

Turning a Lens on Leprosy

A documentary filmmaker talks about the discoveries he made during the filming of *Leprosy in the 21st Century* for BBC World Television.

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David Notman-Watt is founder of back2back productions, Ltd., an independent television production company based in Brighton, England.

At the start of 2006 I began working on two 30-minute documentary films to be aired on BBC World Television this November. Working closely with the Sasakawa Memorial Health Foundation and The Nippon Foundation, I devised a schedule that included filming trips in Ethiopia, India, Brazil and Culion Island in the Philippines.

As a journalist and filmmaker for over 10 years I have been fortunate to cover numerous stories on diverse subjects. I must confess, however, that I knew very little about leprosy. I am ashamed to say that I blindly believed many of the untruths that I now know surround the disease. Stereotypes and fabrications seem to have become part of its history. Friends jokingly told me to be careful when I prepared to leave for my first filming trip. Many were worried I would be infected. My insurance broker expressed concern.

Once I began to research the topic, I was shocked to discover the culture of folklore that has developed around the disease. The general public seems to have drawn conclusions about leprosy from how it has been portrayed in Hollywood films rather than from any factual knowledge — and I include myself in this shameful ignorance.

Many people I spoke to weren't even aware leprosy still existed today. Where other diseases still grab headlines (and rightly so), leprosy seems to have been banished to the sidelines. As I learned more, opinions expressed in articles or interviews came to seem ill-informed. I began to feel that leprosy had become a forgotten disease.

An islander in Culion, Nestor Lisboa, summed it up quite well one evening as we sat talking

about how those with leprosy have been treated over the years. He said: "Probably because of the stigma of leprosy, they want to separate it, not to contaminate other people, healthy people. At that time, leprosy was treated like AIDS is today — to segregate these people — because they are grotesque, but most of all because of the fear of this disease."

I'm pleased to say my eyes were opened as I began filming. In every country I visited, patients and those cured of the disease could not have been further from the Hollywood myth. Birke Nigatu and the villagers of Denebework in Ethiopia; Francisco da Silva and his wife Maria Soledade deep in the Amazon jungle; Mr. Diwali and the residents of Satya Jeevan Kusht Ashram in New Delhi; the residents of Culion Island with their extraordinary history...

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I did not meet victims. Far from it. I met strong, committed people focused on overcoming the stigma and ignorance that still surrounds leprosy today. Organizations like ENAELP, the Ethiopian National Association of Ex-Leprosy Patients, and communities like Bharat Mata Kusht Ashram in India showed me that people affected by leprosy are now organized. They have created working business models and formed impressive networks that allow them to interact with society on a level playing field. These films are not a depressing tale of broken souls, but rather a positive investigation into individuals around the world taking control of their lives — together.

It is impossible to tell the whole history of leprosy in 60 minutes of television. But what I have tried to do, by recounting some of the remarkable stories I was told this year, is destroy some of the myths surrounding the disease. I sincerely hope I have managed to capture the spirit and bravery of the people I have had the pleasure of meeting in the making of these two films. And I thank them all for making me, and the rest of my team, so welcome.

Leprosy in the 21st Century is a back2back productions ltd. film for BBC World Television, filmed and directed by David Notman-Watt. It airs in November. ■

Interviewing Yohei Sasakawa in Culion in May

