

MOTHER COURAGE

Haiti has the highest HIV/Aids levels outside Africa, but efforts at prevention and treatment are hamstrung by fear, superstition – many believe it treatable only by voodoo priests – and the armed gangs that rule the slums. **Veronique Mistiaen** followed a group of women who dare to care. Photographs by **Caroline Irby**

Above left Madame Jean-Claude Edouard leads the Delegate Mothers, a group of poor, uneducated, HIV-positive mothers who care for and support 250 families. **Above right** a street market in the Pétionville district of Port-au-Prince, the capital of Haiti

'It's here,' Madame Jean-Claude Edouard says, pointing to a dirt track off the main road north of Port-au-Prince heading towards Cap Haïtien. The driver of our Jeep blanches. Mme Edouard steps out and strides purposefully towards a cluster of mud-and-concrete houses where she visits families affected by HIV and Aids. She usually walks to reach her assigned families or hitches a ride on a tap-tap – one of the handpainted minibuses with names such as Dieu est Amour and Souvenir de Mon Frère that scamper across Haiti's capital city – but today, on the third anniversary of the bloody rebellion against former president Jean-Bertrand Aristide, she has brought along outsiders. 'Bonsoir!' She waves at a couple of women sitting under an almond tree. The women stare; the children stop playing. The driver locks himself in the Jeep.

Mme Edouard lives in the area, so her visits don't usually attract suspicion. This is important in a country where people with HIV/Aids routinely lose their jobs, their houses and often their friends and families. It is also a matter of survival



because this area, Wout Nef (Haitian Creole for New Road), is an extension of Cité Soleil, Port-au-Prince's largest and most dangerous slum, run by ruthless armed gangs that have replaced the law, the police and the state. Many Wout Nef residents moved here from Cité Soleil to escape the daily shooting, looting and kidnapping, but the violence has followed them. 'Whenever I leave the house, I lock all my children inside and only walk out with my eldest son, who is 24,' says Jésusla Michel, a mother of seven, whom Mme Edouard visits. 'If you leave your children alone here, they would be kidnapped, raped and killed. If I had money, I would send my children to the countryside. This is not a place to live.'

Since African slaves working on sugar plantations overthrew their French masters and created the world's first black republic in 1804, Haiti has been plagued by political violence, civil unrest, environmental disasters and crippling poverty. The tiny country, shaped like a horseshoe on its side, covers the western third of the Caribbean island of

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Hispaniola (the Dominican Republic occupies the rest). It is now the poorest country in the western hemisphere with 80 per cent of its population living in 'abject poverty', according to the World Bank. Life expectancy is 51 years. After the long and brutal dictatorship of Duvalier father and son, Aristide was elected president in 1990 and (after a four-year hiatus) again in 2000 with the support of the long-neglected poor. The future looked brighter, especially as Aristide chose to negotiate with gang leaders acting as spokesmen for the slums, but he soon became implicated in gross human-rights abuses himself. Like other rulers before him, he had even created his own militia – the Chimeras – recruited from the slums to suppress political dissent. Since the 2004 coup, armed gangs for

and against Aristide, drug traffickers, bandits and United Nations peacekeepers sent in to restore order have been locked in fierce battles, and the population has been living under siege. So far, the current president, René Préval, elected in February 2006, has not been able to control the situation. The worst of the violence has been mostly confined to Cité Soleil, other shanty towns in the capital and a few provincial towns, but over the past year thugs have also started grabbing people off the streets all over the capital, demanding ransoms – initially in the region of \$500, but now \$200,000 and more – which they use to buy more arms. Lately the kidnapers have targeted children, snatching them on their way to school, and they have grown more violent, often mutilating or killing their victims.

Roughly a third of Haiti's population of eight million live in Port-au-Prince, which sprawls from the turquoise waters of the Caribbean Sea to the surrounding hillsides stripped bare by relentless deforestation. Some 300,000 of them are squeezed in a steaming maze of slums. In a city where very

few people have regular jobs, men, women and children spend their days sitting on the pavements under colourful umbrellas in front of displays of coconuts, bananas, chicken roasting on metal drums, scraps of metal, sugar cane to chew, large white cloth bags filled with flour and peas, stainless-steel pots, engine parts and anything else they can find to sell. Some stand proudly in front of larger and sometimes incongruous displays: a massive dresser, an ornate bedstead, a long row of shiny black shoes, secondhand clothes hanging from ropes tied along the walls, a dozen ghetto-blasters – all shipped in bulk by relatives in Miami. Outside the slums, the streets are lined with half-built concrete buildings and pastel-coloured two-storey houses with iron gates and walls topped with barbed wire and bougainvillea. Painted slogans sprout on every visible surface: many are political, such as 'Viv Retou Aristide Wa' (Welcome Back Kind Aristide); others ironic, like 'Vote Djakout' (a Haitian pop group); some spiritual, such as 'Friend, magic is not eternal. It is only the eternal which is eternal.' There are also hundreds of signs advertising schools, from Gentile Alouette kindergarten



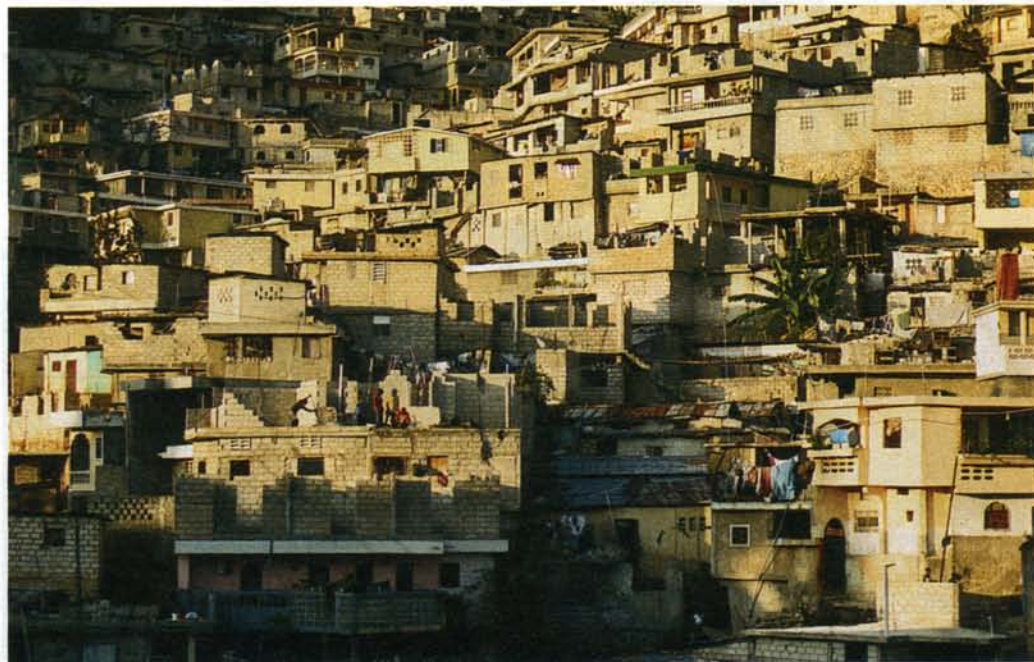
'PEOPLE ARE SO AFRAID THAT THEY'D PREFER TO DIE IGNORANT THAN REVEAL THEIR STATUS'

From top Tata Ladouceur doesn't dare reveal her HIV-positive status to anyone, not even her daughters; Pétionville slums; Marie-Lucienne Milotes uses her own experience to bring hope to HIV/Aids sufferers

to Emmanuel Kant college, which children in crisp shirts and gingham pinafores flock to every morning and afternoon. (Nearly 85 per cent of education in Haiti is privately run; private schools of various quality and price compete for students; most children cannot afford to go to school.)

In Wout Nef, Mme Edouard stops by a shack painted bright blue. Inside, Tata Ladouceur, a slender woman with a beautiful but emaciated face covered in a straw hat, sits on a single bed by a table and two chairs. Clothes are drying on the roof outside. The 43-year-old mother of three smiles and kisses Mme Edouard on the cheeks. 'When I see Mme Edouard, I feel good,' she says in Haitian Creole, a musical language full of imagery. 'I can share some of my problems with her. I cannot talk about my situation with anyone else. Even my daughters don't know.' Tata Ladouceur's husband was killed three years ago in the anti-Aristide coup, and she is one of 280,000 people in Haiti who are HIV positive or have Aids. With an estimated three to five per cent of its population infected, the country is the hardest hit by the pandemic outside sub-Saharan Africa. Aids reached Haiti in the 1980s via tourists. The epidemic then solidified through private contaminated blood banks before spreading to the general population through sex workers. Now women and children – particularly teenagers – are the most affected, says Dr Charles Macarthur of Gheskio, a Haitian non-governmental HIV/Aids training, research and medical centre in downtown Port-au-Prince.

Tata Ladouceur readjusts her straw hat over her short, thinning hair. 'I know I need to eat well, but there are many days when I cannot find anything to eat. I spend my whole day sitting here, doing nothing,' she says. Living in a neighbourhood with no water and electricity is a struggle for people like her with compromised immune systems, she adds. 'I am always afraid to catch infections and I don't have money to buy medicine.' With help from the Global Fund and other international donors,





Gheskio is able to provide free antiretroviral (ARV) drugs to those who can visit its Port-au-Prince clinic and the few hospitals in the provinces where the drugs are also available, but other medicines have to be paid for. Yet only 20 per cent of those who need ARVs receive them, according to a 2005 report by the World Health Organisation. 'We now have ARV drugs, but not the infrastructure to reach people or the necessary support and follow-up to make the drugs effective,' Dr Macarthur says. There is only one doctor per 10,000 Haitians, and many are leaving the country because of the growing insecurity. 'Also, travelling to the clinic is expensive and may take a long time – roads are very bad in Haiti. People are told to take their medicine with food, so when they don't have anything to eat, they don't take their medicine. People are hungry. They need food. It is as simple as that.'

Once a month Mme Edouard brings Tata Ladouceur a large pot of wheat, two of peas, one of flour and half a gallon of oil. And she comes twice a month to help her clean the house, wash the dishes, and to make sure her daughters go to school and do their homework. She takes Tata Ladouceur

THERE ARE 200,000 AIDS ORPHANS IN HAITI, 'A GENERATION OF DEEPLY TRAUMATISED CHILDREN'



From top a homework session at Rainbow House, Haiti's first shelter for Aids orphans, where 37 children now live; Jacmel on the south coast; market sellers in a covered bazaar in Pétionville

to the hospital when she needs to go. She has also taught her how to live with the disease, avoid infections and change her sexual behaviour. 'Now I have hope,' Tata Ladouceur says. 'I cannot change the past, but I can fight. I am hanging in there.'

'Without Mme Edouard, I would be dead or I would have gone mad,' echoes Jésusla Michel, 43, another HIV-positive mother in the area. 'She is my sister and when she comes to visit me, I feel good. We talk about our women's problems and our financial problems. Sometimes, she tells me her problems, sometimes I tell her mine. Life doesn't stop with a positive diagnosis.'

Mme Edouard, 44, is one of a group of 15 poor, uneducated, HIV-positive mothers who bring medical care, material assistance, psychological support and education to some 250 families affected by HIV/Aids – including 500 children – in Cité Soleil and some of the other poor and volatile slums of Port-au-Prince. Calling themselves the Delegate Mothers, the women work with Maison Lakansyel (Creole for Rainbow House), a local Haitian charity, and Plan International, a children's humanitarian organisation working with communities in developing countries all over the world. Rainbow House created the first shelter for Aids orphans in the country in 1996 in partnership with Plan. The house, on a hillside on the outskirts of Port-au-Prince, is home to 37 children, but there are some 200,000 Aids orphans in Haiti.

'They have seen their parents die, they went hungry and became street children,' Andrinette Cadet, an HIV/Aids adviser with Plan, says. 'They have lived through so much. They are a generation of deeply traumatised children. But the country is not ready or equipped to deal with them.'

Rainbow House and Plan then decided to try to help parents and children with HIV and Aids survive in their own communities. 'The idea was to try to lessen the stigma and create a viable atmosphere around HIV-positive persons so that they could still live together as a family,' Cadet explains. In





outreach centre. 'But I tell her, "I was like you," and I show her a photo of me taken in 2000 before my antiretroviral treatment and say, "Now I am standing here in front of you. Look at me."' Marie-Lucienne, 37, was diagnosed HIV positive in 1994 after a test for a vaginal infection. Like most people at the time, she didn't believe it until she developed Aids six years later. 'I had diarrhoea, high fever, was vomiting and had violent headaches. I was losing my hair and my body was covered in a rash, so people knew I had Aids. They were mean and laughed at me. Children didn't want to play with mine and taunted them,' she recalls. 'I stayed at home, waiting to die. I didn't have any money left. I was terrified and worried about my children. They were hungry and couldn't go to school.' In the church across the street, a preacher bellows, 'Thank you, God,' and the congregation chants it back.

Soon after, Marie-Lucienne's landlord evicted her, and her husband left. He had become ill a year before her, but always denied he was positive. Discrimination not only causes a great deal of suffering, but it also fuels the epidemic, she adds. 'He never agreed to take the test and kept having sexual

'AT RAINBOW HOUSE WE HAVEN'T BEEN STIGMATISED. THE STAFF ATE, DRANK, MINGLED WITH US'

1998 Rainbow House nurses and social workers started to visit families in the community and invited mothers to the outreach office to meet one another, discuss their problems and learn more about hygiene, nutrition and medical issues. A similar programme was later created for their children. But in 2004 clashes between anti-government protesters and armed gangs made parts of Port-au-Prince a virtual no-go area for outsiders. Many foreign aid workers were forced to flee and even Haitians from outside the slums couldn't venture there. The home-care team had to stop their visits. Rainbow House tried to recruit volunteers from the community to replace them, but the stigma of Aids made it impossible. No one wanted to risk coming into contact with anyone known to have HIV or Aids. It was the end of the lifeline programme.

Then Mme Edouard and other HIV-positive mothers who had met at the Rainbow House outreach centre stepped in and offered to replace them. 'Rainbow House had supported me and my children. They had embraced me when I felt excluded

from society, so when they needed help, I decided to offer my services,' Mme Edouard says. The Delegate Mothers are trained, given a schedule of visits and receive a transport stipend and money to buy small items for the families they visit. They meet with a social worker twice a month to give an oral report of their activities and jointly work out solutions for the families' problems. In many ways, these women are better equipped for the job than professional home-care workers. They are street-wise and live in the neighbourhoods where they work, so they can visit the families without attracting attention, and they know how to dodge bullets and where to hide. But more importantly, they can relate to the families: they have been there, they have felt the fear and the stigma. And better than anyone else, they can bring hope.

'As soon as a person learns she is positive, she sees death in front of her, she sees her children shamed and abandoned,' says Marie-Lucienne Milotes, another Delegate Mother, sitting under a mango tree in the courtyard of Rainbow House's

Above Roseline, 15, lives at Rainbow House; she would like to be a seamstress. **Below** Charline, 17, another Aids orphan, recently moved off the streets to this dormitory at Rainbow House

relationships with other women after he had left me.' He died last month. 'People are so afraid of Aids that they prefer to die ignorant, rather than reveal their status to the world and to themselves. If an infected person is rejected by her family and finds herself without a place to stay, she will have to work the streets to survive and will keep infecting other people.'

By chance, Marie-Lucienne was brought to Gheskio by a Jehovah's Witness. There she received antiretroviral drugs and was referred to Rainbow House. Her T-cells – the white blood cells that are key to the immune system – shot up from 13 to a healthy 650 today. Not only had she regained her health, but for the first time since her illness, felt accepted. It was like a new life, she says. 'At Rainbow House, we have not been stigmatised. The staff ate, drank and mingled with us. They told us to take precautions, but to treat HIV/Aids like any other diseases. They taught me about hygiene, clean water, nutrition, how to avoid infections, how to change my sexual behaviour and how people with and without HIV can live together. Now I share everything I have learnt with other mothers.' And they, in turn, will share it with other mothers.

Haitians fear HIV/Aids so much because of the many superstitious beliefs surrounding the disease. Many people, especially in the countryside, believe that Aids is caused by magic rather than a virus, Dr Macarthur explains. They shun HIV-positive people for fear of attracting the evil eye on to themselves, and if infected, they believe that only a voodoo priest can help them. 'They believe it is a curse from somebody who wants to harm them so they see no reason to change their behaviour and take their medicine,' Dr Macarthur says. 'Instead they seek help from a hougan [a voodoo priest]. Even some of the people we treat here at the clinic don't believe they have a disease and still go to see a hougan.'

Flying from Port-au-Prince, we reach Jacmel on the south coast, a pretty town with a hint of old





their treatments don't work, he adds. 'Some do it for the money, others because they really believe it's not a disease. I know houngans who sleep with infected women, if they are still beautiful, as part of the cure.'

Superstition and misinformation around HIV/Aids are exacerbated by a culture where no one talks about sex. 'Sexuality is a taboo subject. No one would talk about it at home or at school, so children remain uneducated and unprotected,' says Sissi Lamour, a nurse who is involved in a pioneering HIV/Aids and reproductive health education programme in schools in the Jacmel area. This type

Voodoo priest Cebento Mentor with his brother's skull: 'His spirit guides me'

'I KNOW VOODOO PRIESTS WHO SLEEP WITH INFECTED WOMEN AS PART OF THE CURE'

New Orleans. White sandy beaches stretch along the shoreline and clusters of pastel-painted houses and huts hide among banana trees. People here live like 60 per cent of the population in Haiti: eking a precarious living from smallholdings and informal agriculture work. Traditional beliefs are strong.

In the Péristyle de Grand Lacou de Montagne near Jacmel, a walled compound of various sacred buildings, structures and gardens, the voodoo priest Cebento Mentor sees people about family disagreements, disputes between bosses and workers or land ownership, health and many other issues. Judging by the size of his temple, he is doing brisk business. Depending on the problem, he will invoke one of the many spirits residing on his land, such as Ougoubatagi, the high spirit of Haiti; Baron Samedi, who decides who should die; and Cerceuil Ma Douleur (My Sorrow Coffin), who deals with 'sorcery and the high service of evil'.

Each of the buildings in the compound has its own set of ritual clothes, objects and offerings – a dusty assortment of plastic flowers, egg shells, pots and numerous wine and liquor bottles. On a shelf in Mentor's consultation room sits his brother's skull, along with a set of femurs and tibias. 'That way, my brother's spirit continues to be with me and guides me,' the priest explains matter-of-factly.

Unlike many of his colleagues, Mentor says he believes Aids exists and is an infectious disease, but maintains voodoo priests could cure it if they had access to the same resources and technology as scientists. He says he treats the symptoms of the many HIV-positive people who come to see him with herbs, bark and plants, but sends them to the hospital for further treatment. Many voodoo priests prefer to look after people with Aids themselves, even when they know

of prevention and education campaign is crucial in a country with such a young and sexually active population as Haiti's. More than half of the population is under the age of 18, and many are sexually active by the age of 11 or 10. Many young people are also forced to sell sex to survive. As a result, many become pregnant, unwittingly contract sexually transmitted diseases, and go on infecting others. Attitudes and behaviour are slowly changing in areas reached by education programmes and radio and television campaigns – most sex workers in the capital now use condoms, for example – but people in rural areas and the slums are harder to reach.

The Delegate Mothers are optimistic about the future. 'The more people receive antiretroviral drugs, the more will see that being HIV positive is not a death sentence or a curse,' Marie-Lucienne Milotes says. The Delegate Mothers are upbeat about their job and say it has greatly increased their self-esteem and given them renewed hope in their own lives. 'I love this job, I love working with these people, I love Rainbow House,' Mme Edouard says. 'I've gained sisters, mothers, brothers and fathers.' Their energy is infectious and the best source of hope among other families living with HIV and Aids in the shanty towns.

Marie-Lucienne met her former landlord on the streets a few months ago. He did not recognise her. She approached him and said, 'Whenever you meet someone, do not say blindly he has Aids, do not throw him out of the house. A person who knows his HIV status and takes his medication can live longer than you, who do not know yours and trust the bush doctor.'

Some names have been changed.

For more information about Plan's work in Haiti and to find out how you can support it, visit plan-uk.org or call 020-7482 9777

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