

## Health & Fitness

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### **Giving voice and a face to tuberculosis**

Daenchai Narai traveled thousands of miles from Thailand to Columbia in late March to talk about what it is like to live with TB.

He is cured and hopes that by talking openly about the often-stigmatized disease he can help others learn more and act to help improve conditions for people who have the disease, or who are at high risk of getting it.

"I don't want people around me to discriminate against people with TB," he said through interpreter Ratdhapongsa "Luke" Peewsook, a USC electrical engineering major from Hilton Head. "Society stigmatizes TB and HIV because (people) don't know what TB and HIV truly are."

Narai's trip is sponsored by USC's TB PhotoVoice project, Walker Institute for International Studies, and Institute for Families in Society.

He is a participant in Thailand's TB PhotoVoice, a project through which people with TB tell their stories through photography. TB PhotoVoice projects also exist in South Carolina, the Texas/Mexico border, and Brazil.

The aim is to encourage the public, lawmakers and other public officials to address the situations and policies that make it difficult to eradicate TB.

To see 30-year-old Narai in person and hear him talk about TB helps make the condition seem more real to observers, who might otherwise see only suffering "at a distance," said Romel Lacson, who founded TB PhotoVoice after his wife, Claudia, died of tuberculosis in 2004.

Having "real people" talk about their lives helps to put the pictures in the context of history and puts a focus on global policies that have created social inequities and made it hard for many in developing nations and poor parts of the United States to have basics such as sanitary conditions in which to live, said Lacson, a doctoral candidate in anthropology at USC.

Current approaches at controlling the disease largely focus on medical and public health interventions, without adequately accounting for social and economic factors, Lacson said.

Many who contract TB get cured with medicine, but get re-infected by returning to unsafe living conditions.

"That's why with the advent of a cure, TB still exists today," he added.

Narai said he wants to pass on knowledge about the disease because he doesn't want others to suffer in the same way he did because of stigma and poor conditions.

As a PhotoVoice participant, he feels that his voice is stronger and people will be more inclined to listen to him than when he spoke as a single "ordinary" villager, and not part of a group.

The photographs the project participants take are sometimes more persuasive than words, he said.

He showed one he took of a baby whose parents had TB. People in his village didn't want to hold the baby or play with it.

"It's not the baby's fault," he said through the interpreter. "The baby is innocent."

People around him were disgusted by him, he said. He did not know where to turn for help. He eventually went to a doctor who told him he would have to take medication for six months.

Another photograph, taken by Kanyakorn Kodtoe, shows someone holding a handful of pills that someone with TB takes every day for at least six months.

People who get TB have to take medicine not just for that disease, but for other opportunistic infections that occur because a person's immune system is weakened. Narai got rashes, throat infections and fever. He went from 143 pounds to 88 pounds in a few months.

The medicines in turn made him throw up, and he became so weak he couldn't continue working.

A third photograph, taken by Saengmuang Muangchongsang, shows someone in a cornfield carrying a bundle on his back. Narai said the picture emphasizes the point that when people get sick with TB, they can no longer do the physically demanding work through which many earn their living. Many are day-workers, so on days they do not work they earn no money, and can't provide for their families.

Narai said traveling to Columbia will help him speak more confidently when he returns to Thailand. While here, he gave presentations to various groups of USC students and faculty, including those in anthropology and public health. He also gave a presentation at the Columbia Museum of Art TB PhotoVoice Exhibit, and at health department offices in Sumter and Columbia.

Students Peewsook, Tuangporn "Trisha" Sittisuntorn, and Chalumpol Kasamameteephong said they have learned more about TB while translating for Narai.

Sittisuntorn, who is from Florence, said she had learned the definition of the disease and about its symptoms, but not much more, in high school.

She and Peewsook said they didn't know people could walk around with inactive TB in their bodies for years without knowing it.

"I was shocked by the fact that all I thought I knew about TB, most was wrong" Peewsook said. "(Narai) helped correct them."

— Czerne M. Reid