Letter from Sri Lanka: Island Fever

A tropical paradise wakes up late to AIDS

December 1, 1998 By Gerard Raymond

In 1995, Dr. Kamalika Abeyratne, a prominent Sri Lankan pediatrician with some 30 years' experience, was badly injured in a car accident. She developed hepatitis B a month after her hospital discharge and was tested for HIV without her knowledge or consent. Word of the results—she was positive—spread like wildfire through Colombo, the nation's largest city.

"The story reached my aunts, who were playing mah-jongg somewhere, even before my doctor knew about it," Abeyratne says. "I was truly shattered, but then I decided that I should do what I can to help other people similarly affected." Now a kind of Sri Lankan Mary Fisher, Abeyratne has become a trailblazing HIV positive spokesperson and chairs the Coalition to Protect the Rights of PWAs, a newly hatched strategy group made up of the nation's leading AIDS advocates.

That Abeyratne's private tragedy was compounded by public insult surprised few observers of the epidemic in Sri Lanka. On this tropical Indian Ocean island of 18 million people, formerly known as Ceylon, AIDS has long been woefully ignored, they say, even though the country lies just off the coast of India, estimated to have the world's largest number of HIV positive people. According to Sri Lankan government statistics, the island has seen a scant 233 cases of HIV. That official number, computed since 1987, includes 66 people who died of AIDS over the past decade and some 33 foreign nationals deported after testing positive. But most experts agree that this count is grossly deflated because it represents cases only at government hospitals; the World Health Organization (WHO) estimates that there may be as many as 8,000 Sri Lankans with HIV who have never been tested.

As Sri Lankans cope with the political, social and economic fallout from an ethnic-based civil war that has raged for more than 15 years, a head-in-the-sand mentality toward AIDS has developed. For many years, on the few occasions when a person's HIV status was reported publicly (generally by releasing enough information so the person was identifiable, but not printing the actual name), the newspapers always attempted to establish some "foreign" connection—a reflection of the general reluctance on the part of both the government and the public to treat AIDS as a pressing health concern.

How does this affect PWAs in Sri Lanka? At first glance, there seems to be plenty of support from a wide range of Sri Lankan nongovernmental organizations (NGOs). A recent count lists over 150

local NGOs in the field of AIDS—more than two for every officially recorded AIDS death. But with one notable exception, these groups do not provide hands-on care or services for PWAs, focusing instead on prevention and education aimed at people who are negative. And up until three years ago, people with HIV had no voice at all in issues relating to their welfare or their rights.

The NGO that has bucked the trend is NEST. “There is an attitude here that if you are HIV positive, you are going to die. It’s accepted that there is no point in doing anything,” says Harini Amarasuriya, NEST’s executive director. “Some people just die from malnutrition.” NEST provides nutritious food to HIVers in hospitals, works with their families to help set up home care and, perhaps most important, offers support and friendship.

But NEST cannot reach everyone, and the group focuses on care provision rather than political activism. Given the horror stories about the mistreatment and even abuse of people with HIV by hospital staff, it’s not surprising that some PWAs simply elect not to seek medical treatment, preferring instead to live out the rest of what they believe is a death sentence.

Companions on a Journey, Sri Lanka’s only gay organization—which is fighting to lift a century-old statute that criminalizes homosexuality—has also taken up the banner of rights for PWAs. “We need to be open about our sexuality and need services like everybody else,” says 26-year-old Sherman de Rose, the group’s founder. He has been instrumental in galvanizing various constituencies—human rights activists, NGO personnel and PWAs—to form the Coalition to Protect the Rights of PWAs.

Nigel de Silva represents that rare Sri Lankan circumstance: a person with HIV living a relatively normal life. De Silva, now 28, tested positive in 1995. He is currently employed at an English-language radio station in Colombo, and is blessed with a thoughtful boss who not only gives him time off when he’s feeling under the weather but encourages him to produce HIV-related educational radio programs. But de Silva’s luck stops there: The harsh reality is, only the most affluent Sri Lankans can afford medication, and de Silva has had to postpone even the substandard Crixivan/AZT combo recommended by his doctor because his monthly salary is barely a third of the cost of the monthly regimen. Sri Lanka’s otherwise-generous national health program provides no HIV meds free of charge.

De Silva’s plight infuriates the nation’s few AIDS specialists. “It has been over 10 years since we found the first patient, but we are still at a primitive stage,” says Dr. Mallika Gannasinghe, who argues that for Sri Lankan PWAs, improving primary care is a more urgent priority than accessing new treatments. When Gannasinghe’s late husband had to be hospitalized for a urinary complication (non-HIV-related), she recalls, she had to take her own bed linen into the hospital because of the appalling sanitary conditions. Furthermore, there is no foolproof system or legal precedent to protect the confidentiality of test results.

Ironically, Sri Lankan health authorities have recently developed a forward-looking project to deal with many aspects of the epidemic. For example, in a year’s time, with the help of the World Bank, the National AIDS Control Program plans to open a new facility equipped with up-to-date AIDS

technology; for the first time, people with HIV may have access to their own space rather than being sent to the Orwellian “Room 33,” the stigmatized, if anonymous, AIDS ward at Colombo General Hospital. But a chasm looms between these enlightened intentions and their actual implementation. Under government bureaucracy, AIDS-trained doctors and administrators are often transferred to fields where their expertise is wasted. Without skilled staff and adequate primary care, the new building will be of little use.

Meantime, de Silva is taking matters into his own hands—he’s launching a support network for Sri Lankan PWAs. “We are sick of institutions and counseling offices,” he says. Content to let organizations such as Companions on a Journey and the Coalition to Protect the Rights of PWAs battle on the political and legal fronts, de Silva wants to establish a “safe haven” where HIV positive people can hang out and relax. “I want to have fun,” he says with a laugh. De Silva brainstormed a support group after attending a workshop for Asian–Pacific Islander PWAs held recently in Hong Kong. He allows that he has been lucky to keep all his close friends after he told them of his HIV status, but has long felt that something was lacking nonetheless. “No matter how many hours my friends spend with me or how close they are, there is still that loneliness, which I can’t explain,” he says. “But when I walked into the workshop and saw the others, it was like we had known each other for years.”

De Silva is confident that he can muster up international funding for his support group, but first he must prove that there are sufficient Sri Lankans with HIV to justify the expense. To start, he has come up with a name intended not only to evade the stigma with which this nation burdens all AIDS matters but, more important, to broadcast his philosophy for the future. “I call it Kaleidoscope Plus,” de Silva says. “There’s colorful hope at the end, and it’s up to you to change the patterns and get a different picture each time.”

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