



# In the face of AIDS, the only responsible action is to treat patients in danger of dying

## Report

A supplement to Messages, the Médecins Sans Frontières newspaper  
N°123, December 2002

Document en provenance du site internet de Médecins Sans Frontières

<http://www.msf.fr>

Tous droits de reproduction et/ou de diffusion, totale ou partielle, sous quelque forme que ce soit, réservés pour tous pays, sauf autorisation préalable et écrite de l'auteur et/ou de Médecins Sans Frontières et/ou de la publication d'origine. Toute mise en réseau, même partielle, interdite.



**In the face of AIDS,  
the only responsible  
action is to treat  
patients in danger  
of dying**

**MSF, DECEMBER 2002**

Supplement to Messages # 123

DIDIER LEFÈVRE / EDITING



# **AIDS**

## **The Urgency to Treat**

Issue produced by Caroline Livio (writer) and Jacques Péron (editor)  
with assistance from Olivier Falhun, Anne Fouchard, Laurence Hugues, Yarri Kamara, and Isabelle Merny  
English Translation: Leah Brumer  
Photography: Didier Lefèvre / Editing, Andrew Njoroge  
Cover photo: Andrew Njoroge

# **s u m m a r y**

- 4**     **Six months after Barcelona...**  
**UNMET PROMISES REMAIN**
  
- 8**     **BY THE END OF 2003, 4,000 PATIENTS WILL BENEFIT**  
**FROM ARV TREATMENT**  
**By Jean-Hervé Bradol, MSF President**
  
- 10**    **42 MILLION PEOPLE ARE LIVING WITH HIV/AIDS**
  
- 11**    **MSF FRANCE'S SIX PROGRAMS**  
**Cambodia**  
**Guatemala**  
**Kenya**  
**Malawi**  
**Uganda**  
**Thailand**
  
- 48**    **THREE PROGRAMS DEPICTED IN PHOTOS**  
**Cambodia**  
**Kenya**  
**Malawi**
  
- 60**    **PATIENT CARE**  
**The medical side**  
**Triple therapies: What do they cost?**
  
- 62**    **THE CAMPAIGN FOR ACCESS TO ESSENTIAL MEDICINES**  
**Progress in HIV/AIDS**  
**The challenges ahead**

**Six months after Barcelona...**

# Unkept Promises

**M**ore than 20 years after the emergence of the AIDS pandemic and six months after the World AIDS Congress, held in Barcelona in July 2002, no one questions the calamity's current and future breadth and significance. *"Five million people were infected in 2002, including 800,000 children,"* reported the Joint U.N. Programme on HIV/AIDS.

Catastrophic announcements mount, noting that, *"If nothing is done to care for or treat them, over the next decade the infected people will join the more than 20 million who have died of AIDS since 1981."*

With 8,000 deaths daily, the urgent need to provide treatment in the poorest countries, where 95 percent of people with AIDS live, is clear. Inequality in the face of this disease is equally clear: of the 6 million people in those countries who need antiretroviral (ARV) treatment, only 4% of them—some 230,000 people—are benefiting from it. And half live in Brazil, a country that has made generic drugs available at affordable prices. It is obvious that calls for care continue to be ignored. Speeches have not produced action. How else can the willful negligence and the delays that stand between awareness and action be explained?



Homa Bay, Kenya, October 2002.

ANDREW NJOROGE

## Unreleased Funds

First, we must note that funds required for treatment programs have not yet been released. However, at the July 2000 G8 Summit in Okinawa, the leaders of the wealthiest nations made this promise: *"We commit to mobilizing additional resources and to making existing cost-effective interventions—including essential drugs, vaccines, treatments, and preventive measures—more universally available and affordable in developing countries."*

In June of that year, UN Secretary General Kofi Annan announced the creation of a global fund and appealed to wealthy countries, foundations, and private donors to contribute \$7 to \$10 billion annually. A Harvard University study estimated the annual cost of the fight against AIDS at \$10 billion.

Today, two and a half years later, despite new promises, only \$700 to \$800 million has been released in 2002—less than 10 percent of the amount needed—while total contributions pledged have reached barely \$2 billion. The necessary sums would seem to be well within reach of the wealthiest nations' budgets. A \$9 billion payment to the fund would represent only 0.035 percent of these nations' total GDP. Of the wealthy countries, only Sweden and Italy have paid 15 percent or more of their 2002 share. The developing countries seem incapable of meeting their public commitments. Funds allocated to health care are inadequate and rarely a priority.

## Obstacles to Generics

Prohibitive costs have long constituted a very real obstacle to a mass-treatment policy. At the 2001 World Trade Organization (WTO) meeting in Doha, members acknowledged the priority of public health over patent protection issues. Following the Pretoria process, they approved the manufacture of generic copies of the ARVs that are sold at high prices by pharmaceutical laboratories.

In April 2001, 39 pharmaceutical companies took the South African government to court, challenging that nation for seeking to introduce generic copies. After a public relations battle, and the vigorous mobilization of people living with AIDS organizations and some NGOs, including MSF, the companies withdrew their complaint.

Following the Doha meeting, a solution was

to have been drafted by the end of 2002 for those countries that could not manufacture their own generics but wanted to import them. Another WTO meeting was held in Sydney in mid-November. Access to generic drugs for poor countries was at the center of the discussions. The proposal that emerged from the meeting, unanimously hailed as an advance, was instead a shock. If accepted, it would have tightened restrictions on poor countries' access to generic medications by requiring that compulsory licenses be issued for each product, even for each order, at every step in the process.

For developed nations, however, the regulations require only that the country that needs generics have compulsory licenses. In addition to creating new complex administrative procedures, if the producing country does not

wish to export a generic, all it has to do is not issue a compulsory license! However, progress has been made in the area of ARV

costs. Today, the average annual cost of first-line treatment with generic medicines is around US\$ 300 per patient.

***The Sydney proposal represents a step backward in the fight for access to medicines.***

## Penalties for the Poor

The battle for equitable access is not over. Some obstacles must still be surmounted, including the excessively high cost of second-line treatments and the political and administrative obstacles that certain poor countries themselves impose.

With respect to second-line treatment, two and a half years ago, Roche, the producer of the protease inhibitor nelfinavir (Viracept®), announced a major drop in the medicine's price. Today nelfinavir costs US\$ 8,358 per patient per year in Guatemala and US\$ 7,110 in Ukraine, compared to US\$ 6,169 for a patient in Switzerland. Surprised that the poorest countries were subject to higher prices, MSF, in November 2002, asked the pharmaceutical industry giant to reduce the price for less-developed countries by 85 percent of the Swiss price. MSF also asked Roche to develop a coherent differential-pricing policy for middle-income countries like Ukraine and Guatemala, rather than force them to engage in case-by-case negotiations.



## Governmental Barriers

The governments of developing countries impose other obstacles to introducing medicines at affordable prices. Some, for ideological or political reasons, have not modified their laws and national regulations to allow compulsory licenses to be issued for the import and use of generic ARVs. Efforts in Kenya should serve as an example. Last August, after only a year of pressure by the Kenyan Coalition for Essential Medicines (which includes MSF) Kenya adopted a law allowing the import and production of less-expensive AIDS medicines.

## A Question of Profitability

Given scarce resources, the debate inevitably arises over their allocation. The key word is profitability. Some say it would be more profitable to focus on preventing the disease rather than undertaking ARV-treatment programs. Not only is such economic reasoning sickening—patients' lives being at stake—but those very necessary prevention policies cannot be considered a substitute for a real policy linking treatment with prevention/awareness. Even if discussion were limited to economic concerns, patients' stories published in this document show clearly that treatment is profitable. A patient whose health and weight improve after six months of treatment is able to resume economic activity, feed his or her family, and take part in overall economic growth.

*"One of my patients gave me a lesson in profitability," says Catherine Quillet (read also page 22), manager of MSF's AIDS program in Cambodia. "Before treatment, he didn't have the energy to do a full day's work. He earned only the equivalent of US\$*

***The economic advantages of ARVs are obvious: Patients remain active members of their communities.***

*1.50 a day. Since he began taking ARVs, he works a full day and earns US\$ 4.50. He can now take responsibility for his family and also contribute to his own treatment."* (His medicine costs less than US \$1 per day.)

## The Economic Impact of AIDS

The significant social and economic advantages of treatment are worth noting. In Brazil, treatment has reduced the overall costs to public agencies by decreasing the number of hospitalizations and the burden of opportunistic infections. Between 1997 and 1999, Brazil saved US\$ 472 million dollars, and 146,000 hospital stays were avoided. The number of new orphans has declined, patients are living longer, and, given their improved health, they remain productive members of their community and society.

AIDS has a considerable economic and social impact in developing countries. During last August's summit on sustainable development, the Joint U.N. Programme on HIV/AIDS reported that the disease destroys the human resources required for economic development. The report published at that time showed the epidemic's impact on labor markets in countries threatened with development decline and erosion in productive sectors, consumption and, thus, in national growth.

## Through the Prism of Prevention

Prevention has been the only proposal offered to poor countries since the pandemic began. Today, the progression of the disease reveals the inanity of that proposal. But how could things have been done differently without the counterpart of treatment? How can we moralize about prevention and encourage people to be screened to prevent the spread of AIDS even as we say, *"If you are ill, we can't treat you to prolong your life as they do in wealthy countries. But, you've got to change your sexual practices"?* Sexual transmission is put forth as the primary cause of HIV infection in less-developed countries.

Choosing prevention for the poorest countries means, clearly, abandoning patients and infected people to their fate and to certain death—for lack of treatment. Providing differential treatments to people with AIDS is a crime of omission; one that takes refuge behind convenient speeches claiming the impossibility of giving appropriate care to patients in poor countries. Their health facilities are supposedly too poorly equipped in diagnostic and monitoring facilities and their patients too numerous to treat. In

our countries, such programs require considerable resources. *"Is that an excuse to treat no one?"* asks Jeanne Gapiya, president of the Burundi support organization for people with HIV and AIDS (ANSS).

## Everyday Stereotypes

Beyond the issue of resources, people from poor countries are supposedly incapable of maintaining life-long treatment *"for cultural reasons."* Fred Minandi (read also page 38), a patient from Malawi under MSF's care, spoke to that issue during the Barcelona conference. *"There are people who say that, in Africa, patients can't take medicines correctly because they don't know how to tell time,"* he said. *"I might not have a watch, but I can tell you that since I began my triple therapy in August last year, I have never forgotten to take a single dose. My CD4 count was at 107/ml when I began treatment. It is back up to 356/ml, and I am very proud of that. I am one of the first people to benefit from free antiretroviral treatment in Malawi. The fact that I am here to talk about it today is because I am receiving treatment."*

## MSF Pilot Projects: Demonstrating That It Is Possible

MSF has been steadfastly involved in treating people with AIDS for one and a

half years. Twelve programs are currently underway, including six operated by the French section in Cambodia, Guatemala, Kenya, Malawi, Uganda, and Thailand. Nearly 1,400 people, including approximately 100 children, are being treated with ARVs in these six projects, and a total of 2,300 are being treated in all 12 MSF programs combined.

This is only a drop of treatment in an ocean of need. We must do more to include as many people as possible. *"There is so little care available that the only responsible ethical position is to take action,"* says MSF president Jean-Hervé Bradol. *"That is where our true responsibility lies as doctors."* MSF France's goal is to provide ARV treatment to 4,000 people by the end of 2003.

That may be too few, given the need, but it demonstrates, yet again, that people with AIDS in poor countries can be treated. And while it may be possible, it's still not easy in such precarious settings. Interviews with patients and with our programs' national and international health care staff presented here remind us of the personal tragedies brought on by AIDS. It stigmatizes patients, isolating them from the larger society and often from their families, thus heightening the disease's impact. Patients' fears can be eased by offering an alternative to death and by showing them that they can live with AIDS. They are well aware of the burden their illness imposes on their families. Their fears will not be eased by leaving them to choose between suicide and death that comes inch by inch.



Chiradzulu, Malawi, October 2002.

DIDIER LEFÈVRE / EDITING



***By the end of 2003, 4,000 patients will benefit from antiretroviral treatment***

# **In the face of AIDS, the only responsible ethical position is to take action**

**By Jean-Hervé Bradol, Médecins Sans Frontières President**

At the beginning of the AIDS epidemic, this untreatable illness and its victims were not at the heart of our organization's work. We focused on aiding victims of conflict or natural disaster. However, this is an emergency. In some countries, AIDS-related death rates have reached crisis levels. In certain regions of Africa, the death rate has reached almost one death per 10,000 people per day. That constitutes an emergency.

In many locations, MSF teams began by treating AIDS-related opportunistic illnesses—primarily tuberculosis—before starting to use antiretrovirals. In December

***There are real possibilities for treating patients even when the health care context is unfavorable.***

2000, in Surin, Thailand, the first MSF patient began receiving triple therapy. Since the program's inception in 1996, MSF had been following patients receiving double therapy through the Thai national program. Two years later, nearly 1,400 people (including 100 children) were being treated in six MSF France programs (Cambodia, Guatemala, Kenya, Malawi, Uganda, and Thailand). All told, 2,300 were being treated

in the 12 programs established by the group's operational centers. In some countries, like Cambodia, Kenya and Uganda, MSF is the only organization providing free antiretroviral treatment in public-health facilities, although still on a very modest scale. Our primary responsibility is to care for patients in danger of dying, whether or not health care exists in the countries where we work, and to begin to treat patients, paying close attention to the quality of patient care.

With two years' experience, we have already demonstrated that it is possible to use triple therapy to treat patients, many at an advanced stage of the disease, in countries with limited resources. Compliance rates show that this approach is entirely realistic. At around 85 percent, the rate is quite comparable to patient compliance levels in wealthy countries. Despite a relatively small decline, patient survival rates in these programs are also similar to those observed in wealthy countries. This experience proves wrong those who claim that conditions in countries with limited resources preclude satisfactory results. The decline in ARV prices bolsters the very real potential to treat patients even when the overall health care environment is unfavorable.

Today, we see it as our responsibility to pursue and develop similar experiences. We must do more because, even in our specialized programs, two of every three patients who should receive ARVs cannot yet benefit from them. MSF's goal is to increase the number of persons under care. Guillaume Le Gallais, Operations Director, proposes that we treat 4,000 patients through the six programs by the end of 2003.

We must also expand AIDS treatment in our field practices. Beyond the specific ARV-treatment programs, MSF teams are also starting to care for other people with AIDS. For example, in Maesot, Thailand, where MSF provides medical care for people in Karen refugee camps, the team has already begun to treat AIDS patients with triple therapy. We are not suggesting that we set up AIDS programs in all countries where MSF is active, but rather that we provide this care on a case-by-case basis when conditions allow. Finally, we are also responsible for monitoring and providing ARVs to all MSF staff members who require them. We work with men and women who, given the HIV prevalence rates in their countries, are affected by this disease. How could a medical organization not be concerned about its own staff?

Today, MSF France's six AIDS programs vary widely in their experiences with patient monitoring and treatment. There is no single approach because our level of involvement and the problems we encounter in each country are different. Through these programs, we are inventing ways to manage these patients' care. Before developing a stable model that can be replicated easily by others, we still need to gain more experience. Treating AIDS patients in poor countries requires specific knowledge. We have developed this knowledge for all other aspects of our work and we will do the same for AIDS.

But we won't get there on our own. Part of the job involves creating partnerships with other local groups and patient organizations. In Burundi, for example, we do not have an AIDS program in place, but we support ANSS, the organization for people with HIV and AIDS. ANSS was founded by and for people with HIV/AIDS

and today provides ARV treatment to nearly 700 people throughout the country. These kinds of partnerships are important to develop. For us, they are also a way to learn and exchange experience and knowledge.

MSF's programs have an impact that goes beyond treating patients. Through these experiences, we are helping to raise public awareness about the issues involved in AIDS treatment, particularly in the area of access to essential medicines. With 1,400 patients currently under treatment and 4,000 anticipated by the end of 2003, MSF remains—and will remain—a modest player in the struggle against AIDS. But if our goals still remain modestly ambitious, they still allow us to participate in the current debate. Brazil demonstrated on a national level that effective political action can be mounted in the fight against this disease. Thailand, too, was moved to act by the activism of hundreds of patients.

***Through  
our programs, we are  
inventing ways  
to manage  
these patients' care.***

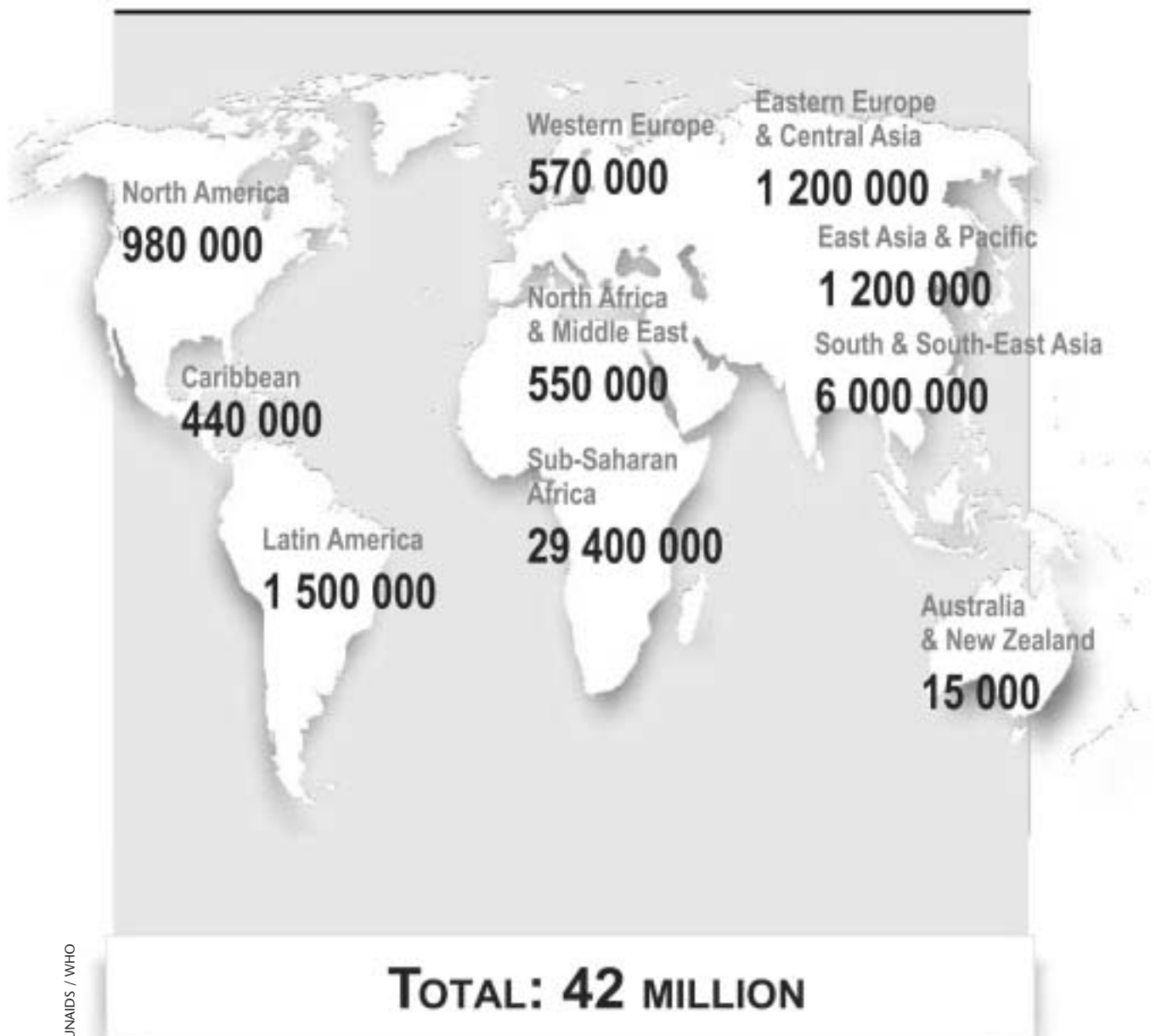
By showing that effective, high-quality care for people with AIDS in poor countries is possible, our experience plays a significant role. Our role is not to advise governments but to offer a model of what can be done by suggesting new practices. It is then up to each person—whether in the public or private sphere—to assume his or her responsibilities. Our goal is to obtain single daily-dose triple therapy for first-line treatment at a cost of less than US\$ 100 per year, per patient.

Finally, the question of ethics in treating people with AIDS often arises. "Experts," whether donors or political leaders, put forth the dangers of treating AIDS patients—the risk of causing drug resistance to emerge, for example—to support their refusal to commit to treatment. But the unethical course would be to refuse treatment to patients at risk of dying. There is so little care available that the only responsible ethical position is to take action. That is where our primary responsibility lies as doctors.

## ***December 2002 report from UNAIDS***

# 42 Million

**ADULTS AND CHILDREN ESTIMATED TO BE LIVING  
WITH HIV/AIDS, END 2002**



# Médecins Sans Frontières France

## Six Programs...



### *SOUTH AFRICA*

(MSF BELGIUM): 300 PATIENTS

### *CAMEROON*

(MSF SWITZERLAND): 133 PATIENTS

### *GUATEMALA*

(MSF SWITZERLAND): 160 PATIENTS

### *HONDURAS*

(MSF SWITZERLAND): 25 PATIENTS

### *THAILAND*

(MSF BELGIUM): 300 PATIENTS

### *UKRAINE*

(MSF HOLLAND): 18 CHILDREN.

THERE ARE 2,300 PEOPLE RECEIVING  
ARV TREATMENT THROUGH ALL  
THE MSF'S PROGRAMS.

### In brief

Statistics

Context

Program

### In words

Analyses

Stories

Portraits

Interviews

### In photographs

Three reports: Didier Lefèvre in Cambodia  
and Malawi, Andrew Njoroge in Kenya.

# CAMBODIA

MSF currently operates a 60-bed HIV/AIDS treatment program within the infectious disease unit of Phnom Penh's Norodom Sihanouk hospital. MSF has been working in this facility since mid-1997, and triple therapy ARV treatment was introduced in July 2001.



DIDIER LEEVRE – EDITING

## KEY STATISTICS

- Between 150,000 and 200,000 people of Cambodia's 11.5 million inhabitants are estimated to be infected with HIV, with more than 40,000 AIDS cases.
- The prevalence rate for adults (15-49 years) is 2.7% (UNAIDS figures, 2002).
- More than 22,000 Cambodians developed AIDS in 2002. In 2002, 21,200 people died from the disease and 7,300 people, including 2,600 children, were infected with the virus. (Source: National Centre for HIV/AIDS, Dermatology and STDs).



## THE CONTEXT

Cambodian authorities give funding priority to prevention activities. For example, the government committed \$14 million to this year's efforts against AIDS. The majority of those funds were dedicated to education and prevention. Nothing—or very little—has been done nationally to treat HIV-positive patients.

Only 100 “specialized” beds for adult HIV/AIDS patients exist across the country. All are located in Phnom Penh and 60 are at the Norodom Sihanouk hospital, where MSF works. The other beds are in facilities run by private groups. Those groups only treat opportunistic infections and do not provide triple therapy.

MSF is the only NGO in Cambodia providing free triple therapy treatment to AIDS patients in a public health facility. Some patients travel for a full day or more for HIV appointments with MSF staff at Norodom Sihanouk hospital.

## MSF'S PROGRAM IN NORODOM SIHANOUK

The program's general goal is to provide the hospital's HIV/AIDS patients with access to the most effective therapies (including medical monitoring and treatment and psycho-social support). The program has three parts:

- HIV consultation: medical follow-up for patients who have tested positive. Construction is underway on a new building so that patients can be seen and medical and psychological follow-up can be provided under optimal conditions. Some 5,878 consultations were held in the first 6 months of 2002.
- Hospitalization: comprehensive care for hospitalized patients. This includes diagnosis and treatment of opportunistic infections, development of palliative care and pain treatment and psychosocial support to patients and their families. On average, 110 people are hospitalized each month.
- ARV: triple therapy treatment for HIV/AIDS patients, with priority to patients at greatest risk of death (CD4 level of less than 200/mm<sup>3</sup>). To learn about his or her illness, the patient will meet with the team—the doctor as well as the social worker—several times before beginning treatment. The goal of these meetings is also to allow the patient time to reflect before making a decision. Each month, some 20 to 30 patients join the program.

**As of late October 2002, 273 people, including 11 children, had begun triple therapy treatment.**

**By the end of 2002, some 350 people are expected to benefit from the treatment.**

Many of MSF's patients live in the provinces. MSF is currently evaluating the possibility of providing triple therapy treatment to HIV-positive patients in other facilities throughout the country.



# Cambodia, Norodom Sihanouk hospital

## Patients Stories

**KEO S. IS HIV-POSITIVE.**

**HE WAS TREATED AT THE HIV CLINIC AND HOSPITALISED FOR AN OPPORTUNISTIC INFECTION.**

*Keo S. was hospitalized for a few days in the infectious disease unit. The MSF team decided to accompany him when he returned home.*

Psar Toch, the 'little market,' is in northern Phnom Penh. Keo S. lives there in a little wooden house on stilts, which sits among a dozen similar rickety dwellings. These bundles of planks and sheet metal are accessible only via thin wooden slats spanning the river. This is one of the capital's countless small shantytowns. The Cambodians call them "unplanned buildings." Assembled from whatever materials are at hand, they house entire families, with six, eight or more people crammed into tiny rooms of a few square meters. Inside, the houses are dark, as daylight only filters through gaps in the walls and roof. Water is visible, flowing between the cracks in the floor. During the monsoon season, when the river rises and overflows its banks, people living here must raise the floor until it almost touches the roof. It is impossible to stand up and everyone has to crawl around inside for weeks until the river settles. There is nowhere else to go for shelter. Living conditions here are precarious and miserable.

Yet life is very different in the nearby Phnom Penh that is being rebuilt. Along the road a few yards away, houses are being erected, each more garish than the next. Walls are painted in loud colors and multicolored dragons guard front doors. Streams of Japanese cars and dozens of motorbikes, carrying as many as 4 or 5 passengers, weave along the roads, creating wild traffic patterns. A few rickshaws snake through the chaos carrying their cargo of tourists. Young people with mobile phones and hawkers walk side by side. The little houses on the river are not part of this world. There, children play in stagnant water among rubbish and waste. Small fish dry on a window ledge. A woman kneeling in her doorway eats a bowl of rice, her face turned up to the sky. But her eyes have long

lost the power of sight, and her wizened face is ageless. The only sense of shared life comes from the distant sound of children's laughter.

Groups of children run out of their homes as Keo S. arrives. He can't walk on his own, so his wife holds him up. Her sister-in-law and MSF's social worker, Mr Parith, help out. His neighbors come out to greet him. They are happy to see him back home. "He's a good man, everyone likes him here." Some visited him



**The Psar Toch neighborhood, where Keo S. lives.**

CAROLINE LIVIO / MSF

at the hospital, a rare show of support in Cambodia where AIDS patients are likelier to experience discrimination than receive sympathy from friends and families. They all escort Keo S. and his wife to their home. A small mat fills the space in the single room. It is hot and humid inside. Daylight barely pierces the ceiling's wooden planks. A neighbor brings a fan. Keo's brother-in-law quickly hooks up an electric cable and lends him a bulb to light the room.

Keo is 38, but looks 15 years older. He is very weak and can't speak. He lies down on the mat as his neighbors and family surround him. A neighbor explains that she went to see him at the hospital once, but couldn't go again as the trip by moto-dop is expensive. At 4,000 riels (around \$1), it costs nearly as much as a day's salary. *"All we can do is offer moral support to Keo and his wife,"* she says. *"We know this disease well here. He's not the only one to have it. Many have already died."* Another neighbor interrogates Keo. *"You know what's made you ill, don't you?"* Keo shakes his head, no. *"Why do you say that?"* she responds, annoyed. *"You took the AIDS test. You know you've got the virus. There's no point hiding it. You have to face the truth now."* He doesn't answer. His wife doesn't say anything either. She seems stricken. Facing the truth also means accepting that death may be on its way.

As the couple does not speak to the MSF social worker, the neighbors speak for them, explaining that the family has almost nothing. Keo used to be a rickshaw driver, but hasn't been strong enough to work for several months. His wife sells cakes in the street, earning 3,000 to 5,000 riels/day (around \$0.75-1.00). That's just enough to feed her family. They wonder whether the family will survive. Keo was treated at the HIV clinic for four months. Before he left the hospital, the social worker contacted the home care network to ask them to visit and make sure that Keo and his family do not become isolated – and to maintain a link with him.

**CHAM S., 35, IS THE FIRST ARV PATIENT IN PHNOM PENH PROGRAM. HE BEGAN TAKING THE DRUGS IN JULY 2001.**

*Cham S. has come to the hospital this morning for his monthly appointment. He has been taking ARVs for thirteen months. He is*

*beaming, happy to be here and to be able to tell his story.*

Cham S. display his medical file, which he seems to know by heart. *"Look,"* he says, pointing to some figures on the page. *"Look at my CD4 count. In May 2001, before starting treatment, I had 3 CD4/mm3. Only three. And you see, now it's back up to 226."* A large smile lights up his face, as if to show his pleasure at having accomplished the long, hard task. He is no longer scared to speak about himself, his illness and how he helps other sick people—friends or other patients in the same unit. They are all HIV-positive and are experiencing what he did several months ago: worry, shame and denial of their illness, a worsening physical state and fear of death.

Seven years ago, Cham was shocked to learn he was HIV-positive. *"In 1995, I took a blood test because I wanted to get married. It was just to confirm that I was in good health. My test showed I was HIV-positive. I was terrified. I refused to believe it. When someone talked about AIDS on the radio or TV, I would turn it off. I didn't want to know or hear. I never talked about it to the woman I was supposed to marry. And I didn't get married. I even ran away. I was ashamed. But at least I didn't infect her. You know, in Cambodia you can't sleep with your wife before the wedding."*

***"I didn't say anything to the woman I was supposed to marry. I ran away, but I didn't infect her."***

Between shame and denial, many months passed, and his health worsened little by little. *"The first time I was hospitalized, I was in a room with five other patients. They all died. The nurse told me, 'You're the last one.' I was furious, but I didn't say anything. I still blame her for speaking to me like that."* Cham S. doesn't remember if it was then, watching other people with AIDS die next to him, that he began thinking about a different attitude toward the disease. He wants to talk about his battle against AIDS, which he fought alone at first. *"For four years, I had a lot of problems, a lot of diarrhea and frequent fevers. Each day brought a new lot of worries. One day, I heard people talk about antiretroviral drugs on the radio. You can find them easily in Phnom Penh. I had money, so I bought some at the market. I took them for six months, but then stopped because my money*

ran out. Then I took them again for four or five months until, one day, I had no money left. I stopped everything and fell ill." Cham contracted pneumocystosis and tuberculosis and was hospitalized again. In October 1999, he went to Norodom Sihanouk hospital. The following year, he started going to regular appointments. And in July 2001, he began triple therapy.

*"At that time, I couldn't walk anymore," he says. "I weighed 48 kilos. I was incredibly weak." Because he had already taken antiretrovirals, the doctors knew that a first-line treatment might not be effective. They tried the first drug combination for a few weeks, but Cham S. didn't respond well. "I had terrible side effects," he says. He doesn't say what they were, but explains that the doctors prescribed another combination and that "this time, it worked." He shows us his medical files again, noting the slow upward climb of his CD4 count. He now takes his medicines scrupulously: 5 pills in the morning, 4 in the evening. To make sure he doesn't forget, he's set his mobile phone to ring when he needs to take his treatment. "And yes, I'm much better," he adds, still smiling broadly. Nothing on his face or body reveals that a few months ago, the virus was sapping him.*

But although his body is back to normal, he's not the same man as before. Not one to worry about others before his illness, he's now very involved in patient care. *"I support those who need it, and try to do my best. I explain how they should take their medicines, and I help them when they have side effects. For instance, I sometimes do their shopping. I tell them my story and how I did everything to get strong again. Many people with HIV in Cambodia refuse to accept their disease. They stay at home and try to*

*care for themselves, sometimes with traditional medicine. I know that feeling. That's why I can help them and offer moral support."* Cham, too, experienced the loneliness of patients living with AIDS. *"I stopped working between 1998 to 2001. But I didn't say I was ill. I was just absent. I'm a civil servant and if I had talked about my disease, no one would have spoken to me. I would have been rejected."*

Today, Cham is a member of a support group created by HIV/AIDS patients treated in the hospital's infectious disease unit. MSF launched and supported the group. *"We talk about our lives and our problems," he explains. "All HIV-positive people go through the same difficulties: tense relations with those close to them, often painful side effects, fear of the future and difficulties living with the disease. It helps to talk about it all. I always try and talk in very positive terms. When someone isn't well, I try to find out what's wrong, I push him to talk so that we can find solutions to the problem."*

Cham has no more regrets. *"I'm still not married, and I probably never will be. Not telling the woman I was supposed to marry about my disease was my last lie. I know my life is likely to be short, but I'm no longer afraid. The only thing I want now is to help other people."*

#### **SREY M., A YOUNG MOTHER, HAS COME FOR HER APPOINTEMENT. BOTH SHE AND HER CHILD ARE TAKING ARVS.**

*Srey M., a young mother, walks shyly into the consulting room. Her 5 year-old son is with her. He's shy too, his gaze questioning, but he walks with a determined gait.*

Mother and son are both under antiretroviral treatment; she for a month and the little boy for two weeks. A few weeks ago, he weighed just eight kilos. Today, the scales hit 13. His round little face is evidence of those five kilograms regained, a victory against the disease. But his mother is worried because he has a cough and, sometimes, a fever at night. She feels it when she touches his forehead as he sleeps. The examination reveals nothing wrong. Didier, the MSF physician, reassures her. He asks if she talks to her son about their disease, the one that took his father and that



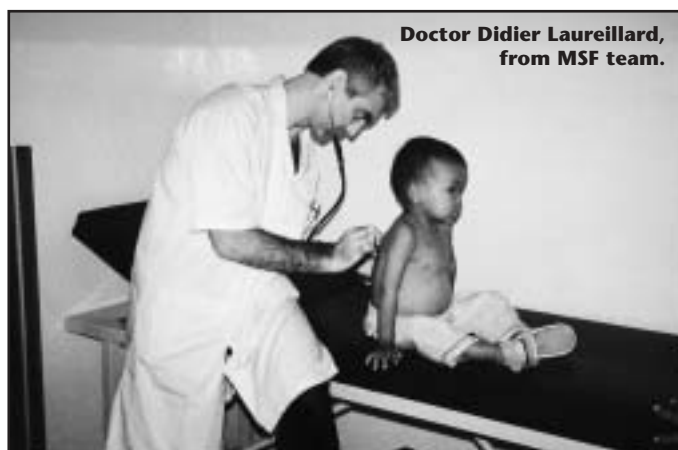
**Hauling wood near the hospital.**

DIDIER LEFÈVRE / EDITING

she's fighting, too. No, the mother doesn't, she doesn't know. She's a little embarrassed. Didier explains that the child has a right to know and that he can understand if it's explained in simple terms. If he knows, he'll understand better why he needs to swallow so many pills every day. Srey agrees, nodding her head slightly to show she knows all that. While he's been talking to the mother, Didier has given the boy a piece of paper and pencil. The child concentrates on producing large drawings. "What are you drawing?" Didier asks. "I'm writing," the little boy responds proudly. The doctor encourages him, and explains to his mother that she, too, must encourage him to draw and play, just like other little boys.

Now that her worry for the little boy has been eased, Srey can talk about herself. She's well, she says. No fever and no more diarrhea. Her skin problems are starting to fade, she explains, showing us her arms. In recent weeks, life has picked up again. She has been able to rent a small house through Maryknoll, an orphan care association that pays their rent. She used to work in a sewing factory. She doesn't any longer, but thinks she may be able to go back soon – once her face is beautiful again, she explains, smoothing her cheeks with her hands. A smile lights her face a bit. That smile expresses all the hope the antiretroviral drugs have offered her. And it masks her shame about the telltale marks on her skin that reminded others, probably even more than they did her, of the virus in her body. The disappearing marks also gradually erase the memory of her life before ARVs. A few words capture it: Srey no longer wished to live. She was an HIV-positive widow, unemployed, lacking all resources and rejected by others. Her only child was infected with the same deadly disease. Her body was in pain and no longer responded. How could she live, when everything seemed to lead to death?

It took time to convince her that antiretrovirals – which the Cambodians call "life-lengthening medicines" – could help her. It took all the persuasion, patience and support that the medical team and social workers could muster to help her decide to make this choice. Now that her body is responding well to the treatment, that difficult choice seems so obvious. Yes, she takes her medicines regularly, she tells the doctor. She's brought all her pills in



Doctor Didier Laureillard,  
from MSF team.

CAROLINE LIVIO - MSF

a black plastic bag. She pulls them out and lays them on the desk. First, the tuberculosis treatment, which she takes at 5 a.m. Then the antiretrovirals: five pills at 8 a.m. and four at 8 p.m. She also shows us what her child must take. The doctor opens the boxes. There are still many pills left, more than there should be. Srey must have forgotten several doses. Didier explains how she should take her medicines and goes into detail again about why it's so important that she remember to take every dose. He writes a prescription for the next few weeks. The pharmacist will show her which ones to take at what time of day. He patiently takes the pills from their boxes to make sure she understands. Srey doesn't know how to read, but she's the one who points out which of the multicolored pills she has to take and when.

***The child has gained  
13 kilos in two weeks  
of treatment.  
"He should draw, just  
like all little boys,"  
the doctor says.***

## **S. IS A HOSPITALISED PATIENT WAITING FOR ARVS**

*S. would like to sit up in bed, but she doesn't have the strength. A few weeks ago, the medical team decided to start her on antiretrovirals...*

ARVs ... She greeted this news with great hope. Since that announcement, she has come twice for medical appointments and to meet with the social worker, who discussed treatment with her. Today is visit V3—the third, when the doctor was supposed to prescribe the triple therapy for her. But a few days ago, she was hospitalized with diarrhea and vomiting. She has terrible stomach pain.



She's frightened that the doctor will tell her she can't begin treatment today. This was supposed to be an important and wonderful day, but this morning, her beautiful face and big green eyes show no signs of joy, only worry, pain and disappointment. *"She takes her TB treatment every day,"* explains her mother, showing the boxes of pills. *"But she can't eat. She vomits everything she swallows, and her diarrhea has weakened her terribly."* Today, S. weighs just 29 kilos.

Her mother asks Ms. Sopha, the social worker, what will happen if S. can't start the *"life-lengthening treatment."* Ms. Sopha explains that since the medical team has decided to include S. in the ARV program, she will definitely receive the drugs. S's mother says that a young man living near them also has the virus. He's been very ill, but has been much better since he started taking antiretrovirals. She's very worried that if

***S. shows a photograph of herself, almost plump, in a pink dress. She's wearing make-up. The disease has left her looking like a different person.***

her daughter gets worse, she'll die before having the chance to start treatment. *"We live far away, in Kandall province,"* she adds. *"I came here this morning to look after my daughter, but I have ten other*

*children who are alone at home, and they won't have anything to eat today."* She starts to cry and her daughter does, too. Ms. Sopha listens and comforts them, encouraging the two not to feel hopeless and to continue taking the current treatment so that S. can get strong again. The doctor will prescribe the antiretrovirals soon.

Mrs Sopha speaks clearly. She is attentive and gentle, but not pitying. She always has the right tone and words. She is more than just a presence. Encouraged by the trust her manner inspires, S.'s mother continues. *"Two days ago, I told my daughter that I am her aunt, not her biological mother. I took her in when she was two months old. Her parents were killed during the Pol Pot regime. But I love her as if she were mine. She's known for ten months that she's HIV-positive. But she doesn't know if she got the disease from her first husband, whom she divorced, or from her second, who also has the virus. Her second husband is not kind to her. He's always causing arguments, and he beats her. He's never come to visit her at the hospital. A*

*year ago she got pregnant, but she lost the baby because he had beaten her. She lost a lot of blood. That's when she started getting really ill."* So yes, she is worried for her daughter. She talks again about antiretrovirals and explains that she doesn't trust traditional medicine. Many people she knows who have the same disease use them and they don't work. She only trusts "real" medicines.

It's now time to meet with the doctor. He confirms that S. can't start antiretrovirals immediately but must wait a bit. The complications of her illness require treatment that cannot, for now, be combined with antiretrovirals. Back in her room, S. is desperate. She doesn't want to stay in the hospital but wants to go back home to die. Ms. Sopha again spends a long time sitting with the two women.

In the days that follow, S. starts eating again. The diarrhea is improving. S. takes a photo album out of a small plastic bag. She shows the photos one by one. They are recent pictures of her, dressed in traditional Khmer costumer, on her second wedding day. Others show her among family and friends. She points out one photo in which she stands alone in front of a painting of one of the Angkor temples. She wears a pink lacy dress and jewelry. Her hair is done in a sophisticated style and she's wearing a lot of make-up. There is an entire world between the sad, painfully thin figure lying on a hospital bed and this photo of a healthy, smiling, slightly plump woman. The virus separates them, a virus that has ravaged S's body and destroyed the life she had before. But today she's showing the picture to demonstrate her will to fight, not to lament her lost life. She doesn't want to die any more. S. continues to take her medicines.

# **Denis Galin, Social Worker**

## **“To Support People”**

### **What do social workers do for patients at the Norodom Sihanouk Hospital?**

The social-work team (two Khmer and one international volunteer) has three roles that correspond to the ways in which MSF works with the medical program. First, the team works with hospitalized patients, helping the indigent and those without families to prepare to leave the hospital. They provide supplies (mosquito nets, bed linens, etc.) to patients without resources to make sure that they will have a certain level of comfort during their hospital stay. More generally, they provide psychosocial support to all hospitalized patients and make contact with the network of home-care services and with visitors and members of organizations who visit patients in hospitals, some of whom provide financial aid.

Another important aspect of the social workers' role involves making hospitalized patients' partners aware of the availability of HIV testing. The social workers encourage screening and record partners' requests for it. The latter are often HIV-

positive, too, but in two out of three cases are unaware of their status. Some partners may not even know that their husbands or wives are HIV-positive, even though a patient's hospitalization in the infectious-disease unit means the person is developing an AIDS-related opportunistic illness! This happens more commonly than the Khmer doctors and nurses know—or want to know.

The social workers' role is to explain the importance of HIV testing and to support partners so that they will take the test. The same social worker who encourages the partner to be screened relays the test results. If the result is positive, the social worker will suggest that the person be seen for an HIV follow-up consultation, usually within 48 hours. If the result is negative, the person is still interviewed and receives information on the disease. This is a difficult task. Informing someone of a positive test result is always very hard, but for patients to return for a follow-up visit, they must have a clear understanding of the disease and the monitoring and care this department provides.



**Paying attention to patients is essential to treatment success.**

DIDIER LEFÈVRE / EDITING



## **Are social workers also involved in the HIV and antiretroviral consultation?**

That is the second aspect of their work. All new patients are interviewed after the medical consultation. The social worker assesses the patient's understanding of the disease and goes back over what the patient may not have understood. Even after discussing AIDS with a doctor, some people do not realize that they are infected with the virus. The social worker's goal is to help them understand that they are HIV-positive, what that means, and why regular monitoring is necessary.

Overall, it is clear that, for whatever reason, there is a severe lack of information on this disease. Some Khmer doctors do not provide the necessary explanations, whether because they do not know how or because they have limited time with each patient. In each case, the social worker's role is to make sure the patient has all the information required to understand the disease and its course.

The third aspect of their work is conducted as part of afternoon antiretroviral (ARV)

consultations and involves helping patients with treatment compliance. Social workers see patients after the ARV medical consultation. They counsel patients regarding the problems associated with compliance; that is, those related both to the illness and to adhering to the

treatment. It is extremely important to support patients and remain in close contact with them.

In addition to these three activities, social workers lead discussion groups for ARV recipients who, after several weeks of treatment, do not necessarily need individual counseling. They help organize ARV patient self-help groups in which people who have begun triple therapy meet to talk about their lives with the disease and about their medication. Finally, they hold HIV-education sessions for hospitalized patients' family and friends. These are primarily discussion sessions. The social worker does not lead the conversation but helps people to express themselves, keeps the discussion focused, and answers families' questions.

## **What does "counseling" involve?**

"Counseling" is undertaken through an individual relationship established between the social worker and the patient. It is based on the principle that, when a patient encounters a problem, he or she is the only person who can solve it. The social worker must not offer advice. Counseling is the antithesis of advising. However, the terms "shared advising" or "co-counseling" may sometimes be used to describe the process by which two people reflect together on a problem faced by one of them and to try to find a solution together—or a way to reach one. In this context, patients generally raise problems about changes in their lives related to their HIV-positive status. Generally, they do not address economic or financial problems, which we do not get involved with. Patients talk about their unease, about the difficulty of overcoming the ordeal, and about relating to themselves as an HIV-positive individual.

This work is focused on the person with the problem, is based on his or her current emotions and feelings, and demands respect for that person's values. The aim is not to discuss the problem in general or absolute terms, but to focus on how the person being counseled presents his or her problems. The goal is to help the person move ahead, reflect, and adapt. In return, the social worker explains his or her response to what the person says. This is not a psychotherapeutic relationship but rather a helping relationship. In other words, the patient is helped to make decisions. In this way, patients taking ARVs will follow their treatment protocols not because they are submitting to a regime or following someone else's orders, but because they understand why it is important to take medicine every day at specific times. Some even respond to the point of apologizing for being a half-hour late taking their medicines!

## **What are the distinctive features of this approach?**

The notion of "social worker" does not exist in Cambodia. There is no training offered for this profession, so there are no social workers in Cambodian hospitals. The approach is completely new for both caregivers and patients, and, as such, was difficult to establish. Before initiating this program, the Khmer staff tended merely to reassure patients. But you cannot say, "Don't worry, it's

***"Informing someone of a positive test result is very difficult, but you've got to offer a clear explanation."***

*not serious,” to a desperate person who wants to die. Our goal is to help the person confront a very difficult situation. Cambodians are not used to this kind of relationship. They say to themselves, “I am ill and poor and someone is interested in me? People are talking to me? They’re letting me express myself? They’re not asking me for money?” When some patients meet a social worker for the first time, they are extremely surprised. After several visits, they are the ones who call out for us when we pass by in the hallway.*

Caring for AIDS patients involves more than providing treatment, because, for them, lack of treatment compliance means failure. If ARVs are to be prescribed, patients must have support. What holds for all chronic illnesses is even truer for AIDS. But this is not DOTS (Directly Observed Treatment Strategy). DOTS does not continue for a lifetime. With DOTS, it’s the treatment that sticks to the patient and not the other way around! In short, this pathology can only be treated with the patient’s involvement. Social workers do not operate autonomously in this program. They work together with doctors and nurses. If one group fails, the entire program collapses. The full team participates in patient care.

### **Was this program created because patients are illiterate?**

Studies have examined compliance based on patients’ socio-cultural differences. They show that poor compliance rates are not based on poverty or illiteracy. In fact, patients with the lowest treatment-compliance rates are doctors. No link exists between social or educational level and compliance. The program operating in the Norodom Sihanouk infectious disease clinic is identical to one that would be found in a private medical clinic in an industrialized country.

The decision to devote resources to creating this system was based on the belief that, with ample support and information, patients would follow through with treatment. The person who understands nothing about his or her treatment is less likely to comply. And finally, it is the individual who decides whether—or not—to follow the treatment. The decision is an individual one, but it is made with the help of the health care team, and social workers are a part of that team.

### **What key problems do social workers face?**

The first is emotional, because they deal with situations that can be extremely intense. Nonetheless, patients are thrilled with ARVs. For many of them, ARVs are a miracle. They had thought that they were going to die, but they are still alive and their health has improved. What has changed over time, for most of them, is that they can begin to return to work and can earn money again. When they began treatment, they understood that these medicines would “prolong life,” but the notion remained abstract. After several months, they have integrated the idea and incorporated it into their long-term understanding. But being treated with ARVs does not mean patients’ problems have disappeared. The early patients talked a lot about physical side effects. More generally, they expressed anxieties about the treatment’s long-term success and MSF’s continued presence. Many were worried about the state of their health, the failure or even death of some patients on ARV treatment, the success of a second-line treatment, and the consequences if it were not effective.

### **A doctor, a nurse, and a social worker: that’s a lot of health care staff for just one patient. How can others reproduce this approach?**

It’s true that the position of social worker or “counselor” may be a bit unwieldy at the outset. But eventually, we will have less of a presence with patients who are doing well. At that point, the self-help group will take over and replace the social worker. The patients will take responsibility for themselves. It would be a problem if people assumed that only social workers could support patients. The goal is to work with patients so that, eventually, they will be able to support themselves.

With a few exceptions, patients join these groups. Those who have been in treatment for only several weeks ask a lot of questions of those with several months’ or a year’s experience. The questions deal primarily with side effects, real or anticipated, and with the way others organize their lives to take their medication regularly. They also raise long-term concerns: for how long will the treatment be effective? What happens later? The support groups make it possible to share experiences, which is a factor in improving treatment adherence.

# **Catherine Quillet, Head of Mission**

## **“Of Course, It Works”**

“First, let me note that, in Cambodia, there are only a few players and donors involved in patient treatment. The health system is deficient, and political will is lacking. Only a few health players are already involved in treating AIDS patients. But they are not financially independent and/or do not have adequate funds to develop these activities. Instead, they remain dependent on donors who are not especially focused on financing treatment programs. The European Union and USAID provide AIDS funding, but it is geared toward information, prevention, and home-care programs, not to treatment. AusAID is more involved in research projects. Some NGOs, like the Center of Hope and MDM, have applied to the Global Fund to Fight AIDS, Tuberculosis, and Malaria to launch ARV programs. MSF Belgium expects to initiate a program in Siam Reap. Aside from these few organizations, there are no other partners in Cambodia—nor are there likely to be in the foreseeable future—with the human and financial resources to create ARV treatment programs for people with AIDS.

More generally, access to basic care is lacking in Cambodia. For people with AIDS, care is non-existent. There are only five testing centers in the country. Beyond our program in the Sihanouk Hospital, public-health facilities do not provide HIV consultation or primary prophylaxis (like cotrimoxazole), let alone appropriate tuberculosis care. If all those needs were already

***“In Cambodia, there is no political will supporting ARVs. If things move forward, it will be thanks to patients.”***

being met, it might be possible to imagine creating supplementary ARV projects.

However, patient care cannot start with ARV treatment. In our program, we first set up an HIV consultation, then improved the treatment

of opportunistic diseases in the infectious disease units, and then initiated patient monitoring by social workers. Some say that the best way to treat opportunistic diseases is to put patients on ARV therapy. But without monitoring, simply handing out ARVs is not an effective way to address the problem.

Not only is international funding lacking to pay for ARVs in Cambodia, so is political will. The director of Cambodia’s National AIDS Program does not anticipate that the government will be involved in establishing this kind of program within the next five years. Unlike Thailand, which chose to include ARVs in its national budget, Cambodia has made clear that it has other priorities and that funds are not available to purchase ARVs. But the government is also aware that the country has neither the infrastructure nor the human resources (that is, adequately trained and paid doctors) to introduce these drugs. The average doctor’s salary is US \$30 per month and a nurse earns, on average, US \$15 per month. Even if AIDS has become a national priority, it is treated as a matter of prevention and a struggle against discrimination. If anything is to change in Cambodia, it will be because of the NGOs, not the public sector. Unfortunately, most NGOs are working on programs dealing with prevention, information, and condom distribution, or are providing training.

Now that we have a year’s experience with our ARV program, what can we report? A new building is under construction, which will contain facilities for improved patient care. The building will have a waiting room and doctors’ offices. This will allow us to improve the quality, as well as quantity, of care, since our numbers continue to increase. We are “pushing back the walls,” although we know there is a limit to the number of patients we can monitor properly. A doctor’s ARV caseload is about 100 patients. With eight Khmer doctors, we expect that 800 patients could benefit from triple therapies and regular medical monitoring. But it will take time to reach the maximum number of patients who can receive ARVs.

At the same time, we need to launch other projects. The first is to put children under treatment. Pediatric AIDS care in Cambodia is at the embryonic stage. Maryknoll, a US organization, is starting to treat some children, but it is the only example of such AIDS care in the capital. In Phnom Penh, another approach is to support patient care



A patient and companion take an evening walk.

DIDIER LEFÈVRE / EDITING

and monitoring by Khmer doctors in the private sector, to address the question of assuring quality care. Treatments exist and are available in Cambodia at an average cost of US \$30 per month, and some patients are able to afford this. But can MSF encourage the introduction of these medicines? Give them out? Sell them? Can MSF encourage patient treatment in the private sector by providing free medicine?

At the provincial level, we are considering creating a simpler project. We do not want to try to reproduce the Norodom Sihanouk Hospital experience by setting up a smaller project in a hospital. We need to be more innovative and do things differently without opening a second program. Our approach could entail extending the main project. Many patients on our waiting list come from the provinces, and we could set up an HIV office in a provincial site with an international doctor and a social worker. The site—whether a hospital or private clinic—remains to be chosen, but would also allow us to lighten the patient load at Norodom Sihanouk.

Medically, the results of our program are what we had anticipated. The statement: "It works, it's possible," is not—or is no longer—relevant. ("It works 'with those people,'" also is no longer newsworthy.) A year ago, the mood at MSF was one of excitement over launching a new project. We wanted to place large numbers of people under ARV treatment quickly in the hopes that others could reproduce our experience elsewhere. In Cambodia, we have seen that this will not be possible for several years.

Internally at MSF, we are trying to be rational while dealing with factors outside of our control. For example, we do not know what future therapies will be. But without devoting all of MSF's resources to AIDS, we can do more than we are doing today. MSF can move things forward—not just with its ARV projects, but also by playing the role of agitator. Those who will make the most progress are the people with AIDS themselves. The more people who benefit from ARVs, the more they will behave like a pressure group. MSF will not solve the AIDS problem in Cambodia or anywhere else, but, as in other countries, patients can have an impact on the authorities and influence AIDS policies. Thailand, for example, changed as a result of pressure from patient groups. South Africa did, too. Thailand is the example for Cambodia to follow. By caring for the greatest possible number of people, we can support the emergence of patient groups that can move things forward. In Phnom Penh, we can reach city residents and the media. People talk about AIDS on television and the radio. The disease is not taboo.

Our project has its greatest demonstration value for donors, not public authorities. By the end of the year, with a budget of 900,000 euros we will have between 300 and 350 patients under ARV treatment, nearly 12,000 people monitored through regular consultations, and 1,000 hospitalizations. By comparison, the Home-Based Care Network's budget is around 4 million euros and it cares for only 800 people. And that's without treatment."

*Catherine Quillet  
Head of MSF France Mission in Cambodia*

# GUATEMALA

In March 2002, MSF opened a clinic in Guatemala City, Guatemala's capital, to monitor and offer triple therapy treatment to HIV-positive patients. The Yaloc clinic, (the word Yaloc means "to fight" in Quiche) offers comprehensive medical, psychological and social care and targets the destitute.



JUAN CARLOS TOMASI - MSF

## KEY STATISTICS

- 67,000 people in Guatemala, including 4,800 children, are living with HIV/AIDS (figures from the National Program for the Prevention and Control of STDs, HIV and AIDS, 2002). Almost 50% of them live in Guatemala City.
- The prevalence rate among adults (15-49) is 1% of the population.
- The number of new infections for 2003 is estimated at 15,418, and the number of declared AIDS cases at 9,151. Between 6,000 and 8,000 people are estimated to be receiving antiretroviral treatment.





## THE CONTEXT

In Guatemala, people living with AIDS receive inadequate attention. Antiretroviral drugs are available, but their high price put them out of reach of the vast majority of patients. Treatment costs about 10,000 quetzals/month (around \$1,250/month), while average income is 1,000 – 1,500 quetzals/month (\$125-190/month).

Moreover, there is no clear political will on the part of health authorities to improve medical services for AIDS. There are only two public facilities in the country that provide outpatient services to HIV/AIDS patients--San Juan de Dios and Roosevelt hospitals, both in Guatemala City. The two lone doctors in these facilities care for around 1,000 patients. Guatemala's social security system guarantees access to free medical care, including care for HIV/AIDS patients and ARV treatment. However, only 15% of the population benefits from this coverage.

That is why MSF decided to offer ARV treatment, giving priority to low-income AIDS patients.

## MSF'S YALOC PROGRAM

This program offers comprehensive care to HIV-positive patients, including medical visits, psychological monitoring and social support. MSF offers patients free access to triple therapy ARV treatment.

- During the first consultation, a social worker, psychologist, nurse and doctor see patients. On average, about 20 to 25 medical consultations are conducted every day.
- Patients included in the ARV access program have a CD4 rate of less than 200/mm<sup>3</sup> or are in stage 4 of the illness (WHO criteria). Discussions about which patients to accept are held every three weeks among the head of mission, the program director, the psychologist and the Guatemalan doctor, as well as a representative from a local organization of people living with AIDS.
- After treatment begins, patients are seen regularly by the nurse, doctor and social worker. For the first two weeks, they are seen weekly. The next visit follows two weeks later, after which they are seen monthly until the third month. Finally, they are seen every two months.
- If necessary, the team visits patients in their homes to conduct social service investigations, when the patient has a medical crisis or when the patient does not keep a scheduled appointment.
- The community educator organizes community information sessions on the disease. The team will also set up support groups led by the psychologist.

The MSF team is composed of 11 people, including seven who make up the medical team--three doctors (the program director, an MSF volunteer and a Guatemalan infectious disease specialist), a Guatemalan nurse, an educator, a social worker and a psychologist.

**As of October 2002, 155 adults were receiving ARV treatment.**

**The goal is to offer treatment to 180 patients.**

The MSF team also expects to include children in the program.



# KENYA

MSF has been working in Nyanza province's benchmark Homa Bay hospital since 1996. The organisation launched its ARV treatment program for AIDS patients on November 15, 2001.



## KEY STATISTICS

- Some 500 people are estimated to die daily from AIDS in Kenya. Declared a national crisis in 1999, the epidemic has affected 2.2 million people, or 13% of the population.
- About 3,000 people receive ARV treatment in Kenya, primarily in private health facilities, where they must pay for medicines.
- MSF offers free ARV treatment to patients at the public hospital in Homa Bay. The province has an alarmingly high HIV prevalence rate: 35% in Nyanza province, compared to the national average of 13%.



## THE CONTEXT

After a long legal battle, generic ARV drugs can now be imported into Kenya. However, the Kenyan health ministry is still slow to register these generics, thus limiting the possibility of regular imports. Thanks to generics, the cost of triple therapy treatment has fallen to about 1 euro per day (around \$1), 40% less expensive than treatment with brand-name drugs. That price is still too expensive for Kenya, but many more patients now have access to ARV treatment.

## MSF'S HOMA BAY PROGRAM

The MSF AIDS program includes several activities:

- Within the hospital, the HIV clinic offers counselling and HIV testing (VCCT, Voluntary Counselling and Confidential Testing) and free medical care.
- MSF also conducts follow-up care of hospitalized adult patients. Patients infected with tuberculosis, the primary opportunistic infection affecting AIDS patients, are cared for by the hospital's tuberculosis department and in outlying health centers.
- In February 2001, MSF and the Kenyan health ministry signed the first agreement to introduce ARVs into MSF's Homa Bay program. Several meetings with authorities and health personnel and additional agreements followed on technical issues.
- Implementing the agreement required months of negotiations. On November 15, 2001, the first patient began ARV treatment. Since then, 25 new patients have been incorporated into the program each month.
- New patients are included based on clinical diagnosis and a CD4 rate below 200/mm<sup>3</sup>. A health counselor from the MSF team conducts interviews with each person being considered for the ARV program. The medical team monitors patients included in the program.

**By late October 2002, 240 people, including 20 are children, had begun ARV treatment.**

Today, MSF hopes to convince other partners of the feasibility of such programs. To fight the AIDS pandemic in Nyanza region and elsewhere in Kenya, availability of ARV treatments, which have proven their effectiveness widely, must be improved.

MSF also works in Nairobi, in the "Blue House," the HIV clinic in the Mathare shantytown, where antiretroviral treatments are set to begin in 2003 (read the statements following from patients treated at the clinic).

# Kenya, Homa Bay hospital

## Breaking the Curse

Some forms of violence are less visible than others. There are no Kalashnikovs or mortars here. The men sail off to fish for tilapia on Lake Victoria while the women dry the catch on the beaches. Some violence is mute and kills quietly. Some still call it the chira, the curse. Others know that ayaki, AIDS, affects nearly one in three people. The monitoring form shows a sun and a moon, indicating when to take the medicines. There are boxes to check, too. Today, John (names have been

***Along with tradition, churches preach only abstinence and fidelity.***

changed), 32, is starting his triple therapy. He is weak and emaciated. Terror is deep in his eyes. That terror is even

more evident than the physical signs of the disease among the patients hospitalized here. These are men and women in the prime of life, struck down by the virus.

Homa Bay is the only public hospital in Kenya where antiretroviral medicines (ARVs) are free. That means that AIDS could become a chronic—and no longer fatal—disease. People are dying here like flies because they cannot afford to pay for medicine. It is as simple and frightening as the title of a Clint Eastwood spaghetti Western: Life versus a Fistful of Dollars.

*"Sometimes it's hard,"* says Agnès, a doctor and the MSF program director. *"There are so many people waiting for treatment."* With Vincent, the HIV physician, she established the ARV project in November 2001 in Homa Bay Hospital. Over five years, MSF managed to put effective hospital standards in place for sanitation, water, and waste management, while maintaining good relations and constructive dialogue with authorities.

Leaning on his cane, his other hand gripping the plastic bag holding his medicine, a man leaves Vincent's office. Other patients wait in the hallway. Some are receiving triple therapy, and others have just been tested for HIV. MSF keeps a low profile at Homa Bay Hospital—no logos or posters. It operates by word of

mouth. People who come to be treated regain their strength in a few months, proving that AIDS is not necessarily a death sentence.

*"They say that ngima is the life spirit and that death (tho) occurs when ngima has left."* Here, illness is often seen as a curse, sent by the vengeful spirit of a wronged ancestor. Chira, the curse, presents the same symptoms as ayaki, AIDS. Even if ideas are changing, the line between the visible and the invisible remains blurred, and the elders reject scientific explanations about how AIDS is transmitted. Further, the church and religious sects preach abstinence and fidelity, but oppose the use of condoms.

The Luo are the region's ethnic majority. In Luo society, a widow must marry her dead husband's brother. While this tradition may ensure social cohesion and the survival of women, who own nothing outside the family, it promotes the spread of the epidemic. The Luo practice polygamy, which, in the absence of systematic use of condoms, greatly increases transmission risks.

With adult prevalence of HIV at more than 30 percent, the Homa Bay region is breaking grim records. MSF has 240 patients taking ARVs. At the tuberculosis clinic and in the general medicine departments, the fight against opportunistic diseases has slowed the epidemic's ravages. But the morgue still is not empty. *"Every time I feel discouraged, I think about Paula, one of our first patients,"* Agnès says. *"When I prescribed ARVs for her, she weighed 36 kilos (79 pounds). Today, she weighs 57 (125). Her CD4 level has risen from 57 to 132."* With the immune system strengthened, life can return to normal. Thus, ARVs should not be considered a luxury reserved for a minority.

At Homa Bay's beach, between the boats and the strong odor of fish drying, the women wait for the next market day when they'll earn a few shillings. Tomorrow, one of them will be too tired to get up. With a little luck, one of her neighbors will pick her up, lift her into a cart and wheel her to the HIV clinic.

# At MSF's "Blue House" in Nairobi

## Waweru, a counselor

*"I want to love and be loved. I want to work and contribute to society. I still have dreams and feelings, but I'm living with AIDS. To be seropositive is not just a nightmare, it's a social stigma, too. Other people perceive me as an AIDS patient before they see me as a human being."*

Waweru, a counselor at the Blue House, the HIV clinic that MSF opened in the Mathare shantytown in Nairobi, wrote this passage based on the comments of patients he sees every day. He talks with new arrivals about the disease and how it is transmitted, the need to be tested, and what a positive result means. If the person agrees to be screened, he will administer a blood test. Rapid laboratory tests provide results very quickly. Waweru will also deliver the results—positive or negative—which can turn a life upside down in an instant.

– *"Can you keep my secret?"*  
– *We may be the only two who know the secret. Perhaps this woman will decide to hide her HIV-positive status from her husband for fear of being thrown out of the house. Often, the family doesn't know until the last moment, when the person is close to death."*

Wearing an old jacket and a faded shirt, Waweru dresses like the people he counsels. And he's not one to sit behind a desk. The fewer the barriers, the easier it is to build trust. The key word is empathy. Don't judge, but listen and give energy and hope.

*"Our parents talk about morals. We talk about condoms."* Like the vast majority of Kenyans, Waweru is a religious man and an observant one, but he doesn't mince words when it comes to religious leaders who refuse to discuss AIDS or who oppose the use of condoms.

*"We're living in a state of hypocrisy. Some people follow the moral rules that the church preaches. For the rest, real life doesn't have much to do with sermons."*

*"Often, after the test result is announced, I see the face of the person in front of me fall apart and the tears flow. After several appointments, it's good to see them start smiling and laughing."*

Waweru's work helps people both face reality and find a taste for life again, and it provides continuing support for the clinic's medical activities. Patients return to the Blue House because they feel safe there. The treatments they receive for opportunistic diseases allow them to recover their strength. Next year, the team expects to begin providing ARVs.

*"More and more patients talk to me about ARVs. I explain that we don't have them yet. Most of the people who are seen here take their medicines regularly. I don't think we would have compliance problems with ARVs, either. When you know there are treatments, effective treatments, but you can't offer them to patients yet, you feel really powerless."*

LAURENCE HUGUES – MSF



Waweru, MSF counselor,  
in the Mathare shantytown.

# **Mathare shantytown, Nairobi**

## **In the Patients' Words**

### **LUCY RECEIVED ARVS FROM A KENYAN FRIEND LIVING IN SOUTH AFRICA.**

*Lucy (not her real name), 31, is from Mathare, in Nairobi. She learned she was HIV-positive when her husband died, leaving her with a 14 year-old son. She began ARV treatment a few months ago, when a friend from South Africa decided to help her.*

"When my husband passed away in 1999, I didn't know I was HIV-positive. I was healthy, but I started getting sick. I was coughing too much and I went to see a doctor who told me I had tuberculosis. Then I met somebody from here [MSF's HIV/AIDS center in Mathare], and he said I should be tested. I was working then and I had medical insurance. My employer realized that I was often ill and I received a letter telling me that I should not work for medical reasons. Basically, they fired me. They didn't say they were firing me because I had AIDS, they just referred to the state of my health. What could I do? I took my things and left.

"I'm educated. I've worked with computers and done a little accounting. I know I can work but here you're just so stigmatized. You look for a job, you find one and everything is fine. And then at some point you go to the doctor and take a rapid AIDS test. You can forget about your job! That's happened to me several times. They're afraid that you won't be able to work most of the time. So you become sort of

financially disabled. Before, I paid my rent and my son's school fees. Now life is hard.

"You can't tell your friends you are HIV-positive because they'll run away. We were so close ... Even family members consider you a disgrace. They find it immoral, but I've never understood why. When people come to see you, they don't come to comfort you. All they see is that you're going to die. It's not like that with other diseases, maybe because AIDS has a sexual connotation. But what are you to do--kill yourself? If I can't feed us, if I can't pay for my son's education, what am I going to do? Let me work because I have to live. But they don't even give me that chance.

"Now I stay home most of the time. Before I started on ARVs, I used to be sick a lot. I remember when I had herpes zoster [shingles]. I had to stay home for about a month. I haven't worked since the beginning of the year. It's very hard. I have a kid to feed and I have to feed myself. Sometimes we buy vegetables at the Marigiti market and I sell them in the street. I only earn a little but you have to earn a living. It's not enough. My son has to go to secondary school and how am I going to manage? I only receive one kind of help—for getting drugs--but it's very important. I was really sick. My CD4 count was very low and I was in a lot of pain. I could barely get out of bed. The friend with whom I sell vegetables came to my house. She helped me and gave me food. She spoke to a friend

**The "Blue House" should begin dispensing ARVs in 2003.**



LAURENCE HUGUES - MSF



of hers about me. This friend is a Kenyan living in South Africa. They took me somewhere for treatment. It was a private medical office and the doctor gave me drugs. Later he asked me if was taking medication. He told to take these certain drugs, ARVs. I hadn't heard of them. I told him that I couldn't afford them. At the time, they cost 10,000 shillings (around \$130) per month. My South African friend told me he'd help me get ARVs so that I could get back to a normal life work.

"I've regained my strength. My CD4 count is good again. I haven't been sick lately. Now the ARVs are less expensive. They cost around 7000 shillings (\$90) per month, but I can't even afford that. If the drugs were cheaper, perhaps we could buy them and people would survive. You wouldn't see so many people dying."

**JANE ACHIENG ALSO LIVES IN MATHARE. STRICKEN WITH AIDS, SHE WAITS IMPATIENTLY FOR ARVS AND THE BENEFITS THEY OFFER.**

*Jane Achieng (not her real name), 27, had been married for four years when her husband died last year from AIDS. Her 6 year-old daughter also has the disease.*

"My husband became ill first. We bought medicines, but they didn't do anything. A doctor gave us an AIDS test. We were both positive. I didn't expect that at all. I thought it was the end of everything and that my life had been cut short. I was afraid no one would take care of us and if I died that no one care for my daughter. My husband was very weak. He was being treated for the illnesses that made him sick, but not for the HIV. At one point he developed heart problems. It was Thursday. He died on Saturday, December 1. It was World AIDS Day. I was there. The situation for AIDS widows is very bad. The relatives take everything from you after he dies. I had lots of things and they took them all. After he died, I went to stay with my sister, but life was hard because of the way they treated my daughter and me. Not everyone understands HIV and AIDS. Some people think that if you are HIV-positive, you are a prostitute. That's not true. I didn't know that my husband was HIV-positive. At my sister's house, we ate separately. I had a bowl,

plates, glasses and cutlery for my daughter and me. I'm sorry that I told my sister that I had AIDS. We are no longer friends. No one in the family supports me. Most of my friends don't know and I'm afraid to tell them.

"I tried to find work, any kind of work. I didn't go to school. I have no practical experience so I'm looking for a job as a housecleaner. No one in my family is helping me, just my friends. They are giving me money. One of my friends is renting a house for me and another is paying my daughter's school fees. If you came to my home, you'd see that it's very simple. I have nothing valuable. I have no bed, only a little mattress. I have gotten sick. I had ulcers and sometimes I would bleed heavily. I went to the hospital for treatment and began following the doctor's advice. I started going to the counseling program [at the MSF HIV/AIDS center in Mathare]. Since then I have been taking the medicines and antibiotics and I'm doing everything they told me to do. I haven't been very sick since then. I come for a check-up every month. It is very far away

but I like coming here because they take care of people like me. I come by foot even though there's a mini-bus that comes here. I can't afford to buy a ticket. From my home it takes about 45 minutes to get here. If I have a problem, I come here. I talk to them and they give me advice. They are very busy helping me and many people in Mathare.

"I can't get ARVs and they can't give them to me here yet. It's very expensive and there are so many of us. My doctor says that if the prices go down, perhaps they can give them to me. With ARVs, perhaps I could survive and take care of my daughter. I don't want her to suffer the way I'm suffering now."

***"The situation for AIDS widows is very bad. The husband's relatives take everything after he dies."***



# MALAWI

MSF works in the Chiradzulu hospital in the southern part of the country, home to about 235,000 people. The ARV treatment program for AIDS patients began in August 2001.



DIDIER LEEVRE / EDITING

## KEY STATISTICS

- In Malawi, 850,000 people are affected by AIDS, including 65,000 children and 400,000 women. This corresponds to about 10% of the total population and 15% of the adult population (15-49 years). (UNAIDS figures).
- Women between 15 and 19 are 5 times more likely to be infected than men of the same age.
- 390,000 children have lost their mother or both parents since the start of the epidemic. There are 70,000 new orphans every year.
- Between 2001 and 2005, AIDS will be the cause of death of at least 125,000 children under 5.



## THE CONTEXT

AIDS patients in Malawi have had access to triple therapy treatment since the government authorized the introduction of ARVs on May 31, 2001.

## MSF'S CHIRADZULU PROGRAM

The MSF project is intended to provide HIV-positive and AIDS patients with access to treatment and quality care.

- Patients join the program based on two criteria. The medical criteria require that the patient's CD4 level be below 200/mm<sup>3</sup> or that the patient be at stage 4 in the progression of the disease, based on WHO standards. Pregnant women must have a CD4 level below 350/mm<sup>3</sup>. According to the non-medical criteria, patients must live in the Chiradzulu district and each patient must be accompanied by a "guardian" (that is someone from the patient's immediate family who will help the patient take his/her medicines and who must accompany the patient to his/her weekly appointments at the hospital for the first eight weeks of treatment).

- Currently, 70 new patients are accepted each month.

Program structure

- Free and anonymous testing center within the hospital.

- AIDS consultations are held daily in the hospital and twice monthly in the health centers. They are run by MSF doctors and health staff, as well as by the Malawian medical staff from the health ministry.

- Information and counselling sessions are organised for HIV-positive patients, whether or not they are under ARV treatment. These provide information on AIDS, opportunistic infections, treatment, prevention, the use of condoms and hygiene.

- For the first eight weeks of treatment, the patient must come to the hospital to obtain his weekly medication. This allows the staff to monitor his physical status, the presence of side effects and any difficulties the patient may be encountering in taking his daily medication.

- A group of HIV-positive people founded the PLWA group (People Living With AIDS) two years ago. This group is supported by an MSF counsellor and brings together people with AIDS, some of whom are under ARV treatment. The patients meet monthly to talk about their illness, their lives and prevention. They put on shows (plays, songs) in the local health centers to inform people about AIDS and encourage prevention. Some people in the group are also active in the distribution of male and female condoms.

**Of the 915 patients in the program, 302 were receiving ARV treatment as of late October 2002. (Included in the program are 170 women, 11 children and 6 pregnant women).**

Forty people have died and two have dropped out of the program.

# Malawi, Chiradzulu hospital

## In the Patients' Words

### ENA IS PARTICIPATING IN THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV/AIDS PROGRAM (PMTCT).

*Ena A., 28, is HIV-positive. What makes hers an exceptional case is that her husband is HIV-negative, so she is particularly aware and sensitive about prevention issues. She benefited from the PMTCT programme \* and her baby is HIV-negative. Ena is very involved in efforts to fight HIV/AIDS and would like to become a volunteer MSF counselor. She's taken in two orphans from her village and is raising them along with her own four children.*

"I was infected in 1998. I think I got it from my brother-in-law. He was very ill and covered in open abscesses. I was the one looking after him and disinfecting his wounds. There was always a lot of blood, and my hands were cut. He has since died, and given his symptoms, I'm sure he died of AIDS. In May 2001, I was pregnant. I didn't feel bad at all. I just had a gynecological problem and that's why they suggested I take the test. As soon as we found out I was HIV-positive, my husband took the test. He was negative. Ever since, we've been very careful every time we have sexual intercourse. We systematically use female condoms. Then I joined the PMTCT program and took ARVs when my baby was born. He got a single dose of ARVs. It worked. He's now fifteen months old and he's fine."

\* An estimated 10% of HIV infections occur through mother-to-child transmission. Through the PMTCT program, the mother receives ARVs at childbirth as soon as contractions begin. Then the baby receives a dose just after birth, in syrup formulation. Before the baby is 18 months old, there is no point in screening for HIV as the child still carries his mother's antibodies.

Ena and her whole family.



ISABELLE MERNY – MSF

### JIMMY IS WAITING FOR ARVS. ONE MONTH AGO, HE LEARNED THAT HE IS HIV-POSITIVE.

*Jimmy M., 34, is a farmer. He's very thin and wears a ripped T-shirt. He tells his story, but his gaze is turned away. He's withdrawn.*

"I met a woman while I was travelling. I was married, but unfaithful. That's how I got ill. I had already heard of AIDS. I thought it might happen to me one day because I travelled a lot and stayed away for long periods of time. Sometimes I used a condom, and sometimes I didn't. In 1998, I started feeling ill. My legs were very sore and I had diarrhea a lot. I took the test last month. Before that, I didn't know what to do. Only my parents know I am ill. My wife died in 1998. I had three children with her. They're all grown now and they're healthy. I didn't remarry after her death.

Now I just feel so weak and tired! I can't work anymore, and I've had to go back and live with my parents. I have to tell my friends – but I'm not worried about their reaction.

I have an appointment with Médecins Sans Frontières in a few days. I hope that I'll be able to start ARVs, and that I'll get better and will be able to work on my land again."

### DIXON BENEFITS FROM ARV AND ANTI-TUBERCULOSIS TREATMENTS. HE IS WORKING AS A VOLUNTEER COUNSELOR.

*Dixon O. is 41. He's a farmer and builder. He and his parents greet us at his home, sitting on a mat under the trees. He is thin and his legs are swollen. During the interview, he insists on getting up to fetch his boxes of medicines to show us that he's been taking them properly.*

"Once when I was feeling ill, I went to a traditional doctor who gave me an injection. The problem was, he used the same syringe

for everyone. I think that's how I got infected. My wife died. Maybe she died of AIDS. I don't know. My legs started to swell and I had high fevers. I had already heard about AIDS in group meetings. I decided to take the test in 2000. I wasn't worried when I found out I was ill. I expected it.

I didn't have particular problems with the people around me because I was still strong and in good enough health to work, cultivate my land and build houses. Only my legs were a problem. I started taking ARVs in June 2001, and I didn't have any side effects. I sleep and eat well and I feel better every day. My legs are less painful now. I don't have any problems taking the pills. I haven't forgotten a single dose. It's easy: one pill when you get up – it's the first thing I think of when I open my eyes – one before eating, and one before going to bed. I have TB, so I combine two treatments without any problems. I finish my 8-month TB treatment next February.

The MSF doctors and nurses have looked after me like a mother would have done. They saved my life. Today, I work as a volunteer counsellor for PLWA [People Living With AIDS – a Malawi association]. I lead information meetings once a week in my village and I give people advice. I've encouraged more than 16 people to go and get tested.

I would like to start a fish business. And I have to build a house for my mother. I'm getting married in three months to a woman I met through the PLWA group. She looked after me when I was in hospital for my TB (everyone in the group is responsible for looking after one other person). She's HIV-positive too. We use condoms and we're very careful. I already have two children – they're 11 and 15. They live with their mother's family, but come to see me often. And my future wife also has her own two children. We're just going to live together. That way we won't be alone anymore, and we can support each other. Other than that, I've sowed my field. I'm waiting for the rain now."

## GEORGE MARUWO, MSF HEALTH WORKER

"I've been working in the MSF programme in Chiradzulu since May 2002. I did a general medicine training for three years and then started working at the hospital where I had done my internship. I saw a lot of people with AIDS, and I wanted to do more against this disease. I look after all the patients in the men's department, particularly AIDS patients, both in the hospital and in the district health centers (there are 10, soon to be 11).

When AIDS first appeared in Malawi, no one wanted to talk about it. It was totally taboo. Many people got infected because there was no information and no prevention. Even two years ago, people didn't use condoms because it went against our country's religious beliefs. People are very devout here. It's only now that we're starting to hear people talk about it. The ARV programme is a real success. Every day, I can see that people are getting better as they take their treatment. They gain weight, get out of bed, start to work again, look after their children, send them to school...These medicines perform miracles. Some patients come from far away, because they've heard good things about antiretrovirals. Our patients comply with the treatment very well because we explain at length and several times how they have to take them, but also because they realize themselves how much better they feel taking them. It's sometimes hard for those who live far away. They have to walk for a long time to get to the appointment. Some have to take public transport, and that's expensive. That's why mobile clinics are so important for patient monitoring. I think this treatment arrived just in time. We have to increase the number of patients under ARV. That's what MSF is trying to do here in Chiradzulu."



George, an MSF health worker.

ISABELLE MERNY – MSF

# Maryline Mulemba, Head of Mission

## “Not Aliens After All”

“I’ve worked with the AIDS program since November 1998, but I had already been in Malawi for several years, from the time that MSF was helping refugees. These are two very different periods. We had a lot of experience with refugees, but we were pioneers in dealing with AIDS. There were no manuals. We learned in the field with help from MSF technicians and other partners. Since we are nearly the only ones running this kind of program, we really have the sense that we’re working on behalf of the most destitute people, the ones no one bothers with.

It’s also fascinating to observe how differently other humanitarian agencies view our work now. Two years ago, when

***“If I wanted to stir people up, I’d say that dispensing ARVs is almost as easy as treating malaria.”***

we made the rounds of donors, everyone treated us like we were aliens from outer space who didn’t understand anything about the local situation. How could ARVs be

introduced when there weren’t even any oral rehydration salts? Today, no one criticizes us and everyone agrees that treatment is necessary. Unfortunately, aside from the Global Fund for AIDS, Tuberculosis and Malaria, there are still no donors here in Malawi involved in a concrete way.

Nonetheless, the results go well beyond encouraging. We have put more than 320 patients on ARVs, including women and children. More than 85 percent of them are still alive, despite the fact that their health status was disastrous when they entered. Patients are very serious about taking their medicines. We were concerned that they would not understand that this treatment involves taking medicine every day for the rest of your life. Here, thanks to the activity of the support group PLWA (People Living With HIV/AIDS) and the work of the team, which explains the importance of

compliance, almost no one has dropped out. It is still too soon to analyze the treatment’s impact on the problems patients face being stigmatized by the community. But we see that some of our patients are talking about and acknowledging their HIV-positive status. That’s very unusual here! The program is a success one year after it began. Most of our early fears have dissolved.

Our real challenge is providing services to all the patients knocking on our door. Up until now, it’s been done on a small scale. We will have to streamline the process from a medical point of view and in dealing with laboratory tests. I also believe strongly that the community must support patients in treatment. We will have to take new risks. For example, we will have to monitor patients only through the HIV clinic and reduce the laboratory’s involvement. Donors and governments will also have to address the human-resource problem: how can quality care be provided when we are short-staffed?

At the Chiradzulu hospital, there are always at least 170 hospitalized patients, but only 12 nurses to cover all the shifts! This staff shortage doesn’t affect only the patients receiving ARV treatment, but extends to caring for those with simpler pathologies, like malaria. If I wanted to stir people up, I’d say that dispensing ARVs is almost as easy as treating malaria!

In Malawi, the key challenge for the authorities will be to make wise use of the resources provided by the Global Fund. The authorities will need good partners who will be able to help them become operational. They will also need to increase staff-training capacity and find a way to keep staff in the country. Perhaps they should ask the wealthy countries not to hire them away. Last year, 100 nurses left for England, while Malawi only trains 60 per year. AIDS in Malawi? It’s a question of survival.”



# **Philippe Abboud, Physician**

## **“That’s Not Very Much”**

*Philippe Abboud, 34, is a doctor specializing in internal medicine and infectious diseases. He has worked in the MSF program since July 2002.*

*One week in particular, in late October 2002, began badly. Since Monday morning, Dr. Abboud had “lost” a child and an adult female patient, the latter the sister of a national staff member, in whose care he had been particularly involved. She died three days after being hospitalized. His week ended just as it had started.*

“The pathologies most commonly associated with AIDS are tuberculosis and genital and lung infections. There is no real malnutrition in Malawi. It’s more of a problem that compounds the already fragile health of children. We began treating children two months ago. Today, eight are benefiting from ARVs. We don’t have enough distance yet to evaluate the results, but compliance appears to be quite good. The mothers nearly always show up for their appointments and never lose the child’s treatment book.

This work requires a lot of energy. That’s why we can’t ask the Ministry of Health staff always to be as motivated as we are. We’re just passing through. They are here full-time. On average, they lose two or three patients every day. It’s normal that they would pull back. It’s also a way to protect oneself. They’re under-staffed, but that’s a problem in France, too. I wouldn’t say it’s a question of lack of motivation. Maybe it has more to do with a sense of fatalism.

We ought to go out and find patients, not wait for them to come to us. That’s what we’ve started to do with the mobile clinics. There’s no question that it has a snowball effect. Word of mouth operates quite well. The number of patients we’re seeing is growing on its own. Some patients even come from Blantyre, the capital, but because they’re not within a certain distance from the Chiradzulu Hospital, they don’t meet our inclusion criteria. It’s very hard to refuse to

treat them. What should we say to these patients? Of course, we make exceptions, but how far can you go? We need to have a clear and coherent discussion of this subject, especially with the staff, the national clinicians. They are even more affected than we are. We’re talking about their country and sometimes even their family or friends. Blantyre is more easily accessible than some of the district villages. The policy may be clear in theory, but in practice it’s not so obvious.

The program operates well. We should continue treating those who don’t have the material or physical means to get to the hospital. If we went to them and treated them at home, we would also relieve the hospital overload. In the long term, we’ve got to anticipate turning the program over to the local authorities. Given the number of patients, a government agency has to manage things. But at what point will MSF know that its goal has been achieved? After how many patients are being treated? Thanks to ARVs, we have demonstrated that treatment is entirely feasible. Now we’ve got to move to a larger scale.

Caring for three hundred patients is certainly important on an individual and human level. But compared to the number of people with AIDS here, from a public health perspective, three hundred people is far too few.”



**Philippe Abboud,**  
in Chiradzulu for six months.

ISABELLE MERNY – MSF

# **Fred, a Witness of the Effect of ARVs**

## **“Why I Must Live”**



Fred and his wife, Steria, in Chiradzulu.

ISABELLE MERNY – MSF

*Interview with Fred Minandi at the World AIDS Congress, Barcelona, July 2002.*

“Hello.

My name is Fred Minandi. I am 42 years old, and I am a farmer from Malawi. My wife is a farmer, too, and we have two children. The older one is married, and the younger one is still in school. I am lucky to be among the patients benefiting from ARV treatments as part of one of MSF’s projects. My village is in a rural area. My house has a thatched roof and one room. I earn a little money from my garden because I grow food.

Malawi is probably one of the poorest countries in Africa and has the highest HIV rate on the continent. Fifteen percent of the adult population is infected. Where I live, 24 percent of the pregnant women who have been tested are seropositive. Ten percent of the youth in secondary school are ill. Those are the statistics, but what I see in my village are young people who are too sick to work in their gardens and feed their families. Families spend huge sums trying, in vain, to find medicines. I have seen parents die, leaving behind orphans to be cared for by elderly people who have no hope of providing them a future.

I became ill in 1997. Over four years, my health was sometimes better and sometimes

worse. Finally it became hard for me to work or do anything. I was tested in 2001 and was lucky to live where MSF was just starting ARV treatments. I am one of the first to have benefited from free ARVs in Malawi. The fact that I can talk to you about this is because I am in treatment.

Some people will say that Africans cannot take their medicines properly because they don’t know how to tell time. Maybe I don’t have a watch, but I can tell you that since I began my triple therapy in August of last year, I have never forgotten to take a single dose. Why? Because Margo, the MSF nurse, took the time to explain to me how these medicines work. She told me that if I wasn’t serious about taking them, they would have no effect. She told me about the side effects and said that I’d feel better after a while, but that it would be difficult. At the beginning, I was nauseous but that disappeared after two months.

All my friends in the support group of people with AIDS think as I do. We are 60 in the group and we meet every month to talk. We explain to the ones being treated what they should do in case of side effects. We help each other if one person is too ill to pick up his or her medicines. We support the people in the group who don’t have anyone to talk to about being seropositive or about treatment. This means we go with them to the first session, and we then help them take their medicines at home. We try to help the family when someone dies, but our primary activity consists of talking about how our health has improved and how the treatment helps us to live again. We are going to try to develop some fundraising activities. We let our community know about the medical services (the HIV clinic, the program for infected pregnant women, the voluntary counseling center, and where to get condoms and information) that are available to everyone who lives in the district.

My CD4 count was 107/ml when I began treatment. Today, it is at 356/ml, and I am very proud of that. When I became ill, I knew I was seropositive but I never wanted to

admit it or talk about it. My neighbors saw me get weaker day by day. Of course, they knew what was wrong but no one asked questions. Little by little, they just stopped coming to see me. Most people are like that in Malawi. They don't raise the subject because they don't want to know. That is why my country is dying in silence.

Now I work in my field, I have returned to my church, and I can feed my family. Over the last two years, I harvested only two bags of corn because I was so weak. This year alone, I harvested 10. I feel like I have a future. My neighbors have started coming to see me again, like they did before. When there is a meeting in the district, I go and talk about my disease because I'm not ashamed anymore. I know I won't be rejected, because I'm like the others. Someone who has AIDS and is very ill frightens everyone because people see their own death in his eyes. But once you are being treated, you feel better, you look better, and people don't reject you anymore. I would like to tell you all that treatment is the best weapon against stigmatization. I thought there was no hope for seropositive people, but the treatment has changed how I see things.

Some people will also tell you that treatment is too expensive and that a country like Malawi should only work on prevention. First of all, would that mean that all my friends in the People Living With AIDS group, the million people infected in Malawi, and I, myself, must die? It is too late for us to talk about prevention, but I strongly believe that we have the right to be treated. I would like to say that I consider my life to be important, not just to me, but to my family and my whole country. I think that my contribution, as small as it might be, to my family, friends, neighbors, and the country of Malawi, complements the work of everyone who keeps Malawi alive.

Second, I think that providing affordable treatment will encourage many more people to face their HIV-positive status. This will allow the silence to be broken. My friends in the PLWA group and I have been trained as counselors. We have been able to convince many people to take the test because they know they will be treated if they are positive. Third, we use generic medicines from India for the Malawi program, which lowers the price. The less

expensive the medicines, the less costly the program and the more people we can treat.

I would like to say that treatment and prevention are linked. I am sure that today I could convince more people to change their behavior, use condoms and take the test. Because I am being treated, I can also explain to them that treatment is very difficult and they must be very careful to avoid becoming infected. I would also like to ask of those who say we should only do prevention: If there were so many victims of this epidemic in your community, would you let all those who were already seropositive die? I hope I will be able to meet many seropositive people so they can help me to be even more active. We are the ones who need these medicines, and it is up to us to fight for them. I hope we will make ourselves heard by decisionmakers and will be able to convince them to give money to buy medicine.

***"My life is important to me, my family, my friends and my whole country."***

To conclude, I would like to appeal to the pharmaceutical laboratories that manufacture ARVs to reduce the prices of their medicines for all low-income countries, to our governments to support treatment and demand help, and to the governments of the wealthy countries to give us money so that we can reach our goals.

Thank you for your attention. This is the first time that I have been outside of Malawi and it is an unbelievable experience."

*Fred Minandi*



DIDIER LEFÈVRE / EDITING

# UGANDA

MSF has been working in the Arua hospital in northern Uganda since February 2000 and in July 2002 launched an ARV treatment program for HIV/AIDS patients. Today, MSF is the only organization in the country to offer free triple therapy treatment in a public facility.



DR

## KEY STATISTICS

- Over 20 years, nearly one million Ugandans have died of AIDS and illnesses caused by the virus, according to an annual report published by the Ministry of Health in October. (At the last census, taken in October 2002, Uganda's population totaled 24 million.) Of the 947,552 deaths recorded, 45% were women, 44% men and 1% children younger than 15.
- The AIDS prevalence rate in Uganda is 5% of the general population and may run as high as 6.5% among pregnant women.
- Today, 600,000 people have the virus, including 110,000 children. (Sources: UNAIDS and the Ugandan Ministry of Health).



## THE CONTEXT

Uganda was the first country in Africa to mobilize vigorously against AIDS, specifically by implementing national prevention program in the 1990s. Today, the health authorities' goal is to provide antiretroviral drugs in public health facilities.

## MSF'S PROGRAM IN THE ARUA HOSPITAL

- The MSF team in Arua runs a PMTCT (Prevention of Mother-to-Child Transmission) program. MSF supports prenatal consultations and maternity programs, and tests pregnant women in collaboration with AHAP (Arua Hospital AIDS Program), a Ugandan organization that helps HIV-positive people.

- In April 2002, MSF constructed a building within the Arua hospital complex to serve HIV-positive people. The team has offered triple therapy treatment in this HIV clinic since July 2002 and provides all necessary medication. Since the facility opened, the team has taken on 60 to 70 new patients each month (compared to 30 to 40 before April 2002).

- The team monitors, diagnoses and treats HIV positive patients who have been hospitalised in the hospital's internal medical and infectious diseases departments.

- MSF works in collaboration with the Ugandan group NACWOLA (National Community of Women Living With HIV/AIDS in Uganda), which provides food assistance to HIV-positive patients and organizes support groups, as well as home visits.

- The team also provides support in implementing general hospital safety measures, especially providing single-use supplies so that the hospital stocks do not run out. MSF has also participated in rehabilitating certain sectors of the hospital, specifically the laboratory, which analyzes CD4 tests and monitors side effects of the antiretroviral drugs (blood enzymes and hemoglobin).

Since November 2001, 691 patients have been seen in the HIV clinic (figures from October 15, 2002).

**Currently, 59 patients are receiving ARV treatment.**

**The goal is to offer this treatment to at least 400 patients by the end of 2003.**



# **Uganda, Arua Hospital**

## **Prevention of Mother-to-Child Transmission Programs + Antiretroviral Drugs = A Chance of Hope**

***In this room, it's as if they are counting out so many disappeared CD4 cells.***

The prenatal clinic in Arua's regional hospital serves about 100 women. The hall outside the program for the prevention of mother-to-child transmission of HIV remains crowded. It is difficult for mothers to cross the threshold into the program's offices. Will they agree to be tested for HIV at the risk of having their lives turned upside down? Since space is limited, counseling sessions are held in groups of 10. Group pressure can influence one's decision to be tested—in either direction. But with more than one million Ugandans out of 24 million infected with AIDS, that reality demands

that they make some compromises. At the Arua Hospital, MSF supports the HIV clinic and the prevention-of-mother-to-child-transmission program. An antiretroviral

(ARV) program began at the end of July 2002. On October 15, 2002, there were 691 active cases receiving psychological support or awaiting ARV treatment. Most are women (more than 450)—and most are widows who have no resources.

The pace at the hospital is rushed. It is a rush against time that is palpable in people's words, gestures, and the hurried gait of MSF's midwife, Donna, who joins us a few moments before she leaves again for the maternity ward. Time seems to slow down when we get to the end of a hallway, where we see a door on the left. Inside this tiny closet of a room, Rita and Joyce carefully count out the capsules they are going to deliver today. With a little luck, they will offer some hope of a future free from suffering. The ravages of AIDS impose certain priorities; specifically, to treat those whose immune systems are the most affected. In this room, it is as if they are counting out so many disappeared CD4 cells. These two "counselor-nurses" will spend their afternoon visiting three new ARV treatment-program patients. We head out in MSF's 4X4 to meet with the three, identified as R., J., and L.

R. has been under our care for about two months. Her CD4 count is 9. She had to stop

treatment for three weeks because she could not eat. She is lying down behind her house, a little metal shack behind the police building where she worked before she became ill. Two women watch over her, but her body refuses everything that a body needs. She has excruciating headaches and grimaces with pain. She can barely hear and struggles with her body, seeking the composure to preserve her dignity. Rita and Joyce sit down on the mat, both extraordinarily patient and willing to listen. Their presence calms R., as if they were the last bastion of protection from the AIDS assault. Words become artifice; silences say more. The two women will not leave R. until this silence has settled in. Perhaps this is one way of being with her.

L. is 34. She lives with her mother, who has a tiny shop in front of her house. She has just started treatment, and the only problem she has experienced is memory lapses. Tall and slender, L. carries herself well even though her thinness is revealing and severe enough to keep her from her job as a secretary at the Arua post office. This visit doesn't last as long the first one. The nurses leave satisfied with her health, which is unusually good for someone whose CD4 level is below 100.

J. is 29. She is separated from her husband and has lost two of her four children. It's hard to reach her *tukul* (hut) deep in the bush. She lives with her mother and brothers. Seated squarely at her doorstep, hands on her knees, she greets the two nurses. She had been afraid that they would not come and had a bad dream last night. Rita and Joyce sit down next to her. In addition to updating the treatment record, the nurses examine each dose of ARV medication that is still bagged, to confirm that J. is following her treatment. Perhaps these gestures are intended to reassure the neighbors, who gather around, that the patient is being monitored very vigilantly. J.'s fixed, empty expression brightens when they join us, a sure sign that the general level of apprehension around AIDS is fading. Three of them have also contracted the disease.

# **Jane, an HIV-positive patient in Arua**

## **“I Had a Dream...”**

*Jane is 40. Widowed since 1993, she lives alone with her three children, ages 14, 11, and 9, in a little pink tukul, in an Arua neighborhood. Goats, chickens, and children mingle on the red dirt paths leading here.*

Jane is stretched out on a mat outside her house. Her neighbor Salomé is close by. Gertrude and Baife, members of NACWOLA (National Community of Women Living With HIV/AIDS), have come to visit. NACWOLA, which has nearly 100 members in Arua, is made up of HIV-positive women. All volunteers, they rely only on themselves and the group's strength to live with the disease, although they know no one ever recovers from the illness. And to continue to live under discriminatory conditions, many prefer not to know and refuse to be tested. They say that many people, especially men, are afraid. Even knowing they are infected, and fully aware of the devastation the disease will cause, they take no precautions. *“They don't want to die alone. They would rather infect other people and pass the disease on to them.”* Like Gertrude and Baife, and like Salomé, too, Jane has chosen to accept and bear the status of being an HIV-positive woman. *“We want to stay alive as long as possible,”* they say. Like their carriage, their words reveal an uncommon dignity.

However, the road to acceptance can be long. *“My husband died in less than a week,”* Jane says. *“He had stomach pains and he died just like that. At the time, I didn't know much*

*about AIDS. Even so, in 1992, I had an appointment at the Arua Hospital and participated in a counseling session. They offered to test me, but I refused. My husband was still alive, and he forbade me to take the blood test. When he died, I suspected he had AIDS. He didn't always sleep at home. But in spite of everything, I didn't go to be screened. One night that year, I had a dream. Someone said to me, ‘Your blood is infected.’ I didn't make up my mind to learn my status until several years later. First, in 1995, I joined TASO (the AIDS Support Organisation, a Ugandan group financed by private donations that provides counseling and home visits and distributes food and medicines), and the next year I got tested. They told me about the disease, explained that a virus had infected my blood, and explained that it wasn't the virus that would kill me, but other infectious diseases. They also told me that no medicine could cure me and that the only treatments that existed were ones that treat the opportunistic diseases.”*

TASO did distribute medicines but then stopped. After some time, the Arua Hospital AIDS Program replaced the group. Jane says that, during that period, *“I don't know how many people around me died of AIDS.”* Today, she goes regularly to the HIV practice that MSF opened in November 2001. *“I go there when I feel tired.”* She says she supports herself and her children by selling peanuts or tablecloths in the markets. *“We only want one thing—medicines. Will MSF continue to give them to us?”*



CAROLINE LIVIO – MSF

**This isn't Eden but Arua Hospital's garden.**

# THAILAND

MSF has been working in the Surin hospital since 1997. Triple therapy treatment for AIDS patients began in December 2000.



LAURA HAKOKONGAS - MSF

## KEY STATISTICS

- At the end of 2001, there were 670,000 HIV-positive people in Thailand, including 21,000 children under 5 (UNAIDS figures).
- AIDS prevalence in adults (15-49 years) is 1.8 %.
- In 2001, 55,000 people died of AIDS. In the same year 25,000 were infected with the virus.
- Since the beginning of the epidemic, about one million Thais, out of a population of 60 million, have been infected with HIV. One-third of those infected have died.



## THE CONTEXT

Thailand was the first country in Southeast Asia to document the AIDS epidemic and establish a national policy to fight the disease. Thailand also produces generic antiretroviral drugs. The GPO (General Pharmaceutical Organisation) laboratory, associated with the Thai government, produces GPO-VIR, a combination of three antiretroviral drugs, Stavudine, Lamivudine and Nevirapine, at an affordable price (less than \$1 per day).

## MSF'S PROGRAM IN SURIN HOSPITAL

- Since 1997, the hospital in Surin has offered bithérapie treatment (AZT/DDI) to some 100 patients infected with HIV.
- MSF gradually introduced triple therapy treatment, starting with patients seen at home (December 2000 for the first patient), and later for patients seen in the hospital (April 2001).
- Because more than 60% of patients treated at the Surin hospital lived in districts outside Surin Muang, in October 2001 MSF decided to provide treatment in other health centers in the region. In October 2001, MSF opened an HIV clinic in Thatum hospital. In December 2001, the clinic in Sikhorapum hospital opened and in May 2002, the Sangka clinic opened. Additional collaborations with other health centres are anticipated by the end of the year.
- Antiretroviral treatment is offered to patients with a lymphocyte CD4 count of less than 200/mm<sup>3</sup>. Doctors give priority to patients in an advanced state of illness.
- Before treatment begins, patients are seen several times to learn about taking the antiretrovirals and about the importance of strict treatment adherence.
- Once treatment has started, follow-up visits are arranged to monitor the patient's condition and treatment adherence. These visits also allow the patient to bring up other issues, including family or financial problems and psychological difficulties.
- 40 to 60 new patients join the program each month.
- 85% of patients adhere to treatment.

**As of late October 2002, 369 patients had begun ARV treatment, including 57 children.**

Most patients' immunological status has improved significantly.

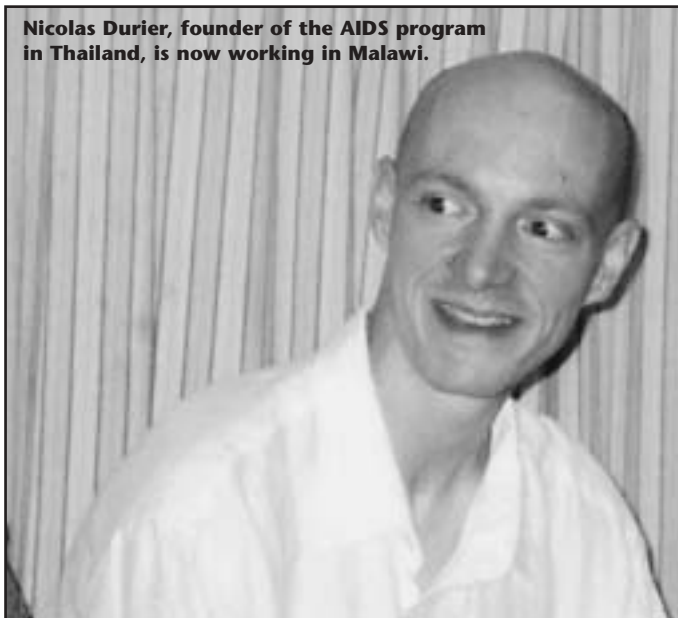
Some 1,200 people are estimated to need triple therapy treatment in Surin.

MSF hopes to provide 500 patients with ARV treatment by the beginning of 2003.

# Thailand, Nicolas Durier, Physician

## “It was April 15, 2000”

Nicolas Durier, founder of the AIDS program in Thailand, is now working in Malawi.



ISABELLE MIERNY / MSF

*Nicolas Durier, a physician, is the Malawi field coordinator. He gained extensive experience with AIDS programs in Thailand, helping to introduce ARV treatment in the hospital in Surin. In this personal account, we hear from a doctor who does not accept the denial of potentially life-saving treatments to poor people. It all began back in 2001.*

“February 2001. MSF’s Paris headquarters was focused on AIDS. Surin was one of the six MSF France projects about to begin treating patients with antiretrovirals (ARVs), triple therapy and HAART (Highly Active Antiretroviral Therapy, as the specialists say). Preliminary discussions had gone on for two years before MSF decided to launch the program. Finally, we took the big leap. Recall that at that time, very few people, if any, were recommending that this kind of program be established. Most held largely pessimistic views about it, assuming that “poor people” wouldn’t know how to take these medicines properly.

But MSF viewed things differently. The organization wanted to begin ARV treatment programs and to prove that “poor people” do not want to die of AIDS when effective

treatments exist and are being used in wealthy countries. Obviously, the goal wasn’t for MSF, on its own, to save everyone with AIDS in the developing world, as Jean-Hervé Bradol reminds us. We had neither the resources nor the intent. Rather, the goal was to show the skeptics that you can be successful providing triple therapy to poor people. And to demonstrate that success to others.

Those were the circumstances when I left for Surin to help the team as they were about to begin treating patients at the provincial hospital. The protocols were written, equipment had arrived, and everyone was motivated. I knew something about AIDS and I was available, so my assignment was set. I left for Thailand with a six-month contract.

In June 2002, I was still there. You could say I was pleased with the work. And what had transpired? Who was proven right? MSF, or the big-deal specialists and laboratories that had said that it was a mistake to provide triple therapy in the Third World?

The initial goal was to take in 20 new patients per month. By June 2002, 230 had taken the plunge. The first patient arrived at the hospital on April 15, 2001. I still remember the date. Today, 90 percent remain in treatment. And surprise! They’re full of energy and, what’s more, the vast majority are taking all their medicines.

Imagine that! It is the same with MSF’s other AIDS projects. The patients are taking their medicines, doing much better, gaining weight quickly and returning to work and normal lives. This experience is not unique to Surin, where conditions could be described as somewhat better than other sites, given that Thailand is more developed than other countries where we took the leap with the same program.

As a result, a little more than a year after the project began—and even earlier—the way we see the problem has changed. The



question MSF faces now is: What do we do about the monthly patient quotas? Should we go all out (I think we have the resources) or bring in new patients at a more moderate pace? Things are working so well that this is our current dilemma. There are many, many patients in Surin who need triple therapy.

And in other countries? The other angle of the problem is that we'd like to be able to develop "sustainable" programs, which, eventually, local health systems would take over and operate on their own. We have promised the patients that, once their therapy is started, it will not be stopped. What happens if, in 10 years, 5,000 patients are receiving triple therapy in Surin and the Thais cannot carry the program on their own? Will MSF stay for 20 years? Will we refuse treatment to patients who keep coming, on the grounds that Thai agencies can't take over? Will MSF continue to use a major part of its resources for several thousand patients who "aren't like the others"?

This is an endless debate, made all the more uncertain because no one knows what will happen in the next few years. What if a cure becomes available by then and we had intentionally limited the number of patients receiving triple therapy? Many whom we could have kept alive will have died waiting for the cure. It is a difficult issue. We have no idea what the future holds. We know only that 40 million people around the world are living with HIV; that, according to the experts, the problem has just begun; and that too few are willing to risk starting HAART programs in the third world. But we also know that we at MSF do not want to stand around with our arms crossed while we watch patients die.

Predicting the future is impossible, and the debate may continue over what should or should not be done. But meanwhile we are pulling out all the stops to simplify triple therapy in these settings and to obtain medicines at cheaper prices. Perhaps we will have played a role in demystifying this process and making it increasingly affordable. That's also part of working toward 'sustainability.'

As a clinician, I admit that I have a problem with the quota issue. To me, it is better to include as many patients as possible. To do the opposite is a bit like planting a tree and then covering it up so it will not grow too

quickly. With AIDS treatment, it is even more dramatic because, once patients are on triple therapy, they undergo a metamorphosis. They resume their activities and their work; they're no longer hospitalized; and they need to come to the hospital only every three or four months for a routine visit. The contrast with the others with this disease is dramatic. Management of treatment is simpler in medical terms, and maybe even less expensive. That savings will have to be evaluated under the conditions in which we're working, but it has been demonstrated in the wealthier countries.

Conditions for ARV treatment seem more favorable in Surin than in the other countries where MSF France working (Cambodia, Guatemala, Malawi, Kenya, and Uganda.) The Thais have developed a generic triple-therapy combination in a single tablet. They expect to include it in the list of medicines overseen by the public health agency and to make it available to patients for free. This won't happen tomorrow, but, with pressure from MSF, among others, and influenced by solid results from this kind of program, a program for distribution can be set up.

MSF is taking a real gamble here. But that is exactly what MSF does.



LAURA HAKONGKAS - MSF



# CAMBODIA PHNOM PENH

## *Photographs*

***Didier Lefèvre / Editing***

The Norodom Sihanouk Hospital in Phnom Penh is the only public hospital in the country to treat AIDS patients with triple therapy. Mr. Pharith (below, seen from the back) is a Khmer MSF social worker. He is in regular contact with patients' families.



C. (above) thought for a long time that his illness would keep him from ever holding his baby. He still wears gloves to hide his skin problems, but thanks to the social workers' efforts, he has a much better understanding of his disease. The antiretroviral medicines allow him to continue to work as an itinerant merchant. Even so, Cambodian society is far from accepting the phenomenon of AIDS.



The number of HIV-positive patient visits increases steadily. There were nearly 6,000 office visits in the first six months of 2002, the same number for all of 2001.







Doctor Cua (above), an expatriate, and Doctor Sreng, one of the Cambodian physicians, visit their patients: Decisions can be difficult. A 28 year-old patient (below) is in a very advanced stage of AIDS. Should he be put on ARVs? The answer is yes, because this is his last chance for survival.





(From top to bottom) Three women watch over a dying person; a mother calms her worried son; another feeds her; a woman is very concerned about her husband, who suffers from cryptococcus-related headaches. The doctors can tell that the need is urgent—and the families do, too.







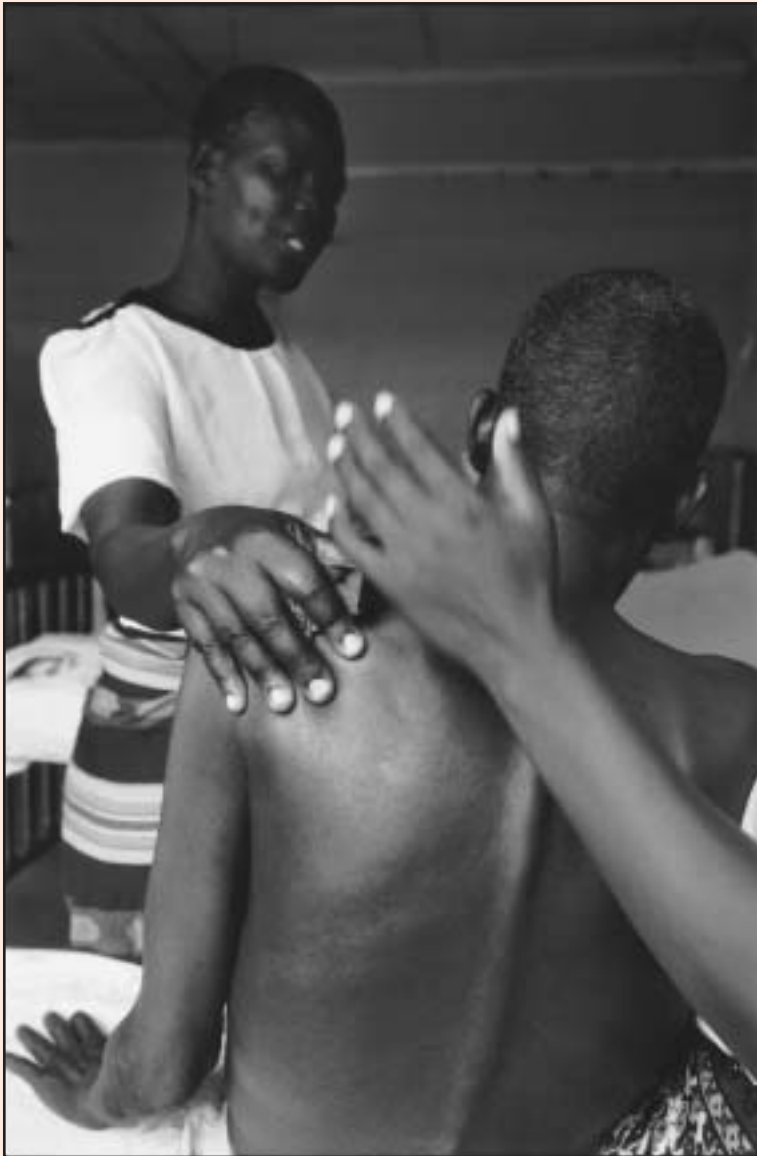
# KENYA HOMA BAY

*Photographs*  
*Andrew Njoroge*



AIDS has taken this little girl's parents (left). She has only her grandmother left. In the Homa Bay region on the shores of Lake Victoria, the epidemic affects nearly one in every three adults. MSF offers comprehensive care in the city's public hospital, from HIV testing to triple therapy. ARVs are provided here free of charge. Two hundred forty people, including 20 children, have begun treatment.



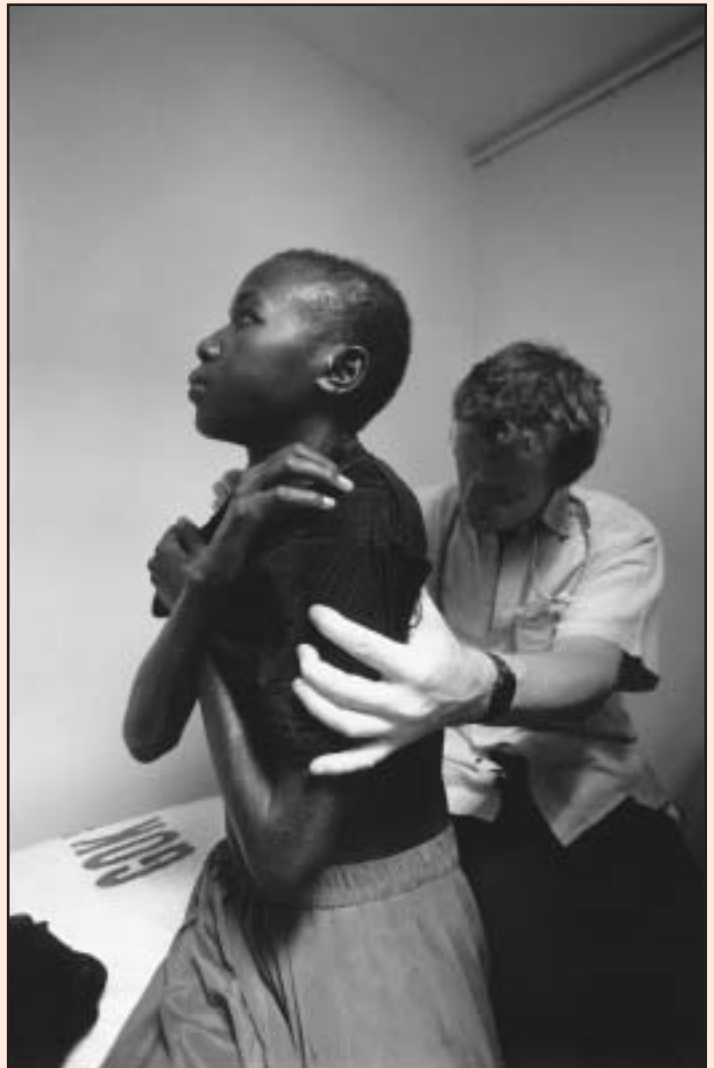


Deborah (below), a doctor specializing in tuberculosis, has been working in Homa Bay for more than six months. TB, the primary opportunistic disease associated with AIDS, requires long and demanding treatment, along with regular patient monitoring. In the hospital units where MSF's international teams work, the fight against opportunistic diseases offers increased hopes for survival.





Since beginning her treatment, this little girl (right) has regained nearly 10 kilos (22 pounds), and her health is greatly improved. With her immune system strengthened, her life is almost normal again. Antiretrovirals should not be a luxury reserved for those who can pay.







In Homa Bay Province, the number of patients who should begin triple therapy is estimated at around 6,000. The MSF team hopes to convince other partners to set up more programs in the region's hospitals. In the meantime, the casket sellers get richer.





# MALAWI CHIRADZULU

*Photographs*  
*Didier Lefèvre / Editing*

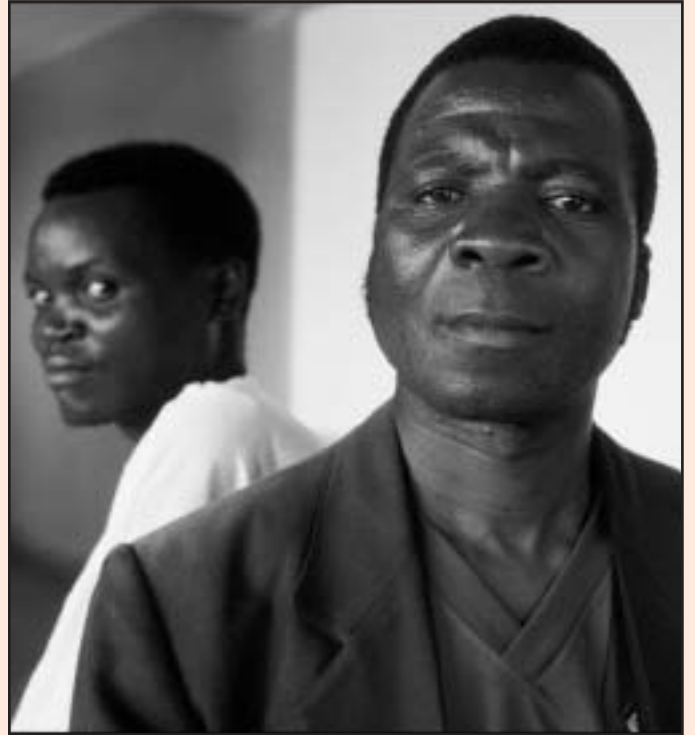
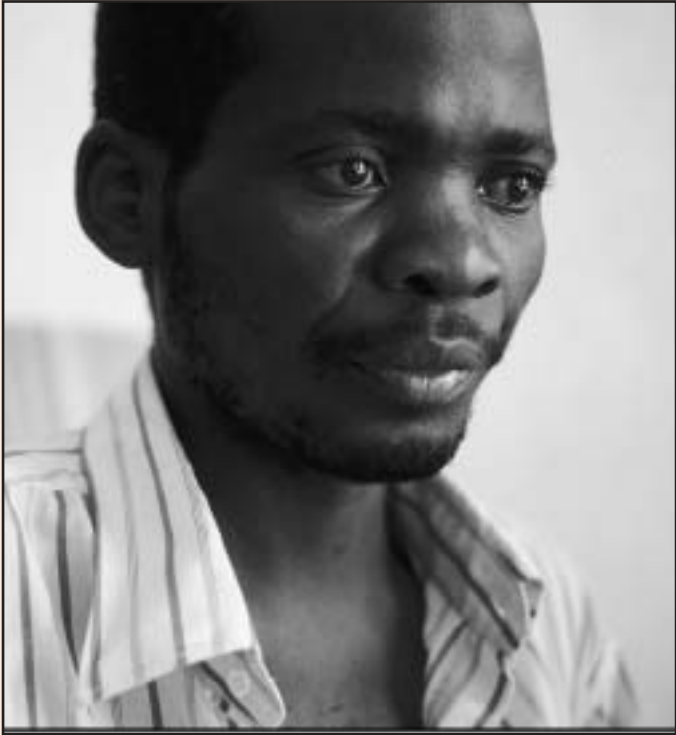


In the rural district of Chiradzulu, 20.8 percent of the women have tested positive for HIV. MSF has been working in the district hospital since 1997. Seventy percent of the women patients there have an AIDS-related disease, including tuberculosis (like Doreen, a 28-year-old mother, above), meningitis, and other STDs.

Some 10,000 patients are estimated to be in need of ARV treatment.

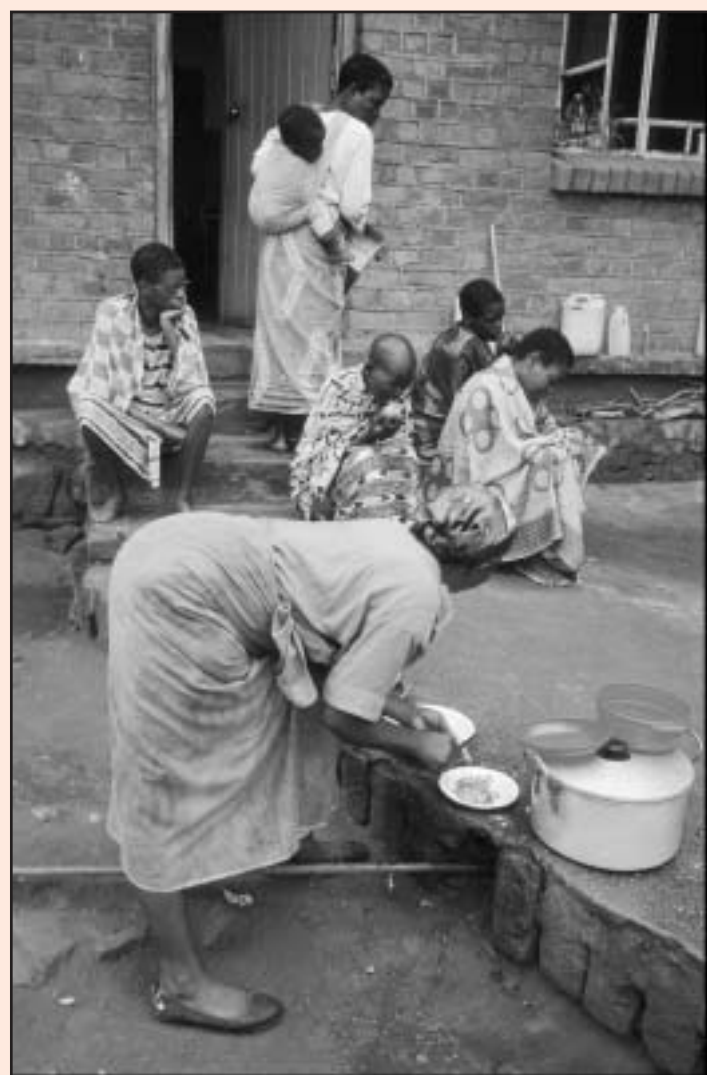






George, Jimmy, Michael, Ena and her baby, Rosa, Dorothy, and Fred (from top to bottom) are HIV-clinic patients. George has just learned that he is HIV-positive. Jimmy hopes he will be able to start taking ARVs soon. Michael, a farmer, has returned to the living since he began treatment. Ena avoided passing the virus on to her son thanks to MSF's program for the prevention of mother-to-child transmission. Rosa and Dorothy are afraid that they will be stigmatized by their community. Fred, the teacher, has come to accept his situation.







The Chiradzulu AIDS clinic operates like a real village. The families live with, feed, wash, and support their hospitalized relatives. The courtyard serves as a cafeteria. The daily market is held on the other side, near the washhouse. When they can, patients take an active role in AIDS-prevention and -education activities. Many belong to People Living With AIDS groups (support groups of and for patients) that organize demonstrations on the use of condoms and present songs, dances, and skits in villages and schools. Since MSF's ARV program began, only two people have dropped out.





# ***AIDS patient management***

## **The Medical Angle**

### **Inclusion Criteria**

In MSF's AIDS programs, the first patients treated are those at imminent risk of dying; that is, those whose immune defenses are very low. The medical criterion for inclusion in these programs therefore rests on the number of CD4 cells in a patient's blood per cubic millimeter of volume. (This rate measures the degree of immunosuppression and, thus, the patient's level of ability to fight opportunistic diseases.) MSF has given priority to treating those patients whose CD4 counts are below 200/mm<sup>3</sup>. Below this rate, the patient's risk of developing an AIDS-related opportunistic disease becomes increasingly significant. It is very important to begin treatment by this point. Most patients treated in MSF's programs have very low CD4 counts when they begin triple therapy. In our Asia programs, two-thirds of patients have counts of less than 50. Between 30 and 40 percent of patients in our Africa programs also have CD4 counts below 50.

They are in urgent need of treatment. By comparison, a person in good health has a CD4 count of between 500 and 1,500. In the industrialized countries, studies are underway to determine whether patients should be placed on triple therapy when the CD4 count drops below 350.

### **CD4 or Viral Load?**

The measurement of CD4 cells establishes the patient's degree of immunosuppression. The measurement of viral load reveals the amount of virus in the blood. These two tests are always used in the industrialized countries, but measuring viral load requires a very complex and expensive test, most often available only in a capital city. That is why MSF's medical teams only measure patients' CD4 rates.

### **Opportunistic Diseases**

When a patient develops an AIDS-related opportunistic disease, that infection must be treated before triple therapy begins. (These diseases include tuberculosis, which appears in every country, meningitis and cryptococcus in Asia, and severe bacterial infections in Africa.) Such infections must be treated first, both because the patient could die from the infection and because some ARVs may cause interactions with other anti-infective therapies. For example, if a patient is being treated for TB, antiretroviral treatment should not begin until—at best—after the two-month intensive TB treatment phase (the full treatment lasts eight months).

### **Which Type of Treatment?**

At first, MSF treated AIDS using a combination of three molecules made up of two nucleosides (AZT and 3TC) and one non-nucleoside (efavirenz). At the same time, the Campaign for Access to Essential Medicines' pharmacists were validating a fixed combination (that is, three molecules in the same tablet) called Triomune (d4T + 3TC + Nevirapine), produced by the Indian generic manufacturer Cipla. The availability of a less-expensive medicine (under 300 euros, or US\$ 334 per year, per patient) that is also easy to take eases patients' adherence to treatment.

If the treatment fails, a second-line treatment is used. The second-line treatment uses completely different molecules from the prior treatment, because cross-resistance exists among the molecules in the three classes of available medicines, the nucleosides (AZT, d4T, DDI, and 3TC), the non-nucleosides (efavirenz or Nevirapine), and the protease inhibitors (nelfinavir, indinavir, and lopinavir/ritonavir). The choice of a second-line combination is, therefore, limited.

## Treating Children

All the key principles associated with adult treatment can be adapted to children. Only the dosages need to be changed, according to the child's weight. When the child reaches 6 to 7 years of age, pediatric doses approach adult doses. The pediatric forms of the medicines come in syrups or powder, which is reconstituted for use. Children cannot be

given capsules or tablets to chew. In general, when no pediatric form of a medicine exists, it is difficult to find the proper dose. Some medicines cannot be easily divided or cut (because, for example, the three molecules are not evenly distributed in the tablet, as is the case with Cipla's Triomune). Some syrups taste bad, and other medicines do not dissolve easily in water. Compliance is also a major problem in treating children. Families or caregivers must work very hard to ensure that medicines are taken regularly.

# Combination Therapies: What Do They Cost?

When MSF decided to launch antiretroviral treatment programs for people with AIDS, the cost of triple therapy had reached more than 10,000 euros (US\$ 10,439) per patient, per year, using patented drugs. Competition generated by generic drugs has helped reduce treatment costs significantly to around 300 euros (US\$ 334) per patient, per year. (Hetero, an Indian generic drug manufacturer, offers triple therapy for US\$ 209). In some countries, where average daily income is below \$1, that price is still high. Through the Campaign for Access to Essential Medicines, MSF continues to call for an equitable pricing system to bring prices down as much as possible, to around 50 euros (US\$ 56). Such a system would also free patients from being dependent on laboratories' goodwill.

The cost of second-line triple therapy remains extremely high. The use of a protease inhibitor like nelfinavir (Viracept™) increases the cost to several thousand dollars per patient, per year. In some cases, the producer charges governments of poorer countries prices that are much higher than those charged in the developed world. Roche, the Swiss pharmaceutical giant, for example, charges the Guatemalan government US\$ 8,358 per patient, per year, and the Ukrainian government US\$ 7,110 per patient, per year. The same drug costs US\$ 6,169 per patient per year in Switzerland.

Other key drug producers use differential pricing systems for poor countries. Most

offer reductions of 87 to 92 percent compared to Swiss prices. MSF is asking Roche to apply the same policy and to offer the least developed countries a reduction of 85 percent from Swiss prices.

### Examples of the Cost of First- and Second-Line Triple Therapy Used in MSF Programs

#### First-Line Treatments

In Cambodia, Malawi, and Guatemala, MSF teams use a fixed combination called Triomune (d4T + 3 TC + nevirapine), produced by the Indian generic drug manufacturer Cipla, at a cost of US\$ 304 per patient, per year. In these three countries, the most commonly used first-line treatment (d4T + 3TC + efavirenz) costs, on average, US\$ 664 per year.

#### Second-Line Treatments

As a general rule, second-line treatments include a protease inhibitor (Merck's indinavir or Roche's nelfinavir).  
- In Guatemala, the d4T + 3 TC + indinavir combination costs US\$ 834 per year, per patient. The combination of d4T + 3 TC + nelfinavir costs US\$ 4,150 per year, per patient. The protease inhibitor, nelfinavir, represents 94.9 percent of the cost. The other two molecules are generics produced by the Indian laboratory Cipla.  
- In Cambodia, d4T + 3 TC + indinavir costs US\$ 764 per year, per patient. The combination of D4T + 3 TC + nelfinavir costs US\$ 3,304 per year, per patient. The protease inhibitor represents 95 percent of the treatment cost.



## **Campaign for Access to Essential Medicines**

# **Progress in HIV/AIDS**

**November 1999:** Formal launch of the Campaign for Access to Essential Medicines.

**March 2000:** MSF supports the Treatment Action Campaign (TAC), a coalition of South African activists demanding that the U.S. manufacturer Pfizer Inc., the exclusive producer of fluconazole, reduce the price of this medicine or allow generic manufacturers to produce and sell it at an affordable price.

**April 2000:** Pfizer announces that it will provide fluconazole to South African AIDS patients free of charge.

**July 2000:** Access to treatment is the central theme of the World Congress on AIDS meeting in Durban. MSF organizes a satellite meeting with TAC and presents a study showing the effects of competition among anti-AIDS-drug manufacturers on prices.

**July 2000:** A Thai legal organization challenges Bristol-Myers Squibb's monopoly on sales of DDI (an antiretroviral drug used in combination therapy for treating AIDS) and seeks to revoke its patent.

**February 2001:** Cipla, an Indian producer of generic medicines, offers an anti-AIDS triple-therapy treatment for US\$ 350 per year, per patient. In early 2000, the price of triple therapy with patented medicines had

been more than US\$ 10,000 per year, per patient.

Competition generated by producers of generics lowers the price of brand-name triple therapy significantly. The pharmaceutical laboratories propose price reductions of nearly 85 percent.

**March 2001:** Under pressure from South Africa, MSF, and other NGOs, Bristol-Myers Squibb announces that it is offering *"a free licence under the Zert (d4T) patent for treatment of AIDS in sub-Saharan Africa."*

**April 2001:** Giving in to public pressure, thirty nine pharmaceutical companies withdraw their complaint against the South African government. They had tried to reverse the 1997 drug law allowing the parallel import of patented drugs and the substitution of non-patented, generic medicines. MSF had launched a "Drop the Case" campaign to bring the lawsuit to the public eye.

**June 2001:** The Kenyan Parliament ratifies an intellectual-property law allowing the import and production of less-expensive medicines for HIV/AIDS and other diseases.

The Kenyan government acted under pressure from the Kenyan Coalition for Access to Essential Medicines, of which MSF is a member. There will, however, be an additional waiting period, as the law will not go into effect until August 2002.

**June 2001:** The United States drops its disagreement with Brazil, having accused it of violating the TRIPS Agreement (Trade-related aspects of intellectual property) by encouraging local production of generic medicines. Now Brazil can safely continue its ambitious national anti-AIDS program, through which it treats more than 90,000 patients.

**November 2001:** At the end of the World Trade Organization (WTO) meeting in Doha, Qatar, the 142 member countries acknowledge the priority of public health over patent protections, announcing, *"We agree that the TRIPS Agreement does not and should not prevent members from taking measures to protect public health."* Henceforth, all countries may turn to generic drugs to protect public health without fear of legal action.

**April 2002:** The World Health Organization adds 10 antiretroviral drugs to the list of essential medicines. This new list now contains 12 antiretrovirals and nearly 60 medicines used to treat AIDS.

**April 2002:** One year after the Pretoria conference, the South African government announces a radical change in its anti-AIDS struggle. It decides to make treatment available to all HIV-positive pregnant women to prevent them from transmitting the virus to their babies.

**June 2002:** MSF, Unicef, and the Joint U.N. Programme on HIV/AIDS publish a survey on "Sources and Prices of Selected Drugs and Diagnostics for People Living with HIV/AIDS." The report is an important step forward, providing clear information to poor countries seeking access to the least-expensive medicines.

**November 2002:** An informal WTO meeting is held in Sydney on the issue of access to generic medicines for developing countries lacking the

capacity to produce them. A solution is to be drafted by the end of 2002, specifically for countries that wish to import generics.

Although the proposal that emerges from that meeting is greeted as a *"step forward,"* it is really a dramatic step back, compared to what was gained at Doha. If accepted, the proposal would impose much stronger restrictions on poor countries than on other countries in their efforts to have access to generic medications.

Several WTO meetings are to be held by the end of December. MSF hopes that an equitable, simple, and effective solution will be found that allows poor countries to easily obtain the medicines they need.



ISABELLE MERNY / MSF

# The Challenges Ahead

More than a year after the WTO announcement at Doha, the great progress that was made in giving priority to public health over industrial protection is at risk of being compromised. Under pressure from the pharmaceutical industry, the European Union and the United States are trying to limit the export of generic medicines. Currently, countries may use compulsory licenses to produce generic medicines if they need them. However, one question has not been resolved: how to provide for the export of generic medicines to a country that has a compulsory license but does not have the capacity to produce generics? The pharmaceutical industry wants to prohibit countries like India and Thailand, which have significant generic-manufacturing capacity, from exporting their generic medicines to African countries, thus driving the latter toward more expensive alternatives. Further, the United States is increasing the pressure on developing nations to restrict or slow local production or import of generic medicines. The spirit of Doha may yet be destroyed.