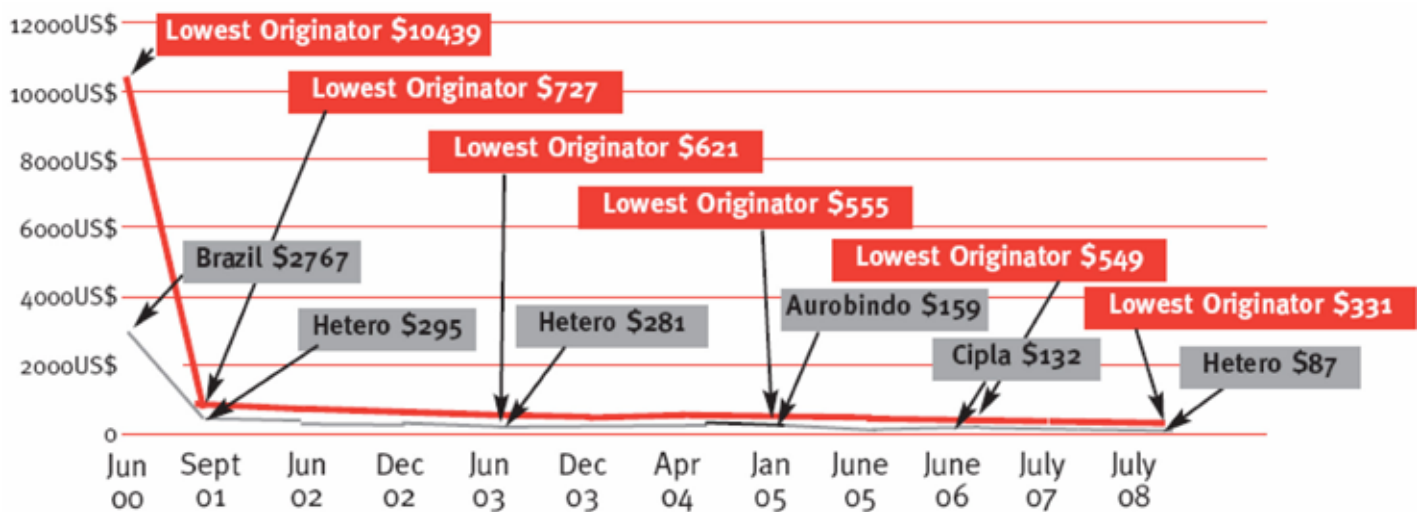
**What is your standpoint on the compatibility of universal access to treatment and the protection of intellectual property rights? How can the obvious conflicts of interest be overcome?**

The right to good health has absolute priority over private business interests. In other words: patients not patents. In order to assert this priority effectively, we help developing countries make use of the scope legally available to them through the WTO Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). Too few people realize that the poorest of the developing countries are allowed to produce generic drugs themselves and to export them to other developing countries until 2016. We actively help our partner countries to make use of this opportunity. [...]

# Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS)

This agreement, concluded within the framework of the founding of the WTO in 1994, sets global minimum standards with regard to intellectual property rights in the context of international trade. It requires the members of the WTO to translate the regulations into national law gradually according to an agreed timetable. After this transition period, all inventions, be they products or processes, must be granted patents for a period of at least 20 years. During that time the patent holder is to have sole authority over the production, sale and price of his brainchild, possibly a vitally important drug.

In the industrial countries practically all ARVs are patented; in developing countries the situation is extremely varied. The members of the WTO (except for the least developed countries) have meanwhile been compelled to adopt the TRIPS regulations and so these now apply to all of the newer drugs. Once patents have been granted, the production and marketing of generics are only allowed when a third party has been granted the legal right of use. A state can grant it arbitrarily, if negotiations with the patent holder for a voluntary licence are unsuccessful. Under certain conditions (the declaration of a national emergency, for instance) compulsory licensing is possible directly, even without prior negotiation. In that case, the patent holder is to receive adequate compensation.



## Price reductions as a result of generic competition

US\$ 12,000 | Lowest Originator \$10,439 | US\$ 10,000 | US\$ 8,000 | US\$ 6,000 | Brazil \$2,767 | US\$ 4,000 | US\$ 2,000  
 Yearly cost of Stavudine (d4T) + Lamivudine (3TC) + Nevirapine (NVP) per patient

(Source: MsF, Untangling the Web of Antiretroviral Price Reductions (2009), 11th edition)

# Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS)

Most developing countries do not have access to the technological requirements for local production of the drugs they need. They must rely on imports from the few threshold countries that have a generic drug industry. In 2003, the WTO decided to allow drugs protected by patents to be exported to the LDCs (least developed countries) and other countries that have no production facilities of their own. But this means that the neediest countries depend on the willingness of other governments to cooperate.

Although these protective clauses are a legal instrument in full compliance with the WTO agreement, the few countries that tried to make use of them suffered reprisals at the hands of the pharmaceutical industry and the governments of several industrial countries. However, with the gradual implementation of the TRIPS agreement as the various transitional periods terminate, it will become ever more important to make systematic use of these legal options. Otherwise the market potential for generics will dwindle and their economic feasibility will no longer be assured. This increases the risk that the most effective mechanism for reducing exorbitant drug prices will be lost.

## Generic drugs

A generic drug is an imitation of an already existing medication containing the same active pharmaceutical ingredient(s). The production of generics is allowed only when the patent on the initial drug has expired or when a production licence is granted to other manufacturers by the patent holder or the state. In order to be allowed onto the market, the generic drugs must meet the same requirements as other drugs and must present proof that they have the same biological properties and effects as their original brand-name counterpart. For instance, acetylsalicylic acid was first marketed by Bayer under the name of Aspirin. The patent on this drug has meanwhile expired and so other manufacturers are now allowed to produce and market this drug. In countries such as Brazil and India the production of generic versions of many first-generation ARVs was allowed because these countries did not recognize drug patents before the transition periods accorded them by the TRIPS agreement had expired. Only because of that was it possible to generate the competition that eventually reduced the cost for first-line drugs by up to 99%. So, at best, first-line treatment meanwhile costs as little as US\$ 87 per patient per year.

In the next few years the number of patients in need of second-line treatment will rise drastically. In South Africa, for example, it is currently about 5% of the patients. The Clinton Foundation estimates that by 2011 a quarter of a million patients in the developing countries will be receiving second-line treatment. The actual number of people needing this treatment adjustment will be substantially higher. However, most of the drugs in this and further therapy lines are not available as generics and so the price for second-line treatment is about 9 to 17 times higher than the price of the first-line treatment.

## A question of solidarity

In recent years instruments have been developed for the allocation of funds to support health programmes. Of particular note here is the Global Fund to Fight AIDS, Tuberculosis and Malaria.

From its foundation in 2002 to July 2009 the fund has supported programmes in 140 countries to the tune of more than US\$10 billion. With this money 2.3 million people were able to receive antiretroviral treatment and support was provided to 3.7 million orphans and vulnerable children by the middle of 2009. It is true that the German government increased its yearly contribution to 200 million Euros in 2008 but it has not, as yet, reacted to the financial gap that looms ahead. In total, the members' contributions will almost have to be doubled if life-saving health programmes are to be expanded further. Nevertheless, the increased funds must not be wasted on higher drug prices. They must be used to ensure truly universal access.

At the moment there is a serious danger that treatment costs will rise drastically once again. The latest medications, which must be administered for tolerance reasons or due to the failure of earlier forms of treatment, have already been patented in the countries where they are produced or patents have already been applied for. Open competition by means of the production and marketing of generic drugs is only possible if the countries involved resort to issuing compulsory licences. The political sovereignty and the interest in the general welfare this calls for are, unfortunately, not always given. That is why Action against AIDS demands that pharmaceutical companies waive their patent rights in developing countries and withdraw the applications they have already submitted there.

Until now contracts containing so-called 'TRIPS-plus' agreements have been negotiated mainly by the USA with developing countries. These obligate the developing countries to toughen the measures of patent protection prescribed by the TRIPS Agreement, by extending the validity of patents beyond the 20 years designated by the TRIPS Agreement, for instance. Likewise, terms are agreed to that no longer allow the generic drug producers to use the available data on the safety and effectiveness of the medication for the registration of their own equivalent alternative products. There is currently a danger that the EU will follow the bad example of the USA and try to set up similar barriers to access to treatment in the developing countries. The German government, unfortunately, (as in the declarations of the G8 countries) also supports the strengthening of intellectual property rights on a global scale – and this includes the enterprise-friendly elaboration of patent laws.

Monopoly rights reinforce the tendency of large companies to invest in research and development mainly for the economically better off sectors of society with strong purchasing power rather than for the basic needs of the majority of the world's people. As a result, only a very small proportion of the available resources are used for research on tropical diseases that afflict the poor and for the development of treatments that cater to the specific needs and conditions in developing countries.

## A question of solidarity

The greatest burden of disease is to be found there but the profits that can be expected are lower because the low incomes in those countries would hardly allow the companies to benefit from the monopoly their patent rights provide them with. Finally, in the German case, strengthening patent rights would conflict with the previous efforts of the Federal Ministry for Economic Cooperation and Development (BMZ), which has several projects supporting the production of antiretroviral drugs locally in developing countries and promotes access to these drugs through the Global Fund and bilateral health programmes.

Establishing local drug production to make it easier for the countries concerned to have access to inexpensive drugs is an important factor in the sustainable reduction of drug prices. The TRIPS Agreement is a very strong hindrance to access to generic drugs and to their production in other countries (such as India).

One possible way of overcoming these problems is what is referred to as product development partnerships. These international institutions or partnerships promote the development of new products for the fight against neglected diseases. Up to now, however, the German government has not participated in these partnerships to any appreciable extent.

Public-private partnerships (PPP), when they effectively support the poor, provide a way to distribute the cost burden over several shoulders. For example, when local drug production is being set up, the public partner could provide the funding and the private partner could contribute the necessary know-how.

In 2008, the international organization UNITAID decided to set up a patent pool for HIV drugs. The institution, supported by 26 countries, wants to ensure that low-priced generic drugs used for the treatment of HIV will in future remain available to poorer countries. The idea behind the patent pool is to persuade the patent holders, pharmaceutical companies, universities and research institutions to give all patent rights on HIV drugs in the poorer countries to the pool, which will then licence generic drug producers to manufacture the drugs in and for the poorer countries.

The German government should seize on these approaches more often and consistently support them with more funds than is now the case.

In order to reach the goals that have been set by the developing countries themselves, UNAIDS estimates that at least US\$ 25 billion will already be needed by 2010. In 2008 only US\$ 13.7 million were available. In many countries, however, the goals that were formulated remained clearly below universal access and so considerably more funds are actually needed. It is assumed that countries poor in resources will themselves not be able to raise more than one-third of the amounts they need. It is obvious that the amount the donor countries are contributing so far are totally insufficient if the epidemic is to be countered successfully.

# What we expect of the Federal Government of Germany

In recent years the German federal government has publicly affirmed that universal access is an important concern. Nevertheless, in various documents such as the Action Plan to implement the Strategy of the Federal Government to fight HIV/AIDS, concrete measures and concrete time frames for achieving its goals are missing.

By signing the Declaration of Commitment on HIV/AIDS and the follow-up political statement, the German federal government recognized its responsibility for putting the goals laid down in these documents into action. In order to do justice to this task, the German government is called on:

- To play an active role in the international forums and committees and to work systematically towards the achievement of these goals;
- To base its strategy in the fight against HIV/AIDS and the Action Plan that goes with it on universal access and, accordingly, to formulate concrete objectives and measures, which it has not done sufficiently up to now;
- To press ahead on the development of an international code of conduct which will discourage the luring away of qualified health-care personnel from developing countries.
- To develop a coherent policy for all ministries so that human rights and especially the right to good health always has absolute priority over intellectual property rights;
- To support the concern recorded in the UN-Declaration of Commitment that it is essential to have a systematic evaluation of the impact of international trade agreements on access to drugs and on the development of new ones;
- To plan its strategies in the area of development cooperation and other relevant areas of politics in such a way that they will improve the social position of women and vulnerable groups in the population and put everyone in a position to protect themselves against infection;

## What we expect of the Federal Government of Germany

- To increase the proportion of public development aid to Gross National Income (GNI) from the actual current rate of 0.27% (2008) to the minimum specified by the EU of 0.51% in 2010 and to comply with the UN guideline of 0.7% by 2015 at the latest;
- To increase Germany's contributions towards universal access in accordance with its economic power and the importance of EU development policies and thus to cover at least 10% of the international cooperation that is required;
- To increase its contribution to the Global Fund to at least 10% of the total funds required as well.
- To increase the amount of development cooperation specifically aimed at health programmes from the currently totally inadequate amount to a minimum level of 0.1% of GNI by 2010, which means more than quadrupling it compared to 2007;
- To press forward on debt relief parallel to increasing development aid and no longer to deduct the former from the latter;
- To provide massive support for research on HIV so that better compounds for children, further lines of the therapy and additional preventive measures become available in the near future;
- To adjust Germany's financial commitment to research on neglected diseases in accordance with its economic power. That would mean providing seven times the funds made available up to now.

## Interview partners

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Sheila, HIV-positive woman.

Susan, HIV-positive woman.

Flora, HIV-positive woman.

Andile, HIV-positive man.

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