

# DIAMONDS

Stories of Women from the Asia Pacific  
Network of People Living with HIV



United Nations Development Fund for Women



# ABOUT

Women of APN+ (WAPN+) is the women's working group of APN+.

Its vision is the empowerment of women living with HIV and AIDS in the Asia-Pacific region to provide a united voice, improve the quality of our lives and ensure our leaders protect our rights.

WAPN+'s mission is to increase solidarity and communication among women living with HIV in the Asia Pacific region and improve our skills, knowledge and opportunities to fully participate in an effective response to HIV and AIDS, and to advocate for the needs of women living with HIV at a regional level.

UNIFEM is the women's fund at the United Nations. It provides financial and technical assistance to innovative programmes and strategies to foster women's empowerment and gender equality. Placing the advancement of women's human rights at the centre of all of its efforts, UNIFEM focuses its activities on four strategic areas:

- Reducing feminized poverty;
- Ending violence against women;
- Reversing the spread of HIV/AIDS among women and girls;
- Achieving gender equality in democratic governance in times of peace as well as war.

## Disclaimer

The following stories are based on the transcriptions of interviews with the subjects. The views expressed in this collection do not necessarily represent the views of UNIFEM, the United Nations, or any of its affiliated organizations.

DEDICATED TO  
Oom, Suzana and Sarah Jane

The first diamonds to shine in our region.

United Nations Development Fund for Women



August 2009

# ACRONYMS

APN+	Asia-Pacific Network of People Living with HIV/AIDS
ARV	antiretroviral
AusAID	Australian Agency for International Development
CCW	Cambodian Community of Women living with HIV/AIDS
CPN+	Cambodian People living with HIV/AIDS Network
GIPA	Greater Involvement of People living with HIV and AIDS
GNP+	Global Network of People Living with HIV/AIDS
ICAAP	International Congress on HIV/AIDS in Asia and the Pacific
KLASS	Kuala Lumpur AIDS Support Services Society
PWN+	Positive Women's Network of India
STI	sexually transmitted infections
TB	tuberculosis
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNIFEM	United Nations Development Fund for Women
CD4	Cluster of Differentiation Antigen 4, to measure the level of immune system

## Foreword

United Nations Development Fund for Women



**Dr. Jean D’Cunha**

**Regional Program Director  
UNIFEM East & Southeast Asia  
Regional Office, Bangkok.**

**“When I talked about the experiences I had gone through with my children, I could see that all the mothers were crying. It really touched them...I thought, my story is powerful. I can use it to change people’s attitudes”, says Maura, a HIV positive woman, whose story like the other women featured in this publication, “Diamonds”, challenges us to LISTEN to the concerns and priorities of HIV positive women.**

As the world witnesses a sharp increase in the number of women living with HIV, women leaders like those telling their stories in this publication need to be heard. Coming from different socio-economic and personal contexts in the Asia Pacific region, these women speak of the power dynamic in their relationship with men, weighted in favour of the latter. They speak of discrimination and violence that they endure, rendering them vulnerable to HIV – a lack of information about HIV, a lack of knowledge about a partner’s HIV status, an inability to negotiate sex or safe sex, because they fear violence. They speak about the stigma and discrimination they face and the burden of secrecy that weighs down on them (and women do face disproportionate discrimination when compared to men), unaffordable healthcare services and the burden of care-giving responsibilities.

Emerging from the shock of testing HIV positive and the implications this has for their lives and relationships, transcending the trauma of stigma and discrimination - these women demonstrate remarkable courage in breaking the culture of silence enveloping their HIV status. They show intense resilience in picking up the pieces of their lives and deciding to LIVE, and in inspiring other HIV positive women with similar concerns, to LIVE. They are crucial advocates for the rights of women, and in particular the rights of HIV positive women. It is critical that we help them robustly inform the formulation and effective implementation of policies and programs with budgets, that address gender and HIV/AIDS issues in relation to prevention, treatment and care.

Through the personal narratives of these amazingly strong women, Diamonds foregrounds the link between gender-based discrimination, violence and HIV/AIDS. It is a frightening reminder that unless inequitous power equations, whether between men and women, adults and children, or in same sex relations, are transformed into equal relationships marked by respect and dignity, the pandemic, especially its “feminine face”, will continue unabated.

Co-chair  
Asia Pacific Network of People Living  
with HIV/AIDS (APN+)

**Naoko Kawana**

Foreword




**It is my pleasure to let you know that “Diamonds” is published in the year of the 15th anniversary of Asia Pacific Network of People living with HIV (APN+).**

APN+ is the network of people living with HIV (PLHIV) in Asia Pacific region. It was established in 1994 at a meeting in Kuala Lumpur by 42 PLHIV from eight countries. It was established in response to the need for a collective voice for PLHIV in the region, to better link regional PLHIV with the Global Network of PLHIV (GNP+) and positive networks throughout the world, and to support regional responses to widespread stigma and discrimination and better access to treatment and care.

Women of APN+ (WAPN+) was formed in 2006 as one of the working groups of APN+. Its vision is the empowerment of women living with HIV in Asia and the Pacific. Women who share their life stories in this book are good examples of our vision being realized. They have become leaders despite severe discrimination and stigma, and are inspiring and empowering other women. Above all, these eleven women in the book are great advocates of people living with HIV rights and voices, whose stories are sometimes not being told. Through these stories, we are being reminded that the numbers indicated in the HIV data represent people who have different life stories, stories of hopes, dreams, love, passion and life experiences to share with all of us.

I would like to thank all the women who contributed their time and effort by telling their stories as well as UNIFEM for their support. I would also like to express my sincere appreciation and deep admiration to Dr. Susan Paxton, author of this book, respected researcher, wonderful trainer, and above all, good friend of ours for her extraordinary work.

I hope as the title represents, our “Diamonds”, which are formed under immense pressure to become the strongest and most brilliant natural resource on earth, are beautiful and colourful, and will keep on sparkling, shining and inspiring many people, including other women living with HIV.



**Author/Editor:** Susan Paxton

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# INTRODUCTION



This is a compilation of stories about the lives of women living with HIV in the Asia-Pacific region. Each woman has overcome incredible challenges to become a strong leader, advocate and role model for other HIV-positive women. These women are like diamonds, formed under immense pressure, hewn from the darkness to shine, strongest and most brilliant of all gems. Interviewing these women and crafting their stories has been one of the most joyous tasks I could have undertaken. I know each woman to some extent because they have all attended at least one of the training workshops I have conducted in the region and several have become my close friends. I have witnessed many of these women blossom over the last few years and I wanted to document their life stories to challenge discriminatory attitudes towards HIV-positive people and to inspire more women living with HIV to speak out. Thank you to UNIFEM for enabling me to bring these diamonds into the light.

When I started talking to health professionals and students about living with HIV in 1991, I realised how powerful my story was, and I was amazed there were not more positive people speaking out publicly. Early in 1995 I attended the International Conference for People Living with HIV in Cape Town and was appalled by the absence of HIV-positive women from our region. I spoke to all the Asian males there and was told that positive women were speaking out in Asia, particularly in the Philippines, although none had made it as far as the conference. Soon after this I met Suzana Murni, who went on to establish Spiritia, the first network for people affected by HIV in Indonesia, and Oom, a tiny courageous Thai woman who advocated for HIV-positive women's rights to reproductive choices and who set up a home for babies of positive women in Bangkok. When I was elected the Australian representative to the Asia-Pacific Network of People Living with HIV (APN+) in 1996, there was a dearth of positive women leaders in our region.

In 1997 I attended the International Congress on HIV/AIDS in Asia and the Pacific (ICAAP) in Manila and met many positive women who gave public talks, most under a pseudonym with the exception of the sharp and dynamic Sarah Jane. At the next International Conference for People living with HIV in Chiang Mai, still there was only a slow trickle of positive women who were “out” and open about their HIV status in public.

Most women diagnosed with HIV tend to keep quiet about it. For many years I was terrified to go public in the media for fear that my son would face discrimination, but he didn't. My PhD study of HIV-positive speakers indicated that going public is paradoxically both terrifying and provides enormous relief. I wrote “Lifting Burden of Secrecy” to help positive people who want to speak in public and I became fascinated by the diverse life journeys of positive women who become activists.

In 2001 APN+ conducted the first regional documentation of AIDS-related discrimination in Asia and we found that within families and communities, women face more discrimination than men do. I became increasingly committed to training positive people on how to advocate for their right to live free from discrimination. For several years I worked with mixed groups of men and women and got to know positive women from Bangladesh, Guam, India, Papua New Guinea and Singapore. I met both Frika and Maura, two women who continually amaze me. Women in Thailand were already politically active and India was building robust women's networks, but in comparison to other parts of the world, female positive leaders in our region were quieter and slower to emerge. I decided it was time APN+ offered women-only training workshops in advocacy and facilitation skills and the first was held in Bali in May 2004. It was an exhilarating, electric experience for us all.

Women began mobilising in many countries. I worked with positive women from Cambodia, China, Fiji, Indonesia, Iran, Japan, Malaysia, Mongolia, Myanmar, Lao PDR, Nepal, Pakistan, Samoa, Sri Lanka and Viet Nam. I felt proud to see women who were participants in one of my training of trainer courses conducting meetings, running sessions, facilitating networks and managing organisations. Today we have a groundswell of inspirational positive women leaders throughout the region who are passing on their skills and helping to build the confidence of more positive women and their stories need to be told.

There are so many strong positive women who could have been included in this book; a volume could be written focussing solely on women in the Pacific or women in India. APN+ received funding for travel only in South-East Asia and I was fortunate to have the opportunity to capture a few additional stories from women outside this sub-region.

Most of the interviews were conducted during a whirlwind journey in March 2009 when we filmed the documentary that accompanies this book. In addition, I interviewed Princey when she attended an advocacy training workshop in Bangkok in 2007, Maura when I was working in Papua New Guinea in 2008, and Rinarsi when she visited Australia on a leadership program in early 2009. I am indebted to several people who helped with translation. My interviews with Princey, Huyen and Rattana were conducted via translators: Geraldine, Yen, Tom and Meiji; Saranya was interviewed by Shakthi Nataraj on my behalf; and Mae Zhou interviewed Chengli and translated her story. I thank them all so much for their invaluable contributions. My son Tsari was the first person to read each of the stories and give me editorial advice and I thank him enormously for his canny eye. So many thanks also to Cathy Kolokitas at APN+ and Jane Wilson at UNAIDS for feedback on the draft.

I feel honoured and excited about this work. Because I am a trusted advocate for my peers, women allowed me tell their stories, and that is an enormous privilege. Thank you to each woman<sup>1</sup> who shared her story in this book, and thank you to all the positive women in Asia and the Pacific who speak out and counter HIV-related stigma and discrimination every day.



SUSAN PAXTON  
APN+ Advisor

<sup>1</sup> Each woman in this book gave her voluntary informed written consent for the publication of their story.

“ In 2001 APN+ conducted the first regional documentation of AIDS-related discrimination in Asia and we found that within families and communities, women face more discrimination than men do. ”



## MAURA

Papua New Guinea

I was born in Port Moresby General Hospital on 3 December 1975. I have four older brothers and three older sisters and my younger sister was born in 1978. She and I were very close. My father worked as the Senior Storeman in the Health Department Medical Store, in charge of dispatching medicine to various provinces. As a kid, I was my father's favourite. He didn't take part in looking after my elder brothers and sisters. He would never carry them or play with them, and they grew up fearing him.

But with me, it was different. I would sit on his lap, or he would ask me to do little tasks for him, like make him a cup of tea, and he would always give me money. If I wanted things I would go straight up to him and ask and he would say, "You can have it if you do this", so I would do whatever he asked and then I would end up getting what I wanted.

I used to be good friends with a neighbour's daughter who had leprosy. We played together and I picked up the infection. I was quite sick and had to have treatment throughout primary school, so my father tended not to scold me. In the evenings I always wanted somebody to take me to bed. My father would get my big sisters to carry me into the bedroom and put me to sleep. If I wanted something from my brothers or sisters or cousins I would just start crying and then my father would get angry and start shouting at them. I could get away with things easily.

Sometimes I tried to get out of going to school by pretending I was sick, but my mother would say, "If you stay home, we'll make you cook everyone's food and clean the house and wash everyone's laundry." My parents knew I was useless at housework and hated cooking and I would get scared and go to school. When I came home my father would say, "We're doing this because you have a future. At one point we'll leave you, so you must go to school and work hard so you can earn a living." My father brought me up to listen to what people say, "Whether it is good or bad, you listen to it and wait. Never talk back when somebody is talking to you." So I listen, and always weigh up the situation, and if I know I am right, I never take no for an answer.

I spent a lot of the time with my brothers as a child, so I was a bit of a tomboy. I used to dress like them and try to look like them. Sometimes they would fill up the car with food and take me and my sister to the drive-in movies or we would go down to the beach. In those days it was very safe and we would run around the beach and make friends with the expatriate kids. There were a lot of expats in Port Moresby until the late eighties.

In 1988, during my first term of grade six, my younger sister became very sick. Her face started to look bruised and she kept vomiting. She was in and out of hospital many times but the doctors couldn't diagnose any specific illness. This went on for two months, and then she died. My parents believed she had been cursed. We took my small sister's body home and buried her in the village. Her death affected the whole family. My father was devastated, so my mother decided we would stay in the village, and that is where I finished grade six. At the end of the year I was the second-top student in Gulf Province.

From there I went to high school as a boarder for the next four years. I found it tough to be away from my family. I was so unhappy and told my parents, "I can't stay here", but they said I must. It was like survival of the fittest. Sometimes our school would run out of food. If people from our village passed by, I would write notes to my father to tell him what was happening, then he organised for somebody to cook food and bring it to me so I didn't go hungry. Every afternoon throughout grades seven and eight my brother used to come and drop food to me, but once I got to grade nine, I didn't want my brothers or my father to visit. I'd feel embarrassed when I saw them and I asked them not to come any more. My father didn't understand, "But you used to be so excited to see us" and I replied, "But now I am a senior so you can't come unless I ask you."

Throughout high school I wasn't at all interested in boys. All my classmates had boyfriends and I thought they were stupid. I couldn't imagine what they would talk about to their boyfriends and I didn't feel I needed one. At the end of 1991, after Year 10, I went to spend Christmas in Port Moresby with my older brothers and that is when I first met Max. He started asking who the new girl was and my friends told me he liked me so we started talking to each other, then by January I was gone again.

I got a scholarship to go to the National Fisheries College. It wasn't my top choice and I found it hard because I couldn't grasp all the technical terms related to boat building and marine engineering. I wasn't cut out for it and at the end of the year I told my father I didn't want to go back. My parents asked me what I wanted to do and I said I wanted to be a flight attendant. They didn't like that idea, so instead I stayed with them throughout 1993.

But my father wasn't happy with me doing nothing and, without my knowing, he went to the village health centre and asked if any colleges had new intakes for nurses, and he submitted my name. In September, the health centre called me and said I was accepted to go to a nursing school. I was so angry with my father. I said, "What makes you think I'm going to be a nurse? I don't want to be a nurse." He said, "I want you to attend college because you are a very clever girl. You are bright and I can see that in you. I'd rather you go and build up that knowledge and have a bright future." I didn't say anything. A month after that conversation, he died. I had been so close to my dad and after he died I was so depressed.



The following January I got a message from nursing college that I had to go for the start of the new year. I wondered what I was getting myself into. The first year was hard. I was scared of sick people and I didn't want to see sores and ulcers. At one point I fainted at the sight of blood. But I overcame that and by the end of the second year I was getting used to the system. In my final year I still didn't have a boyfriend, so I decided to write to the pen pals column in the Post Courier newspaper. I got about 300 replies, which I gave out to my girlfriends who all got busy writing away. There was only one letter I replied to. It was from a boy who had just graduated from Uni Tech and had got a job at Oktedi. We became pen pals.

I graduated at the end of 1995 as one of the top two nursing students and I was offered two scholarships. The first was to further my studies in Mt Hagen. I wanted to go but my mother didn't want me to, so I said no. The second offer was a nursing diploma in New Zealand. My mother again would not give her approval and I was so upset. I was 21 and I said, "Okay, you people have to find me a job." My big bother said he would help me, but there were no nursing positions available, and eventually I got a job in a pharmacy dispensary in Moresby, where I worked throughout 1996.

I met Max again, but we didn't spend much time together because I was working a lot. Sometimes I'd see him when I was out walking and we'd talk together. My pen pal wrote that he was coming to Port Moresby, so we met up. He was so nice and I started going out with him. Every time he came to Moresby he would take me for lunch. He introduced me to his family, and after that his cousins would come and visit me. At the end of the year he told me he was going to get a house in Oktedi and he asked me to marry him and go and stay with him. He told me I could get a job there – he had already asked his boss who had said I could work there. I wanted to go with him, but I started worrying about whether I was making the right decision and whether I would regret it.

In January, Max invited me to go to his cousin's birthday party. I went for a while and intended to come home, but somebody told my cousins that I was talking to Max at the party, and they got angry. My brother was away and I was afraid that my cousins were going to beat me up, so I told Max, "I can't go back home because I'm scared they might kill me." Max told me I had to go home and tell them that I was only talking to him, but I said, "No, I can't. I'm scared." So Max was stuck. He kept telling me to go back but I said, "No, I'm not going. I'm not going to let them bash me up and then I'll look stupid in front of all these people." So I went and locked myself in Max's room. I stayed away from home for two days. When my brother came back, instead of coming down and sorting everything out and listening to my side of the story, he said, "I don't care what happened. You are going to get married to Max." My sisters were really angry because they didn't want me to marry Max but my brother said, "If you are going to support Maura, then I'll kick all of you out too." My cousins then beat me up; one of them hit me on the head with a piece of wood and I had a deep cut on the right side of my head. I still have the scar. So that is how I ended up marrying Max. It was not what I wanted but the situation that forced me to do it.



I was so angry and immediately regretted what had happened. Soon afterwards my boyfriend came to Moresby. He was very excited because he had got the house. He asked me if I had made a decision. I didn't know how to tell him I was already married. He told me he'd found me a job. I looked at this man who had such a bright future for me. He said, "Are you going to say 'Yes'?" and I said, "Let me think about it." He said, "But you told me you wanted this." That night I didn't sleep. I was crying and crying. After he went back I wrote and told him all about the situation because I couldn't tell him face-to-face. He called me, crying, "How could you do this?" I explained everything and he said, "But you can still move out." I said, "I can't. I can't." Because I thought that if I did, everyone would think that I was a prostitute. I felt trapped. He went back but he didn't continue with his job. He couldn't live in the house so he returned to Moresby. He later got married and had two children but he didn't have a good relationship with his wife and she left him and the children. He still calls me from time to time to ask how I am.



As soon as I married Max, I could see signs that something was wrong with his health. The glands on his neck were swollen and I told him that maybe he had tuberculosis. I asked him to go and get it checked out but he refused, saying it had been like that for a long time. I said nothing else but it bothered me. Then in the middle of 1997 I found out that I was pregnant. I went to the antenatal centre and they didn't tell me that they were going to test me for HIV but when I came back for the next visit, I saw a red dot on my card and asked, "Why have they put that red dot on my card? I know it means high risk, but how am I high risk?" The nurse told me to wait for the doctor. When I walked in, the doctor just told me they had tested my blood and it was HIV-positive. I looked at him and said, "This is not true. This is not happening to me." He replied, "I just wanted to tell you. Come back in two weeks time and we will test your blood again." That was it. I didn't get any information, support or counselling.

When I walked out I felt as if I didn't know where I was going. I didn't know anything about HIV. At the nursing school there was no information about HIV apart from the fact that it was an STI and there was no cure. I said, "Okay, I'm going to die now." When I saw Max I told him that my blood had tested HIV-positive. He replied, "Are you sure it's your blood? The doctors must have made a mistake. It's not your blood. There are so many blood samples so they must have mixed up yours and confused it with someone else's blood." But I said, "No, I am sure that everything in the lab is in order. It's my blood."

The next two weeks were hell. I didn't eat or sleep properly. When I returned for my second test, the doctor had asked Max to come and they tested him. Both our results came back positive. From that moment, Max was so angry. At first he was in denial and he said it wasn't his blood. Within a week, his habits changed and he was drinking and coming home late, at one or two in the morning, and then he started becoming violent. He would say, "You are the one who got tested first so it must be you who infected me."

They picked it up in you”, and then he beat me up. I went through so much violence from 1997. I began to fear him, hate him and I certainly regretted marrying him.

In December 1997, I gave birth to a small girl. When she was three months old, she was sick and had problems breathing. We brought her to the emergency department but nobody attended to us once they looked at my medical card. They assumed that the baby was positive and they kept saying somebody would see us later. We sat waiting for medical help throughout the night but nobody came to attend to her. The next morning we knew nobody would help us so we went home, intending to go to the pharmacy but a few hours later she died. That made me so angry and confused and I didn't know what to do.

Max continued to be violent and beat me up. In the middle of 1998 I became pregnant again, and I gave birth to a beautiful boy in 1999. He was so cute and I loved him so much. I saw my own face on that small boy. I didn't want to go to work and I told the pharmacy that I was going to stay home and look after my baby. After the birth of my son, Max kept forcing me to have sex with him and whenever I refused he would bash me up. The more he beat me, the more I hated him. I didn't have any good feelings for him by then, and sex was the last thing I wanted.

When my son was only a few months old, I got pregnant again and that really depressed me. Max wouldn't wear condoms and I wasn't using any contraception because I was afraid of the side effects of hormonal contraceptives on HIV. I didn't have any information about how they would affect my HIV and I had no doctor monitoring me. I felt I couldn't cope with another pregnancy so soon after the birth of my son. When I went to the clinic the doctor looked at me and said, “You shouldn't have become pregnant in the first place.” I was embarrassed that my second child was only a few months old and I was pregnant again. In our culture they blame the woman whatever happens – it is my responsibility if I get pregnant, and if I refuse to have sex with my husband, people say I deserve to get beaten up because I didn't do my proper duty as a wife. The doctor told me, “We can give you a termination, on one condition.” I asked, “What's the condition?” and she said “That you are sterilised.” I told her “I don't want to be sterilised. I just don't want this pregnancy. I'm not ready for it.” But I felt I was caught in between, so I said okay. They told me to bring Max to the clinic, so I did. Max didn't want to sign the consent form, and they replied, “Well if you say no, we can't terminate the pregnancy, so you better just sign it.” So he did and I went through the termination of pregnancy and sterilisation in September 1999.

After the termination I had severe bleeding and back pain, and when I wanted to stand up, I couldn't; blood just poured from me, and within seconds I was sitting in a pool of it. I was haemorrhaging so badly, it was terrible. It lasted for one week. I was given medication to stop the bleeding but it didn't work. I went back to the hospital each day and the staff told me, “It will go away.” On the third day I went to the hospital and fainted. My mother wanted to organise, “puri puri”, where people would come and chant to get the sickness out of my body but I was scared it could make things worse so I told her not to worry. After a week, the haemorrhaging stopped.

In November, when my son was eight months old he got diarrhoea. I took him to the children's clinic and the paediatrician wanted to admit us. I said, "I don't think you should because he is so small and I don't want him to pick up other infections. Just give us some medicine." But they admitted us and when he was still sick, they gave him a polio vaccine. Soon afterwards we went back home but he was not improving and I could see something was wrong. At the same time I became so sick myself because I had no support with the baby, I wasn't getting enough rest and I wasn't eating well. So we were both admitted into hospital. I still didn't tell my family I had HIV because I didn't know how to do it or how they would react, but later I found out that the nurses had told my brothers without my permission. After a while we were discharged but the baby's health went downhill. His joints started swelling and he'd cry in pain throughout the night. His arms and legs became scarred and his skin became yellow. I will never forget the pain and suffering he went through. He had developed polio after receiving the vaccine. That was the first case of polio I saw in my life.

My son died on 23 December 1999 at the age of nine months. I was so upset and scared. I didn't want anything to do with anybody. I just wanted to go somewhere alone. I was angry and I regretted that I had been forced to get sterilised. I was surrounded by people who were celebrating Christmas, but for me, I had no reason to celebrate. I sat alone, thinking, and I decided I wanted to go away from Moresby and forget about everything. I was in a bad financial situation and Max was not working, so a couple of weeks later I forced myself to go into a recruitment office to ask if they had a nursing vacancy. As soon as I walked in the secretary said, "You start in two days time." I couldn't believe it. I said, "I'm not ready," and they said, "Whatever you need, it's okay, we'll give you a cash advance." I came back home and told Max, "We're going to Central Province."

I enjoyed it there, but Max was always jealous of the male staff. Whenever I was on duty with them, he would be suspicious. After work, if we had staff meetings, he would be waiting outside, screaming bad things at me. It affected my work because the male staff avoided me, and didn't want to be on the same roster with me. Max didn't work and he used to stay around the house all day, cleaning, fetching water and cooking. Sometimes on pay day if I was on duty he would go and collect my salary and get drunk and I would get so angry.

The hospital had a staff shortage so I was always working double shifts, morning and night, and it was not good for me. I was in charge of the labour ward and it was so hectic. In the night mothers would come to give birth and I was the one who did all the deliveries. I was always scared that I might infect the women or the babies so I would wear two or three sets of gloves. In April they put me on the TB ward. Towards the end of the year I picked up a TB infection and I was so sick, I couldn't eat. They put me on a drip but I was not responding. I didn't tell the sister in charge that I had HIV; I didn't really know how to disclose so I asked them to send me down to the General Hospital in Port Moresby.

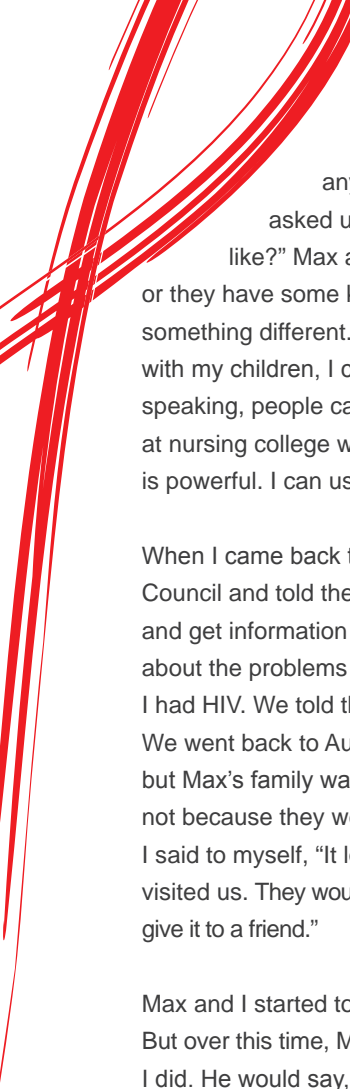
I spent four months in hospital, from January to April 2001. I saw many people dying and I saw how the nurses ignored the patients who were positive and I wondered how they could be so rude. One time I saw this young lady who was about eighteen. Her glands were very swollen and painful and she was screaming and I asked the nurses, "Can't you give her some pain relief?" They said "We don't want to waste the medicine. She's got AIDS and she's going to die anyway so what's the point?" That put so much fear in me. I realised that if I had the same problem, they were not going to help me; they were just going to ignore me and leave me to die. That thought nearly drove me crazy. From then on I wouldn't sleep; I was scared of the darkness; I was scared of the food my family brought. I would ask them what they had put in the food. If they washed my clothes I would ask what washing powder they used. I was afraid that if I slept somebody would come and stab me and kill me. I became paranoid and was driving everybody around me crazy.

The doctors put me on anti-depressants and after two weeks I felt better. I could think clearly and I was more relaxed. My mother asked me to come to the village and stay with her for a while. I stayed two weeks, but I got worried that I would die there. I was worried about the health system and the water supply. They didn't have the basic medicines and I thought I might get sick. I wanted to be in Moresby, closer to services, so I made the decision to move back to Max.

He had just returned from a workshop in Fiji. He said, "It's not only both of us. There are people in Australia who have HIV. I met people from Fiji and other Pacific Islands who also have HIV. It's a big problem." I looked at him and asked, "Why are you so excited?" He said, "Because there are a lot of things happening and you should get involved." Max showed me all the pamphlets he had brought back. He said we must go to the AIDS Council and talk to the support project people and they would tell me more about it. Over the next weeks I kept myself busy reading all the material and I found it interesting. I wanted to get more involved but I was afraid that my family would find out and I was not ready for that.

In August 2001, I met Elizabeth Cox who was an Adviser on Care and Counselling to the National AIDS Council. She was very interested in my story about how I got diagnosed, my children, and the treatment they got in the hospital. She told me that my experiences were breaches of my rights. I told her I didn't know anything about that. She started to help me. I didn't know anything about computers and she introduced me to the internet and got me onto an e-forum sharing issues on positive living. I found it so interesting and I started applying some of the ideas to my own life. Elizabeth told me about a conference coming up in Melbourne, the ICAAP.<sup>2</sup> She had secured scholarships for three women to attend. I was so excited. By now, I wanted to see what other people were doing. She helped me to get my passport, but my application for an Australian visa was rejected because I had treatment for TB in the past. I was crying but Elizabeth said, "Maura, there are lots of opportunities." One day she asked me, "Have you ever shared your story in public?" I said, "No, I'm, scared." Elizabeth said, "If you want, I can help to prepare you." I said I would want to do it outside the province, so she suggested I go to Sepik where there are a lot of people who could support me and look after me. Then she started counselling me for the first time. She started working with me, getting me talking, preparing me for World AIDS Day 2001.

<sup>2</sup> International Congress on HIV/AIDS in Asia and the Pacific.



When the time came, Max and I flew to Wewak for our first public talk. I didn't have any idea of how to present. There was a big gathering at the market. Some women asked us, "We heard there is someone with HIV here. Do you people know what they look like?" Max asked them what they expected and they said, "We don't know. Maybe they're blind or they have some kind of mark on them." Max and I went out and I said, "I think they are expecting something different. We'll give them a surprise." When I talked about the experiences I had gone through with my children, I could see that all the mothers were crying. It really touched them. When I finished speaking, people came up and shook my hand and hugged me. I met one of my friends who had been at nursing college with me, and she was crying and we were hugging each other, so I thought, "My story is powerful. I can use it to change people's attitudes."

When I came back to Moresby, I felt I had some new inner strength. In 2002 I approached the AIDS Council and told them I felt there was a need to start a centre in my community where people can come and get information about HIV and they thought it was a good idea. Max and I talked to our community about the problems that were out there and most people said they knew I was sick but they didn't know I had HIV. We told them about our idea to build a community centre and everyone was happy with it. We went back to AusAID and wrote our proposal. I wanted the drop-in centre to be on its own land, but Max's family wanted it built next to their home. When it was finished, people brought their children, not because they were infected but because they wanted basic treatment for malaria or diarrhoea. I said to myself, "It looks like I'm becoming a nurse again." We gave a condom to every person who visited us. They would ask why and we would say, "Just in case you might need it or you might want to give it to a friend."

Max and I started to travel a lot. We went to several provinces doing talks for the AIDS Council programs. But over this time, Max was drinking more and he became more violent. He was trying to control everything I did. He would say, "Maura, you are stupid. You don't know how to do things. You should ask me first." I became so scared but I couldn't share this with anybody. Whatever I wanted to do, I had to ask for his permission and if I didn't and he found out, he would beat me up. At other times he would steal money from me – he'd open my wallet and take my money and I didn't like that.

I fell sick again and by the end of 2002, I was bedridden. I was so thin, just lying there. The National AIDS Council wanted to help me but they didn't know what to do so Elizabeth used money from her own pocket and sent me to a private clinic so I could start on ARV medication. I got the medicine, but it wasn't good for me. The doctor put me on a combination that included Indinovir. When I took it, I couldn't keep anything down. I was already weak and I started vomiting all the time. I knew the medicine was not working but the doctor told me that if I stopped taking it, I was likely to develop drug resistance, so I didn't know what else to do. I really started wasting away; my bones were poking out of my skin. At that point, a friend brought an Australian positive woman, Susan, to visit me. Susan looked at me and I knew what she was thinking. I said, "I'm not going to die." I told her what was happening and she suggested that I stop Indinovir immediately. She gave me 14 days supply of Nevirapine and told me how to use it and what side effects to look out for, and promised me that she would get more. I was so happy when she

gave me that Nevirapine. But with only 14 days supply, I was concerned. I thought about contacting the AIDS Council before I started but I wanted to get well so I decided to go ahead and take the Nevirapine first. I didn't go to the clinic or the doctor; I just went ahead and took it.

Nothing bad happened. I didn't have any side effects. By the second day I started to feel good and I was so happy; happier than I had been for the past five months. I started eating and I had a real appetite for the first time in ages. I wanted to eat. I went back to the AIDS Council and they said Susan had told them the problem and they had arranged everything. The drugs were there and the money had come from a fund set up by some Australians. My health improved from then.

In May 2004, another positive woman and I got an invitation from APN+ to attend the first women's training in Bali. When the day came and we got on the plane, she and I both started crying, I don't know if it was out of fear or happiness. That workshop was an eye-opener for me. It made me see who I was. I sat back and looked at my life, thinking of all the abuse and violence I was experiencing, without saying anything about it and without my family saying anything about it. I thought, "I can't make my own decisions and I'm living in fear in my own country." I listened to other women and heard their stories. The Indian and Thai women really impressed me. They had all this energy and when they talked, I thought. "I want to be like them and go out there and talk strongly. I can be like them. I'm not going to give up." So when I came out of that workshop, I had a vision to be a strong woman like the women I'd met. Soon afterwards I got a scholarship to attend the International AIDS Conference in Bangkok. When I was there, every day I would go to the positive people's lounge, not because I was hungry, but to sit and observe what other positive people were talking about and doing – people from Africa, America, Russia, Australia.

For the rest of that year I was increasingly unhappy with my relationship with Max and the violence became unbearable. I tried to keep my distance and I started to withdraw. At the end of the year I told him I'd had enough and I wasn't taking it any more. When I walked out, he was kind of destroyed, but I told myself that I was doing this for myself, and I had to live my life the way I wanted. When I stepped out of his life, I felt a new sense of freedom. I felt as if something that I'd been tied to and that had kept me under had been taken away and I was released. I thought, "Wow, all this time I've been living with this burden."

After I left Max, he continued to drink heavily, his health declined rapidly and he died in 2006. His family blamed me and beat me up. I lost control of the drop-in centre and it closed. In September 2007 I developed resistance to my first-line ARVs and I was really scared that I might die. But I had contacts outside the country and I was relying heavily on them. That was something that made me feel strong inside, that I'm not doing this alone and that there is this positive community that I can fall back on. Friends helped me to receive second-line ARV medication and now the PNG Government is working on getting second-line ARV drugs.





Before I got my current job as a GIPA<sup>3</sup> advocacy officer with AusAID, I strongly felt that I should be working in the health sector, and I was looking at ways I could do that without going into a hospital and having direct contact with clients. In the future I want to focus on advocacy around areas such as treatments or patient care guidelines, on training, and on leadership. These are areas where I feel my skills would be best utilised and I have the most interest.

It's been a long walk for me and I've come a long way. I have learned a lot. What people have taught me and what I have seen have really made me a different person. I now look at life in a different way. I thank everyone I have met in my work in HIV who has helped to make me the person I am.



<sup>3</sup> GIPA means the greater involvement of people living with HIV and AIDS in the response.

“ It’s been a long walk for me and I’ve come a long way. I have learned a lot. ”

**MAURA**  
Papua New Guinea





## NERI

### Philippines

My dad died of leukaemia when I was four years old so I never really knew him. Immediately after my father's death, my mum left Quezon Province and came to Angeles City with my aunt. All my brothers and sisters got split up and I lost track of my two older brothers and my three sisters for many years. I only saw them again when I got back to Angeles City. My younger brother and I went to live with my grandma but she constantly moved around from one place to another. We stayed with different aunts. My mum had nine sisters and every few months we moved to the home of a different relative. My mum used to send money for us. We faced a lot of discrimination because we had no mother or father. People would say, "Why are you living here? You should go and live with your mum." When my mum left the province they thought that she was going to work as a sex worker but in fact she was a factory worker. When you mention the name of Angeles City everybody thinks that you come here to do sex work.

When I was eight my mum brought my brother and me back with her to Angeles City where I did grade two. We stayed for a year and then when I was nine years old she took us back to the province to one of her younger sisters. Mum stayed with us for a couple of weeks and she bought five sacks of rice and gave money to my aunt for my brother's and my schooling before she left. We did not see her again for the next six years and this is when we faced the most difficult part of our lives.

My aunt used to leave home very early every day because she did laundry for the neighbours. If she was there, our uncle was really nice to us and would say, "Come on, eat your food," but when my aunt left he was terrible. After a month he said, "We don't have any more food. You should leave my house. You are bad luck. You must go back. Write to your mum and ask her to collect you." I tried to write but I was not sure of her address and the letter was returned. My brother and I started school again but we had nothing to eat in the mornings. Every day before school, we would go to the highway and beg for food from people on the buses. We were hungry and we needed to survive that day. When the bus came we would stand there begging, "Please give us food. We are hungry." Some people would throw us food from the buses. Sometimes people would throw us coins but other times people would throw dirty napkins or a plastic bag full of rubbish. We stayed with this aunt for four months and our uncle always treated us badly. He was always drinking alcohol and one night my brother and I were asleep under the mosquito net and he came home really drunk. He started an argument with my aunt and told her that we did not belong there and that she should take us back to our grandmother. Then he got a big knife and tried to slash the net. My brother screamed, "Help us. Help us." It was really dark and we were so afraid. My uncle yelled, "You don't belong here. You are bad people. Your mum is a sex worker." I told my uncle that she was not and begged my auntie, "Please take us to our grandma in Quezon Province."

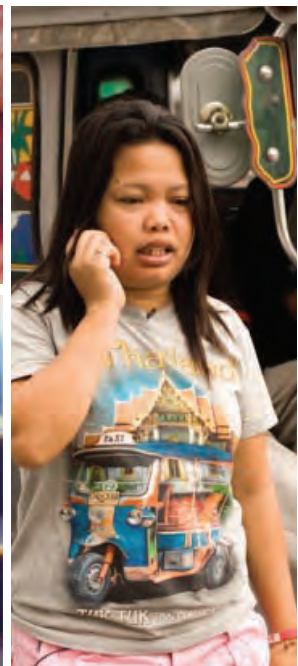
Two days later they took us to our grandma and my brother and I stopped attending school. We all lived with another auntie who was okay. She and her husband treated us well and were good to us, but their son and daughter were awful. They would say, "Your mum is a sex worker. You don't belong in this house." I said, "My mum is not a sex worker. She's a factory worker. That's a different job." We would argue all the time about this, so after a few months my grandmother said, "Okay, we have to build a house for you and your brother." My mum found out what happened and sent us money and we built a small house but we only stayed there for a month because grandma gambled all the money away and we lost the house. So we had to move again.

We never stopped moving from one family to another. The longest time I spent anywhere was when we went to an uncle whose wife had died. I was 14 at the time and I used to look after my uncle's five children. I washed their clothes and did everything around the house. Everybody assumed my uncle was having sex with me and would say, "Your uncle might rape you." After a year the rumours got to him and he said, "Everyone thinks that I'm a bad person. They think I make love to you. I really respect you because your mother is my sister, but you have to leave." My grandmother decided to bring us back to Angeles City to my mum.

When I finally got to Angeles City I was really happy because I had not seen my mum for six years. When we arrived she was in love and had a new baby so I had a stepsister. I told my mum I wanted to stay and finish my schooling and I was tired of all the moving. When I tried to return to school I was only in grade three and everybody in the school said to me, "You don't belong here because you are already 15 years old." I really wanted to go to school but I felt lots of discrimination from everybody so I told my mum I would stop.

One day I made a new friend, a woman who used to pass by our house, and she asked me how old I was. I told her I was 15 going on 16 and she asked me if I wanted a job as a waitress. I said, "Sure. I want a job so I can help my mum." I was very excited because I hadn't finished primary school and this was an opportunity to earn money and help my mother. I started working in the bar when I was a minor, which was illegal so I borrowed a friend's birth certificate to show that I was 18 years old. In return, every month I had to pay her 100 pesos, which in those days was a lot of money.

I mixed drinks for American guys from Clark Air Base. It was easy to make money and I started to help my mum and her new baby. The father was not around much because he had another family. My oldest sister started working at another bar and we both helped mum. When I first arrived in Angeles City the house we lived in was really small. Whenever it rained we had to get a bucket because the roof leaked. I helped to build up the house. My brother said he wanted to go back to school so I helped him to finish his schooling.



When I started living with my mum again, I was looking for her to love me and take care of me, but she never asked anything about my life. My friends' mothers always visited them and asked if they were okay. I felt the other girls were so lucky because if they were sick their mother would bring medicine and take care of them. But my mother never asked me how I was, which really hurt and I became very depressed. After I had been working in the bar for a year I made a new friend from Manila and she said to me, "Come on, take this medicine and it will make you feel good. You won't have any problems. It will relax your mind." I started taking the medicine and I did not know that it was actually a drug. I found out much later that it was ecstasy. Every night I would take a tablet and it would help me forget my problems. My friend would give it to me so I never had to buy it. Before I started taking the medicine, I never went out with any customers. If people asked me to go with them I would say no and I just served beer but once I started taking this medicine I did not feel shy. I could talk to anybody, I could yell, I could laugh, I could do anything. I had no fear and I felt I was a strong woman who could take care of herself. One month later, because of the drugs, I lost my virginity. I really did not know what was happening because I was high and did not realise and I agreed to go out with one of the customers. Later, when the guy realised that I had lost my virginity with him, he apologised and offered to take me out from the bar and look after me but he was married so I did not want that.

After that I started earning a lot more money and we ate three meals a day for the first time in our lives. I kept working in that bar for three years, hoping I could find a husband who would take me to the States so that I could support my family and give my mum a good life. At the bar, we had to have a smear test every week to check whether we had any sexually transmitted infection and every six months we had an HIV antibody test. Some customers said they did not like condoms and you could not force them to use one, so every six months I voluntarily went and had a test, and always it was negative.

In 1991 I got pregnant to a white American guy. I was only 17. When I was pregnant the volcano Pinatubo blew up.<sup>4</sup> Loads of ash fell everywhere and the house I had built collapsed. I asked myself, "Why is my life always so difficult? Why can't I have a good life? Now I'm moving forward and everything has collapsed." We had no house, no clothes; everything was destroyed. That is why I have no photos of me before that time. After the volcano erupted all the American Air Force guys moved out of Angeles City and I lost contact with the father of my child. I tried to find him but I could not track him down. On September 21, I gave birth to my son at my house.

I looked after my son and continued to help my mum. I made sure my older brother finished high school and my half sister started grade one. When I was working in the bar I had been putting money in the bank regularly. In 1993 I decided I wanted to take a rest and look after my son so I stopped work for one year. I stayed at home and lived off my savings but eventually I started running out of money, so in January 1994 I decided to start work in the bar again. I wanted to make sure that I had enough money to be able to send my son to school.

<sup>4</sup> In June 1991 Mount Pinatubo exploded; it was the second largest volcanic eruption of the twentieth century. Over 100,000 people were left homeless and Clark Air Base was evacuated; most of the 18,000 US military personnel and their families stationed there returned to the USA.

In March that year they were offering HIV antibody tests again and I decided to have one, even though I had no partner for a year. A couple of days later I met the father of my second son. He was also from the US Air Force. We only spent one night together. A few weeks after I had the HIV test a staff member from the Social Hygiene Clinic came to the bar looking for me. She told me that there was a problem with my test and they wanted to do it again in Manila. When I came out from the bar, everybody was looking at me and asking where I was going. The staff member said they were going to take me to San Lazaro Hospital in Manila, so everybody said I must have AIDS. A van was waiting for me and there was another woman inside crying. My mind was really blank. I did not know what was happening. I asked her why she was crying and she said, "Don't you know? We have AIDS." I said, "No. That's not true. She didn't say that. She just said there was a problem with our blood and we have to test again." She said, "No. You don't understand. It is true." But I did not believe her.

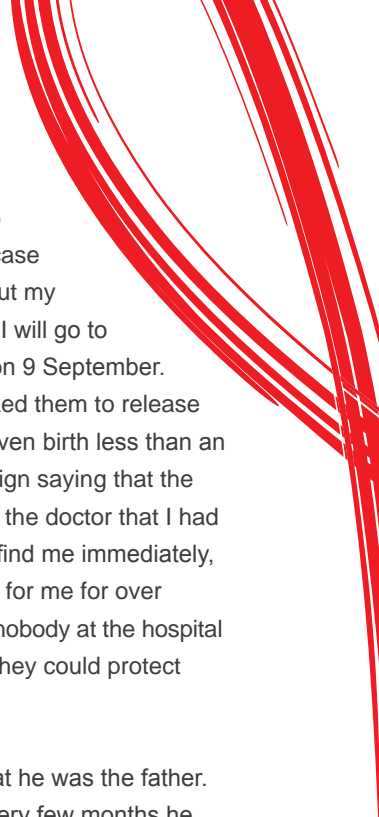


We went to St Lazaro Hospital and stayed there overnight. The next morning the doctor spoke to us. I do not remember anything he said other than "You have AIDS." That is all. Nobody said that we had HIV. They just said straight that we had AIDS. I said, "I'm pregnant. I don't understand. Why are you telling me that I have AIDS?" The doctor replied, "We tested your blood and that's the result." When I saw the other woman from the van she turned to me and said, "See? I told you." We both cried and cried. The doctor told us that we could leave immediately and go back to Angeles and tell our family. I thought, "I'm pregnant. What am I going to do? Can my son get infected with it?" Nobody gave me any information.

When I returned from Manila I went straight to my work.

I did not go to the house and I did not tell anybody. I tried to commit suicide. I bought some razor blades and tried to cut my wrists. I knew there was no cure for AIDS and I just wanted to kill myself. My best friend found me and asked what was wrong and whether I was sick. She begged me to tell her what happened when they took us to San Lazaro. I said nothing had happened and I was okay but I did not want to be pregnant again. She replied, "Then tomorrow I will come and pick you up." She came and took me to her house and her boyfriend was there, an old retired American guy. He said to me, "Narisa, I understand you don't want to have another baby. You're young. Here's the money. Go and have an abortion." I said, "Let me think about this." He said, "Okay. Come back if you're ready for it." I stayed at my house for one week. I was sad but I did not tell my mum. I thought I would probably die soon. Every night I hugged my son but I was afraid that I might infect him because I did not understand how HIV is transmitted. I was afraid he might get HIV from saliva or from mosquito bites. The father of my baby knew that I was pregnant but he refused to believe he was the father because I worked in a bar. I said, "I don't blame you if you don't believe me but I'm just telling you. I know." He said, "Okay. We will see what it looks like. We will see if it's black."





In September 1994 when the time came to give birth I was admitted to the hospital but I did not tell them my HIV status. If people knew that you were HIV-positive the discrimination was really dangerous. People wanted to burn you. I was afraid to stay in the hospital after the birth because I did not want to breastfeed my baby in case he became infected. A gay man who worked at the Social Hygiene Clinic knew about my status and I asked him to help me. He said, "Okay, no problem. After you give birth I will go to the hospital right away and collect you." I gave birth at nine o'clock in the morning on 9 September. My friend arrived thirty minutes later. He went to the director of the hospital and asked them to release me. He told him that I had to go home. At first the director refused because I had given birth less than an hour before. My friend kept insisting, so eventually the doctor gave me a paper to sign saying that the hospital was not liable for whatever happens to me. As soon as I left, my friend told the doctor that I had HIV and it set the staff into a panic. The director of the hospital ordered the staff to find me immediately, but I was gone already. The hospital told the media about me and they tried to hunt for me for over a month. They went to the Social Hygiene Clinic and asked how it was possible that nobody at the hospital knew my status. The hospital complained that they should have been informed so they could protect their staff.

My baby's father wanted to see him but I refused at first because he had denied that he was the father. Once he saw the baby, he knew that it was his son and started buying him milk. Every few months he would come to Angeles City and look for us. After one month I told my mum and my sisters about my status and I said I wanted to move out of the house and live separately because I was afraid that I would infect them. Nobody believed me. My mum said, "No. You cannot. You're lying." I said, "I am not lying. I have AIDS." After that, my sister went to the Social Hygiene Clinic and spoke to the doctor and found out that it was true. My mother begged me not to leave and said, "We will support you." I said, "Maybe I will infect you through mosquitoes," and she replied, "We are going to buy a mosquito net." Then my older brother came home and he got angry and told me that I could not stay at the house. My mother told him, "She cannot leave. She is the one who built this house and you are asking her to leave? What about her two kids?" My brother said, "You can leave your sons here but you must go."

My mother insisted that I stay, but immediately the discrimination started. When we ate, my brother would not eat with me. He would not touch any glass or plate or anything I had used. If I was asleep and he walked past me he would kick me and yell at me, "Wake up. You don't belong here go away." One time I said to him, "This is not my fault. I tried to help you. When I got here, this house was really small. It was like a bird's nest. Now look. Since I started working, everybody has money. And we eat three times a day from the wallet in my pocket because of the job I was doing." But he could not accept me and kept insisting that I should leave. I told my mum I could not live like that and I told my brother, "I am leaving, okay. But I want to take my two sons with me. I want to spend the rest of my life with my two sons. If I die, you get my sons. Just give me my two sons now," but he refused. When I left that house, I said to my mum, "I will be back to get my sons. I will rent a small house." I still had money in the bank so I went and lived alone. My oldest son was in kindergarten and every morning I went to see him and ask him how he was. I missed my sons so much. One day it was too much and I picked up my son from kindergarten without telling my mum. Everybody was looking for him for one week. When they found us, my mum claimed

I had kidnapped him. I replied, "How can I kidnap him? He's my son, and I want to get my youngest son also. As long as I'm alive I want to give them love. Before I die I want to give them everything that I can." But my mum told me to bring back her grandson. I felt I was dying inside.

Two years after I left my family, my brother came to visit me. He knocked on my door and I was surprised to see him. He said, "Can we talk? Now I understand you." He hugged me and I was crying and I said, "Now you accept that it's not my fault." My brother apologised and replied, "Let's go home and start from the beginning." From there, we started afresh. If he saw that I was sad, he would say, "Come on, let's eat together. You can share with me. If you have any problems I will help you." I said, "Thank you. Finally I can move on." My brother asked me how I got HIV and I told them that it was because of my job and I said, "Don't think I will infect you by sharing plates or glasses. You can only get it from blood, sex and breastfeeding." My brother said, "Yes. I know." On television there had been a show about a woman who was HIV-positive and my brother had watched it.

For the next six years I did all sorts of jobs. I did not want to go back to the bar. I really hated men and I was afraid that I might infect other people with HIV. I decided to look for different work. I worked as a cleaner, as a maid, lots of different jobs. I got a job as a security guard at duty free, checking bags when people were leaving the shop. Sometimes I got paid only half my wage so I was not able to support my sons adequately. My oldest son wanted to start school and I could not afford to pay for his education so I decided I had to go back to the bar. In 2001 I got permission from the Social Hygiene Clinic to work again, providing I came to the clinic every week so they could monitor me. I met lots of guys but I did not go out with them. I felt they had given me this sickness so I only talked to them.

In 2004 I met a member of Pinoy Plus, the support organisation for people living with HIV. She asked if I wanted to get involved in the organisation but I was unsure because I had not really accepted my HIV-positive status. She encouraged me and the next time she went to Manila she took me there. Finally when I met everybody I thought, "I am not the only one. Why am I always hiding? This is the group I've been looking for these past ten years." All throughout this time I had no information about HIV. At Pinoy Plus I came to know three kids whose parents had died because of AIDS. When the community found out the kids' status, because they were always sick, they said they wanted to burn the kids. One of the children was nine months old and she had diarrhoea and the healthcare workers had written that she was HIV-positive above her bed. I asked the doctor, "What are you going to cure, the diarrhoea or the HIV? The baby has diarrhoea. You should write diarrhoea, not HIV." This case made me decide to fight for people with HIV.

I asked one of the doctors whether she could help me to fight HIV discrimination. I told her, "Those people don't understand what HIV is. I want to tackle this discrimination." A couple of weeks later the doctor offered me a job. At first I was cleaning the floors and her office. I continued to attend seminars and workshops about HIV and I learnt a lot. One day I was talking to a young woman who had been

diagnosed with an STI and the head nurse was listening. Afterwards the nurse said, “Ah, you know how to do counselling?” I told her that I had learnt how at Pinoy Plus. So the nurse told me I could work in the office instead of doing the cleaning. Soon after that, the woman who was supposed to do the STI/HIV seminar for the new entertainment workers was very ill and the nurse grabbed me and told me to go and conduct the seminar. I felt I did not know what to do but she assured me that I did. At first I just started training 10 or 20 people because if I talked to many people I would forget what to say. Slowly I started training much larger groups.

One day a teacher asked the doctor if she knew anybody who could share their personal story about living with HIV, and the doctor asked me if I wanted to. I agreed to do it but I covered my face. Only my eyes were visible and nobody could see me. A couple of months later I was asked to do it again and this time I decided not to hide and I faced the reality of HIV. The second time I spoke I felt really free. Beforehand I felt as if I had a bone stuck in my throat but that feeling disappeared and I felt really good. Now I speak to the staff at the hospital and I go to schools and talk to students about my personal story. I usually do it with a doctor who explains what HIV is and how you can get infected, and then I talk. When I do public speaking people respect me and it makes me feel very happy because I help people not to end up with HIV like me. I had been alone, hiding my HIV status for ten years and I wondered why. I have not faced any discrimination other than from my brother. I am very happy because now people understand.

I have been working as a peer educator for the past five years. Every day I conduct seminars on STIs and HIV for new women coming from the provinces to Angeles City to work in the bars. They have to come to the seminars before they get their clearance certificate to work. In the afternoons sometimes I do counselling for women who are diagnosed with STIs.

We have a small group for HIV-positive women called Sister Plus. Last year we got funds to start a livelihood program. Every woman could receive 50,000 pesos<sup>5</sup>; 20,000 for burial expenses – that is really funny – and 30,000 to set up a small business. Everybody said, “But we are still alive. I won’t take that.” I said, “Come on. Yes, we are still alive but some day we will need it. This is a big chance for us.” Five women got the grant. I started a small store at my house. I sell candy, cigarettes, alcohol, anything. I am the only one who managed to build a successful business. The others bought cell phones, clothes and a motorbike. The store is at my house and it helps to bring in a bit more money.

I tend to spoil my children because I never had a childhood myself. If they want a cell phone and I can buy it, I will. If they want shoes, I will buy them. I try to give them everything I can. In 2004 the father of my youngest son came again to Angeles City and managed to find out my telephone number and gave me a call. Since then he kept in touch and helped his son and sent him to a private school. In 2005 I took my youngest son to have an HIV test. Every time he got sick I would cry because I was so afraid that he might be HIV-positive. When I telephoned the doctor for his results the line got cut off and I thought this was bad luck. Then the doctor sent me a text and said the result was negative but I did not know what

<sup>5</sup> Approximately US\$1,000



that meant and I assumed it meant that my son had HIV. I started to cry and cry. One of the social workers came by and looked at my cell phone and explained what my son being HIV-negative meant. I was so happy. A year later my son asked me whether he and his brother were HIV-positive. He said, "I know that last year you tested my blood but you didn't say anything." I apologised and explained that when I was pregnant with him I got diagnosed with HIV and I had to know if he was positive and I was sorry I hadn't told him that he isn't. He said, "It's okay, I love you mother."

The first time my immune system was monitored was in 2005. Before that I had no doctor. The President of Pinoy Plus took me for the tests. My first CD4 cell count was 500.<sup>6</sup> After that my CD4 count kept going down. In December 2007 it was 325. My sons encouraged me to begin taking ARV medicine. The doctor told me I had to take my ARVs at 7am and 8am in the morning and then at 7pm and 8pm in the evening, exactly on time and he told me not to drink any alcohol. So I have been taking ARVs for over a year and I have not drunk any alcohol during that time, and if I am five or ten minutes late taking my medicine I get really worried. I always follow the doctor's orders. Every month I have to go to Manila to collect my medication. When I get to Manila I meet many friends, and some have no relatives to visit them so they have no money. I always leave home with money and come back with nothing. I have to help them because I was once in the same situation as them, and now I have money I can help them a little. I asked the doctors to give me medicine for two months because it's difficult to pay for transport every month but they refuse and say they have to monitor my health. So every month I have to go there. I told the doctor that I am okay; I have my mother and my kids to look after me. If I forget to take medicine my youngest son bugs me to take it because he wants me to stay alive.

Now my life is so much better than before. I am happy because I have broken through a wall. Sometimes I think of the past and what happened to me when I was young, but I do not blame anybody. It was a hard life but I just say that is life. I have no regrets. I say I got HIV because I did not look after myself. Nobody forced me to do the job. I just wanted to help my family. I helped the people that I love. I have one brother and one sister who finished their high school because of me. Why would I regret that?



<sup>6</sup> "CD4 cell count" is a measure of a person's immune system; WHO recommends that an HIV-positive person with a CD4 cell count below 350 should commence antiretroviral therapy (ARVs).

“ Now my life is so much better than before. I am happy because I have broken through a wall. ”

**NERI**  
Philippines



## PRINCEY

Sri Lanka

I was born in Colombo on 27 March 1960, the second in a family of seven children, three boys and four girls. My father was in the navy, stationed far away and only came home every three months and my mother worked as a nursing attendant in Kuwait. She sent money home regularly but returned home only once a year. Her visits were always exciting because she would bring things we had never dreamt of – exotic food, hair combs. My brothers and sisters and I were brought up by our maternal grandmother and she provided us with all the love and care of a mother. Our uncle also lived with us. It was not a luxurious house but it was very large and had many rooms. Often we used to play house by draping one of our grandmother's saris over a table. We would pretend to cook rice and the first person we would give our food to would be our grandmother. We were a close knit family and did everything together. When our grandmother was cooking, all the children would be in the kitchen. When we went out to play, we all played together.

I attended school up to the tenth grade, and then I stayed home, like most young women in Sri Lanka, and helped to look after the household. I enjoyed keeping the house tidy and in order. Because I had a small build I was spared the heavy housework and I spent much of my time crocheting covers for the chairs and tables. When my mother returned for a visit in 1991, I met her at the airport and we went to the cargo office to collect her duty free goods. There we met a man called Bandula who took my mother's passport and helped her with the paper work. He looked after us well and offered us tea. My mother wanted to give him a gift but because everything was packed away, she suggested that he visit us at our house. The following morning, my mother and I were on our way to church when suddenly we saw Bandula. I turned to my mother and asked, "Isn't that the person who helped us yesterday?" When we returned from church, he was at our house talking to my uncle and my brothers. My mother gave him a present of a shirt. After that, Bandula became a regular visitor to our house, and would spend time talking to my uncle. He was very kind and polite and spoke very openly and I quickly became infatuated with him. To me, everything he did was perfect and I fell in love with him. My family also liked him and approved of the relationship that slowly began to develop between us.

On 6 May 1984, Bandula and I got married. I wore a beautiful white sari and hundreds of people visited the house throughout the day. After the marriage, I moved into his parents' home on the other side of Colombo. My mother-in-law provided us with the title to a piece of land next to her own house. We built a basic house of stones with a large adjoining room made of wood. The following year I gave birth to my elder daughter. It was the happiest moment of my life. Two years later, I gave birth to our second daughter.

By 1991 Bandula was working as a bell boy in a hotel when he was offered a job as a personal care assistant to an elderly man in Germany. He went abroad to work for several years with the expectation that he would earn money to build our future, but only once when he came back from Germany did he return with money, so my mother was left to look after our needs. Each year, Bandula would return home in the company of his German employer who owned a hotel in Sri Lanka. He would spend most of his time at the hotel, but when he was home he was loving and kind. I felt shy to acknowledge, in front of my daughters, that I shared a bed with their father. When Bandula was home, I would lie with the girls until they fell asleep before I joined him. Sometimes I would fall asleep on the girls' bed and Bandula would come in and take me to our bedroom. If he called for me before the girls were asleep, I felt embarrassed.

Each time Bandula had to go back to Germany he went reluctantly. As the years progressed, he began to drink heavily. He returned in 2000 and was in the country for three days before we discovered he was back. He was not well and had lost a lot of weight and he was behaving differently. In the past, he had always been interested in his daughters. He would check their teeth and ask if they were okay, but this time, he showed no interest in them. He spent all his time either sleeping or drinking and little time interacting with his family. His father complained about the bad company he was keeping. "We didn't bring you up to act like this," he said. "You need to get out of this situation." Instead of returning to Germany, Bandula found work as a cook in the Maldives and he spent the next seven months there.

When he returned home, his health was worse than ever. He was very thin and had constant diarrhoea. His parents shouted at him, "Look at you. What are you doing to yourself?" He visited the local doctor who gave him medicine and told him not to worry, but his health didn't improve. I took him to the hospital. The medical staff checked him and told him he had gastritis. I brought him back home and tried to nurse him to good health, preparing food that was not too spicy, but every night his temperature soared and his body was in high fever. I took him back to the hospital and he was admitted. Each morning I would go to the hospital to visit him and spend the day caring for him. I did not meet the doctor so I could not ask anybody about his condition. I did not know what was wrong with him and spent my days worrying about his condition. On 1 July 2001, when I went to visit him, he told me that the doctor wanted to see me.

I didn't get to see the doctor that day. The following day when I returned to the hospital, there was a commotion and many people were shouting. I didn't think twice about it and had no idea that it was related to my husband. I went directly to visit Bandula but when I arrived at the ward, I discovered that he was not there. I approached a nurse and asked, "Where is my husband?" The nurse replied, "Don't worry, he has been moved into an isolation room." Previously, each day when I arrived at the hospital, the nurses would ask how my children were but this time, they turned their faces away from me. I found his room but when I tried to enter Bandula told me, "Please, do not enter. Do not come in." Then several doctors entered the room. I noticed a bucket of disinfectant in the room and I asked one of them what it was for, and a doctor replied that it was for me to rinse my husband's clothes before I took them home. I asked the doctor what was wrong with my husband but he refused to answer. The doctors stayed in the room for a minute or two and then came out. One of them said he needed to talk to me and took me to another room. He began to ask me questions about my marriage, and about the birth of my two daughters. I didn't know



what was happening. I asked the doctor what this had to do with my husband. "What is wrong with him?" I asked. The doctor said, "You are not to worry. You can take your husband home today."

I was overjoyed to hear the news that I could take Bandula home. Then the doctor started talking about condoms. I had never seen a condom before and suddenly the doctor was telling me that I had to use them. I just said, "Okay, okay." Then the doctor told me that my husband had HIV. I had no idea what HIV was. The doctor repeated that I must use condoms. He told me that I could eat and drink with my husband and nothing would happen. But he said that if he was in an accident, I must tell the doctors what he had said, "Otherwise, it is not necessary for you tell anybody about it." I was not worried because at that point I did not understand what HIV was. I was just happy that my husband was being discharged.

When we left the hospital we went to a small cafe. Bandula ordered an orange juice for himself and a cup of tea for me. When our order arrived, he said, "I don't need orange juice. You drink it. I won't live for very much longer, so I don't need anything." I replied, "But the doctor has given you some medicine. Why are you talking like this?" He continued, "I have an incurable sickness and the medication for this illness is very expensive. The doctor told me not to tell anybody about it. He said that provided I don't tell anybody about it, I can come home, so I promised him I would not tell anybody." I said that he was not to worry and that we would collect money in the village to pay for the medicine. The people in the village liked Bandula very much. Every time he came back, they would come flocking to talk to him. We used to sleep on a hard floor and because Bandula's body had been aching so much recently, the villagers had bought him a soft mattress. I said we would get vitamins and sustagen to build up his strength and I would not tell anybody what the doctor said and we would do a lot of "merit making" at the temple, to make him better.

The past two years had been very lonely because my grandmother had died during that time, so it was wonderful to have my husband home with me at last. Many of the villagers called in to wish him good health. The following morning, when I was getting ready to take our two children to school, the owner of the small shop next to the school telephoned and asked to speak to me. I said that I had to drop the children at school and the shop owner said, "Okay, drop your daughters and then come and see me for a few minutes. I need to talk to you." When I visited him, he asked about my husband. I said, "They sent him home. They told him that he has an incurable illness." The shopkeeper replied, "I heard that he has got HIV." "No, no. That's not true," I said. "Who told you?" "One of the people who works in the hospital," he said.

I returned home quickly. I realised that despite the promise my husband had made, many people already knew about his HIV-positive diagnosis. When I got home, unlike the previous day when many villagers had come over to see him, the house was quiet. My father-in-law went out to buy some food. He had not been gone long before he came rushing back to say that everybody was talking about us. Everybody was saying that his son had AIDS. My father-in-law asked us, "Is it true?" I replied, "No, it is not true." That afternoon I intended to go back to the school to collect my children but well before the time to leave, they returned home. My eldest daughter was crying. She was sobbing and wailing. "We cannot go back to school. Everybody says that our father has got AIDS." Some parents had already come to the school and taken their children away.



Over the next two days, everybody shunned our family. If I walked along the road, people would quickly walk over to the opposite side. We lived next to my husband's brother and he began shouting at us constantly, "Why have you come and brought an infectious disease with you? You can't stay in this village. Go away. Go away." The village was in an uproar and we felt as if we were trapped in a cage. Every morning my father-in-law would visit and ask what he could do to help. I lost the heart to prepare food and I stopped cooking. My father-in-law would cook something for the girls while I administered medicine to my husband. I talked about sending our daughters to my mother's house. I telephoned my mother to say that I was bringing the girls over. She said, "I'll come and collect them." I quickly responded, "No, no. I will come and drop them to you." I was worried that if my mother came, she would get to know about our situation. I told my daughters not to tell anybody that their father was unwell.



When I came back from my mother's home, I saw a huge crowd gathered on the road outside my home. I went inside quickly and closed the door. My husband was not there. After a while, I went out to look for him. I saw my father-in-law who said that Bandula had got dressed and walked out of the house while I was away. He had told his father to tell me to look after his children and had asked his father to look after me. The neighbour on the other side of our house was a policeman. I went and implored him to go and look for my husband.

Two days later, the policeman returned to tell me that somebody resembling my husband had been admitted into Colombo South Hospital after taking poison. I went straight to the hospital. I was so happy and relieved that I had found Bandula. I asked, "Why did you do this when you have the children? I told you I would drop the children at my mother's house and then we would deal with this together." Before he had time to answer, a doctor appeared and began to ask me what kind of poison my husband had taken. I had no idea. I told the doctor about my husband's HIV, and was surprised to find that he still treated my husband with kindness and consideration. Over the next two days my husband's health deteriorated rapidly. On 27 July, he died. It was less than a week since I had found out that he was HIV-positive.

When the people in the village heard that Bandula had passed away, they worried that I intended to bring his body back to the house and they were angry and agitated. The hospital staff did not know much about HIV and they advised me that it was better if I did not take his body home. They told me that I would have to dig a deep grave for him, down to nine feet. We did as we were told, and we buried my husband in the hospital cemetery. When I returned home, my mother said, "Come, let's go back to our home, our village," but I replied, "No. This is our home. We will stay here."

The neighbours continued to shout at me. They told me that if I did not want to get killed, I should move out. My children and I stayed at home and each day my father-in-law went to the shop to buy provisions for us. Three days after Bandula's death, shortly after midnight, somebody set fire to our house. I woke up to the clamour of screaming. Smoke was clawing at the back of my throat. I slowly realized that my daughters were calling, "Come, come and help us." Somebody grasped me and dragged me out of

the house as flames began to consume my home. All the people in the village came running and they pulled my two children out of the house before the wooden extension burst into flames. As the fire took hold, I scanned the crowd that had gathered outside. It seemed as if everybody from the village had woken in the middle of the night to watch the destruction of my simple home. I spoke to the crowd, "How can you pretend to care? There is one person among you who started this. You set my house on fire and now you come to save us?"

I turned my back on my neighbours, knowing that among them was an arsonist who had tried to kill us. I took hold of the hands of each of my two daughters and walked away, away from the village. Carrying only my handbag, I set off with my daughters for my mother's house. We walked to the bus station and at 1.30 am we caught the bus to the train station. Only when I arrived at the train station and sat down did I realise that we were not dressed for travelling. My hair was not brushed and I was shabbily clothed but I didn't want to draw any attention to myself and the children so we sat very quietly in the corner. The next train was departing at 3.30 am. Hundreds of thoughts raced through my mind. At that moment, I had so much anger inside me that I felt I could face any situation; at the same time I wanted to make sure that my daughters were safely protected and sheltered. I arrived at my parents' home at dawn and told them everything that had happened. My mother said, "Never mind. You do not have to go back there." Bandula's story was soon in all the newspapers in Sri Lanka. One headline read, "Father of two contracts AIDS takes poison and dies." Over the next weeks, I went everywhere with my daughters. At night, we used to cry together. They had been close to their father and they missed him. I still had no real understanding of HIV so my sadness was over the loss of my husband rather than any concern relating to my own health. Although Bandula didn't live in the country, I had always felt he was there with me. I could always recognise his knock on the door, no matter how long he had been away, and now I would never hear it again.

The trauma of all I had gone through over the previous weeks resulted in me losing my voice and I could not speak. My health started to deteriorate. I assumed that I also had HIV and would die soon. My mother and sisters began to look after me and started feeding me well, plying me with fresh juices and medicines. My brother-in-law suggested that I go and get tested for HIV so I did; when I returned for the results, the doctor confirmed my suspicions that I was infected with HIV. At that point, I resolved that, no matter what had happened, I still had to look after my two girls, who were 15 and 17 years old by then.

The doctor gave me a visiting card and asked me to go to the place on the card. It was Lanka Plus, the peer support organisation for people living with HIV in Sri Lanka. The late Dr Kamalika, an openly HIV-positive activist, met with me and counselled me. She told me that there were many other people in the same situation, and convinced me that I was not going to die tomorrow. Then I met another founding member of the group and he also reassured me. I looked at him, and thought, "He is also infected but he is normal. Why can't I live like this?" Two days later he offered me a job in Lanka Plus working two days a week. I was grateful to the supporting hand that was being offered and threw myself into the work. One of the Lanka Plus projects at the time was working with sex workers. I reflected on the fact that they did not have HIV and I had stayed at home and yet I had contracted HIV. I decided that I was going to do something helpful for people with HIV.



When I started working with Lanka Plus in September 2001, there were only four members. When people were diagnosed, I was always keen to meet them and find out if I could help them in any way. I began visiting the hospital twice a week to provide support to HIV-positive clients and do whatever I could to make them feel comfortable. One day I was dressing a blind man and he mistakenly thought I was his wife, so I allowed him to think that because I thought he would feel more comfortable. I can give people comfort without compromising who I am. I could not provide the care I wanted to give to my husband, who was with us for such a short time after his diagnosis, so I like to care for others. It is what I do best. When I hear that somebody is sick, I take a bus and go and visit that person.

In 2003, I became the Secretary of Lanka Plus, and then in 2006 I was catapulted forward in the organisation, following the departure of the previous President who had attended the Toronto World AIDS conference and stayed in Canada. The members voted me into the position of President of Lanka Plus. In 2007, for the first time, I was offered skills training. I travelled to Thailand to attend my first capacity building workshop in advocacy with other Asian women.

Since becoming the President of Lanka Plus I felt that the care needs of members were not being looked after so well and at times I felt that I wanted to give up my role as President. But I was committed to building our organisation into one that is accountable to all its members and has the ability to make a difference in HIV prevention, treatment and care in Sri Lanka. I have now served the maximum of three years as President according to our constitution and this year I became the Vice-President. The organisation has grown and now we have about one hundred members. Now I have a very active life. At times I find myself in places I have never visited before. I am leading a completely different life and my family is surprised how I am so strong to go out at night or to go abroad.

Today, I am not concerned about the fact that I am living with HIV but that I am living in a society that discriminates against people with HIV. I have the infection, but I don't feel it. I have medicine and I have a job and I can lead a normal life. It is the people around me who are worried. Whenever I have the opportunity to talk to people about HIV, I do. Many people have now accepted my HIV-positive status. My husband's brother is now very considerate. Before, he did not know about HIV and he was angry but now he understands. When my daughter recently got married the people in the village allowed me to give my land as dowry to my daughter and that made me very happy.



“ Today, I am not concerned about the fact that I am living with HIV but that I am living in a society that discriminates against people with HIV. ”

**PRINCEY**  
Sri Lanka



## FRIKA

Indonesia

I am the first child in my family and I always felt I was loved by my parents. I was born a year after my parents got married and I have two sisters four years and ten years younger than me. I always knew that I was a wanted child because my parents told me they had been waiting for me. Mum had a miscarriage during her first pregnancy so when I came they were really excited. I was premature and was in an incubator, so maybe I was always curious and impatient to see the world. As a child, if I wanted something and my parents could afford it they would buy it for me. When they married, my parents were not very wealthy and we lived in a really small house, but over the years they worked hard and tried a few different businesses to see which was the most successful. I am sure I get some of my fighting spirit from them.

I am Chinese Indonesian and throughout my childhood I felt that the various parts of my life were disconnected. I went to a Catholic school where the majority of students were Chinese but in our neighbourhood in Jakarta we were in a minority – that was dad's decision; he wanted us to integrate, to blend in and not isolate ourselves from the rest of society – but it was not easy when I was little. Sometimes people mocked me so I always felt I was a bit different from my friends in the neighbourhood. My parents discouraged me from mixing too much, inferring that I was somehow from a better class. My dad would make comments like, "You're Chinese. You are not one of them."

Every day after school I went to my mum's restaurant in the shopping mall. This was unusual in a way – most of my friends stayed with a babysitter but my mum would pick me up and take me to the mall and I would play video games or go on the escalators with the other children whose parents had a business there. Then I would do my home work in the restaurant. Sometimes I helped my parents as the cashier. I used to love counting the money. Other times I would take people's food orders, so I learned to get on well with people from an early age.

I got very good marks throughout school and I was the most adventurous in my family, always looking to try new things, so when I was 15 years old, in the second year of junior high school, I decided I wanted to experience living outside Indonesia, and I wanted to make sure that I decided where I would go, not my parents. My parents' business had expanded and was booming at the time. My dad started doing property development and my mum opened some clothing shops. They were good business people and I knew they could afford to send me abroad so I started looking around. I was trying to decide between Australia and Singapore, and I thought my dad would be more willing to let me go to Singapore because there were lots of Chinese there and the change would not be too radical. At first my dad didn't want me to go but my mum encouraged me and arranged for us to go there on a shopping trip. Mum and I started talking about how wonderful Singapore was, and suggested that if I studied there they could visit me often and my dad finally agreed.

The following year I went to Singapore. It was exciting exploring a new culture. At first I lived with a local family and studied English. After six months I took a test to see what grade I would go into. Usually Indonesians get downgraded one year, but I went straight into the ninth grade. My plan was to study in Singapore for four years and then go to the United States. Once I started school, my sister joined me.

Almost a year later, my dad invited us back to Jakarta for the opening of a mall that he had been building. He wanted all the family there because it was one of the biggest achievements of his career. At the opening I met the daughter of one of my dad's business partners who was about my age and also studying in Singapore. The next day we went walking around Jakarta together and she asked if I knew anywhere she could buy heroin. I said I didn't use heroin but I had a good friend who might be able to get it. I contacted him and we managed to buy some and she asked me if I wanted to try it. I was curious and wanted to experience what it was like. I thought it would be alright to try it once so I said yes. You hear lots of stories that people get into drugs because they're not happy or they come from a broken family but that wasn't the case with me. I had a good relationship with both my parents. Heroin was just another experience.

The first time I tried it was terrible. I vomited and felt dizzy. My friends said I should try again. "But it's awful," I said. Yet I could see they were enjoying it and I wanted to enjoy it too so I decided to try one more time the next day. I had never smoked anything before and I felt so different. But it was not only the feeling of being high for the first time that was so good. There was also a feeling of closeness to these people whom I barely knew. I felt I belonged and that felt really good. I started to think that maybe there was another part of the world where people who use drugs feel they belong. We were doing something illicit together, something euphoric. When we were high there was no barrier between us. When we blacked out, we didn't know what we looked like and we didn't care; we were with each other in another world.

My life changed quickly after that. Back in Singapore this girl introduced me to her friends who all smoked heroin and I started avoiding my old friends. I was 16 years old and I managed to keep up with my studies and I got good grades. At the end of my first year of high school I wanted to study in another school because I wanted to accelerate my course. I enrolled in the International School and I took lots of extra classes. I never had meal breaks and in one year I finished eighteen months of study. I continued to smoke heroin for the next three years. Money was no problem at first because my dad was always worried that I would not have enough money abroad, so whenever I asked him to send money he would. I made up stories, that I wanted a new bag, or I needed money for a school trip.

In 1998 the economic crisis hit. My parents could no longer keep both my sister and me in Singapore so they pulled her back to Jakarta and kept me there to ensure I finished high school. In May 1998 many of my dad's businesses were burned down in the riots in Indonesia. A year after the shopping mall opened it was completely destroyed. My father was very down in spirits for a long time after that. It was shameful



for him and he lost face, a successful businessman who had so much and now had next to nothing. Both my parents are fighters and they successfully built their business back up bit by bit, but at the time, I knew it was difficult financially for them. I didn't want them to start asking why I needed so much money so I had to become more creative and resourceful. I started to deal drugs.

Just before I finished high school my parents found out I was using drugs. One of my friends was caught using and he told his parents that he had used with me. Damn it. His parents called my parents. I denied it but the next time I went back to Jakarta they started asking me so many questions. I insisted I was not using drugs so they asked me to prove it by having a urine test. I was feeling stubborn and I said, "Fine, if you don't believe me I'll have a test," even though I knew they would therefore find out. When the results came back, I suggested they get me into a detoxification centre so I could go back to Singapore and finish my studies. In fact, I just wanted to get away from them. Despite the good relationship I had with my parents, at that moment I felt as if they were monsters.

I convinced them to take me to a psychiatrist who treats drug users. At that time there were a lot in Indonesia. People say we are the lost generation because a lot of people my age started using drugs, particularly during the financial crisis. The psychiatrist gave me codeine to get through the cravings, which were really painful, and Xanax to make sure that I slept through most of it. Five days later when I woke up my body no longer physically craved the drug. But I missed it mentally. It was the life I had known for the past few years.

Not long after I returned to Singapore I started using again. I finished my second year at the International School and returned to Jakarta in 1999. At this point I wanted to go to university in the United States but my dad said no, I had to stay in Jakarta where he could keep his eye on me. I complained that it was so difficult to move around in Jakarta and my dad said if I studied there he would give me a car. I thought I could stay for one year until my parents were sure I was clean and then they would send me to America, so I said, "It's a deal." In my mind I thought, "I'll prove to you that I can get clean and stay clean." And part of me did intend to. We tried the same method again and they took me back to the psychiatrist.

I enrolled in a graphic design course at a university in Jakarta. It was a new environment, a new school, and I didn't know where you could get drugs. I stayed clean for quite a while, but it was as if people knew I was a user, even though there were not many Chinese Indonesians using at the time. Somehow users can identify each other as if there is a magnet drawing us together. Again I thought it would be okay to use once or twice. But of course that was not the case and I got hooked again.



I got really depressed. My father had omitted to inform me that he was giving me a driver with my car. I wanted to drive myself and I asked "Why don't you trust me?" Suddenly I had no independence, and part of me did not believe that my dad was going to send me to the States. I felt both angry and sad and I didn't care about anything anymore. To cover my feelings I started using a lot. Over the next three months I started injecting because it was more economical and money was getting more and more scarce. To pay for my drugs I started stealing things from the house and selling them. By now there was no way my parents would give me money. If I asked for money to photocopy a book, they would ask for the book and get it photocopied for me or else I needed to give them a receipt.

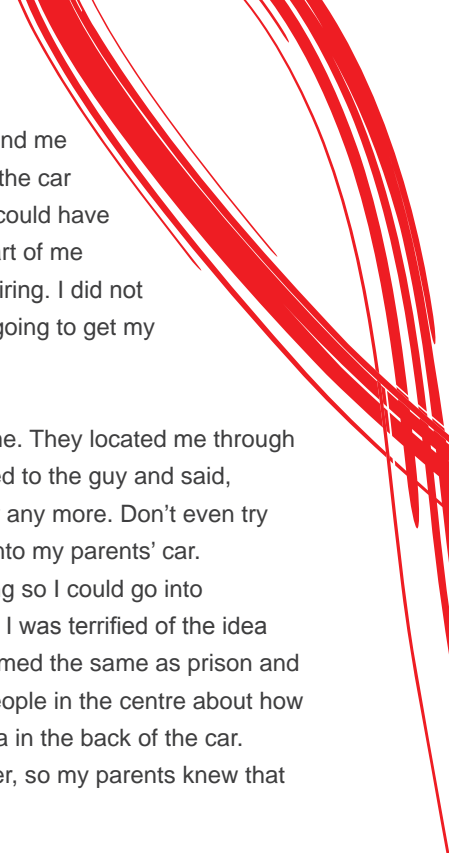


When I was in Singapore I had contacted Action for AIDS to get HIV-positive speakers to come to talk to my fellow students so I had already heard about HIV and I knew how people contracted it. I had injected once or twice but I was very careful and I always used a clean needle. It was easy in Singapore. I could go into any pharmacy and get a whole pack and it was not expensive. But in Jakarta access to needles was really difficult and by that time I didn't care so I started sharing needles.

My parents realised I was behaving differently. We talked and I admitted I was using again. By this time I was getting desperate and I actually wanted to stop. But because I had failed detox so many times I needed to find another way. I decided to try rapid detoxification, a new method from Israel. I was admitted into intensive care and given an anaesthetic for a day and when I woke up I was kind of okay. They gave me Naltrexone, which I had to take every day to block the nerves and stop me from getting high if I used heroin.

In the hospital I was given an HIV test and the result was positive. I was really angry with myself because I knew about HIV and still I had been careless. The doctor told my parents to keep my dishes and utensils separate from other people and from then my parents started treating me differently. I became really depressed and angry and I felt I wanted to kill the doctor who had told my parents to be so careful with me. Then I started isolating myself from other members of the family.

I went back to university but it was hard because I was trying to keep clean and at the same time I was coping with my HIV status alone. After a few months I started to use ice (methamphetamine). We had lots of homework so I liked ice because it kept me awake at night. I tried heroin but I could not get high because of the Naltrexone. My parents were supposed to monitor me taking the drug but then I found a way to hide it in my mouth. I stopped swallowing the Naltrexone and I got back into using heroin again.



I blamed my parents for what had happened because they had refused to send me to the States. I never blamed myself. I started to act really wild. I would take the car from the house and I was rarely home. I rented a small room in Jakarta so I could have some independent space. My life became quite desperate and painful but part of me refused to surrender. I knew I could not continue like that indefinitely. It was tiring. I did not want to spend the rest of my life waking up every day wondering how I was going to get my drugs, and I still wanted my parents to send me to study in America.

I was away from home a lot and one day my parents decided to search for me. They located me through friends and found me with a boyfriend, and with some needles. My dad turned to the guy and said, "Here's some money for your transport. Go home and don't call my daughter any more. Don't even try and talk to her again because she's coming with me now." He left and I got into my parents' car. They gave me an ultimatum. They said going to a psychiatrist was not helping so I could go into a rehabilitation centre or else they would put me in prison. I agreed to rehab. I was terrified of the idea because I knew that you had to stay there for more than a month, which seemed the same as prison and I had heard it could be really violent. My parents had already talked to the people in the centre about how to handle me. I was crying and wanted to run away but they had my grandma in the back of the car. She is my mother's mum and the oldest person in the family and I respect her, so my parents knew that if she was with me I would stay calm and not disobey them.

Suddenly I was in rehab. I went in on 6 October 2000, a year after I got back from Singapore. When I found I had to stay for six months I wanted to cry. I asked, "Can I just stay here three months?" The staff shook their heads, "No, no way." They told me that if I wanted to walk out I could, but that was the length of the program. I thought it was a waste of time and that maybe in the second month or so I would be able to get myself out. They said, "If you want to leave, leave now. But if you want to change your life, we're here. If you want to run away it's not difficult at all." That was their attitude. And it touched my conscience and got me to think for myself. I wanted to stop living that kind of life. So I stayed. Maybe it doesn't work for some people but it worked for me.

I found the place very different to what I expected. People were really friendly. There were no bars on the windows, just a gate with one guard. The place was run by ex-users, so they understood where I was coming from. In the women's compound I again got the feeling of belonging. I enjoyed the company of the other women and I was part of a group of people trying to stay clean together. We had the same vision, the same pathway. We knew it was going to be hard but we all had similar experiences, similar goals, even though our lives were different. It turned out to be good.

What was most amazing was that I felt I was learning a lot. Twice a day we had classes and they taught us about our junkie self, how our mind and our body work when we use drugs, and why we get cravings. I found the place interesting and I got to like it. Of course, my feelings went up and down. At times I got



bored, seeing the same people every day, sleeping under the same roof, eating together, and there were times when I wanted to leave, but I could see there was value in what I was doing and that kept me there. What I particularly liked was that they understood about HIV. They tested everyone and if you were positive, they accepted you. Not many places would let HIV-positive addicts stay but there it was okay. I met other people who had HIV and I no longer had to keep my HIV status to myself. I felt I belonged.

The centre had a parents' program every Sunday. They taught about the behaviour of addicts and what to expect when we got out of rehab. My parents travelled with me on my journey. It was different to saying, "Here's my child I'm putting her into rehab. Fix her." It was like, "Okay, your child needs to recover, but you need to be there as part of that process. Your child is not like a car that you put into the garage for servicing." I liked that approach. My parents learnt about HIV, that it was not necessary to separate the dishes and it was fine to touch people with HIV. So it built up our relationship again and re-established the trust.

Six months went by and I finished the course. There was another six-month program to become a peer counsellor and to my surprise I was interested in it and wanted to stay. Afterwards you could work there as a staff member and get paid. My parents asked, "Are you sure? Don't you want to go out? We think it is time for you to start your new life. You can go back to school, start a business, whatever you want. Why get yourself stuck in this environment?" I begged them, because they had to pay for the training, "Please. I want to be here. I feel I don't have enough tools yet. I want to learn more and this is where I feel useful. I want to learn how to help other addicts who want to recover." So they agreed.

During that year in rehab I was trained in counselling, public speaking and how to facilitate sessions. This was the foundation for me running trainings now. I started to speak out in schools and seminars. Not just about my HIV status, but also about my journey from being an addict. I felt it was a relief to share my experience in public and be open. It also felt good to be educating people. I'd been feeling useless for so long, only thinking about me, me, me and how to get my drugs each day. This training made me feel that I could use my experience in a positive way to help other people.

I became interested in working on social issues. I finished my peer training and then I had to make another big decision, whether to stay, working there and helping people, or try my luck outside. My parents expected that I would go back to study and start my own business or become a career woman. I was very comfortable in the rehab environment and it felt safe, but a friend challenged me. He had been at the centre and when he finished we had kept in contact. He said, "Frika, you're very smart. Why do you want to get stuck in rehab?" "What do you mean 'stuck'?" I felt offended.

“Don’t you understand that I’m helping people?” “Yes, you are helping people but are you becoming too comfortable? Maybe you should start thinking about coming out of your comfort zone.” I said that outside there were too many challenges and I was afraid that if I got pressure I might get back into using. He said I could always come back to peer support meetings or counselling. He was a lawyer and said that when he was a drug user he had been very manipulative and now he uses those skills in court defending people. “I think you can do that as well.” I found this idea fascinating, looking at my weaknesses and trying to change them into positives in my life. I wonder if that is why I have become a good negotiator, because I developed that skill before.

I started working in the rehab centre and two months later I got involved with Spiritia, the national network for people infected and affected by HIV. In the rehab they were more concerned with addiction and in Spiritia they dealt with HIV and I didn’t want to choose one over the other. Around this time I started a relationship with a guy who also worked at the centre, and that was against the workplace policy. The program at the rehab centre focuses on oneself and the director felt my foundation was not strong enough yet. He tried to tell me not to get into the relationship but I was stubborn. I hadn’t had a relationship for over a year and there were sparks between us and it felt so good. The director said, “Frika, you are positive, he is negative,” and I resented this. He recommended that a positive person should only go with another person who is positive. He explained that often addicts are not very strong and the attitude of “I don’t care” comes back easily, so when sex is involved, we might face situations where we don’t use condoms, but at the time I felt he had no right to say that. Now I understand what he meant because I got close to him again later. His program helped me so much in my recovery and I wanted to acknowledge that; even when I hated him I loved him at the same time.

I left the rehab centre and started working for Spiritia. I organised trainings and assisted in running programs. I got involved in public speaking and staff training. In 2002 I became the APN+ representative for Indonesia. I started opening up more but I was not yet ready to be open about my HIV status in Jakarta. I talked on the radio and gave interviews for magazines providing they did not show my photo. My dad was concerned about what his clients would think if they knew he had an HIV-positive child and I thought I might go back into the business sector so I felt I needed to protect my identity.

The salary I earned in Spiritia only lasted me two weeks each month so I decided to earn some extra money and went into business. My mum gave me a kiosk and I opened a clothing shop. My business sense came back into play and it went really well. In one year I went from one to three shops, rolling over the capital. By the end of the year I did not have much money to spend on myself but I had a very successful business. I worked for Spiritia three days a week and I worked in the shop at weekends. Over this period I had no time out, no breaks and I got really tired. So my CD4 count began to drop really quickly. In 2003 I started on ARV medication. I said to myself, “This is not a healthy lifestyle. I’m only working, working, working. I don’t want to lead my life like this.” In the end I closed all of the shops and started working for Spiritia full-time.

My mum kept trying to encourage me to go back into business. She knows I have a good business sense and my parents would love me to take over the business they have built up over the years. After some time I decided to work for my mother on the stock market full-time. I was supposed to be taking life easier, but it didn't turn out that way. There was part of me that wanted to get back to social work and I wanted to open up about my HIV status. "Why should I keep it closed?" I thought. It felt like a burden inside me. I realised that part of the reason I was keeping silent was because of other people, not because of me.

I found I could do more speaking by going to the provinces with Spiritia. I gave interviews for local magazines that had no circulation in Jakarta. Slowly in Jakarta I then started opening up. I did an interview in a tabloid magazine. In 2003, I was elected as the co-chair of APN+. As a spokesperson for the Network I found I could express myself easily. I was also the regional representative on the global network, GNP+. In Kobe in 2005 I spoke in the opening ceremony of the International Congress on HIV in Asia-Pacific. That was a big decision to go public; if the news got to Jakarta, so be it. The following year I was asked to speak in Toronto at the International AIDS Conference.

In 2007, I started working with APN+ as the women's co-ordinator, another big decision which took me out of Indonesia again. I am now based in Bangkok with APN+. My parents keep asking me if I want to go back to Indonesia and take over the company but I know that working with family does not work for me. Eventually I would like to find a way to combine my business skills with my community development interests. I feel more independent now than ever before. I know I can stand on my own two feet. I am stronger and more confident. Even though life is difficult I can share my experiences with others and I help people and that makes me feel useful and gives me a reason to live.



“ I am stronger and more confident. Even though life is difficult I can share my experiences with others and I help people and that makes me feel useful and gives me a reason to live. ”

**FRIKA**  
Indonesia



## PHAROZIN

Cambodia

I was born in Phnom Penh in 1982, the eldest of three children. My sister is two years younger than me and my brother is thirteen years younger. He and I were both born in the Year of the Rooster. Most people in our family have only two children but my mum wanted to try and have a son. Until I was about twelve years old our family lived with my grandparents, several aunts and uncles, and two cousins. Everybody supported each other. My dad worked in the army and because that did not provide sufficient salary, he also had a small business transporting people from the border. My mum worked in a factory until I was about six years old when she started a small business from home. When my grandfather died our family separated. Two of my aunts moved close to our house and another went to live in central Phnom Penh.

My aunt and my mum often complain that I was troublesome as a baby because I used to go to bed later than anybody else. Every night I needed somebody to scratch my arm gently to help me to get to sleep. My mum would lose her patience and send me to my grandfather who was the only one who would talk to me gently. He would say, "Child you need to sleep now. Maybe tomorrow I'll take you to buy some fruit if you're a good girl," and with his soothing words I would fall asleep. My daughter likes to be scratched the same way I did. It is how she likes to be comforted, but if she asks to be scratched when she's falling asleep my mum tells her, "No, I'm too lazy to do that any more. I had to do it too often for your mother."

When I was young I was a very happy child but I was also very reserved. I rarely talked to anybody and never shared my concerns with my mother or father. I would just come home and help with the housework without being asked. I was active and adventurous and was always having accidents. I burnt myself on the fire, I stabbed myself with a needle, and I was always falling out of trees. Whenever I saw a tree, I wanted to climb it and pick the fruit. One time I fell and cut my ear very badly and I had to have stitches. I still have the scar from it.

I always did well at school and from the first to the sixth grade I came first in my class. My parents were very happy with me. Each afternoon at school the students helped to look after the vegetable garden and I enjoyed working in a team together with my class mates. Because I was bright, teachers used to ask me to help them to correct papers and add up students' marks. A small group of about five or six girls did extra tuition in mathematics and chemistry. We would each contribute a little bit of money and when we finished our class, we would have a small party at the teacher's house. We became very close friends.

I finished high school in 1998 and went to university. In the mornings I used to study short courses – accountancy and English – and in the evenings I attended university. I wanted to get a daytime job but in Cambodia it is difficult to get work if you have no experience, so I helped my mum with her business. By then she had a market stall and I was in charge of it in the afternoons. In my first year at university I met my husband. He was taking the same course as me, a Bachelor's degree in Finance and Banking. I had never had a boyfriend before. Whenever we had a break from class we sat together, chatting and slowly we got close. In the second year he asked me to marry him. I said he should ask my mother and father and they agreed because they could see that I was in love with him.

We had a big wedding in January 2000 and his parents gave us our own house to live in. I got pregnant a couple of months later and I did not know what was happening, only that my period had stopped. I knew nothing about pregnancy because there was no sex education in school. Cambodia was recovering from the war and was starting to become more developed and the curriculum only focused on academic subjects so I was very naive.

From the beginning of our marriage my husband was continually sick. He had constant diarrhoea and we could not understand why. We were living with my parents and they began to suspect that he might have HIV. In August they asked us to do a blood test and took us to the hospital. The following month the test results came back. We were both HIV-positive. I was in shock. I had so much pain in my heart and I felt

very afraid. I felt I had lost everything. I wanted to run far away from my mum and my dad and everybody around me. I had no information about HIV and I thought that I would die soon. I felt hopeless, without a future. I wanted to find a quiet place so I went to my aunt's house in central Phnom Penh and stayed in her kitchen, crying. My aunt could not get me to say anything. My sister tried to talk to me, then my parents tried, but I would not talk to anybody. They knew about my HIV diagnosis but I had nothing to say to them. I thought I should have an abortion but I was afraid. My mother said, "Whatever you decide, I will support you." So I stopped thinking about an abortion and went ahead with the pregnancy. It was a really difficult time for me because I was studying, I was pregnant and I had just received news of our HIV diagnosis. I started to think that I ought to stop studying but my mum said that it would be better for me to finish. My family offered me a lot of support so I decided to continue with my studies.

After my daughter was born in November the relationship between my parents and my husband became very difficult. They were angry with my husband because he always went out at night, even after we were married, and although they did not say it, I know they blamed him for my HIV. My father asked me if I wanted to divorce him. I said that I did not want to. In my heart I was never angry with my husband because he said he was not aware that he had HIV and he did not want to give it to me. It became increasingly difficult at my parents' house so when my child was ten months old we decided to move in with his family.



My husband worked for the government and received a very small salary, so I started a business from the house selling things like salt, sugar, noodles and rice to local families. That way I could feed my daughter and continue my education. I changed my study time to the afternoons and worked in the mornings and evenings. I used to bring my daughter to the classes with me and when she was two years old I enrolled her in kindergarten. I earned enough money to pay for the next two years of my fees. I spent very little money on daily living and I was very good at saving. Every few months my parents would help me out and give me some money because they knew I did not have enough to support myself. At the end of 2003, I graduated and wanted to apply for a job in a bank but a relative told me that they would do a blood test so I was afraid to apply. I decided instead that it was easier to continue running my business from home and looking after my child.



My husband's health was not good but he would not go to the doctor because he was afraid of people knowing his status. After we had been married five years, he became very sick and was admitted into the hospital. He recovered, but a week later he got sick again and he was re admitted. He had TB and was on antibiotics but he did not respond to the medicine. His weight was very low. I had to look after him and sometimes I could not sleep because he was so sick. I had to do everything for him as if he was a child. ARVs were not available then. He stayed in hospital for a month and it was a very difficult time. I was afraid that if my daughter was in the hospital she would get some kind of bacterial infection so I asked my mum and dad to look after her. I stayed the whole month in the hospital caring for my husband until he died in May 2004.

After my husband passed away I went back to my husband's house and my daughter kept living with my mum and dad. I lived with my in-laws for about a year just sitting at home thinking that my life had ended. Then his family told me they wanted the house back. I said nothing but I cried a lot. I felt very angry with them because what they did was so unfair. It seemed that they did not love me or my child. It was a very hard time. I walked out of that house with nothing and moved back into my parents' house. I never saw my in-laws again.

I felt I did not want to do anything but my mum encouraged me. I realised I was not earning enough to support myself and my daughter. I knew I had to help myself and I did not want to depend on my family. I considered studying beauty therapy and setting up a hairdressing business but my mother said I need not do any more study and that I should find a job with a company or an organisation. She also supported me emotionally and helped me to get the information about HIV that I needed. She spoke to a woman who had a shop in the market and whose son worked for an organisation involved with HIV. She told her I was HIV-positive and I wanted to do some volunteer work. I met the son and he gave me lots of information about how I could do some volunteer work and I got in touch with the organisation. Soon afterwards they contacted me and asked me to join a workshop to establish a self-help group in the province close to my house. I had no idea what a workshop was but I decided to attend. After that I volunteered for the local self-help group and I continued to run my small business from the house.

The self-help group asked me to join another workshop on leadership run by Susan Paxton. That was the first time I attended a women's workshop and I learnt so much. All the women shared so many experiences. I realised that it was not only me who had this problem and many women faced the same problems as me. At first it was hard to talk about my life in front of other people and remember all the sadness again. I cried when I spoke about what had happened to me but I also felt something in my heart was released. As I met other women, I thought about what kind of work we needed to do together to support each other and overcome the challenges we faced.



After the training we decided to establish a women's income generating group, Women of Hope. We invited other positive women to be involved and we selected a leader for the group. I was elected the vice-chair. As volunteers we had no financial support and very soon the leader found a job in an NGO so the group asked me to become their leader. We learned how to make bags and we sold them to NGOs. Sometimes we only earned ten dollars per month but we persevered with the project. Sometimes we worked the whole day and throughout the night without sleep because we wanted to support the group. It was very hard work at the beginning because we had to support ourselves. Slowly some NGOs got to hear about us and started buying the products and we were able to buy new sewing machines.



After I had been volunteering for Women of Hope for about five months I heard that there was a position being advertised for a women's focal point within the Cambodian Positive People's Network, CPN+. By then I had attended many trainings and workshops, and I started to think, "Okay what do I need to do for the future?" I decided I wanted to work in the HIV sector because I wanted to support other positive women who faced stigma and discrimination. I thought that we had to give more information related to HIV to all women in Cambodia because I did not want other women to end up like me – I had known nothing about HIV. Women stayed at home and got HIV from their husband and it was hard for women to accept this. I thought that if women and girls had more information about HIV they could protect themselves from contracting the virus. So I applied for the job and fortunately I got it. I started working as the coordinator for the positive women's sector within CPN+ in December 2004.

At last I was able to support myself. Beforehand I would not have believed I could do this kind of work. When my husband died I felt that I was very weak, but within a few months I became strong again. I got my strength back through meeting other positive people. I discovered that I could talk to family members, with mothers and fathers, and I knew how to discuss issues with them. I realised that social work was something that I was very capable of doing. Before, I felt shy and just kept my feelings in my heart. Even when things were very difficult I never shared my thoughts with other people and I never challenged anything. Maybe it was because of my culture or my family, I do not know why but I just listened. But once I started interacting with people in the self-help group I knew I had to talk more. As I got more information I started to feel more comfortable and confident. I attended more workshops and that built my capacity and I built relationships with new friends and I learned how to open up more.

We had challenges within the CPN+ because they did not like the idea of the women's project. I was working alone and trying to implement programs. At the beginning I did not know what was required for this work and nobody was there to tell me what to do so I tried to work hard by myself. Sometimes

I brought my work home and did not sleep for three days because I felt I needed to read more and find out more information. I had no experience on how to write a proposal, develop a work plan, implement activities or manage a program but after three months I started to feel that I understood my role. It was a pilot project and after the first year I had to write a proposal and contact donors to get more support. We were successful in getting more funding to build the capacity of women and we started to link women's networks in different provinces around the country. CPN+ felt that this project did not belong to them and I had to take full responsibility for it. They did not see the work as contributing towards CPN+ because it was only of benefit to women, so I was not given any human resources to support the project. But I learnt a lot by doing it and I enjoyed the work.

In the third year we got more funding to strengthen positive women's leadership and were able to recruit another woman, so there were two of us to support each other in the work. We focussed on advocacy and capacity building of the Cambodian Community of Women living with HIV (CCW). We went step by step and created our own identity and got recognised by other organisations and built relationships with government and other networks. We set up a steering committee to help us become a strong network. CPN+ had many meetings with us to clarify what we were doing. Eventually CPN+ agreed that CCW should become a separate entity. They said we were strong enough to be independent. Before, I had wanted to work within CPN+ and I was afraid of creating a separate organisation, but once we did we got more support from funders.

People working in the HIV sector think that HIV-positive people have low education. This motivated me to show them that positive people can be educated and can study the same as other people so they will not look at positive people as illiterate people. When I started working in the positive women's sector I could not speak English very well, even though I learnt it for many years. I decided to go back to study English again. I enrolled in an evening program for two years. When I came to the end I wanted to learn more, so in 2006 I enrolled for a Masters degree in Development Management because it was related to my work in the NGO sector. At that time, I started taking ARVs. I did not have any opportunistic infections but my immune system was going down and I felt very weak. I could not do much work and I constantly felt tired. I was afraid to start ARVs because of the side effects. I had a blood test and my CD4 count was only 185 so I went to another hospital and I had it checked again and it was 195, then I believed it and started ARVs. After only nine months I faced side effects so I had to change drugs.

It took me two years, studying in the evenings and on weekends to complete my Masters degree. I feel that I must keep learning and improve my capacity by any means. I would like to continue studying English for another two years and get a Bachelor degree in English and then another Masters degree, this time in Business Administration. I still have a lot of learning to do. I hardly thought about family during the time I was doing my Masters degree. My mum and dad took care of my daughter so I had no worries about her and I was able to concentrate on my work and learning.

From the time my daughter was three years old she lived separately from me and because I just focused on work and study and had no free time she hardly saw me. She began to call my mother “mum” and my father “dad”, and she calls me “my sister”. When my mum asks her who her mum is, she knows who I am but she feels shy to call me mum. I do not want to force her to call me anything in particular, it is up to her, but I do not feel the same as other mothers and I hope I can improve my relationship with her in the future. My daughter is still at primary school and I send her to English classes in the afternoon. I want her to learn as much as she can. I hope she finishes high school and goes to university and gets a good job and a good husband, and that she is happy. When my daughter was born I was afraid to get her tested, but when she was three years old my parents took her. My mother phoned me with the result and told me she was negative but I did not believe it. We waited six months and then we did a second test and the result was the same. She was negative. I was very happy. It was the best feeling. I had a future and I had hope for her again.

I worked for CCW for four years. In early 2009 I decided that the network was well established and I moved on to another challenge. I went on a study tour to Australia and on my return to Cambodia I took up a new position as coordinator for the Cambodian Alliance for Combating HIV and AIDS. This is another network working for all people with HIV, not just women. We mobilise our members to do advocacy on Candlelight Memorial Day, Global AIDS Week and World AIDS Day.

When I hear other women say that their husband’s family looks after them and their children and treat them as their own I wonder why I married a man whose parents are so very unkind. Sometimes my friend says it is because of the sins of my past life but I do not believe that. I believe it depends on the behaviour of the person. If I saw my husband’s family in the street I would ignore them and pretend I do not know them. I just believe in myself and I know I have done nothing wrong. My life when I was young and the life I had with my husband were very, very different. I just went to school and learned and if I had no money I asked my mum or dad for help.

I never thought I would face all these problems. I never thought that I would have to support my family alone. It was very difficult to live that life and it hurt me a lot. I do not need another husband. It was a terribly painful period and I would be afraid to face that again. To live alone with my parents and my daughter is good enough. I am happy once again.



“ People working in the HIV sector think that HIV-positive people have low education. This motivated me to show them that positive people can be educated and can study the same as other people so they will not look at positive people as illiterate people. ”

**PHAROZIN**  
Cambodia



# SARANYA

India

I will be 13 years old in November. I was born in 1996 in Chittoor, India, where my mother's family comes from. Soon after I was born we came to live in Chennai with my grandparents. I have one sister, two years older than me. She is HIV-negative and my mother, father and I are all HIV-positive. My sister and I usually get on well together but sometimes we fight. We have a pet dog named Rockey and some pet fish.

I like school and I do well in all my subjects. I especially like maths and science. I am now going into grade eight. I like scary movies – thrillers and ghost movies, and I enjoy watching TV. I also like reading, doing quizzes and playing shuttlecock, but there is no ground space at my home so we only play that at school. Now it is the summer holidays so I paint and read books and play with my friends. I used to go to dance class and I liked dancing but I stopped because we moved house. I am only now learning how to ride a bicycle. There are not many vehicles on our road so when one comes by I get a bit scared and I stop riding.

My mother's parents still live in Chitoor. My mother is the youngest child and she has four siblings, so many of my cousins are there. They all live in one house. Two of my cousins are now in college and some are still young, in third and fourth grade. I visit every year during my holidays and usually spend about ten days there. I enjoy going to that place very much. It is very green and I like to play together with all my cousins. We like to play a game that we call "business" and we use old business cards. We also like to play shuttlecock. All of my relatives know my HIV status and none of them discriminate against me. I don't have any problem with any of my cousins. Many of them don't understand what HIV is so they ask me and I explain, so there is no discrimination.

My mother told me that my growth was not as fast as a normal child initially, and I was tested for HIV at eighteen months. When I was seven years old, my mother told me that I was positive. She said, "You have a disease and you have to take medicine for it. If you take medicines regularly then you will not have any problems." I knew nothing else at that stage and just understood that I have to take medicine. I started going to my mother's office. She has worked in the Positive Women's Network of India (PWN+) for ten years. They have a library and when I was ten years old I began to read lots of books and slowly I learnt what HIV is and how it is spread. I read it in the form of a story. I read a lot of stories. Then I attended some PWN+ programs and I also learnt from them. I do not feel any different to other children. HIV is a disease and if treatment is taken regularly, we don't have to worry so I am not scared of it. Initially I did not know much about HIV so I was a little afraid and I worried about whether I could spread it to other people and whether I would become seriously ill from taking the medicine. But after I read the books, that fear was gone.

I usually visit my mother's office twice a week, on Saturdays and Sundays, and I know everybody there. PWN+ gives counselling to all women and provides children with information and education on HIV. They also counsel children living with HIV on how to take medications and they do lots of life skills activities and I participate in them. They give me skills on how to remember to take my medication, like indicating in the calendar daily. I am used to taking tablets because I have taken them daily since I was diagnosed. Initially my mother gave them to me. Slowly I began to remember by myself that I need to take this treatment and it is not difficult to remember now.

I want to share my status openly but I am always afraid that people will discriminate against me. My science teacher told us that HIV is a virus that reduces immunity but it is not a contagious disease and there are medicines for it and if someone takes them they can live normally. I do not openly disclose my status in the school. I share only with my friends, and even with them I am often in a dilemma about whether to tell them



or not. First I ask them generally about HIV without disclosing my status. Some are at ease with it and say if someone has HIV they will treat them normally but others discriminate and say they would keep some distance from them. From their answer I decide whether I can disclose to them.

In our family we discuss HIV very openly amongst all four of us. If I am staying in my relatives' house, and I am taking my tablets, I don't have any problem, but if I go to school and take tablets, it is difficult. I have to give reasons. Friends ask, "Why are you taking these tablets?" I spoke to the doctor and said that I find it difficult because all my friends ask me about the tablets. So he prescribed different tablets and now it is easy because I only take them in the morning before going to school and at night, thirty minutes after dinner.

I started taking Zidovidine only for nine months when I was two years old and I became drug resistant. Then I started on protease inhibitors and I had problems with them at first. I did not have any side effects but the tablets were very big because I was not on a paediatric regime. My mother buys them from CIPLA, an Indian drug company. Sometimes I have not been able to take my medication because they are very costly and my parents could not afford to buy them for me because three of us are on ARVs. Many times I had to be without medicine for two or three days. A few years ago I met Aunty Susan when she was doing some training for PWN+ and my mother explained my situation and since then she has helped to get funds for my ARVs.

Through my mother's office, I came to know about other children with HIV like me. I made lots of friends, but I was very sad to hear their problems. Lots of them are orphans and some are struggling because they are very poor. In May 2006 I attended a National Consultation for children living with HIV in Delhi organised by PWN+. We, the children, prepared the agenda by ourselves. Ninety children participated



from all states. It was a great joy. I met people who spoke different languages and there was good sharing. We did dances and hand painting and sang "We shall overcome" in three languages – Hindi, English and Tamil. It was nice. Some children acted out a skit about the problems they face in their life. Lots of children spoke about how they got HIV. Most, like me, were born with it. Some met with an accident and got infected through a blood transfusion. At the Consultation I heard many stories about discrimination in the family and in schools. One boy said when his father was sick the doctor told the family that he had HIV and will die soon and to take him home. He did not mention anything about medicine. Later the boy's mother came to PWN+ and got counselling and after she understood about the treatments available, both parents started them and they are doing well. In another family, the mother and father are negative and the girl child alone is positive, so they sent her out of the house and kept only the negative children with them. My parents have always been very supportive to me and when the children at the Consultation shared these stories I felt very sad. They are the ones who are most affected.

During this National Consultation, I met the President of India, Dr Abdul Kalam. We were taken to a tea party in his house. He blessed me and talked about birth stars related to birthdays. He told me that I was born on his birth star day. We also met Sonia Gandhi. All the ninety children were invited to her house. It was very beautiful and we really enjoyed it. There were parrots in her house. We brought up lots of issues that children are struggling with and we said that we need paediatric medicine. On the last day someone from the National AIDS Council Organisation attended the National Consultation. We presented to them and said that it is difficult for us to swallow these big tablets. After that we got paediatric formulations of ARVs. They are liquids so they are much easier to take. I feel very happy because I suffered having to take such big tablets, and I do not want other children to suffer like me.

One boy experienced discrimination after the Consultation due to his exposure on television. A bus conductor recognised him and pushed him out of the bus. He is an orphan – his parents are no more and he stays in a hostel. Wherever there is discrimination, people have the wrong information. Information about HIV should not just come from the media but from different sources. More people should be made aware of HIV through posters and other creative programs. They could have small greeting cards saying things like, "don't worry; get well." If something is interesting and catchy, children will read it. There should be something very exiting for awareness. It is good to have information in pictorial form. If people see a picture, they will go near it, and then they will know what they should and should not do. In schools information is not provided to children. There are no books on HIV or if there are, they give wrong information. It would be good to do some sort of role play for teachers. Only if they have some training will they understand. That's why I want to tell many people.



In 2007 I went to Sri Lanka for a conference. Only three of us got the opportunity to go and all of us said more children need such opportunities to come out and share their issues. That was the first time I travelled outside India. We were there for five days. The conference went for three days and we spent two days on travel and shopping. It was nice and I was happy to share my experiences. I talked about how in India we went to the President, what happened in the National Consultation, and about ARVs. More children need to come and share information about programs in other countries.

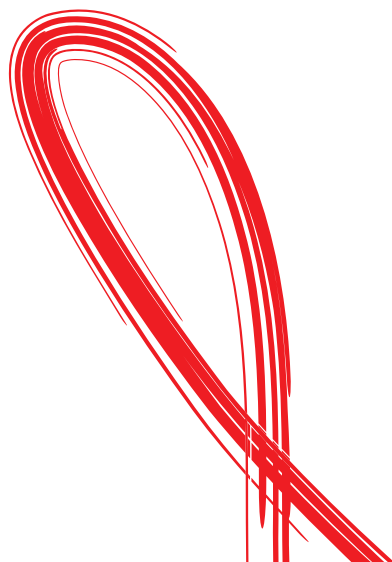
There was a state level consultation on children living with HIV in Hyderabad in December 2008. It was called the “Children’s Parliament” and 132 children from all over Andhra Pradesh came. The organisers asked me to perform a drama and at first I could not think of what to do. Suddenly I decided to get a chart and fill it with pictures and I wrote that all the people in the village must get tested for HIV and below that I put ‘signed by Government’. In my role play, all of the villagers went for testing, and only my sister was positive. She got counselling but I did not get any counselling and I was constantly scolding her and keeping my distance from her. After some time I had an accident and got a blood transfusion and I got tested again. I found out I was HIV-positive. Only when I got counselling did my character come to understand that such things may happen to people.



I recently went to Ireland with my mother for the Global Partners’ Forum for Children. I was the only representative from India invited by UNICEF and I was the youngest participant at the conference. Flying into Ireland was unbelievable. I saw the greenery of the country and I loved it. Ireland was nice but it was very cold. I met lots of other young people from many different countries. I made friends with children from Nicaragua, Uganda and Tanzania, as well as from Ireland – some of them were very tall. We shared experiences and I remember one case very well, about a person who was working in an office and was sent out of it because he has HIV and everybody found out, so he has suffered a lot. At the forum the Prime Minister gave a beautiful speech about HIV but the speech that really touched my heart was from Annie Lennox, the beautiful singer, who is passionate to work for HIV and AIDS.

After I went to Ireland I understood that HIV is a big issue not only in my country but in the whole world. I wish that every child could have the opportunity to learn about HIV like I have. One day I want to see the Seven Wonders of the World and travel everywhere, particularly China and Japan because people are different there, and I can learn their habits and their language.

Right now, everybody in our family is worried about my father because he has been sick. Initially he had hiccups continuously for three days. He was admitted to the hospital and was supposed to have two injections but after the first, he had a fit. He also had a fit last year and my mother immediately took him to the hospital. When it happened for the second time, we were afraid. It was very difficult because we didn't know what to do. I was very scared. My uncle was there at the time and he controlled him by holding his hands. In the hospital, when they found out that my father was HIV-positive, they said we should have told them as soon as he was admitted, and the nurses had touched him and they might get infected. From then, we did not go back to that hospital.



One doctor in another hospital is very friendly and gives good advice. My father was sick many times, and people told him that he will die but he is still alive. This doctor said we need not worry and if he takes the medicine properly he can live longer, but now my father has confusion in his brain and he is not doing well. The doctor said that there is some brain dysfunction due to encephalopathy. We are all concerned only about how father is. Grandmother is very concerned because he is her brother – my father is my mother's uncle – my father married within the family. I used to go swimming with my father but now I don't go anywhere with him. We stay at home because we worry that something may happen to him.

I have wanted to become a doctor ever since I knew about my HIV status. I am interested in knowing information about diseases. I have collected the scientific names of parasites, viruses, animals and plants. I want to invent medicine for HIV. I also want to give lots of counselling about HIV treatment, and tell people that they should take it regularly so they can live well.



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I want to invent medicine for HIV. ”

**SARANYA**  
India





# RATTANA

Thailand

I am thirty six years old and I was born in Ubon Ractchathani Province in the north-east of Thailand. My parents were farmers who worked other people's land so we were always very poor. I am the first born and I have two brothers and three sisters. Until I was four years old we lived with my mother's parents, but my father did not get along with them, so we moved to an uncle's house and when I was ten years old we moved again to live with another relative.

I had a very difficult childhood compared to most children. I had to work in the rice fields early in the morning before school while my friends got up and went straight to school. I remember one really cold winter when I was about eight or nine years old. The weather was terrible and I had no blanket to cover myself during the night. Once we had only one peanut salad to share between eight of us. There was often not enough food. We would take the sticky rice and scrape the inside of the cooking pot to get some flavour. Today whenever I smell oranges or limes it reminds me of my childhood because I always wanted them but we could never afford to buy them.

My parents did not have a good relationship. They were always arguing about money and I never felt very close to either my mother or my father. I always felt they loved my younger brothers and sisters more than me. If I ever have serious problems I talk to my close friends rather than any of my family members, however if my siblings have problems they often come to me.

I was quite a stubborn child and sometimes I was a bit mischievous. I was just a kid and I wanted to have fun but sometimes that got me into a lot of trouble with my father. He would often beat me on my back or my head with his shoe or a piece of plastic industrial piping. Once I took all my brothers and sisters to swim in the pond in the village. When my father found out he was really angry and hit me very hard and then he chained me by my ankle to a post underneath the house. I managed to escape but my father ran after me and caught me and he hit me even harder. Later I realised that he was angry because he was concerned that we would all drown in the pool, but at the time I did not understand and I felt he treated me very unfairly. Another time I had an argument with my cousins and one of them ran to my father and lied to him and said I was not doing my work. My father believed him and without asking me any questions began to hit me.

When I was twelve years old I finished grade six and had to stop school. My parents said they did not have enough money for me to continue with my education. I was very upset and I cried and cried. I started working and I moved away from home. I hated working in the rice fields because I had been doing it since I was a child, so I always looked for other types of jobs. I had many different jobs, as a house maid and babysitter, but I did not last long in any particular one because I would always get homesick. I used to make sure I came home just after harvest time so I could avoid the hardest work in the fields. Once I started earning money I helped to support my brothers and sisters. If I was between jobs and I was back at home, my father would give me some pocket money and I was able to go out with my friends in the village whenever there was a festive event.

When I was fourteen I met my husband. He was six years older than me. He was my first boyfriend and my first and only love. Originally he was dating one of my close friends and one day I visited her and he met me and liked me more and started going out with me instead. We dated each other for three years before we got married. When I was fifteen he had to do his military service. When he was away we would write love letters to each other every month. Whenever he was on leave he would visit my house and spend time with me. Sometimes we went out to festivals together. I always knew that he was the person I wanted to marry and my parents did not object to my decision. I thought to myself, "If I do not marry him I will not marry anyone." We were together all the time and right after he got out of military service both our



parents suggested that we should get married in order to avoid gossip from people in the village. I was not really ready for marriage at that point in my life but because I was 17, I followed my parents' advice.

After we married in 1990 we moved to the town to find work. My husband started working for one of his brother's in his tailoring shop and I worked in a laundry service. I decided to learn how to sew at that point. At first we lived with my brother-in-law but the business was not doing very well and my husband was not getting much work so we decided to move out. Eventually my husband and I started our own small tailoring business. My husband was very bad at saving money. I was working so hard to sustain the family but he was very laid back and would spend whatever he earned without thinking about the future. He was not a strong-minded man and I had to make all the decisions and do everything. If I had problems I could not discuss them with him because he was not able to give me good advice. I loved my husband but he was not very sensitive to my needs.

Once we moved to the town, my husband started going out with friends and leaving me behind in the room. That time was torture for me. He went out almost every night and sometimes he would not get home until after midnight. Occasionally he did not come home at all and that got me very worried. I could do nothing except cry and wait for him to come home. Sometimes if he did not take his motor bike with him I would get it and go looking for him but whenever I found him in a restaurant bar he would refuse to come home and I would have to sit there and wait for him. I used to argue with him about going out all the time. A couple of times he got very angry with me and slapped me. Two years after we were married I was pregnant and one day we had a very big argument. I said, "Don't go out. You need to do some work. It's not good if you go out looking for ladies." He refused to listen and slapped me across my face until I started bleeding from the lip.





After the birth of our son, my husband became more of a family man and stayed home more often. One reason was that most of his friends were married by this point and had their own families so he had nobody to hang out with. Some of my friends had husbands who would help them at home, but not mine. My husband was brought up in a very traditional family where the roles of men and women were clearly defined and there was no crossing the line. Women were responsible for all of the housework. One time when I was really sick I still had to cook and look after the baby and do all the household chores while he sat and did nothing.

Over the next few years we worked together in our tailoring business and our son grew strong and healthy. After we had been married nine years I noticed that my husband had blemishes on the skin all over his body. His friends started teasing him, "Hey, have you got AIDS?" I did not believe that he had that disease but I suggested that he go to the hospital to see the doctor. When he eventually did go for the test, he returned home and told me that he was fine, but he was very quiet and the look on his face told me that something was wrong. From then, sometimes when we had sex he would use a condom. As his wife I could not ask him the reason for wanting to use a condom. I thought it was strange but I did not have the courage to ask why.

Soon after this, my husband got very bad diarrhoea and he was admitted into hospital. I went with him and the doctor came to me and told me that my husband had HIV. I was so upset but I had no thoughts of leaving him because I loved him so much. The doctor told me that even though my husband had HIV, I might not have it. After I found out my husband's diagnosis we immediately closed our tailoring business and moved back to the village to live with his parents. A month later I decided to have an HIV test at the local hospital and I discovered that I was also HIV-positive. I was really sad and I could not believe it could happen to me. I went home and told my parents. I wanted to get my son tested because when I was pregnant nobody told me about HIV and I had breastfed him, so I took him to the hospital. It was really hard because he tried to escape and he was fighting everybody. He was six years old and quite strong and they had to grab him and hold him to do the blood test. He was HIV-negative and that news made me so happy.

My husband was constantly sick once we returned to the village. He became very, very thin and we tried hard to find a cure for him. We chased after every treatment that we heard about, herbs or whatever, but nothing helped. I did everything for him over the next year but his family avoided touching him and they would not hug him or bathe him. His parents gave alms to the monks on his behalf. We Buddhists believe that if we do good deeds in this life, our next life will be better. My husband and I were preoccupied with the fear of discrimination and thought the monks would discriminate against us, but they did not.

My husband died a year later and I stayed living with his parents. They gave me my inheritance, which was a rice field, and I used to work in it. Some of the neighbours tried to avoid me and would not talk to me. I did not tell them that I had HIV but they assumed I had it because my husband had died of an AIDS-related illness. Some of them started making comments, "Why do you stay here? It's not your home. You should move back to your parents." I liked living with my parents-in-law because they loved me and they did not fight like my own parents but after I had been with them for four years, all my younger sisters and brothers had moved away from home and there was nobody to take care of my parents, so I decided to move back to my own family.

After my husband died I had joined a recently established self-help group at the hospital. I was eager to learn as much as possible about HIV. There were only seven members when I first joined but they made me realise I was not alone. I also realised that some people had much more serious problems than me. Some people had been abandoned by their family whereas my family and my in-laws were very supportive of me. One woman was not allowed to drink the water from her own house. I assumed that I was not going to live very long and I decided that I wanted to spend the rest of my life, whether it was short or long, helping other people with HIV. A nurse counsellor conducted training on how to take care of ourselves. After that I got involved in the income generation group. I met with the group every Friday and spent the whole day there. We would make artificial flowers and sew clothes. The original intention was not to generate sufficient income to live on but to get people doing activities together. The group was not in a good financial position back then and we had no money for transport to get to the centre and no money for food, so the nurse counsellor looked for funds for our transport and the hospital and the temple donated some food.

In 2000, three years after I joined the self-help group I was elected to represent our group in the provincial network of people living with HIV. That is when I received a lot of training. I learned how to write reports and how to be a trainer. Some of us went to a workshop and learnt how to write funding proposals. When we came back we wrote a proposal to the Provincial Centre for Disease Control to conduct regular group meetings to address stigma and discrimination in the community and to carry out home visits to provide peer support to positive people in our local area. Sometimes if a group member was sick we would take them some medicine from the hospital. When I first started working in the HIV field, I had no idea what direction to go in or what issues I should be addressing. I just tried out ideas to see if they would work.

I designed and implemented projects by myself and I learned through my own experience. For example, I wanted the community to understand about HIV and AIDS so I would disseminate brochures and condoms that I got from the local hospital and the provincial public health department. I realised that the main reason people died was not because of their HIV but because of the stigma and discrimination they faced. They were stressed and anxious and their morale became very low and that is why they died.

So the next thing I did was to set up meetings in villages where we heard that there were reported cases of stigma and discrimination and we provided the villagers with information about HIV.

Once we became more confident, we started to run workshops for school children on HIV prevention. Then we got additional funding to train school children as trainers and we encouraged them to write a proposal so they could run activities in the school. When I did this work in the community I did not tell people that I was HIV-positive because people only tend to trust healthcare providers as facilitators. I was not a very outgoing person when I started this work but slowly I gained more confidence. Still, whenever there were events in my community, for example in the temple, I did not have the courage to get involved because I was afraid that I might face discrimination. In fact, I have not faced any but my son faced some discrimination at school. When he was about seven years old he was teased by his friends who said he had AIDS parents.



I am now the leader of my local self-help group and I am the coordinator of the provincial network for people living with HIV. I am also on the steering committee of the network of people living with HIV for the north-eastern provinces. Two years ago I was in the Thai national network of people living with HIV as a representative of my province. I would come down to Bangkok every three months or so as needed. I am also a member of the Thai positive women's group, Voices and Choices.

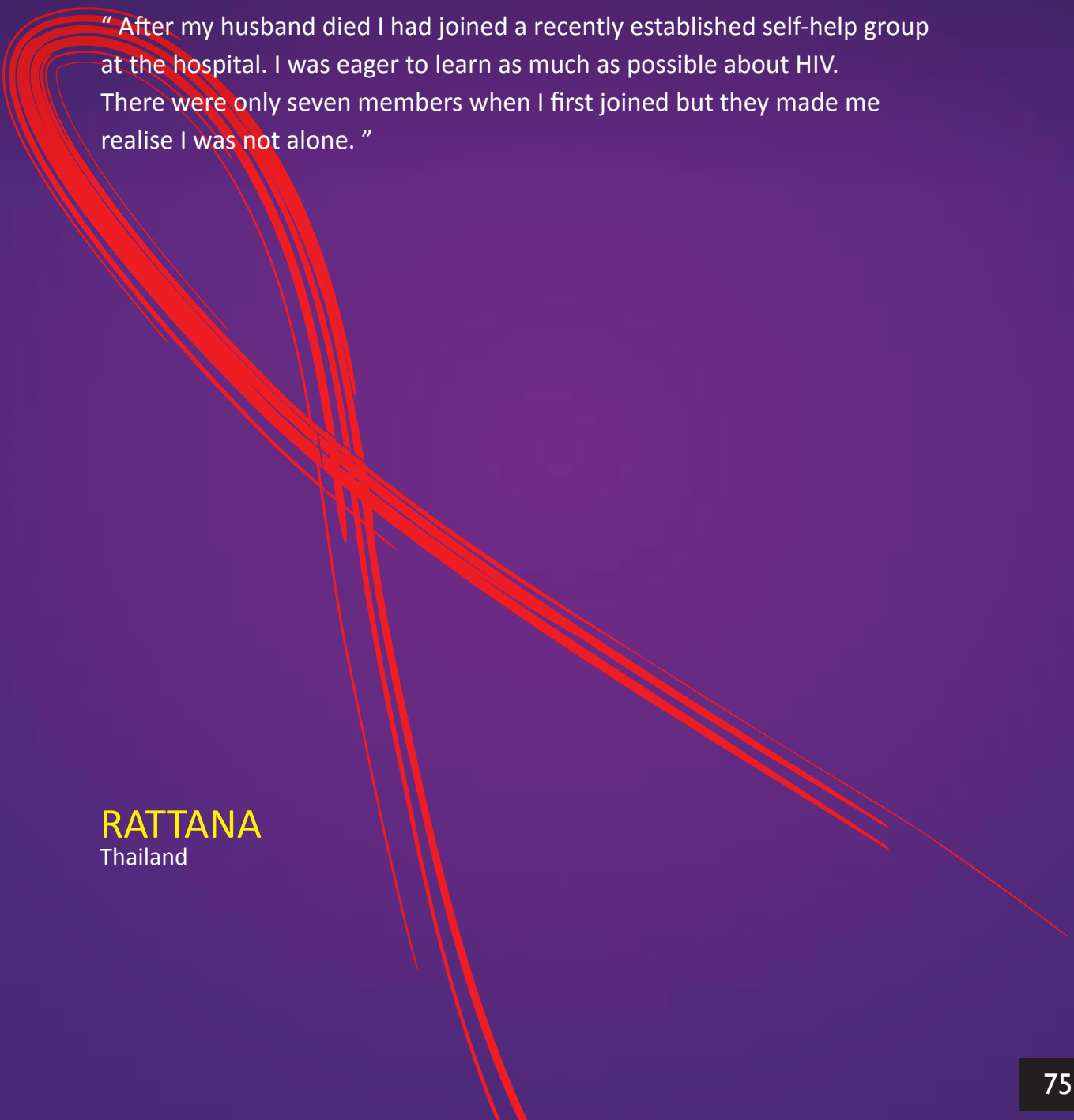
My work keeps me very busy. If I finish my work for the provincial network I get back to my local group. I have three major projects there. We do group meetings and home visits for members who are on ARVs, we conduct workshops for school children on HIV prevention and sex education, and we run an income generation project. That started last year – it is an agricultural project, raising fish, cows and chickens. I survive on the transportation allowance

I receive when I do my work and a small monthly allowance that the local authority provides for people living with HIV, and my son has a scholarship from an NGO that provides scholarships and allowances for children affected by HIV. I try and teach my son to be independent. I have taught him how to cook and how to look after himself. I want him to study hard so that he will be able to get a good job one day.

I am quite concerned about my own health because my CD4 count is now 210. According to the health department I should start ARVs once my count drops below 200 but I am worried because I have found that I am allergic to all prophylaxis for opportunistic infections, so I may be allergic to ARVs as well.

Today the self help group is very strong. It has 135 members and they are now in a position that they can continue to do the work without me. I have trained others to be leaders. I feel proud that I have helped many people. In the future I would like to work for an NGO because I have a lot of experience and I would like to continue to learn more.





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Thailand



## CHENGLI

China

My parents were factory workers in Kunming, the capital of Yunnan Province, in south-west China. Their marriage was arranged, and my mother did not like my father very much so their relationship was not good and they often quarrelled. I have one sister who is three and a half years older than me. Before my sister was born, my parents had male twins, but they both died before their first birthday. My family lived a simple, poor life. My parents loved us very much although my dad was a bad-tempered man and he would argue readily. If mum came back from work late, he beat her with his fists, and my sister and I would try to help her to fend him off. Sometimes he beat me with an iron rod because I played around too much instead of studying. My parents are now old and my mum often scolds my dad for daily trifles but he keeps silent these days.

I was not a good student in primary school and I had to stay in grade five for two years. I only went to middle school for one month and then I left of my own accord. I forged my father's signature and sent a letter to the school saying I was leaving. After I quit, I told my parents I was still going to school but every morning I would play with my peers. After two months, my dad found out because the parents of a classmate mentioned something to him about me having left school; once he discovered I was lying he beat me heavily. I was 14 years old and too young to find a job so I spent my time with my friends going to dance halls.

When I was 16, I started hanging out with a guy I met at the dance hall who was a year older than me. I did not know that he used heroin but one day I went to a friend's home with him, and all our friends were sharing heroin. They encouraged me to try it and I was curious and thought it might be fun, so I joined them. After that I started to use heroin often with my boyfriend.

I did not know heroin was addictive, so when I had a runny nose or my body started aching, I did not realize they were withdrawal symptoms. My family did not know I was using heroin, and every day my sister gave me money for my daily expenses. My sister was good at her studies and she immediately found a job after she graduated from middle school, so she supported our family financially. She only stopped studying for the sake of helping the family.

Nearly eight months after I started smoking heroin, I began to inject. My boyfriend began stealing to pay for our drugs. He picked pockets and heroin was cheap so we lived like that for two years. We lived in his parents' home but they did not know what we were doing because most people did not know anything about heroin in those days. They just thought it was strange that we stayed in his room all day long. My family worried about me because I stopped coming home, and I only went back for money.

One time, when I was 17 years old, I stayed away from home for six months, so my sister started looking for me. She could not find me but she heard that I was taking heroin. Eventually, she found out about the boy I was dating and got his family's address and went to his street and just stood there each day, waiting for me to appear. After one week she saw me and started crying; we had not seen each other for half a year and we missed each other. She said she was worried about me and asked me to go home with her but I refused because I was afraid of the withdrawal pains if I stopped the drugs.

My sister kept urging me to quit drugs, so one day I went and asked, "Give me some money for my last shot." She agreed and after I took it, she organised my detoxification. There was no replacement treatment then, so I stayed with her in her shop and I simply had to bear the pain of withdrawing from the drug. My sister arranged for some health staff to give me several days of glucose infusions. My sister had opened a grocery shop in a small hotel and she lived there in an apartment with her boyfriend. They watched me struggling, crying, shouting, beating my head against the wall, but they could do nothing except encourage me to persist. After a few days, I felt okay but weak; I lay in bed but could not eat and I could only take a shower with my sister's help. Once I felt better, I sat in my sister's shop and helped her. She wanted to keep her eye on me in case I decided to play any tricks and run away to get heroin. One day I tried. I said I wanted to go and get some noodles, but my sister did not agree to let me go outside,



so I started to run. My sister followed me down the street tears pouring down her face. She fell down, then got up onto her knees and begged me to return since she could not catch me. I stopped running and decided to go back with her.

I would sit in my sister's shop for hours, sometimes playing Mahjong with customers. I often played with a particular man and my sister told him my story. We gradually got to know each other and he started to accompany me everywhere. We fell in love and I felt I left heroin behind me forever. For him, I even stopped smoking because he did not like the habit and we would argue about it, so I quit. After I stopped using heroin, I moved back with my parents and my mum found me a job in a factory that made cloth flowers. I helped to cut the material. I worked there for eighteen months until the factory closed down. My sister opened a clothes shop, so I worked there for nearly a year, then she opened a restaurant and I worked as a cashier but the business did not do well and she closed it down. She then bought a taxi with the support of the family – a loan from the bank under my mum's name and some money borrowed from my aunt. In 1994 I was sent to learn driving and then I started to drive her taxi, but I only did it for three months because I was about to get married.

My boyfriend's family had not accepted our relationship once they heard about my drug-taking history but we kept seeing each other for five years. After a lot of pressure from my boyfriend, his parents finally gave up and decided it should be no problem for us to get married since I had quit drugs a long time ago – and I was three months pregnant.

In 1995 we married; I was 24 years old and he was 26. After the wedding, I no longer worked and my husband drove the taxi. He earned enough and we did not need much for our daily living because we stayed with his parents who were well-off peasants. For a long time, I just played Mahjong and went shopping, which I love doing, and my mother-in-law prepared the meals.



I delivered my daughter in June 1996. During the latter part of my pregnancy my husband started coming home very late each night, and this continued after the birth. Because of my past experience I suspected him of using heroin and one night I asked him and he admitted it. Since we had no financial problems, I did not want to worry my parents-in-law so I tried to hide the fact from them, but they found out when our daughter was three months old. I tried to encourage my husband to stop and I sent him to a detoxification centre, but it failed and he kept using.

I stayed “clean” for nine years, but when my daughter was three and a half years old, I met up with some friends from my past, and I relapsed. My husband found out about four months later and from then we passively influenced each other to use drugs over the next three to four years. Both our families asked us to divorce, saying that we were not good for each other, but we did not want to separate.

I used to take my daughter with me when I went to buy heroin, and when I used, she would be nearby without my care or attention. From the age of three there were times when she was left at home alone. When she was five years old she knew her father was arrested, because she was home when the police telephoned her grandfather and she asked him, “Why did the policemen call home?” Her father was sent for compulsory detoxification and stayed away for three months. I was arrested for buying heroin at the bus station, and I too was sent to compulsory detoxification for a few months. Throughout this period my daughter was raised by my mother-in-law, who always took extremely good care of her.

In 2003, my husband and I divorced. Both our families convinced us to. We did not want that, but being drug addicts we could not give each other positive support and I was worried about how our neglect of our daughter would affect her. She was seven years old and did not know about the divorce and when she did find out, it did not make much difference to her since we had seldom taken care of her over the previous few years.

After the divorce I moved back to my mum’s place, and in order to buy my heroin I began to steal money from my sister and my mum. So in 2004, my mum sent me to “Daytop”, a new type of voluntary detoxification centre that had been established in Kunming. I have been involved with Daytop ever since. When I got to Daytop, I was tested and found to be HIV-positive. At the time, I knew nothing about HIV and I was shocked. I thought I might die very soon, and I could only cry. But my peers in the centre gave me a lot of support, and I gained so much knowledge. The more I knew, the less I feared HIV. It took me about one year to face my HIV status calmly, and by then I decided I wanted to work in the centre. Daytop provided me with good access to HIV information which could help not only me but also other people with HIV. After I had been in the Daytop centre for two years I was employed as a staff member because of my good performance.

After I went through the Daytop detoxification program, my daughter still felt insecure and uncomfortable around me. She was a bit afraid of me and I guess that was caused by my drug history. When I asked her, "Do you need anything?" she usually said, "No, I don't." Communication between us was not easy and only when I asked her something directly would she talk to me, so we spent less and less time together.

Her father wanted us to get back together. He tried to have sex with me one night, but by then I knew I had HIV so I refused him. He could not understand why and quarrelled with me as I tried to give him different excuses. At first he misunderstood and thought that I had many sexual partners, and then he thought I did not respect him. In the end, I told him that in fact I was HIV-positive and he was shocked. He got tested and it turned out that he was negative. After he got the news, he was not so interested in me and eventually he avoided me altogether. He has since re-married and has a new son. My daughter was not tested because the health department staff told me that it is not necessary yet.

My daughter lives with her father and he does not encourage us to have much contact. I heard from her that their economic situation is okay and my ex-husband owns a nice car. She is now 13 years old and I live very near her, just one street away, but we only meet each other during festivals and holidays. My mum realised that there is some distance between us and she often encourages me to contact her. Nowadays I try and chat with her on the internet, "It is getting cold now, if you need something, I can buy it for you," and she often replies, "Thanks, there is no need." I feel she is not very interested in me because she has nothing to share with me, since we have not spent much time together in the past. I feel that I hurt her deeply and I am sorry I did not take better care of her. I hope when she is 17 or 18 years old I can share my life story with her. She is nearly my height now. I regret that I did not carry her enough when she was young, and now she is too heavy for me to carry.

My present husband and I got to know each other in detox. When we came out of the detox centre, I called him and talked to him and helped him to find a job. I was really worried about him relapsing but he has not used heroin for many years now. We support each other and work hard, and encourage each other to keep clean. I told him that we cannot have our own child because we have HIV but he said, "I don't care. Let's share our future life together." I am 37 years old and my husband is taking ARVs now, so if we had a child, who would take care of the child if we died? We decided to get married two years ago and from then, my aunt and my mum kept pushing us hard to plan for a child so my husband and I think that one day we will tell my mum about our HIV status.

We live with my husband's parents, and we have not told them about our HIV either. My husband takes medicine at 10pm every night so they often ask him why he always sets the alarm; we explain that "it's our bedtime." Because our health is good, they have not got to the bottom of it. If we maintain a healthy life style, they do not worry about us. Someday we plan to tell them, since we are now clean and have good jobs. I am very lucky because my parents-in-law are so kind and take good care of us. They cook for us and do all the housework and they treat me as their daughter. One day, when my father-in-law asked us when we are going to have a child, we told him that we are going to be a "double-income-no-kids" family and he accepted it. Since my husband and I both have salaries and both our parents give us some extra money, my husband has suggested we buy a car and it can be our "baby," so we are saving money for that and our parents have agreed to help us.

I have been involved in projects related to people living with HIV in Kunming since September 2005. I am responsible for the "Evergreen Tree Project." It is a peer-support group for people living with HIV. My main work is pre- and post-test counselling, and self-help and psychological support for people living with HIV. When I started, I had very little formal education so I found the work difficult. I did not know anything about projects or HIV and AIDS, and I did not even know how to turn on a computer. The leader sent me for a three-month computer course. Today, when I think back on that training, I cannot help laughing because I did not understand anything the teacher said while he was giving the lectures and it was as if he was speaking another language. I had to spend much more time than others after the class practicing on the computers to master the basic skills.



Whenever there are trainings or meetings, the leaders send me. I learnt HIV-related knowledge, how to write a project proposal and how to run a training course. I have been to Thailand three times, once for a seven-day training program on stigma and discrimination, and twice for an information exchange communication conference. My knowledge and skills have grown during the process of working. I have now been involved in the design and implementation of several projects, particularly for HIV-positive women and in 2008 I was in charge of a project looking at care for children affected by AIDS in Kunming, funded by the Global Fund.

Nowadays, in Kunming the attitude of health staff towards people with HIV is very good; they are kind and patient towards us. I think the most important thing for ex-drug addicts is to keep clean and not relapse. No matter how long you have kept away from heroin, once you are back on it, you will lose everything. I think psychological problems are often the cause of relapses, so it is very important to know how to balance your life when you re-enter society after detoxification.

I remember when I first started to organize group activities, I could not control my breath, even for a short time; my face would turn red and I was not able to speak clearly. Through continuous practice, I am now capable not only of organizing group activities but also of conducting HIV trainings for peer groups. I have seen myself grow during the whole process and I have learnt how to help myself as well as help others with similar backgrounds.



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**CHENGLI**

China



## RINARSI

India

I was born in 1970 in Imphal, Manipur, which is in the far north-eastern pocket of India. I am fifth in a family of seven children. I had two elder brothers, two elder sisters and one younger brother and sister. We lived in a large wooden house in town. There were six rooms: a living room, a kitchen, and two bedrooms for the males and two for the females. In our custom, when the children are grown up, the parents do not sleep together any longer; they might sleep in the same room but not in the same bed in front of the children.



My father was a well respected college lecturer and my mother worked for an investment company. Sadly my father, who was a good-natured man, was also an alcoholic, and when I was in fourth grade he had kidney failure. On the day he died my grandmother took me to the hospital and my father placed his hand on my head and said, "My daughter, I bless you with all my heart. Of all my children I want you to bloom like a flower, full of colours, throughout your life." They were his last words to me. After my father's death my mum struggled to raise us. She faced many financial and psychological constraints because she had no support. Suddenly we were not so well off, although my father's government pension helped.

I was the only daughter who assisted my mum in the house. My oldest sister was lazy and used to avoid doing any work and my other older sister was not able to help because she was crippled with polio when she was young and she could not walk very well. I used to do everything – fetch water, cook, wash clothes, mop the floor, so I never got time to make friends in my neighbourhood. Each morning I would wake my young brother and sister and get them ready then I would walk them to school two kilometres away. After school I would collect them and come home and do all the housework. It was hard work and if I did not do it properly, my eldest sister would beat me.

At an early age I realised I was going to have to fight for everything I wanted in life. My younger brother and sister went to a good school but my mum could not afford to send all of us there so I went to a government school. I resented this even though I understood the situation. At school I used to love drama and sports. I did gymnastics, high jump, and I used to run the marathon. Every year I got first prize in the marathon, even when I went to college. In twelfth grade I entered an inter-college competition in mime and won first prize. I acted the part of a deer. After that people used to greet me, "Hi deer."

My eldest brother was an engineering student at Maharashtra University and my youngest brother and sister were learning English at their school. Sometimes when my brother came home, the three of them would talk in English but they did not include me in the conversations. I used to hide and listen to what they were saying and try and work it out. I found a book that showed me how to write letters in English and I started to teach myself. Whenever my siblings spoke in English I would try and capture the words and find out their meaning. I did not know how to use a dictionary but usually I could work out the sense of it because they would use some Manipuri words. Then I started writing English. I sent a letter to my brother in Maharashtra and he wrote back, "I'm very proud of you my sister. You have done a good job to teach yourself how to write in English. Even though your grammar is poor, I can understand your meaning. Keep it up and you will improve." From that point I kept on writing, writing, writing. At home people used to go to bed very early; by eight o'clock everybody was asleep, but I would stay up by myself and study by candlelight. I placed my bed separate from others so that I could study late into the night. I did well in my studies and after secondary school I started a science degree.

When I was in third year at university my brother, who was in his final year of his degree, was killed. He had been an underground resistance fighter but we knew nothing about this at the time. The government police shot twenty-four bullets into him. The fact that my brother's body was riddled with bullets made me feel so sick. I no longer cared about my studies. I was supposed to complete a submission form to

sit my final exams and my friends came and filled it in for me. I sat the exam, and my results were very good but when I graduated I told my mother I wanted to stop studying and get a job to support her. She started crying and said she wanted one of her children to be like my father and get a high position at a college. Just before he died my father had been promoted and was head of the college. My mother said "Please don't stop studying. You are the only hope I have. We've lost your brother. There is no hope for your older sister and your other brother is no good at studying." The other two were good students, but they were very young. "You have to continue with your postgraduate studies so you get a position in the government. Your father was very good but his children are lost. You are the only hope I have of returning your father's glory. I want you to reflect his image." She convinced me to continue my studies and apply to do a Master of Science. I was accepted into Manipur University, but my mother did not want me to study at home. She knew I would face too many demands from the family as I was always the one who solved the family problems, no matter if they were financial or physical. I was also accepted at Aligarh Moslem University in Uttar Pradesh, a state several hundred kilometres away to the west, so that is when I decided to leave home.

I studied in Uttar Pradesh for two years. At first I did not understand the customs. The students had a particular way of greeting each other and I did not know how to make the correct gesture when I said "Salam" but my friends looked after me and showed me so that the seniors would not make fun of me. After my exams my mother wanted me to come home. I did not want to. I wanted to continue to do my Ph.D. in zoology. I was specialising in diseases of plants and ecology of soils. But my mum was insistent, so two months later I returned to Manipur. I got a job in a school teaching chemistry. After six months I applied for a job as a professor at a private university and I was successful. I ended up working there as a lecturer in zoology for the next five years.



After working at the university for a year, I met my husband. My mother discouraged the relationship from the beginning because he was very different from me. He had a much lower education and she said his family was not as good as ours. I told him that he wasn't the right person for me and to forget it but then he cried and I felt very emotional. He was insistent and kept coming back to our house. If he had lived far away maybe I would have forgotten about him but he kept coming to see me and I could not escape him. He was very shy and did not talk much. I decided I liked his character and he was very cute.

In our culture if you have a boyfriend and want to marry him but your family disapproves for one reason or another, you elope and stay together for a day, and then the family usually agrees to let you marry, so that is what we did. When my brother found out, he was very angry and would not let me back in the house and so we stayed together for another three nights, and during that time we had sex. After three days, my family came and brought me home. Everybody in my family scolded me. They asked, "Why did you do this? You have a good position," and "You are not a child. Are you blind?" They asked me so many questions until I felt I was losing my mind.

My mother was insistent on separating us. She said, "I made sure you were in a good financial position. Our family was wealthy again and now you want to go and ruin everything." She refused to give permission for us to get married. Every day my family scolded me and I lay in bed crying. My health started to deteriorate. Then I discovered that I was pregnant. This was very bad luck after we had spent only four days together. My mother was shocked and suggested I have an abortion, but I wanted to keep the baby and my boyfriend did not want me to have an abortion. I decided I had to get married to him. We were kept apart for five months but I knew I was in love with him and he loved me.

The year after we were married, I had a boy child and we were very happy. We lived at my in-laws' place, a banana farm that my husband looked after. When my son was almost three years old my husband started to get sick. He had terrible pain from his little finger all the way up his left arm. It was herpes, but it went undiagnosed for a long time. His whole face became affected. He was in a very bad state and was hospitalised for a month. Once we knew he had herpes, the doctor started to ask many questions, "Does your husband travel abroad? Is your husband a businessman? Has your husband ever used drugs?" I became furious and shouted, "Why are you asking me so many silly questions?" My husband did not drink or take drugs, and he did not have other sex partners. He had a very innocent life. He may not have had a very high position in society, but he was a good man. By then I was pregnant a second time and there was a lot of publicity about prevention of mother to child HIV transmission but we did not know where to go for an HIV test and there was a lot of stigma around HIV so we ignored it. I gave birth to my daughter and she was very healthy and we continued to live happily together with our two children.

In 2004 my mother became very ill. She fell and broke her pelvis and soon after became paralysed from the waist down. We thought it was related to the fall. She decided to go to a hospital in another state that had a spinal ward and she asked me to go with her because I could communicate easily with the doctors. So my husband, my two children and my brother all accompanied my mother and me to the hospital. After she was admitted she had a biopsy and they discovered that she had tumours in her spine. She had lung cancer and it had spread throughout her body and she was facing the last days of her life. It was such a shock and I cried and cried. At the same time my husband started getting sick. As the caregiver I was the only one allowed in the hospital so he had to look after the children, but he needed some support himself. He had an extremely bad headache that would not go away

and he got angry. But I could not help him because my mother went into a coma and then died, and we had to bring her body home. At the funeral my husband was so sick with a fever and headache that he could not stand up. Too many things were happening at once.

We started visiting lots of doctors but nobody could tell us what was wrong with my husband. Some said he might have a brain tumour and that we should get it checked out. We spent hundreds and hundreds of dollars on investigations, tests, doctors' fees, but we could not identify what he was suffering from. I started to think that maybe he could be HIV-positive. Two or three years before I met him he was involved in an accident and doctors had not expected him to survive because he lost so much blood. He needed thirty units transfused and he got the blood from various friends and relatives. Among the people who donated blood were three drug users. I talked to my husband about this and I realised that he might have HIV and that we both needed to be tested.

Another doctor thought he might have TB and suggested some tests. After we got his results I could understand everything in his records except the Elisa test. I was confused so I asked the nurses, "What is the Elisa test? Is it for HIV?" But they refused to answer. They said, "Go to the doctor and ask him. He will tell you. We're just doing the tests." From their response I realised that my husband was HIV-positive. I went to my mother-in-law full of sadness and told her about his diagnosis. He was vomiting constantly and could not even hold down half a teaspoon of liquid. He told me that he felt he did not have long to live. My brother informed all my relatives that my husband was dying but nobody except my in-laws and immediate family was told the reason. I could not think straight. I was really traumatised and I could not eat or talk to anybody. My brother decided to inform my uncle who was involved in the Manipur Network of People living with HIV. He recommended that my husband go to the HIV centre for treatment, and he accompanied us there. At the centre the doctor diagnosed my husband with cryptococcal meningitis. He was given medication and although his CD4 count was only 29, he fully recovered. He is still well to this day but if my uncle had not brought him to that place he would have died.

Everybody in the Manipur Network discouraged me from having an HIV test at that point because I was in such a terrible mental state. Some of them said I might test and find I do not have HIV. They gave me a lot of support but I felt as if I had a big stone in my heart. I thought I could accept whatever comes into my life. I did not mention anything to anybody and went to the voluntary counselling and testing centre and spoke to the nurse. I asked her to give me an HIV test. She asked me whether I was sure and I said yes. I was very anxious, but when I got my result I did not even cry. When I went back to my husband's room my mother-in-law and my brother-in-law were there and I told them, "I have just come to know that I am also positive." My mother-in-law was furious because she did not want my husband to hear in case it upset him more. She scolded me and I felt bad. Nobody was there to console me. My husband was the only one who could but he was sick in bed. I felt very alone so I went to the Manipur Network and told my uncle that I was positive, and then I started crying. My uncle became very angry with the nurse and said she should not have tested me without pre-or post-test counselling.

My husband got discharged from the hospital but I stopped going to my lectures and took one month's leave. My brother-in-law knew we needed psychological support so he came and looked after us. He and my husband also encouraged me to go and visit the Manipur Network. Once I started back at work I used to lecture in the mornings and in the afternoons I would visit the Network. It helped me to accept my situation. In the Network none of the women had much education so they asked me if I wanted to go to a facilitators' training workshop in Chennai. That was an unforgettable experience and I got encouragement from the women there to become a leader. When I returned I was offered a job as a field worker and I decided to do it. I left my position at the University – they still keep calling me to return, but I prefer HIV work. Even though my position was low paid compared to my job at the university where I was the deputy head of our department, I had become increasingly interested in the work.



The behaviour of the people I worked with in the Network was different to what I was used to. As a lecturer I gave advice and directed people but in this field I was not supposed to do that. Many of the members were drug users and I could not tell them what to do. When I started working for the Network nobody could understand me because I spoke so fast and they thought I was too proud of myself. Apparently some members thought I only came to the office to show off my dress. When they got to know me they realised I was not that kind of woman, and that I was very friendly. My boss gave me lots of guidance. She said, "If you go to the office you can wear your sari but not when you go into the field. Most people are from a very poor background so they might not feel comfortable to talk to you if you wear a sari." It was difficult because that was the way I used to dress at the university. Dressing well is a symbol of good character and now I had to start wearing our cultural dress, which did not feel as good. But I understood that in this field it was very different and I adjusted quickly to my new situation.

In my culture, women are not supposed to work late and are expected to be home before dark. My work is different. Sometimes we are in the office until 8pm. I go to rural areas far from home and return late and sometimes I cannot communicate with my family. My in-laws dislike this. My mother-in-law tells people that I do not care about my children or my husband and that I just go out for the fun of it. The community is very tough. Sometimes I have to be away for five or ten days and people judge me and frown at me. But my husband is very supportive. He has no objection to my work. Sometimes I even take him with me so he understands the situations I experience. At one point we quarrelled because he did not want me to do this work and mix with people from different backgrounds. He wanted me to find another job and get out of this field because I did not have enough time to look after him. But in the end he understands. He loves me so much and we have a good, easy relationship.



When I realised what problems women face I wanted to work for them. Most women face a lot of stigma so I have to fight for them. In many families, after the husband dies women suffer. The in-laws throw the wife out of the family, deprive them of their property rights and leave them with nowhere to stay. When they return to their birth family, their brother says, "You bring the virus from your husband. Why do you come back?" I want to change people's thinking. I wrote a proposal for a shelter for women who have been thrown out of their family but it has not been funded. I will keep advocating for it and apply again. There is no financial provision for women's programs.

In my mind I have lots of programs I want to get up and happening. I would especially like to get some livelihood support for women. I also want to run some capacity building in relation to women's rights and inform positive women that they can fight for their rights, and I want to produce a booklet that focuses on women's rights – property rights, legal rights, human rights. It is really crucial for us. In relation to sexual and reproductive health and domestic violence, there is no information or skills building. Women are usually the bread winners but they have no decision-making power in the family. They have to look after their husband and children and if they are HIV-positive they still think they must feed everybody else before they feed themselves so most of the women are not eating nutritious food to maintain their health. Priority for treatment is given to the husband. Women also need medical support, support to do tests to monitor their health. They are responsible for the whole family so they need to be healthy to make sure the family is healthy. I am very passionate about this issue.

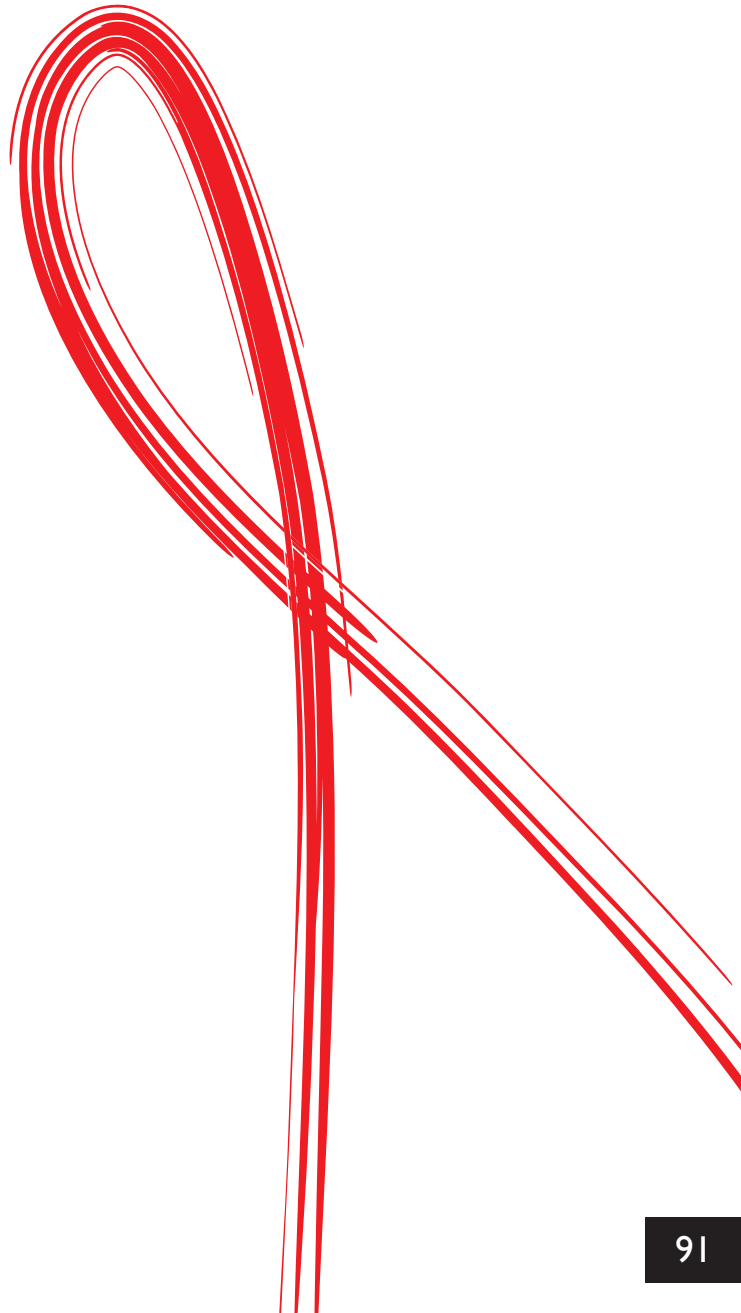


In 2006, after I had been working with the Network for one year, I was appointed as project coordinator. The organisation has taught me so much, like how to use a computer. I try and apply the skills I have acquired but I still feel I lack the skills to empower other women. Now I am a second-line leader in the Manipur Network of People living with HIV and I am the chairwoman of the women's wing of the district-level network. In our women's group we are committed to building the capacity of women

leaders. The leader of the Manipur Network has mentored me and given me courage and the Network fills me with life. Without it I might have died.

I started ARVs but I had bad side effects. After thirty days my whole body was covered in a rash and I had to spend over one month in hospital. Nobody could recognise me. My face looked as if it was burnt. The doctor changed my medication but five days later it happened again so they decided I should come off ARVs for a month and I was too scared to go back. After six months the doctor said there was no need to worry about treatment because my CD4 count was 330 so I could live without them. Now it is 220, so I have to consider what ARVs to go on. I may need to go on second-line ARVs and that will be a big financial constraint for me.

Unfortunately my daughter is HIV-positive. I had suspected that she might be because when she was one year old she often had fevers. I secretly took her for a test in 2006 when she was four years old, without telling my husband. At first he was upset because he loves her so much, and he did not want to know her status. When I told him the result he cried a lot and would not eat anything because his heart was totally broken. I consoled him and said it was better to know because we can get treatment for her when she needs it. She has a good CD4 count. She is a very intelligent girl and she understands that HIV is not a good thing but she does not know yet that she is positive.





Over a year ago I took my son for an HIV test. Again my husband did not want me to but I said it was better to know, "If he is positive I want to do something for him, so do not disturb me." But I could not bring myself to go and get the result. After one month my husband asked me whether I had collected the results and I said, "No, I'm too scared." So my husband became the stronger one and went. When he came home he was crying. I thought my son was also positive and I also started crying. My husband said, "Why are you crying?" I said, "Is he positive?" "No. No, he's not positive. He's negative." Together we started crying with happiness. One person in our family is not positive. It was very good news. We felt very good. We went home and kissed our children and held them tightly.



“ When I realised what problems women face I wanted to work for them. Most women face a lot of stigma so I have to fight for them. In many families, after the husband dies women suffer.... In my mind I have lots of programs I want to get up and happening. I would especially like to get some livelihood support for women. ”

**RINARSI**  
India



## KIREN

Malaysia

I was brought up in Selangor, near Kuala Lumpur, with my parents, two sisters, a brother, my uncle, his wife and their six children. My dad worked in a printing company and was a good provider but we were very poor and my mum used to buy us extra-big clothes so they would last us for a few years. My mum was very pretty and my father, who was very jealous and insecure, was abusive to her. I used to see him beating her, so I was not very fond of him. My mother was a working mum and her health was not good, so as the oldest child, I would take care of the kids and make sure they were all fed. By the age of seven I knew how to cook chapatti.

When I was ten years old my mum started working as a housemaid at a doctor's house. I remember going there and thinking they had a good lifestyle, and I realised education was important. So when I went to secondary school I did very well in my exams and I came top in English. I wanted to go to college but my parents could not afford it, so I got my first job when I was 18. I used to wake up at 5.30am and take two buses to work. I saved money to go to evening classes and enrolled in an accounting course, so I got home after nine. I was very interested in figures; I loved profit and loss, and balance sheets and I was quickly promoted. By the time I was 19, my accountancy skills saw me in a much better job within walking distance of our house. I wanted to make a career in accountancy but my father had different ideas.

My father was looking for a boy to marry me. He had already received three proposals and had brought one boy to the house but I made a big fuss and said I was not interested. I still wanted to pursue my education. My father said, "No, you are a girl. You are 19. You should be married by now." My uncle arranged for me to meet another boy from near Penang. My dad warned me to come home from work immediately the following Saturday, "If you don't, I'll come and bring you back." I took my sweet time to get home hoping they would be gone before I returned but they were still there. My mother ushered me into my room to change into my traditional Punjabi dress and when I came back I was very rude. I didn't smile or say anything and the boy, Amarjit, still said yes, he wanted to marry me. I was annoyed at being constantly presented to potential suitors and I thought this might be a good way to get away from my dad. Amarjit was an only son with three sisters, the same family background as me. He and his mother lived alone in their house – all the sisters were married – and he worked for the electricity department, reading meters. I took some time to think about it and then I said yes because I thought he seemed open-minded and I thought I might get along with him.

We met in February 1993 and a week later on Valentine's Day, he sent me a bouquet of flowers. He made a big effort, phoning the florist and organising his uncle to collect the flowers and bring them to the house, which made me think he was a nice person and I didn't regret my decision. I only met him once more before our marriage. His uncle and aunt brought him to my place and then sent us to a shopping mall. We had lunch and walked around and in the evening we caught a cab back to his uncle's house. I spent one day with him. There was no holding hands, no hugging, nothing. Soon my wedding cards were being printed. My younger sister did all the shopping for me and everything was taken care of. All I had to do was choose my wedding dress.

I was married off on 5 June 1993. I had grown up with a lot of cousins and when I went to my in-laws' house, life was pretty boring because I was not working. How much can you say to your mother-in-law? I found it difficult to adjust and became very homesick. They were worried that I was not getting used to the environment. Amarjit was very nice and took care of me but the sex between us was not so good. I was young and knew nothing, and being a virgin it was so difficult. In October, I had what I thought were pimples around my vagina. I saw a doctor and he said I had warts and referred me for laser treatment to remove them. I spent a night in hospital and the next day I was discharged. I was not told that I had an STI and I was given no blood tests, so I assumed everything was normal.

I decided to look for work and I got a good job as an accounts assistant for a palm oil processing company. A week later I found out that I was pregnant. My mother-in-law was happy, my husband was happy. I continued to work but I became increasingly uncomfortable throughout the pregnancy. I was very weak and could not go into the sun without fainting. I would go to work, come back, clean my room and make the chapatti. My mother-in-law would cook and we would eat and nobody would say much. We had a small living room and we would just watch TV. Whenever I spoke to Amarjit in English my mother-in-law would start grumbling, "Talk in Punjabi." She wanted to be kept in the loop and she could only speak Punjabi. I found it difficult because English was my second language when I was growing up but it had become my first language. Then Amarjit started to have health problems and he was on leave every couple of days with a heavy fever or headache.

Towards the end of the seventh month of my pregnancy, my waters broke. Amarjit rushed me to the local hospital and I was immediately transferred to Penang General Hospital. The doctor said he could not deliver the baby because it was premature and it would not survive. They gave me some injections and put me in intensive care. After I had been in hospital for a week, the doctor said if everything was okay during that night I could go home the following morning. My mother was going to collect me at 7am. At 1am I had very bad contractions. I went to the doctor's room and said, "I can't hold it. It's painful." They took me to the labour ward and within five minutes my baby was born. He was just waiting to come out. When they told me it was a boy I was shocked because when I had an ultrasound they had told me it was a girl. I was drowsy and said, "Are you sure?" They said, "This is your son," then I blacked out and I did not see my baby at all.



I was so happy I had given birth to a boy. When my mum arrived early the next morning, she was shocked to see my flat stomach and said, "You did it already?" I beamed, "Yes, I got a baby boy. I'm so happy." She immediately called my husband. He came, my whole family came. Unfortunately I was not allowed to see the baby because over the next few days he was in an incubator and the incubator room was far away and I was not able to walk. After the delivery I developed a fever and became delirious. My bed was next to a window overlooking the parking lot and on the third day I noticed my aunts and uncles and in-laws arriving in cars but nobody came to see me. I wondered why but did not think much more about it because I was so sick. The doctor warned my relatives not to upset me because my fever was high and I might not come out of it.

I was very anxious to see my baby. People told me, "No, he's in the incubator and you're not ready to see him," and gave me lots of excuses. I would pump my breast milk and put it into a bottle and give it to the nurses or my husband or my mother to take to the baby. My baby was born on 15 May and my husband's birthday was on 26 May. I was still in hospital so I asked my mum to buy my husband a birthday cake. She got a beautiful heart-shaped cake as I requested, but he did not cut it. I asked, "What's wrong? Everybody's quiet. Why are you all unhappy?" Somebody said, "No, we are happy. It's just that you're not well. That's all."

When I was discharged, only my husband came to collect me, no mother or mother-in-law so I wondered what was wrong. I said, "I want to see my baby. I want to take the baby back." My husband looked at the doctor, "I can't tell her, you tell her." I said, "Tell me what? What's happening?" The doctor told me my baby had died after three days. I broke down and screamed at Amarjit, "How could you do this to me? Why didn't you tell me? I asked you. You all came. I saw you in the cars. Why you didn't tell me?"

I realised they had come to take the baby for the funeral. In the Sikh religion, prayers are held twelve days after a person dies, so this was the eleventh day. When I went home everybody was sad. They told me what the baby looked like because I did not get to see him and I had no pictures, nothing at all.

After that, my relationship with my in-laws became very sour. They blamed me because I had insisted on working during my pregnancy. My mother-in-law said lots of things that I tried to ignore. My work gave me two months leave so I told my husband I was going back to my mother's place. On 7 July I turned 21 years old and I was not in the mood for celebrating. My sisters and cousins got together and made a small party for me at home and I returned to my in-laws' house feeling a little happier. But things were not the same. Amarjit was so depressed because we had lost the child. He did not talk about his feelings because he thought that if he did, I would get depressed, so he kept everything to himself. He did not even cry.

Then he started getting fevers and taking more and more medical leave. By 1995 he was spending most of the time at home and I realised something was seriously wrong. We went to Kuala Lumpur and he was admitted into University Hospital. He was there for almost a month and they took his blood three times for testing. A week after the third test the doctor called us both to a room and told us that Amarjit had AIDS. He did not use the word HIV. We were so shocked. It was something we were not prepared for and I was speechless. I only knew that AIDS was a killer and he was already so sick. His CD4 count was below 200, although at the time I didn't know what "CD4" was. They told me he had pneumonia. I did not know



what to do so I told my mum, then his mother and my sisters-in-law. All our close family members learnt of his status. I gave 24 hours notice and resigned from my job. I stayed with Amarjit in the hospital and took care of him.

I was tested for HIV and when my first results came back negative my dad suggested I divorce Amarjit. I was so upset and said, "You forced me into marriage and now just because he's sick, you are asking me to divorce him? This is something that I do not have the heart to do. I cannot do it." I spoke to the head of infectious diseases and she told me, "Your husband is a government worker. You need that benefit. Your results are showing negative at this point but the chance of you being positive is high. It's just the window period now." I was not thinking about the government employee's benefit. At the beginning I was angry with my husband, then I was sad, but I hid my feelings and I certainly had no heart to leave him. I knew if I did not take care of him he would not have survived another week.

From 1995 to 1997 Amarjit only came out of the hospital for short periods. Sometimes we went back to Penang and then he got sick and we returned. He had given up hope on many levels after the baby died. He was depressed and did not talk much. He did not talk about how he got HIV and I did not ask. I assumed it was from unprotected sex because he was ten years older than me and had seen more of life than I had. If his appointments were only a week apart we stayed at my mum's place because he was too sick to travel much and financially it was difficult. My family helped me as much as they could. My uncle would fetch me in his taxi and if I stayed overnight at the hospital, which was most nights, he would pack breakfast and pass it to me in the morning. I would feed and bathe my husband and go home in the afternoon and make him nutritious porridge. He was on a liquid diet so I would cook chicken, tomatoes, carrots then cool it all down, blend it and put it into a container and bring it to the hospital and put it through his feeding tube. My mum would come to the hospital from time to time to give me clean clothes. My siblings and cousins helped by giving me food or dropping me at the bus stop on a motorbike.



In the hospital I knew where everything was: the laundry, bed sheets, pillow cases, nurses' record room and pantry. When you spend most of your life in the hospital you become a nurse. The nurses never touched him. I changed his Pampers, I put in his urinary tract bag and seal and emptied the bag, I measured the urine and I washed the toilet. I made sure that it was clean, super clean. I learned how to change the bed sheets by rolling him on one side and then rolling him back. I could do everything on my own. He was in the intensive care unit four times during those two years and I saw so many people die. I saw doctors bring in machines, and pump chests and try to bring them back. I saw coffins put on the trolley and rolled away in the middle of the night. Trying to get good rest was difficult because I slept on a rattan fold-out chair that I would run to get every night. I would pull it out and then put it back every morning. If I was too slow and somebody beat me to it I had to sit in a normal chair with my legs on another chair and try to sleep in that position. It was terrible but I made it work. That is how I spent two years. I had no life. He was my life. Financially I managed because his salary was still being paid into his account and I gave my mother-in-law money because she didn't have any.

My second blood-test result came back in January 1997 and I was positive, but at that point Amarjit was in the intensive care unit so my results were secondary to me and I was not shocked or sad. I felt nothing. I expected it and I was calm but I did not tell anybody because I was so focussed on my husband. By then Amarjit's mother blamed me for everything. I had lost my child, my husband was constantly sick and I was being blamed. She said, "He's getting very weak. You're not feeding him properly." He was discharged but he could hardly walk. My mother-in-law and sister-in-law decided to pound almonds and cook this in cow's milk with ghee. It was very rich and it took a toll on Amarjit's health. He got diarrhoea and became even weaker but they insisted, "It will be okay. It will take a day or two." I understood he was very thin but he had been surviving, he was alive, but now his health deteriorated further and I had to get him admitted into hospital again. The doctor said he had TB and his lungs were filled with phlegm.

At the end of March, Amarjit was transferred to intensive care because his TB was worse despite taking medication. The doctor said until they treated him for the TB they could not give him HIV medication. Early in the morning on 29 March 1997 I bathed him and brushed his teeth and I was serving him some cereal in milk, feeding him with a spoon. The room was never quiet; because of his TB he made a constant wheezing sound. Suddenly the room became totally silent. His eyes were open but food dribbled from the side of his mouth. I did not know what was wrong. I wiped his mouth and went and called the nurses. They came and checked his pulse then called the doctor. She came and checked his eyes and his pulse and then came over to me and said, "I am sorry Kirenjit. Your husband has gone. He's no more." I said, "No. That can't happen. You can't tell me that he's gone. He's been in ICU four times and he made it." In the past they had prepared me because he was so sick but this time they had not said that he might not make it. They didn't want to have another false alarm. I started screaming, "Bring in the machines. Do whatever you have to do. Pump his chest. Give him oxygen." I was hysterical. The doctor showed me that his pupils were not moving and that his fingernails and lips were turning blue. She hugged me and whispered in my ear, "Amarjit is dead."

It took me over forty minutes to come to realise that it was true, and then tears started flowing like a river. I called my dad's office and told my brother and then hung up. My dad came and brought an uncle. The staff just wrapped the bed sheet around Amarjit's body and tied it in a knot at his head and his feet and lifted him off the bed. Everybody slowly started coming. My mum brought clothes and asked me to wear my Punjabi suit and cover my hair. In the afternoon my sisters-in-law came to the mortuary but they did not want to acknowledge that I was there and I could see they were not happy with me. We were not allowed to bathe Amarjit or change his clothes. In those days the coffin was sealed immediately if a person had HIV. I wanted him to wear his wedding clothes. They had not been dry cleaned and I could still smell his perfume on them. I could only lay his suit on top of the coffin.

An uncle drove us back to Penang with an official from the Ministry of Health who came to make sure we didn't open the coffin. When we got to Penang the night before the funeral, my sisters-in-law had settled down to sleep in my room and there was no place left for me. My eldest sister-in-law told me to go downstairs. There were men sleeping downstairs so I went to my mother-in-law's room. Some children were sleeping on the bed so I squeezed in with them and another sister-in-law started making noise, "Why are you here? Go and sleep in your room." "There's no space for me. Where do you want me to sleep?" I started crying and they left me alone.

The next day they brought Amarjit's body to the house and we laid the coffin across the dining chairs. My uncle took the official to one side for a while and we briefly opened the coffin so we could see his face one last time, according to our custom. His eyes were not completely shut. I started shouting, "His eyes are not even closed." It was as if he didn't want to go and he was still seeing what was happening. At the funeral it was not one family; it was his family and my family. He was keeping us together and when he was not there it was broken.

After the funeral my father asked me to return with him but I said I would look after my mother-in-law and provide for her. Two weeks later a will popped up which I was not aware of. It was made when Amarjit was very sick in 1996 and it stated that the house and all his assets belonged to his mother. Everything belonged to the mother except the car which was still on loan repayments.

In June I had a hospital appointment and I told my mother-in-law I had to go for a check-up. She asked me why and I told her that I also had HIV. The moment I mentioned that, she changed and became very mean. When my eldest sister-in-law found out about my status she claimed that I gave HIV to Amarjit and I had killed him. The verbal abuse really brought me down. The house was already debt free and I could have provided for us quite well but everything became so difficult. Then I was not allowed to use the house phone. At one point I tried to commit suicide. Twice I went to the sea and wanted to walk in – I didn't know how to swim – then I thought about my family back home. I decided I would call my mum and see if she would accept me. Under the pretext of going to

the shop I made a call at a public phone. I talked to my mum and told her about my HIV status and what was happening in the house. She said, "Resign from your job. Pack your things. Next weekend we are going to come and take you. Let her daughters take care of her. You are coming with us. Your health is more important."

I told my mother-in-law that I was going to leave two days beforehand so she could decide what she was going to do. On the Saturday night at 1 am all my sisters-in-law came. I was packing my clothes and the eldest came to me and said, "Don't take any of Amarjit's clothes. Take only what belongs to you." His clothes were all new and he had very good taste. I had been working and could afford to buy him expensive gifts. The only things I kept were one work uniform that had his name on the top pocket and his T-shirt and tracksuit that he used to wear every night. I hid them underneath my clothes. Everything else I left behind.

The next morning, as my bedroom furniture and my bags were loaded onto a hired truck, nobody knew what to say. My sister-in-law checked that everything was properly separated. On my wedding day she had given me a small gold chain, and my mother-in-law gave me an anklet for my first wedding anniversary. I used to wear them every day. I had given back my husband's wedding jewellery and my sister-in-law turned to me and said, "Before you go don't forget to remove the anklet and the chain." I was so shocked and saddened and tears started rolling down my cheeks. I took off the anklet and gave it to her but my hands were shaking too much to undo the chain and she came behind me, turned the chain around, opened the clasp and took it from me. It was so horrible. I left the house feeling naked, empty, with nothing. I was 23 and already a widow.

When I got home my father saw that I had no jewellery. He then had his own business and it was doing well so he gave my mum 1000 ringgit, "Take her to the goldsmith", he said. But I didn't care about jewellery. I was so depressed because of the way I had been treated by my in-laws and it was killing me from the inside. I didn't want to talk to my dad because I blamed him for the whole thing. If he hadn't pushed me into marriage I wouldn't be where I was. My mother refused to go to work and stayed home and fed me. But no matter how good the food was I could not eat. I shared my room with my sister and I would cry silently every night, not wanting my family to hear me. I had lots of dreams of Amarjit and I could feel him next to me for years.

From childhood I used to feed my siblings from my hand. A few months after I returned home my family was having dinner together one evening and my brother was trying to cheer me up. He turned to me and said, "Your food looks nice. Give me one bite." My father called out, "No, no. You don't share your food. Eat your food quietly." I just sat there, so shocked. I felt he'd destroyed my life and that was all he had to say to me? My brother stood up and said, "She's my sister. I am going to eat from her hand and if you are so worried about getting sick and dying, you don't have to." I realised my family loved me very much, despite what my father said. They had been putting up with me being sad for months and I realised I had to change for them. I had to get back on my feet.

I went to the electricity department where Amarjit had worked. They had tried to contact me via my mother-in-law and she said only that I was no longer there. As the wife I was eligible to get a gratuity, a lump sum, and the workers had collected a large donation. It was just waiting in an account for me to collect. I took the money but it disturbed me a lot because it felt like I was being paid compensation for Amarjit's death and for what had happened to me over the years. I didn't want anything that reminded me of my past, so I invested the whole amount into a restaurant business with my uncle. He was a good chef and I had accounts skills and I wanted to have something of my own and move on with my life.



But I worked too hard and neglected myself and in the third year I came down with pneumonia. I was admitted into hospital and the doctors started lecturing me. For one year I had not gone for a check-up. I needed to take ARV medication but it was very expensive and I had invested all my money into the business. The doctor wrote to the electricity department requesting a medical claim. She got me a thirty percent discount off my ARVs and gave me an ultimatum, "It's either your health or your restaurant. You choose." I was very sick, on a drip and oxygen. We decided to wrap up the business.

In 2002, just after we closed the business, my brother got married. I had started working for my parents' printing firm and I was living with them and my brother. In our custom widows are expected to stay on their own or in their in-law's house but my brother said, "We accept you because we love you." When he got married he was very honest with his wife and told her about my HIV status and she accepted me open heartedly. My family did a lot of research and found out that it was okay to share food with me, wash clothes together, kiss me on the cheeks. They educated themselves without me knowing in order to make me feel welcome. Until today my brother's wife and I are like sisters. When my first nephew was born, my brother asked me why I wasn't holding his son. He took the child and gave him to me and said, "He's not only my son. He's your son. Never, ever think that you don't have a son. He is yours." I was so touched and I tried to hide my tears of joy.

My first journey overseas was in January 2004. I went to a wedding in India with my brother and his wife. On our way home we went to the Golden Temple in Amritsar, the holiest place for Sikhs. When I walked through the entrance my tears started flowing. I didn't know what was happening but I could not stop crying. I felt a sense of peace and joy. In the water around the temple there is a tree and people believe this tree can heal your emotional problems. My brother told his wife to make sure I went for a dip. It was winter and the water was very chilly but I did it and I felt overwhelmed with contentment. The feeling was out of this world. After that my life completely changed.

In February 2004 Professor Adeeba asked me to set up a support group at the hospital. I was afraid to do it but I agreed. At the beginning it was difficult as there were just three of us. Now we have over 100 members and we give each other support. We go for karaoke and on retreats. After that I became a member of Kuala Lumpur AIDS Support Services Society (KLASS), and I became very active in the Malaysian AIDS Council and I got a scholarship to go to the Bangkok International AIDS Conference, partly from University Malaya Medical Centre. That was my second overseas trip.

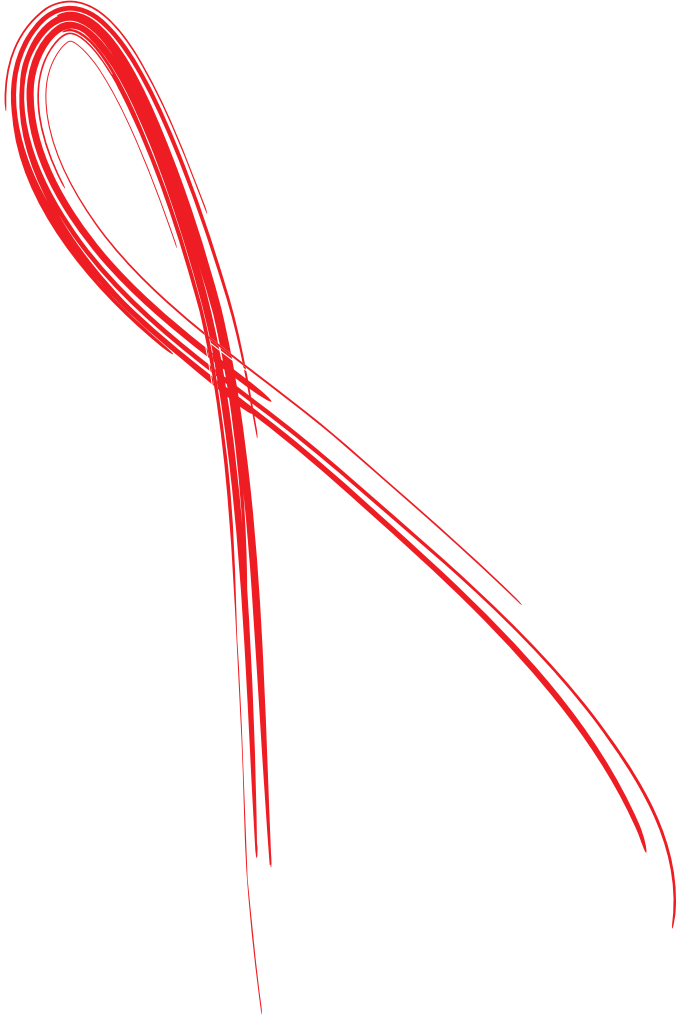
In May 2005 I was asked to coordinate the International AIDS Memorial Day event and that was another turning point in my life. I had a lot of support from community people; we worked together and pulled off a beautiful event. A journalist was surprised that a woman living with HIV was coordinating this event for over 40 partner organisations and over 400 guests. The journalist told me she was going to write a small article and she took pictures of me and said it may not even appear in the paper if there was not enough room. On the morning of the event I was having breakfast in the hotel and a friend came and opened the Sunday newspaper in front of me. There was a full-page feature story about me with a big colour photo. The moment I saw it I nearly choked on my food. I realised why people in the lobby had been looking at me – it was the newspaper they gave to their hotel guests. But it was a good, well-written article. All my relatives and my school friends read it and I got phone calls from people all morning.

From there, the media wanted to write lots of stories and I was invited to do public talks. I went all over Malaysia talking about HIV and I attended the International Congress on AIDS in Asia and the Pacific in Kobe in 2006, which gave me so much confidence. I started attending lots of training on empowerment, reproductive health, advocacy, counselling, updating my knowledge so I could share it with support group members. We are now passing on the ball to the next generation.

In 2007 I received a scholarship from the Malaysian AIDS Council to attend the International AIDS Conference in Toronto, and I spoke on stigma and discrimination at the first National AIDS Conference in Malaysia. By then I was the secretary of KLASS, volunteering with Malaysian AIDS Council, director of the Malaysia Treatment Access and Advocacy Group, still running the support group and receiving lots of calls. I was giving moral support to women whom I hadn't met. I was also working a full-time job at my parents' firm but my heart was telling me that I should be working in HIV. There was satisfaction when I was doing the volunteer work. I really wanted to contribute more to the community and I thought if positive women in other countries can do it I can do it too, but I could not do it 100 percent if I was working with my family.



There was pressure not to leave the family business and it was difficult. I gave it a lot of thought and at last I said, "Full stop. You can hire somebody else. I don't care. I have a purpose in life now. It makes my life worth living. It makes me happy." The (then Interim) Executive Officer of the Asia-Pacific Council of AIDS Service Organisations asked me if I was interested to be their administrative officer. It meant I would have a paid job in the HIV field and I could do my volunteer work at the same time. So I joined them in April 2008. Now I have so many friends from so many other HIV organisations throughout Malaysia; we are forming a national network. There is still so much to be done.



“ I started attending lots of training on empowerment, reproductive health, advocacy, counselling, updating my knowledge so I could share it with support group members. We are now passing on the ball to the next generation. ”

**KIREN**  
Malaysia





# HUYEN

Viet Nam

I was born in 1980 in Ho Chi Minh City. My early childhood was a happy time. I was a very active girl and I liked sports. I wanted to learn foreign languages and my ambition was to be an air hostess and travel around the world. My mother was a government employee and her salary was very low, but with my father's salary as a bus driver my parents were able to provide for my younger brother and me as well as other families in our neighbourhood.



I loved both my parents but I was particularly close to my father. He was always very kind and loving towards me. My mother did not believe in giving us pocket money but my father would always give me a little money to go and play or buy something to eat. Every Saturday he would take us all out to dinner. Unfortunately I did not see my father as much as I wanted to because he was often away. When my mother married him she did not know that he had another wife and three children. When my mum was pregnant with me, she found out about his other family. He used to divide his time between his two families. My half sister was three years older than me and I used to meet her every Lunar New Year at my paternal grandmother's house. I loved my half sister very much when I was young. At first, she was jealous of me because I was very beautiful and also because she had to stop school in grade four and I continued with my education. But later I became very jealous of her because I found out that my father was living with her and her mother.

When I was seven years old, my parents started to argue a lot. I did not know, but my mother had discovered that my father had two other girlfriends as well as his first wife, so she was constantly angry with him. When I was ten years old my parents separated. My father left and my brother and I lived with our mum. It was very hard for her to bring us up alone, and our lives became miserable. There was never enough money. I was angry with my father for leaving us and I could not understand why he would do that.

My mother worked really hard to provide for us but she did not show much affection, even though I was a good girl and used to help her a lot. Every afternoon after school I would cycle 12 kilometres with her to buy apricots. We would buy 50 kilos and return to Ho Chi Minh City and sell them in our neighbourhood. Sometimes I would travel with her to the countryside to buy charcoal and bring it back to the city to sell. We lived close to the zoo and I would help the family by selling iced tea there at the weekends. My mother also took on an extra part-time job, going from house to house collecting electricity and water fees. Another time she opened a small cafe in the apartment block so that she had enough money to feed us, but there was never enough. When I started high school, my family was so poor that I only had one school dress and a pair of old plastic shoes. I felt envious of the other girls who had extra clothes while I had to wash my dress in the evenings. I began to feel inferior to other students.

When I was 12 years old my parents officially divorced. Soon after this, I discovered that my father had another girlfriend as well as his other wife. I was very angry and I blamed his girlfriend for the fact that my father had left us. I wanted to fight with her. Instead, I stole her motorbike and I left Ho Chi Minh City with a boyfriend and three girlfriends. I wanted to make my father come back to our family. We went to my boyfriend's family's house in another province and after four days the police discovered the motorbike. They called my father and he came and brought me and the bike back to Ho Chi Minh City. He was not angry, and he tried to explain to me why he was not living with us any longer. That night I overheard him talking to my mother. He said, "This not my girlfriend's fault. I do not love you anymore and I want to live with her. I know I do not have enough money to look after the children but I will always love them. You must take care of Huyen and make sure she does not go out so much."

My mother assumed that when I was away I had slept with my boyfriend and she would not believe me when I told her I had not. She took me to the hospital to see if I had lost my virginity. Even though she found out I was telling the truth, that night, when I was asleep, she cut my hair. She thought it would make me less attractive to boys and stop me going out so much. I was so angry with my mother, but not my father. I had done what I had done because I wanted to bring my father back home and I did not understand why my mother was angry with me. From then, my mother used to take me to school and collect me afterwards. She told me I had to stay home and I was not allowed to go out with friends but I refused to listen to her.

Over the next few years I became quite rebellious. Sometimes I would stay out overnight at my friend's house and my mum would go looking for me. I began to avoid going to school. I used to love roller-skating and in the zoo there was a skating rink and you could hire roller skates by the hour. I wanted to spend all day every day skating as it was the thing that gave me the greatest pleasure. At first I stopped attending English classes in the evenings and I used the money for the fees to pay for the skate hire. Eventually in the middle term of grade twelve I was expelled from school because of non-attendance. I was afraid to tell my mum at first and she did not find out for several months until my teacher informed her that I had not participated in the final exam and I no longer attended school.

I started to get bored staying at home but I could not apply for a job without my high-school qualification. I asked my mother to help me to go back to high school, and she agreed. She got me into another school and I began to dream of getting a good job after graduating, but things did not turn out as I had hoped.



In my new school, I made many friends. There was one particular girl whom I admired because she travelled to school on a motorcycle and she wore very fashionable clothes. I wanted to be like her and help my mum escape from poverty. I discovered that she went to school in the daytime and worked in a discotheque every night. She introduced me to some of her other friends, and through them I managed to find a job as a waitress in the biggest discotheque in Ho Chi Minh City. When the boss interviewed me, he just asked my age and I lied and told him that I was seventeen years old although I was not quite sixteen. He looked at me and asked if I was able to dance. I said yes, I loved dancing, and I was hired immediately, without any training.

My life immediately changed once I got this job because my income was so high in comparison to the amount of money I was used to. I was earning ten US dollars an hour just for talking to customers. Suddenly I could buy anything I wanted. I did not tell my mum where I was working and she thought I was a waitress in a cafe. A girlfriend at the discotheque taught me how to wear make-up, what clothes were fashionable, how to sing Chinese songs and how to speak some Chinese. We had many Chinese customers. We also had Japanese and Europeans but they usually had translators so I did not need to learn their language. My friend also prepared me for the first time I had sex with a customer so that I was not afraid. It was high class sex work, and I started to do it. The first time, I was 16 years old and because I was a virgin, I earned \$1500 from a Japanese guy.

At the end of 1997 I started to use drugs. Some friends told me that if I took the drugs I would be able to drink wine and not get drunk. They also told me that it would make my skin very light and that I would feel good. The first time I smoked heroin I felt nothing but I wanted to try again because I wanted to stay sober when I was with customers. The Japanese guy came back to the discotheque every day and he fell in love with me. He asked me to go back to Japan with him but by then I was already addicted to heroin and I said no.

I was still living with my mum and one day she became suspicious when she saw me going through withdrawal pains. When she realised that I was an addict she was so disappointed but she kept calm and talked to me about weaning myself off drugs. I listened to her and voluntarily enrolled in a drug rehabilitation centre. I was worried at first about what it would be like but once I got there the conditions were good because I was paying for myself so I had good food, access to the library and I was able to sing karaoke. I stayed there for one month and my parents visited me every week. When I came out of the rehab centre I decided to rent a room and live by myself because I was afraid my mum would be ashamed of me if I moved back into her neighbourhood. But I could not escape the lure of drugs and I smoked heroin with my boyfriend the day after I came out.

I continued work at the discotheque and because I was earning a lot of money I was able to help my mum and I started supporting my brother by paying his school fees. My dad and I got closer and I was able to help him out also. Unfortunately my brother dropped out of school soon after this and he started using heroin, just as I had done. I also left school again so my mother was disappointed and angry with both of us. Because she was poor she could not understand why we did not want to get a good education, and this created some distance between us.



I became very proud and I wanted to show everybody how well I was doing and what a fashionable, sophisticated woman I was. I would not take advice from anybody. I was having fun and I was hungry for success. I saw no problem with my drug use as I was earning plenty of money and I could afford it. Of course the amount of heroin I needed soon increased. I had been very beautiful but over the next months my beauty began to fade. My skin became very blotchy. Eventually I left the discotheque because customers stopped asking me to dance or to go with them to their hotel and I had no money coming in.

I started to work as a waitress in a karaoke restaurant and I earned extra money at night by sleeping with the customers. I charged them much less than in the discotheque. When I had been in the rehab centre people had told me that injecting heroin was much more effective than smoking and because I no longer had so much money, I began to inject. I worked in the restaurant from 10am to midnight and I needed to inject four times a day so

I had to bring my drugs to the restaurant. After working there for two years the manager found out that I was injecting at work so he sacked me. I left the restaurant at the end of 1999.

I moved in with my boyfriend and his family. They were very poor and he would steal in order to pay for our drugs. He had a motorbike and he would snatch women's bags and jewellery. It was a difficult period because I was not earning my own money and often I did not have enough food to eat. When my boyfriend did robberies he had to buy food for all his family as well as buy his drugs. Sometimes he got drugs for himself but not for me.

Over the next couple of years my boyfriend was in and out of jail. During that time, I used to sleep with anyone to get money to buy drugs. Sometimes if I had no money I would steal anything I could from the houses in my neighbourhood – shoes, cassette players, mobile phones, anything I could get my hands on. If I could not get enough money to buy heroin I would writhe in bed with withdrawal pains. I lived like that for two years and in 2000, I realized that I was pregnant.

I was determined to wean myself off drugs for my baby's sake, but my boyfriend would always inject in front of me and invite me to use with him and the temptation was too great. By the time I was seven months pregnant, I was still using, I had no money and I was jobless. My boyfriend was arrested again and he stayed in jail for the next five years.

Because of my drug use I was poorly nourished, and one day it seemed that I was going to miscarry. My mum was visiting me on the day it happened and she immediately took me to the maternity hospital and I was admitted. The doctors made me do some tests, including one for HIV. That afternoon the doctor told my mum that I was infected with HIV. My mother did not tell me but sat outside my hospital room for an hour. Then she got up and started to walk into the street. She later said that she wanted to throw herself in front of the traffic and kill herself but in the end she came back to the hospital and told me what the doctor said. We both felt numb with grief.

The doctors did not keep my test result secret. They told the people in my ward who asked the staff to move me to another room. I was taken to the HIV section of the hospital where the staff did not care for me in the same way any more. I felt terrible because the nurses did not want to talk to me or change my hospital robes, and I had to lie on dirty sheets.

When I came home my mother looked after me very well. I was afraid that the baby would be infected with HIV and I should have an abortion, but the doctor refused to do one because I was too far advanced, so I continued with the pregnancy. At the time I did not know much about HIV except through the posters on the streets, which painted very negative images. I did not receive any counselling before or after the test and I could not accept the fact that I was HIV-positive. I did not know how I would be able to continue with my life and I wondered if everyone would despise my family but my biggest worry was for my baby. Just before the birth I stop using drugs. I knew that it would be too difficult if I was using when I was admitted to hospital at the time of delivery so I stayed home and lay in bed in lots of pain as I withdrew from heroin.

My son was born on 13 March 2001. After the birth I was worried that I would start using again but as soon as I saw my baby I knew I wanted to stop forever. My son was only 2.9 kilograms at birth and he had difficulty sleeping and cried a lot. He had a lung infection and some problems with his heart. I think that because I used heroin during the pregnancy he was addicted when he was born. I assumed that he was HIV-positive and I decided I wanted to stay alive and care for him. For the first three years of his life he was often sick and admitted into hospital and he did not grow as fast as other children. I was convinced that he was HIV-positive.

When I left the hospital I felt hopeless. We lived with my mother and my brother again, but our family began to face a lot of discrimination from our neighbours, who knew that I was a drug user. They would look at me strangely and would not talk to me. I began to stigmatise myself and worry that they would find out about my HIV status and so we moved to another place.



My mum worked hard to feed my son and me. When my son was 18 months old, I got a job in a seafood company and I organized for a neighbour to look after my son during the day. The company had a policy to provide workers with a health check every year, including tests for HIV and STIs. I had worked on the production line for nearly one year when I had to go for my check-up. After the manager discovered that I was HIV-positive, she moved me. At first she said that they did not want so many production workers and that I had to do cleaning, even though I was very good at my job. Then she told me she knew I was HIV-positive and she was worried that if my blood spilled onto the seafood they could not export it to Japan and she did not want to lose money because of me. Then without my consent she told other workers about my HIV status. They spread the gossip around and my co-workers began to avoid touching me or talking to me. At lunchtime they would not stand or sit next to me so I knew that they knew. My new job was heavy work as I had to clean the whole factory. I could not continue working there and after another two months I left. I felt very angry but I could not do anything about it. Once more, I was jobless.

After I left the factory my mother supported me and my baby again for many months. The staff in our local health centre knew about my HIV status because the hospital had written informing them about me. The health centre wrote to my mother inviting me to take part in a class on how to care for people living with HIV and my mother tried to convince me to go. I felt pulled in two directions. On the one hand I was afraid of stigma and discrimination and I worried that if I went to this place I might meet some relatives or people I knew and they would find out about my HIV status; on the other hand I really wanted to learn about HIV and get information on how to look after my son. Finally, I decided to participate, and this was a turning point in my life.

The course lasted for 45 days and I had to attend classes every weekday for four hours a day. At first I was very scared. I thought I was the only person who was HIV-positive but then everybody started to share their personal stories about being positive. Initially I thought they were lying but eventually I began to believe everybody. I met many women, some of whom were much unhappier than me. I discovered that many people had faced more difficulties than I had. I realised I was no different from everybody else and I was no longer afraid.

I met a peer educator who invited me to visit the Friends Help Friends Club. I accepted the invitation and soon I started volunteering there one day each week. The rest of the time I spent trying to find out as much information as I could about HIV. I got involved in workshops and seminars. I became a key member of the club and I got involved in home-based care.



As my life continued I became obsessed about whether or not my son was infected with HIV. At the end of 2003, I had a lot of information about HIV so I decided to take him for a test. I prepared myself in case, and I said to myself that I will try to do everything for him if the result is positive. It was so unbelievably beautiful when the result came back negative. This was the greatest motivation I could have to cope with my own infection.

In the middle of 2004, I joined a workshop aimed at developing self-support groups in Ho Chi Minh City. At that time, there were six groups and they wanted to link together and share information more effectively. At the workshop, I was elected as the coordinator. After the workshop, an NGO, Policy Project, invited me to Hanoi to participate in a 15-day course where I learned how to use a computer and how to manage groups. When I came back I went to each of the six groups and helped them to identify their needs. Policy Project provided support for monthly group meetings. In November 2004 we developed the Southern Self-support Group Network of People living with HIV in Viet Nam.

Soon after this we had another workshop, and 150 people living with HIV and some officials attended. I had never met any person who was public about their HIV status but the organiser convinced me that I could stand up in front of everybody and share my life story with them. I will never forget that day. I was so nervous because I did not think I was capable of doing it and I was afraid of the reaction. I was scared my family might face some discrimination. When I shared my story the first time I felt overwhelmed with emotion and I cried so much. After I spoke the organiser congratulated me. I had overcome my greatest fear and I felt very proud of myself.

And then I fell in love again. He was a security guard who was infected from his old girlfriend and we got to know each other because he came to me for counselling. I was immediately attracted to him because he was tall and very handsome and he had a gentle manner. Over time we discovered that we understood each other well and gave each other good moral support. He began to love my son and accept him as his own. Our wedding was on 17 May 2005 and all our friends who worked in the HIV field celebrated with us.

Soon after we were married, the father of my child was released from prison, and my son and I would meet him every week or two. By then he had TB and his CD4 count was 182 so I advised him to take ARVs but he did not listen. I was the only one who knew his status and he was afraid of his family finding out so he did not want to use the health services available. He became seriously ill and was hospitalised and shortly after that he died, a year after his release. My husband and I had provided care and counselling for him and his family and we organised his funeral. Even though I had not lived with him for a long time, I let my son attend the funeral and take on the responsibility of a son to his father. During this time, I really appreciated my husband, Phong, for his care and support of me and my son.

After that, gradually I became more confident and more involved in the Network. I wanted to make sure that people had access to treatment in Viet Nam and I realized that people with HIV had no voice in government. In 2005 I learned how to manage an organization, how to write funding proposals, how to develop policies, advocate on issues, monitor and evaluate projects and write reports. In 2006 I began to take ARVs and now my health is very good.

I continue to work as a volunteer coordinator for the Network to this day. We carry out various activities in HIV prevention among sex workers and drug users and provide home-based care for people living with HIV. I receive a small living allowance of less than \$100 per month. I love my job and I cannot imagine doing any other work. By coming out, I can encourage other people not to lose hope. I am able to help many people and share information about how to take care of one's self. I am very proud of myself because I can now influence government officers in Ho Chi Minh City. I can talk to them about the difficulties that people living with HIV face. I want them to be more concerned about positive people's issues.

I want to help to protect the rights of people living with HIV. In the past HIV-positive women were coerced into abortion; people were refused treatment in hospitals; people did not have access to ARVs; people were tested at work and then dismissed from their job; and when the family found out that you were positive they threw you out of the house. Discrimination has reduced a little because now we have an HIV law. In the past people who were diagnosed thought they would die straight away but now with the availability of drugs more people are living well. A continuing problem is that ARVs are only available in the large urban centres. Women living with HIV face more difficulties than men because they struggle to look after their children and they are often unfairly blamed by their family as the cause of HIV.

I am lucky because my peers trust me and that helps me to continue my work. I am now also an Executive Board Member of both the Viet Nam National Network of People living with HIV and the Viet Nam Positive Women's Network. I am grateful to the positive community for believing in me and supporting me in my job and I am very happy with my family. My relatives and friends care for me, understand me and love me so much, and there is no distance between us. My son is a wonderful, intelligent child and I believe he will have a bright future.



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**HUYEN**  
Viet Nam



Diamonds are formed under immense pressure to become the strongest and most brilliant natural substance known on earth.

This book tells the stories of ten women and a girl in the Asia-Pacific region who have overcome incredible life challenges to become strong advocates for the rights of all women living with HIV and AIDS.



UNIFEM Southeast Asia Regional Office  
UN Building  
5th Floor, Rajdamnern Avenue  
Bangkok 10200 THAILAND  
[www.unifem-eseasia.org](http://www.unifem-eseasia.org)



Asia Pacific Network of People Living with HIV/AIDS  
51/2 Soi Ruam Rudee, Ploenchit Road  
3rd Floor, Ruam Rudee Building III  
Bangkok 10330 THAILAND  
[www.apnplus.org](http://www.apnplus.org)