

Posted on Monday, May 21, 2007

Mysterious illness haunts Tibetan highlands

By Tim Johnson | McClatchy Newspapers

NARME, Tibet—The villagers amble along the dirt alleys in a robotlike waddle, joints deformed and stunted in height. They're in pain as they move, and unable to lift the tools they need to work the fields.

In this sun-baked hamlet near the Lhasa River more than two miles above sea level, some 40 percent of the villagers have an illness known as "big bone disease."

The ailment, which causes loss of cartilage and swelling of joints, has been around for decades, and officials say it remains endemic in Tibet, present in 379 villages across nearly half this autonomous region. At least 15,000 Tibetans suffer with severe forms of the illness, in excruciating pain.

What causes the illness, also known as Kashin-Beck disease after the two Russian scientists who identified it, is a medical mystery.

"It's painful. It's a burning feeling. Sometimes I can't sleep at night," said Siri, a 28-year-old Tibetan who goes by one name, as aid workers rolled up his sleeves and pants legs to show elbows and knees swollen to about double normal size.

"You see, he cannot straighten his arms," said Rinzen Wangla, field coordinator for the Kashin-Beck Disease Foundation, a nonprofit group based in Ghent, Belgium, that researches and treats the ailment. "All his joints are affected."

The disease can be calamitous to villages, where ailing farmers no longer can grip their tools. The disease can affect children as young as 3 or hit adults in their mid-20s. Victims never recover. As bone cells accumulate in the joints, they block growth and leave arms and legs much shorter than normal.

"The disease is not reversible. As soon as you get it, you can try to stabilize it or have some pain relief. But the deformity of the joint, you cannot help," Francoise Mathieu, the head of the Kashin-Beck foundation, said in a phone interview from Belgium.

The ailment is present in a crescent across 13 provinces of China, in Siberia and on to North Korea in an area where some 30 million people live. It's particularly acute in Tibet, where poverty seems to foster it. It can be highly localized. While one hamlet can suffer grievously, another across a valley may remain untouched.

Some scientists suspect that the disease is caused by a toxic fungus on the barley that's a staple on the Tibetan Plateau, a nutritional deficiency in the diet or an unknown environmental cause.

"In some villages, you can easily find 80 percent of the children who have the disease," Mathieu said. "It's the poorest villages that are most affected."

Victims, some of whom barely reach 4 feet tall in adulthood, spend much of their lives in mud and brick houses, unable to tend fields or livestock.

"If you don't move, you don't have pain. So they move less and less. It's like chronic arthritis," said William Claus, an epidemiologist with the foundation.

In this hamlet of 180 villagers, nestled in a valley 12,000 feet above sea level, the only signs of the modern era are occasional solar panels on rooftops. Villagers use yak dung to fuel their stoves. No indoor plumbing exists. Four in 10 of the villagers have big bone disease, throwing a burden of care on those free of illness.

Villagers understand little about the sickness, attributing it to malevolent spirits.

"It's from the evils in the ground," said Targyel, the 63-year-old village chief.

The disease spiked during the first chaotic years of China's 1949 revolution, then ebbed and spiked again. Now, as economic progress slowly comes to Tibet's rural areas, some villages are reporting lower numbers.

In the 1990s, Doctors Without Borders, an international humanitarian-aid group, began treating big bone disease in Tibet but pulled out for lack of funding, leaving the project to a few specialists who started the Kashin-Beck Disease Foundation in 2002.

Working with Chinese health authorities, the foundation launched clinical tests in affected areas, providing nutritional supplements to some youths and offering placebos to others. The supplements contain selenium and iodine, trace minerals that are in short supply in Tibet. The study should conclude later this year, and may yield insight into the disease.

In some affected areas, food is brought from elsewhere to see if there's an immediate environmental trigger for the disease. If the ailment is prevalent, officials sometimes order displacement of an entire village to a new location.

The besieged Chinese health system, which has transitioned from a cradle-to-grave health plan to one based on patients' ability to pay, is focused primarily on major diseases such as tuberculosis and hepatitis. Big bone disease isn't a priority.

"It is the most neglected disease among the neglected diseases," said Claus, the epidemiologist. "It is like sleeping sickness, maybe Buruli ulcer, or Chagas' disease."

So the Tibetan Center for Disease Control and Prevention, a branch of China's Health Ministry, agreed to work with the Belgian group to conduct research.

"We didn't have enough funding ourselves, and they helped us a lot," said the center's director, Sheerorapten, a Tibetan.

But now money is running out for the Belgian foundation.

"It's at a crisis stage," Mathieu said. With a bit of luck, the foundation may be able to conclude its clinical research by the end of this year, but has nothing for further preventative care, she said.

For more information online, go to www.kbdfoundation.org

(McClatchy Newspapers special correspondent Fan Linjun in Beijing contributed to this report.)

<http://www.mcclatchydc.com/world/story/16460.html>