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Stunted by Illness, Tibetan Villagers Ponder Flight

By JIM YARDLEY

The valley is nestled in the green Himalayan foothills, a wedge of cultivated land where the scenery is so idyllic and the wheat and highland barley grow so high that it is easy to overlook the tiny man sitting by the road with a black pig on his lap.

His name is Gyampa, and when he props up his stunted body with a cane, he stands maybe four feet tall. He is bent at odd angles, his wrists knotted and his elbows swollen the size of lemons. He is not agile or strong enough to control the pig, so he has roped it around the waist and staked it to the ground.

He has what people in this tiny village simply call "the pain," known to medical researchers as Kashin-Beck disease, or Big Bone disease. Nor is he alone. Nearly everyone in the village, including the children who happily show off their swollen elbows, either suffers from or has been exposed to the disease. The situation is so bad that in October the government is planning to move everyone away.

"There is an illness in this ground," said Trakock, 39, a villager who like many Tibetans uses only one name, and whose sister, Trasel, suffers from the disease.

Throughout Tibet, where much of the population lives in villages largely disconnected from the modern world, Big Bone disease is a severe problem, infecting roughly 9 percent of the population. In the most severe cases, the disease can cause the long bones in the arms and legs to stop growing during childhood, as was the case with Gyampa.

Researchers believe that the soil near villages like Boronggang is infected with a fungus that contributes to Big Bone disease. Scientists have yet to discover a cure, but they believe that bad water, poor diet and crops grown in mineral-deficient soil are also at least partly to blame.

"It's really a disease of poverty," said Françoise Begaux, who worked with villagers for five years as part of a research project sponsored by Doctors Without Borders, and who now works for another aid group, Terma Foundation. "It's the people who can't afford to have different kinds of food."

The problem is compounded, Ms. Begaux and other researchers say, because Kashin-Beck is largely forgotten. The disease has been eradicated or brought under control nearly everywhere except China. Within China, it is particularly acute in Tibet, one of the poorest regions. Yet last year Doctors Without Borders halted their Tibet project because of budget restraints.

So late last summer, the physicians and researchers who had been visiting Boronggang about twice a week stopped coming. They did leave gifts: a new grain thresher to help dry the wheat and barley and, in the process, reduce risks of contamination; fungicide to treat the fields; and a final shipment of the iodine and selenium that had been used to offset mineral deficiencies in the children. Those medicines have since run out.

"I don't take any medicine anymore because the doctors are not here anymore," said Tenzen Pungtsock, a 15-year-old boy, whose elbow is knobby, but who seems to have a milder form of the disease.

The children today at least have a better understanding of why so many people are sick. When he was a child, Gyampa, 61, knew only that he stopped growing, not why. In medical terms, the growth cartilage in his arms and legs developed necrosis and stunted his growth. With age, his joints have weakened with arthritis, so that now he earns money by mending clothes. He is too weak to do farm work.

Chinese officials boast that farmers and herdsmen in rural Tibet enjoy free health care, but Gyampa said he never saw a doctor until about a decade ago, when the first Western physicians arrived in the village. Now that the Western doctors have stopping coming, he takes Tibetan medicine for the pain that regularly flares in his hips and joints.

The village is less than 20 miles from Lhasa, Tibet's capital, yet Boronggang seems as if it has barely changed in centuries.

Electricity, and with it used televisions sets, arrived only in July. Sanitation is substandard; there are pools of standing, fetid water, some contaminated with animal waste.

On a recent afternoon, Trakock and her sister, Trasel, 34, invited two Western reporters into their home. The entrails of a slaughtered sheep were drying on a laundry line in the courtyard. Trasel, who is barely three feet tall, stood near the kitchen, where she has spent much of her life.

"When other kids had been in school, I was at home, washing clothes and doing housework," she said, speaking through a translator, as did others in the village.

Inside the dirt-floor kitchen, the two sisters pulled out a bucket with a fine powder derived from highland barley. They mixed in water and made small, bland doughy balls that are a staple of the village diet; no one has the money to grow other crops or to buy fruits and vegetables.

The Tibetan officials who oversee public health for the Chinese government say that cases of the disease have been discovered in 379 rural villages. In some cases, the government has relocated villages, as it plans to do with Boronggang. Medical researchers debate this strategy, but government officials are not hesitating, saying they have already moved more than 12,000 people.

"We have taken a series of measures," said Yang Guo Qing, vice director of the Tibet Health Bureau. "We have invited experts both from within China and outside China, but we haven't been successful in looking for the source of the disease."

Françoise Mathieu, who worked in Boronggang as part of the Doctors Without Borders project, has spent much of this year organizing another five-year research project in Tibet with the Terma Foundation.

She said she is trying to raise money in the United States and Europe in hopes of restarting work on Kashin-Beck in Tibet. She said she must raise \$500,000 by the end of the year or the project will be abandoned. No other such projects into Kashin-Beck are underway in the world, she said.

In Boronggang, villagers who have spent their entire lives on the same land are preparing to move. It is not a very big move, roughly three-quarters of a mile. But opinion is mixed. Gyampa, the man who mends clothing, is excited. The government has provided him enough money to build a larger house and to have more than \$1,200 left over.

But other villages question whether such a move will make any difference, whether the soil is any different less than a mile away.

"We are not happy," said Trakock. "We prefer to stay here. The grass is closer to feed the animals."