

Impact of HIV-related Restrictions on Entry, Stay and Residence: Personal Narratives

INTRODUCTION

About 61 countries deny entry, stay or residence to HIV-positive people based on their HIV positive status only. Of these, 29 deport people when their positive HIV status becomes known; eight bar entry to HIV-positive people based solely on their status; and five deny entry even for short-term stays. The restrictions were imposed in the early days of ignorance, fear and prejudice towards HIV and towards people living with HIV in an attempt by governments to protect the public health and/or avoid the potential costs of care and support of HIV positive people. Since that time, much has changed with HIV having spread to all countries, much greater knowledge gained concerning effective HIV prevention and the introduction of anti-retroviral treatment that has extended the life and productivity of people living with HIV and made HIV a manageable health condition.¹

In early 2008, the Joint United Nations Programme on HIV/AIDS (UNAIDS) established the International Task Team on HIV-related Travel Restrictions to call for and support efforts toward the elimination of HIV-related restrictions on entry, stay and residence. The Task Team, co-chaired by UNAIDS and the Government of Norway, was made up of representatives of governments, inter-governmental organizations and civil society, including networks of people living with HIV.

In its *Final Report*, the Task Team presented its Findings and Recommendations, reiterating and going beyond others before it had said: that HIV specific restrictions on entry, stay and residence that are based on HIV status only do not protect the public health, are discriminatory, may result in other human rights violations, and if applied in a blanket manner do not rationally determine those might become an undue burden on public monies.

The Task Team detailed how the enforcement of such restrictions can violate human rights and curtail important life activities. Medical ethics and rights to privacy and health are routinely violated through mandatory HIV testing conducted without informing people of the test or its results, without providing counseling or confidentiality and without connecting people to HIV prevention and treatment services. Such restrictions also prevent HIV-positive people from uniting with families, doing business or studying abroad, migrating for work, participating in international humanitarian and development efforts, serving in consular services, seeking or receiving asylum, attending conferences, or vacationing. They appear to have a particularly devastating impact on labour migrants who often use all their resources to finance the migration; and when their HIV status is discovered, are deported, resulting in both serious financial loss and return to a community where they are likely to face discrimination and rejection due to their HIV positive status.²

THE EVIDENCE OF PERSONAL NARRATIVES

The International Task Team on HIV-related Travel Restrictions noted the lack of information available on the impact of HIV-related restrictions on entry, stay and residence. There appeared to be few countries keeping publicly available data on when and how these restrictions were

¹ For further details, see the “Mapping National HIV-related Restrictions on Entry, Stay and Residence”, International Task Team on HIV-related Travel Restrictions, available at www.unaids.org and/or visit the *Global Database on Travel Restrictions*, www.hivtravel.org

² See *Final Report*, International Task Team on HIV-related Travel Restrictions, available at www.unaids.org

applied, to how many people and with what effect.³ However, anecdotal evidence and the studies that have been undertaken indicated the high human cost of these restrictions, as well as the complexity of the impacts that they have on individual's lives.

The Task Team felt strongly that the true story of HIV-related restrictions on entry, stay and residence could not be told, or understood, without highlighting the human face and the human cost of such restrictions, as an important form of "evidence" and an important part of efforts to eliminate them. Therefore it asked the International AIDS Society (IAS), in its capacity as Secretariat to the Task Team, to collect personal narratives as examples of some of the impact that HIV-related restrictions on entry, stay have on lives of people living with HIV, their families and colleagues. The IAS developed a document to explain the objectives and process, and a template to guide people and interviewees in preparing their narratives. Two teleconferences (in English and Spanish) were organized to present the Task Team's work and to encourage civil society organizations to reach out and gather narratives from their networks and communities. Partner organizations appealed for personal narratives on their websites and electronic mailing lists.

Individuals were invited to disclose their names and personal details, but it was also made clear that testimonies could be submitted anonymously and that privacy and confidentiality would be fully respected. Consent was obtained from those people who indicated that their testimonies could be published or otherwise made available. By June 2008, 19 personal stories, which are presented on these pages, had been collected. The stories give a voice to those directly affected by HIV-related restrictions on entry, stay and residence. The experiences documented also informed the development of the Task Team's recommendations.⁴ These stories clearly convey the evidence that such restrictions based on HIV positive status only and carried out without regard for the health and well-being of those involved do not achieve valid objectives and are wrong.

The narratives presented below are arranged alphabetically by country, region or territory.⁵ Some impacts, specific to each person's story, are highlighted, as well as the nature of the HIV-related restrictions that was involved or the understanding of those restrictions. Real names were only used when permission was given to do so. Some case studies have been edited for clarity and abbreviated. The facts and assertions presented in the narratives have not been independently verified.

AUSTRALIA

1 – DENIED STUDENT VISA SHATTERS DREAMS

Summary of Personal Impact

"Andrew" was denied a visa to study for his PhD in Australia. He was offered a conditional visa that he believed would have jeopardised the chances of completing his studies. The "fallout" forced Andrew to leave his work and home in Singapore. His right to privacy was compromised, and he believed his career development had been damaged. He believed that an HIV test was not required for a student visa, but had heard that Australia denied long-term visas to people living with HIV.

³ Ibid.

⁴ See *Final Report*, International Task Team on HIV-related Travel Restrictions; www.unaids.org

⁵ For details on country by country policies on HIV-related restrictions on entry, stay and residence visit www.hivtravel.org; the designations employed and the presentation of the material in this paper do not imply the expression of any opinion whatsoever on the part of the authors concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries.

Background

In 2005, Andrew, an educational researcher, was living in Singapore and had been HIV positive for three years. He underwent regular check-ups and his condition did not require treatment. He applied to study in Australia in September 2005, and was delighted when a university awarded him a fully-funded three-year President's Scholarship for a PhD programme. Set to travel to Australia in April 2006, Andrew did not renew his contract as an educational researcher.

In November 2005, Andrew went to a clinic for the medical tests required of student visa applicants. "I was rather anxious because I had heard rumours that Australia denied long-term entry visas to people living with HIV. Though a HIV test was not a requirement for a student visa, I decided to disclose my status anyway." In an email, Australian Immigration told him that his application had been declined as: "You do not meet the health requirements for the grant of this visa". It did not say that he was rejected due to his HIV status, but this was the only logical ground. He could appeal, however.

In the appeal, a doctor pointed out that Andrew would not be a burden on Australia's health system; his condition was stable, and if he became ill, he would seek treatment in Singapore. Australian Immigration granted him a renewable two-year visa, but he would have to register with a doctor of his choice and undergo screenings every three months. After careful consideration, Andrew decided not to go to Australia: "What if, after two years of hard work, I was denied an extension? I would then not be able to write up my research and defend it."

The "fallout", as he puts it, had just begun. "I had to withdraw my resignation letter from my employer, thus forcing my disclosure to my professors and colleagues in a social climate where even being openly gay, much less HIV positive, made it virtually impossible to be a teacher, trainer or researcher working with children and adolescents." Andrew also had to explain to his family why he would not pursue his PhD dream.

The psychological cost and sense of loss of future career development weighed down. "The situation became so untenable that I left my job and my life in Singapore and fled to Europe, hoping to start my life afresh and leave the past behind." Andrew is now an educator of people living with HIV.

2 – NO BURDEN, BUT STUDENT VISA DENIED

Summary of Personal Impact:

Jean, a citizen of Mauritius, was denied a student visa even though his doctor proved that he would not be a burden on Australia's health systems. Solely due to his HIV status, Jean was prevented from studying in Australia. The Australian Embassy demanded full details on Jean's HIV status.

Background:

Jean, 31, was doing technical jobs in Mauritius, and wanted to go to Sydney, Australia, in 2007 for training and work experience. His sister, living in Australia with citizenship, was willing to give him food and accommodation during his studies. Jean gained entrance to an Australian college for a part-time course. He also found a part-time job; the Australian employer put this in writing. Jean submitted his student visa application to the Australian Embassy, attaching a medical certificate, as requested.

In a letter, the embassy requested Jean to submit additional information, including: a current assessment from a treating doctor or specialist regarding his CD4 count and viral load; results of liver function tests; and a report "addressing history, physical examination findings, diagnosis, management needs for the next five years and prognosis". Jean submitted the information, apart from his viral load as these tests were not available in Mauritius. His doctor's elaborated report stated that his CD4 count and the status of his immunity were good, and that he had not

presented major health problems. The embassy denied Jean's student visa due to his positive HIV status.

CANADA

3 – WORK PERMIT REJECTION PRECEDES INTERNATIONAL AIDS CONFERENCE (2006)

Summary of Personal Impact:

Shaun Mellors, an HIV-positive South African activist, was offered a job in Canada. His work permit was refused on the grounds of "medical inadmissibility". The refusal, and a later bid for a tourist visa, sparked an advocacy effort to change the visa form before the XVI International AIDS Conference (AIDS 2006) in Toronto. A special Ministerial permit was required to allow Shaun access to Canada.

Background:

Shaun had been classified as criminal for "fraudently" obtaining a US visa. So he decided to answer questions honestly on the Canadian visa application form when, in 2002, the Toronto-based International Council of AIDS Service Organizations (ICASO) offered him a job. A medical exam was required to determine, Immigration Canada said, whether applicants or dependants had: a serious communicable disease; or a condition that could place an excessive demand on Canada's public health care or social service systems.

In June 2002, Shaun and his partner consulted a pre-approved physician. The exam included HIV tests, and his partner tested HIV negative. According to Shaun, however, "the process left much to be desired". "A person is sent from doctor to clinic to lab, without any form of counselling or explanation of what the tests are for, let alone post-test counselling," Shaun said. The results went to the Canadian Medical Officer for Africa, who asked for viral load and CD4 count tests and "neuro-psychiatric problems which could be considered as a risk to public safety or health". The results for viral load (less than 50ml) and CD4 count (540) were sent to the medical officer. Shaun and his partner sold their house and resigned from their jobs.

On 12 September, Shaun was told that he would not receive the permit as he was "medically inadmissible". He requested reasons. In response, he was reminded that he had been HIV positive since 1986 and treated with ARVs since 1996: "This condition is expected to progress, resulting in requirement for urgent assessment and recurrent treatment in a hospital setting, services that are also expensive ... he would be eligible for these services, thus placing an excessive burden on the health care system." The embassy did, however, request a special Ministerial permit to allow him to work and live in Canada; and after interventions by partners within ICASO's network, Shaun was given a temporary resident's (Ministerial) permit and a work permit. On 26 October 2002, Shaun and his partner flew to Canada.

Two years later, back in South Africa, Shaun applied for a tourist visa to attend a meeting in Toronto. The Canadian Embassy asked for his CD4 count and viral load. According to Shaun: "Our partners in Canada were alerted to this, and because preparations for AIDS 2006 (International AIDS Conference) were well underway, a concerted advocacy effort to change the visa application form got underway. A number of international NGOs, including the IAS, and Canadian NGOs worked tirelessly to change the law around visa applications in time for the Conference."

CHINA

4 – DEPORTED AUSTRALIAN CITIZEN LOSES MONEY, JOB AND DIGNITY

Summary of Personal Impact:

“Ronald” had been living in China on a business visa for about a year when he applied for a resident’s visa and tested positive for HIV. He was summarily deported. He did not receive counselling and was not told of his status. He lost his job, his money and his dignity, and at the time of telling his story, was still unclear about his rights. When Ronald applied for his resident’s visa, he had to undergo a medical exam that included an HIV test. A positive test would result in deportation.

Background:

When Ronald, an Australian citizen who had been living in China for about a year, applied for a resident’s visa, his required HIV test came back positive. “The hospital called me to come back to re-do the blood test, saying that they had lost the samples,” he says. Two days later, immigration authorities called him for a “routine” interview. “They made me have photos taken, pay money, and then sit in a room for several hours. There were no questions and no ‘interview’.”

When Ronald asked to use the men’s room, he was escorted there and back. He asked what was happening, and received a vague “routine” answer. “They then presented me with a letter, typed in Chinese, requiring me to sign it. I advised the officer that I could not read Chinese, but had the services of a translator that I could call to assist me with reading the letter. I was told that if I touched my mobile phone, it would be taken from me permanently.”

Ronald signed the letter, and police officers told him that he would be driven to the Hong Kong border and deported. His request to call his consulate was denied. An officer took Ronald home and gave him 10 minutes to pack. He gathered money, credit cards, an overnight bag and his computer. “All the time, the police officer remained at my side, advising me that I was not to contact anyone. I feigned needing the men’s room, and while in there, wrote a note to my partner.

“I was driven to the border, made to pose for a series of photos with the police – for what purpose I am unsure, but there were about 10 photos with different officers – and then made to leave. I lost my job, several thousand dollars tied up in my apartment – I had to pay the remainder of the lease term – and my dignity.”

Ronald says, “I still do not know what the letter that they forced me to sign said, and am unclear as to what my rights were ... and if they were abused by Chinese legal standards.”

OMAN

5 – RUSH DEPORTATION

Summary of Personal Impact:

Ramesh was deported from Oman after he tested HIV positive. Ramesh was not told he was being tested for HIV, counselled, or given his results. He lost his job, and was exposed to stigma upon his return to India when the press revealed his HIV status. Without information, he spent a lot of money trying to become HIV negative. Oman requires migrants to undergo annual HIV tests in order to renew their work permits; the policy has been that an HIV-positive result leads to deportation.

Background:

Ramesh, from Kerala, India, went to Oman as a car driver in 1992, and obtained a work permit and a sales job in a town called Salalah a year later. In 1997, he returned home for almost a year as he had saved enough money to build a house in his village and find a bride through India’s arranged marriage system. Back in Salalah to renew his work permit, he went to a clinic with his “sponsor” – “all migrants have sponsors”, he says – for the required medical tests. As Ramesh did not understand Arabic, an Arabic form and the test results were given to the sponsor. He was photographed, and with no explanation, his passport and documents were confiscated.

The sponsor then spoke to Ramesh's employer, who was saying, from what Ramesh could make out, that it was the first time in the company's history that such an incident had occurred. He was told that he would be deported; he was aware only that he had "failed in a medical test". His results were known at 11am; by 5pm, the company had settled his accounts; by 7pm, he was on a flight to Muscat, watched by police, and then on to India.

He reached Kerala, where jobs were in very short supply, with hardly any money. Ramesh worried about how he would survive – and he was reeling: "How could a healthy, broad-chested man like me have some germs in my blood?" Then, a newspaper carried a provocative headline: "A Gulf Migrant Deported and Returned after Having Tested as HIV Positive". It named Ramesh's village: he was the only migrant to have returned from the Gulf, and fingers pointed at him. "Some people abused me," he says. "Some neighbours ostracized me. My wife asked what was wrong with me."

Many villagers did not have telephones, so migrants often gave a neighbour's phone number to Gulf employers. A Keralite manager in Oman called Ramesh's neighbour, asking him to tell his family to take Ramesh to a hospital for tests. This was announced to the village. His wife's family forced him to go to a hospital, where his wife tested HIV negative and he tested positive. The couple were still affectionate, but his in-laws forced them to divorce.

"I decided to find out as much as he could about this dreaded disease that had destroyed all happiness in my life," Ramesh says. He went to Mangalore, where doctors explained what HIV was, and how it was caused and spread. He understood that HIV was "a disease that has no medicine in the world". He had no job and no wife, and his life was under threat. With his HIV status broadly known, Ramesh could not find work near his home. He travelled to a faraway city, where he worked as a salesman. His only goal was to somehow become HIV negative, and he spent a great deal of money on the medicine of "quacks". With an HIV-negative certificate, Ramesh knew, he could go back to Gulf and work and be happy again.

Ramesh turned to spiritual support, which he says strengthened him. He became involved in a Kerala State AIDS Control Society project. From this, he now earns a small income, and through his work here, he met his new wife.

RUSSIA

6 – UKRAINIAN CITIZEN WORKS ILLEGALLY

Summary of Personal Impact:

Every three months, "Andrei", a Ukrainian PLHIV, has to travel back to Ukraine in order to be allowed to stay in Russia with his partner. Andrei works illegally because he is HIV positive and chooses not to buy a forged medical certificate to enjoy a stable life in the Russian Federation. If he were to be tested for HIV, as required to obtain a visa, the results would be given to immigration authorities. HIV tests have been required for longer-term stays (more than three months) in the Russian Federation. Foreigners found to be HIV positive are regularly expelled. Foreign employees have to prove annually that they are not HIV positive.

Background:

Andrei met a Russian woman, and in 2004, the serodiscordant couple decided to live together. He moved from Ukraine to Russia. Citizens from the Commonwealth of Independent States can enter the Russian Federation without visas, but they have to register in their city of residence if they plan to stay for more than three months. They can also apply for a work permit or Russian citizenship. Each option involves "passing" an HIV test, the results of which are communicated to the immigration authorities.

Andrei travels to Ukraine every three months in order to avoid disclosing his HIV status to the authorities, and therefore be allowed to remain in Russia. Usually, he crosses the border and

returns within an hour. Some customs officers know him well, know his situation, and stamp his passport without asking him for the reason for his regular short “stays” in Ukraine.

Compulsory HIV-related tests do not prevent entry of foreign nationals, Andrei says. They are forced into illegal employment and economic activities to stay in the country. Many people living with HIV buy forged medical certificates to enjoy a stable life in the Russian Federation and avoid deportation. Andrei decided to respect the law, but is forced to work illegally because he is unable to prove that he is seronegative. This also means he cannot have medical insurance.

SAUDI ARABIA

7 – JAILED AND DEPORTED

Summary of Personal Impact:

“Peter”, an Indian migrant worker, was jailed and deported from Saudi Arabia when a blood test required for the conversion of his tourist visa to a work visa showed he was HIV positive. Peter was left destitute by a futile journey that he would not have undertaken if his doctor had told him, and not his agent, that he was being tested for HIV, and that his test was positive. He tried to hide this “social blemish” when he was deported; he did not seek treatment and became seriously ill. He lost his family when they discovered his HIV status. HIV tests have been required as part of the application for a work visa in Saudi Arabia. HIV-positive people are deported.

Background:

Peter, a chauffeur, had been working in Dubai for five years. When his visa expired in 1994, he returned to his village in Kerala, where the few jobs that are available are poorly paid. So, Peter applied for a job as a driver in Saudi Arabia; holding a job in the Gulf also enhances one's social status in Kerala. To facilitate the visa application process, Peter found an agent in Mumbai, and paid a commission of Rs20,000/-.

In Mumbai, his agent took him to a medical centre for the tests required for the visa application. He paid Rs300/-. The doctor told Peter that there was “something wrong” with his blood test results, but offered to change his medical certificate for a “commission” of Rs2,000/-. On the advice of his agent, Peter handed over the money. Perhaps, he thought, he had diabetes or anaemia; he had heard stories about people with such problems. He put in an application for a visitor's visa; his agent promised that it would easily be converted to a work visa on arrival in Saudi Arabia.

Peter borrowed money from friends and family to fly to Saudi Arabia. It took him 20 days to find a “sponsor” to help him convert his visitor's visa to a working visa. Peter went for the medical tests required for the visa, and worried about his blood test. He was told to wait for his sponsor, who entered and emerged from the centre, glared at Peter and then left. Peter was taken to a cell in the medical centre. He could not understand why he was being jailed for failing a medical test. He spent a day there. “They would give us food, but as if we were some wretched animals,” he says. “They would just throw food inside the room as if we were stray dogs.”

In court the next day, the judge ruled that Peter be taken for a second medical test. Confused, he asked a medical staffer to explain what was happening. The person made him understand that he was HIV positive. He realized that this was why he was isolated in the jail; he remembered that no one accompanied him in the back of the van while going to court. Whatever he knew about HIV was hearsay: that HIV “is a dreadful disease and one would die in two months”, he explains.

He felt cheated by the Mumbai doctor and agent. If they had told him the truth, he would not have been subjected to this humiliation. Apart from the shock of learning of his HIV status in this way, he was distressed by the financial loss incurred by undertaking this futile journey. Two days later, policemen took him to the airport. “Deported” was stamped in his passport. Before taking a bus

from Mumbai to his village, he tore up his passport and visa documents. Fraudulent visas and deceitful agents were common stories in Kerala; Peter told the same story. He did not reveal that he had been deported or that he was HIV positive.

Depressed, Peter became an alcoholic. He tried to hide his status, even avoiding going to a hospital. In time, he developed TB. His family took him to a hospital for a blood test. Only then did Peter's family learn that he was HIV positive. As HIV is regarded as a social blemish, his family ostracized him, his wife left him, and his two children were taken away from him. His family placed him in a care centre, but no relatives have visited him. In his depression, Peter stopped taking his TB medication; he just wanted to die. He began having seizures five to six times a day, which paralyzed one side of his body.

At the care centre, Peter recovered from paralysis and TB. He devoted his services to the centre for nine months and then secured a place in a centre run by a priest who takes care of abandoned people living with HIV. Peter is a positive speaker today and he works with people living with HIV.

SOUTH KOREA

8 – RESIDENT HIDES STATUS TO AVOID STIGMA AND DEPORTATION

Summary of Personal Impact:

“Vincent”, a Thai foreign resident, would be deported if his HIV status was known. He is leaving the country in which he has invested time, energy and skills. Vincent lives in South Korea on a tourist visa, rather than a work visa that would require an HIV test. The financial strain of hiding his status is high. At the time of writing, people living with HIV are denied entry to the country. Names of foreigners found to have HIV are given to Immigration, resulting in swift deportation.

Background:

Vincent has lived in South Korea for more than six years. His work has ranged from teaching kindergarten to developing human resource materials for conglomerates. “I speak Korean quite well, and feel that I have done a good job of accustoming myself to Korean culture and the Korean way of life,” he said.

When he found out that he was HIV positive in 2005, HIV testing was not mandatory for teachers in Korea. In March 2008, things took a swing for the worse; his options of living and working peacefully in Korea as a teacher no longer exist. “I live every day here in fear that the day when I get deported will be the next,” he says. He can understand the possible backlash that he could face by requesting free medication. “But I am in good health ... I do not need medication to live, and I do not pose any immediate threat to those around me.”

The financial impact is high. Vincent spends about \$1,000 every six months to go to Thailand for full tests. Every three months, he leaves the country to renew his tourist visa. With the rising cost of fuel, each trip costs up to \$1,000. “I am no longer eligible for health insurance, so even a common cold can cost me \$100 to \$150 to treat. Anything major would put me under.” He was fined \$300 for teaching a private lesson. Friends and students ask him why he is moving away this year; he tells them that he wants a change. “If they knew the truth – that I am leaving because I can no longer live and work in South Korea because I am HIV positive – I wonder if their views would change ... Based on conversations I have had with people ... and their views of people with AIDS as disease-ridden parasites, I wouldn't be surprised if I were suddenly ostracized because of my status.”

Stigma is a fear for many foreigners in South Korea. “Therefore, instead of tackling the problem head on, they bury it, don't get tested, and act as if it does not exist.” According to Vincent, Korean men who have sex with men don't get tested at all. “The fear that is instilled in people

here about the stigma attached to being positive in Korea scares me more than the disease itself.”

TAIWAN

9 – MEDIA CALLS HIV-POSITIVE TRAVELLER A “GATECRASHER”

Summary of Personal Impact:

“Dr. John” disclosed his HIV status at an exhibition in Taiwan. The media branded him as a “gatecrasher” for daring to enter the country. Officially, an HIV test result must be presented for stays longer than 90 days in Taiwan. Generally, people living with HIV are denied entry even for short-term stays.

Background:

In April 2002, Dr. John went to Taiwan as a visiting scholar to speak at a university and open the *Positive Lives* photographic exhibition. At the exhibition launch, he revealed his HIV status. “The next morning,” he says, “it was all over the newspapers; journals were asking how I got into the country when Magic Johnson had been barred from entry.” The headlines were along these lines: “Dr. John, Australian Researcher Gatecrasher.”

The next day, while he was en route to a lecture he was delivering on “Women and HIV” at a university outside Taipei, he was asked to give several press conferences. That evening, he was on many TV stations. Reporters followed him into his lecture and filmed part of it. “It was massive coverage, and I was back in the paper the next day. Fortunately, this was the day I was leaving the country; I don’t like fame.”

UNITED STATES OF AMERICA

10 – VISA APPLICANT DISCOVERS HIS HIV STATUS WITH NO COUNSELLING

Summary of Personal Impact:

“Victor”, from the Dominican Republic, discovered that he was HIV positive when he applied for a visa to travel to the US in 1997. He was not granted the visa. Tested without counselling, Victor was traumatised by the blunt way he learned of his HIV status. He has kept apart from his family in the US, and does not participate in many HIV-related events as he cannot travel into or through the US, affecting his professional development. Victor was aware that to enter the US on an immigrant visa, he would have to undergo a medical examination.

Background:

The doctor had just told Victor that he would not be granted a visa because he had AIDS. “He also asked me if I had slept with other men,” he recalls. “From that moment on, everything was a blur ... I don’t remember leaving the clinic. All I know is that some time later I was walking along the seafront ... I could feel the tears streaming down my face.”

It was barely 9am, and Victor said he did not come to his senses until that evening. “Because of the stigma attached to being HIV positive, and the fact that I didn’t understand the disease, I could only imagine the worst possible outcome; I didn’t even know if that was death.” He had to tell his family and friends, including his mother and family who were looking forward to being reunited with him, why he was denied the US visa. “All of my neighbours and some friends knew that I had applied for the visa. You can imagine what going to live in the US meant in those times ... it’s very traumatic for people who are diagnosed with HIV, precisely because they will be denied the possibility of experiencing the famous ‘American dream’.”

Victor heard about REDOVH+, the Dominican Network of People Living with HIV/AIDS in 1998, and helped to organize support groups and defend the rights of people living with HIV. He joined

the Greater Involvement of People Living with HIV/AIDS (GIPA) initiative of the United Nations in the Caribbean. He became President of the REDOVH+ Committee Board, and collaborated with the Red Cross and Red Crescent Societies and the Caribbean Regional Network of People Living with HIV/AIDS. He is also coordinating a community-based monitoring programme dealing with sexually transmitted infections, HIV and AIDS in his country.

Victor continues to work in the areas of HIV and AIDS support, but the travel restriction is affecting his professional development. He cannot participate in events in the US, or travel through the US in transit. The International Federation of Red Cross and Red Crescent Societies made arrangements for him to participate in United Nations General Assembly Special Session on HIV/AIDS (2001) in the US, but his visa was denied. He was also invited to the first “City AIDS Colombia and Latin America Workshop” (2007) in Medellin, Columbia, but was not able to participate as it would have required transit through the US on the sponsoring US airline.

11 – “CHANCE AND LUCK” BRINGS ADOPTED ETHIOPIAN CHILD HOME

Summary of Personal Impact:

“Anna” and her husband adopted “Sara”, an Ethiopian child with HIV. Only through “chance and pure luck” were the couple able to bring their daughter home. In a long, traumatic and expensive wait, Anna had to fly back and forth between continents and deal with incredibly slow bureaucracy in light of the fact that their child was HIV positive. During this time, Sara was not receiving treatment in an orphanage in Ethiopia. A special application form for a waiver of the grounds of ‘inadmissibility’ has been required for foreigners requesting a US visa if they have TB, HIV or certain mental conditions.

Background:

Anna and her husband began their adoption of Sara, an eight-year-old Ethiopian child with HIV, in 2006, and sponsored her care at an orphanage for HIV-positive infants and children in Ethiopia. Sara’s parents had died in 2005; both had AIDS. In March 2007, an Ethiopian court legally declared the couple as Sara’s parents. By early April, families whose cases had been approved in court travelled home with their HIV-negative children. “Although they could file their Orphan Petitions in Ethiopia, we were required to file ours in the US,” Anna says. Most US Citizenship and Immigration Services (USCIS) Orphan Petition approvals take a day to process at the US Embassy in Addis Ababa, but they take several weeks, even months, to process if filed in the US.

The state USCIS office asked for death certificates for Sara’s parents, which Anna says are “quite rare in Ethiopia”. So, she travelled to Ethiopia in May 2007 with five days’ notice to file the petition in person at the embassy in Addis Ababa. If the petition was approved, she would then file the 1601 HIV waiver that would take more than three months to process.

“The expense was daunting. By having to make two trips, I spent most of the money we had saved for Sara’s first year of medical treatment. This seemed ironic since USCIS requires proof of financial capability for adoptive parents, yet also requires many financial sacrifices through the expensive fees (\$545 for the 1601 alone) and multiple trips to Ethiopia due to Orphan Petition and HIV waiver processing difficulties.”

While the visa waiver form claims that it should take 60 minutes to complete, this does not take into account the supplemental documents not stated in the instructions that are expected from adoptive parents including letters from doctors, health officials, insurance carriers and adoptive parents. It took 15 hours to collect these documents. In addition, the waiver fee applies only to adoptive parents of children with HIV. Sara adds that, in most cases, the waiting children, who have lost their first parents to AIDS are not receiving treatment. “They remain in orphanages surrounded by TB, chickenpox, influenza, parasites and many other conditions that are life-threatening for an untreated HIV-positive child.” Yet the adoptive parents have completed home studies addressing the concerns of caring for an HIV-positive child, and have health insurance and medical experts waiting to treat the child.

Anna travelled to Ethiopia with many unknowns. “Would our Orphan Petition be approved? Could I push the 1601 HIV waiver through in the three weeks that I was able to stay in Ethiopia? Would the 1601 be approved at all? What was our daughter’s state of health? Would she be able to handle it emotionally if I had to return to the US without her? “The orphanage would not let Sara stay with me because they believed I would not be successful in getting the 1601 approved ... This was traumatic for both of us as I returned her to the orphanage each night and tucked her into bed. She was covered in molloscum and ringworm, had a raging ear infection, severe tooth decay and pneumonia and had lived her entire life without HIV treatment, causing her system to be revved up, fighting the disease with all she had.”

Meanwhile, Anna says, many waiver cases were sitting on a desk, waiting to be reviewed. “They had been there for 12 to 14 weeks ... The waiting families would hope to simply receive a call one day saying their child’s visa was approved and they could travel to pick them up.” She says her family’s story ends well – “only by chance and pure luck”. She was able to bring Sara home because her family was able to find an advocate in Washington, DC to expedite the process. “Sara’s waiver was processed in two weeks, the fastest one ever. Other families who had been waiting for several months received news of their approvals at this time also.”

Sara has been home for several months. “She began ARV treatment a month ago and is doing well,” Anna says. “Although her CD4 count records from Ethiopia were accurate, the clinic there was not able to test her viral load. When she arrived in the US, her viral load was 750,000 – 7.5 times the recommended standard in the US to begin pediatric treatment. “Her viral load will likely be undetectable soon and, due to an amazing new group of HIV drugs, it is predicted that she will live a normal lifespan. Sara is in school now, learning English at warp speed; she is creative, affectionate, giving and remarkably resilient. Had we not found an advocate who pushed for her US visa approval, she might still be at an orphanage in Ethiopia struggling through another year with an untreated HIV infection.”

12 – DELEGATE TO HIGH LEVEL MEETING ON HIV/AIDS DENIED VISA

Summary of Personal Impact:

Pat O. Matemilola was denied a visa to enter the US to attend a preparation meeting that preceded the 2006 United Nations High Level Meeting on HIV/AIDS on the grounds of his positive HIV status. After embarrassment, Pat applied for a waiver for people living with HIV to attend the meeting. The embassy appeared to not be aware of the waiver.

Background:

Pat was nominated to be part of Nigerian Government delegation to the High-Level Meeting in New York City. He filled in and submitted the US visa application form and was given a date on which to be interviewed for his proposed visit at the US Embassy in Lagos, Nigeria. He paid the necessary fees and waited to be interviewed.

The interview lasted barely 15 minutes. “At the end of it, the embassy staff simply told me I cannot obtain an entry visa because of my HIV status,” Pat recalls. “Fortunately, I had knowledge of the fact that a general waiver had been made for people living with HIV proposing to attend the meeting. So I mentioned this fact to the staff who then asked me to wait.” He waited for 10 to 15 minutes while the staff searched the embassy computer system, and was then told that he was correct about the waiver policy, and that he would be issued with a visa. “This enabled me travel to the meeting, albeit after the initial embarrassment.”

“If the US will not allow people living with HIV to enter into its territory, then there will be no moral justification to take any global HIV and AIDS meeting to the US as the important constituency of the most affected will not be able to attend and contribute to such meetings,” Pat says.

13 – DENIAL OF VISA TO SEPARATES PARTNERS

Summary of Personal Impact:

“Caron”, a Swiss citizen, was denied a US resident’s visa because she is HIV positive. Caron is not allowed to live in the US with her partner, and ships her ARVs to the country before travelling to avoid having them with her when she goes through customs. Caron has learned that she would possibly be allowed to live with her partner if they married, but would still have to endure “long and fastidious formalities, answer lots of questions, and hope for the best, leaving the final outcome in other people’s hands”.

Background:

Caron discovered that she was HIV positive in 1996. “I first thought that it was a death sentence, and my main concern was to know how long I could expect to live, followed closely by the fear of passing this on to someone else,” she says. “But I didn’t have the slightest idea then that it would also one day affect my freedom.”

She gave up her job, and focused on art and travels. In the East, Caron met a man, an American citizen. The relationship deepened, and Caron decided to tell him about her HIV status. Although it took some time for her partner to digest the fact, “he did not run away or make me feel like I was tainted or rotten, as had happened on other occasions”.

When Caron visits her partner in the US, she ships her ARVs before travelling. In March 2008, the couple decided to live together “and possibly end what is left of our respective lives together”. They chose the US as their home. They then made a shattering discovery: “I would never be allowed to join him in his country because of my HIV condition, despite the fact that I am not and will not be a threat to public health nor a financial burden for the public purse.”

“After lengthy searches, and with the help of some competent people at my local HIV association, we did find out that there might still be some hope for us if we got married, but that even if we did, we would still have to go through long and fastidious formalities, answer lots of questions, and hope for the best, leaving the final outcome in other people’s hands.”

Caron says the process is still underway. She adds, “It is hard for us to think that in a world that is supposed to be a free world, and in countries that have high ideals of personal freedom and democratic values, it is possible still for governments to interfere in people’s lives and take away from them the possibility of choosing the course of their own lives.”

14 – EVADING RESTRICTIONS WITH “CANCER”

Summary of Personal Impact:

US immigration officials interrogated Jean-Luc Romero when they found his antiretroviral medication in his hand luggage while in transit to AIDS 2006 in Toronto. To avoid being denied transit, he told the officials he had cancer. As a result of this experience, Jean-Luc avoids travelling to or through the US. He points out that many of the UN member states apply discriminatory measures against the free movement of people living with HIV.

Background:

As President of the Association of Local Elected Officials Against AIDS (*Elus Locaux Contre le Sida*), Jean-Luc flew from France via the US to attend AIDS 2006 in Toronto. Immigration officials at Fort Lauderdale searched his hand luggage and found his antiretroviral medication; Jean-Luc has been HIV positive for more than 20 years. “If I had told them about my illness ... I would have risked not being able to go to the conference ... So I lied by claiming that I had cancer,” he says. He says the officials did not believe him, and interrogated him. “Despite their insistence, I continued to claim that these treatments were intended for my cancer. I could, after an hour, finally board. Resting in the plane, I thought: “Was I guilty for being ill? Had I committed a crime? Surely not!”

“I have never been ashamed of my illness; I revealed it publicly and, as a politically-elected representative, it was not an easy thing to do.” Jean-Luc says that he “does not dare to go to the USA anymore”. He stated that the American consul in Paris, indicated in response to an interview with Jean-Luc that HIV-positive people who lied about their condition would be on a permanent blacklist and forbidden entry to the US.

“I learned that by being ill – affected by a transmissible, though non-contagious illness – one could be treated as a threat to public order, and worse, as a terrorist,” Jean-Luc says.

15- GEORGETOWN HUMAN RIGHTS ACTION UNCOVERS DEVASTATING EFFECTS IN HAITI

Summary of Personal Impact:

Georgetown Human Rights Action gathered stories of people living in Haiti that illustrate “most clearly the sad effects” of US HIV-related travel restrictions. “The more stories we heard, the more apparent the devastating effects of the HIV ban became.” These insults to basic human dignities included families being kept apart, people being tested without consent or counselling, and people discovering their HIV status through reading embassy papers. Although the US is trying to position itself as a world leader in AIDS initiatives, its immigration policy is “woefully outdated” and creates a “climate of stigma”.⁶

Background:

Georgetown Human Rights Action (GHRA), a student-led mission funded by Georgetown University, recently completed fact-finding trips to Miami and New York in the US and Port-au-Prince in Haiti to investigate aspects of US immigration policy towards people living with HIV. It found that: “By continuing to exclude HIV-positive individuals, the US creates a climate of stigma and sends a clear message that HIV-positive individuals are second-class citizens.”

In Port-au-Prince, GHRA documented frequent human rights violations relating to the HIV bar. Its visits included AIDS clinics, human rights lawyers and immigration officials, “but it was the testimonials of individuals living with HIV/AIDS that illustrated most clearly the sad effects of this policy ... The more stories we heard, the more apparent the devastating effects of the HIV ban became.” The experiences of HIV-positive visa applicants “are an insult to basic human dignities and are a direct result of US immigration requirements”.

The following are the stories of some of the people interviewed in Haiti. Names have been changed to protect privacy.

16 – JEAN and his three children went to a doctor in Port-au-Prince in December 2006 to be medically examined as required for the visa application. “My children and I hoped to join my father who was already living in the US,” he says. The doctor produced medical reports for the children, but said that he would deliver the results of Jean’s examination to the embassy because “there was a little problem”. Jean reported to the embassy for a 5 December meeting, paid the immigration fees for his family and brought the required paperwork. He was told that his medical report hadn’t arrived. He returned to the embassy and was told, “The medical report has a problem; you can’t leave.”

“Then I was told that I was HIV positive,” Jean says, “and that I would need extra papers from several doctors before I could continue with my application process. They [the embassy officials] told me nothing about what the disease did to people or what I could do to treat it. I thought I was going to die soon ... I was sick. I didn’t want to eat or do anything and couldn’t think of anything but death. I cried all day, every day.” He received no counselling.

⁶ NEED SOURCE!

"I returned to the embassy with information from three different doctors in the US agreeing to treat me when I arrived in the US, but each doctor was refused because the embassy 'doesn't trust them'. I then gave up. It was a very sad time for me."

He sought support from the Haitian Group for the Study of Kaposi's Sarcoma and Opportunistic Infections, a PEPFAR-funded organization in Port-au-Prince. "I began treatment for the first time and saw people living with AIDS who are still strong and leading productive lives ... although being HIV positive will always be difficult, getting information from the clinics made me realize I could live with the disease. I did not feel this way after visiting the embassy."

Jean continues to wait for word from the embassy about his waiver. At one point, he had a lawyer, but he can no longer afford to retain such expensive services.

17 – KATIANA is trying to join her brothers, mother and stepfather in the US. "The embassy contacted me in April 1998, and they told me everything was okay, my papers were okay, and I should make an appointment." At the embassy, "they told me that they had lost my application and it might be in Miami". The file was not found for a month. "I didn't know anything about HIV until I was forced to get tested as part of the application process. When I found out I had HIV, I was afraid to tell my family. When my mother found out, she decided that my youngest brother should come to Miami so that he wouldn't find have to find out. I was so depressed and embarrassed that I terminated my visa application."

She says that in Haiti, HIV-positive people are treated as if they are dead. "Even the people at the embassy are always rude to people with HIV, and anybody who works at the embassy knows that you have HIV/AIDS because you will come on Wednesdays or Fridays, the days for people with health problems. Even then, there are gates only for people with HIV/AIDS."

"I feel I have lost 10 years of my life waiting ... I am lucky to have a mother who is willing to fly to and from Haiti to help with my application process, but I am embarrassed because I am an adult and my mom still has to support me. If I were in the US, I could support myself and my mom wouldn't have to send money to Haiti." Katiana's mother returned to Haiti and took her to a community research organization for treatment. Here, she found out about the HIV waiver, and in December 2007, reactivated her file. She sat in the embassy waiting room for a day, but her name was not called. Talking with a woman who was waiting for a meeting, Katiana found out that the embassy staff only met with HIV-positive applicants on Wednesdays and Fridays. She returned to the embassy on Friday.

Katiana was told that since so much time had elapsed, she would need a letter from her mother, agreeing to sponsor the application. Her mother flew from Miami to Haiti with a notarized letter, but Katiana's name had been misspelled and the letter was rejected. Her stepfather sent another letter to her; twice, Katiana tried to take the letter to the embassy, but she was too sick. Eventually, embassy staff told her that the letter was not adequate because it did not say that she was HIV positive, although she had not been told that this had to be included. The embassy eventually accepted the letter, but then told her that she needed to provide an additional, handwritten letter. She is working on obtaining this letter.

18 – SUZETTE went to a doctor, as required by the visa application process, in 1995. "The doctor told me nothing and sent me to the embassy," she says. At the embassy, she was given a piece of paper with information about AIDS. "I returned to the doctor to ask what was going on. He told me I was HIV positive. It was the worst day of my life."

She then filed the papers with the embassy, but was refused a visa. In December 2007, she was finally granted an appointment at the embassy. "Here, I was given additional papers. I brought a letter saying I was getting treatment and I went to my clinic and had them sign it. The embassy would not accept it."

Suzette's parents found a doctor in the US who said he would help with her treatment there. "But the embassy only told me to come back in another three months. On 1 March 2008, I returned to the embassy, but was told that the required paperwork had not yet arrived from the US ... My mother, father, brother and two sisters are all already living in the US. For eight years, I have been the only one in my family still living in Haiti. Why don't they want me?"

When Suzette discovered her HIV status, she was referred to private doctors who told her to fill their prescriptions at pharmacies, which were expensive. The doctors did not tell her about the free clinics; nor did they provide her with counselling. Since finding out about GHESKIO⁷ (the Haitian Group for the Study of Kaposi's Sarcoma and Opportunistic Infections), Suzette has been receiving free treatment and counseling.

19 – DANIELLE began the visa application process in 1994, hoping to join her mother, husband and eight siblings in the US. She went to a doctor for the medical examination required for the visa; he told her that she should go straight to the embassy. She did so, but the embassy staff gave her papers and told her to go back to the doctor.

She received a form from the embassy. "On it, below my name and identification information, there was a large check mark in a box next to some text which read, '*Votre test est positif pour le Syndrome Déficitaire (SIDA).*' I knew then I had HIV. I had no one to tell. If I told my friends and family, they would not want to see me again. I was so scared. No one helped me."

She called her husband in the US, who accused her of having an affair. "I have not heard from him since ... I asked my mother if she would sponsor me. She said no. I was now completely alone in Haiti. I terminated my application. Why would Americans, after giving so much money for AIDS medicines, not let people with HIV or AIDS come to the US?"

Having found out that she was HIV-positive through her embassy paperwork, Danielle was not referred to counselling of any kind. She managed to find POZ (Promoteurs Objectif Zero SIDA), which provides health care, medicine and counselling to PLHIV. Through POZ, she learned of the HIV waiver process, and decided to re-open her file in 2003. Her mother is also coming to terms with Danielle's HIV status and has agreed to be her family sponsor.

Conclusion:

The above case studies illustrate the devastating impact of HIV-related restrictions on entry, stay and residence on the lives of people living with HIV. These stories show how such restrictions deny people living with HIV the right to family unification, undermine efforts to adopt HIV-positive children, cause deep psychological distress, and rob bright and promising individuals of the opportunity to achieve their potential. The HIV-related restrictions create a culture of blame and environments in which stigma against HIV deepens and discrimination based solely on HIV positive status is practiced with impunity. This document draws the worlds' attention to the heavy burdens and personal consequences borne by people living with HIV as a result of implementation of discriminatory and outdated HIV-related restrictions on entry, stay and residence.

⁷ www.gheskio.org. According to its website, GHESKIO is a Haitian non-governmental organization dedicated to clinical service, research, and training in HIV/AIDS and related diseases.