

D10 BELGIUM

Foundation fighting KDB in China

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ON a visit to the Kashin-Beck Disease Foundation's program in the Tibet Autonomous Region last year, Dr Françoise Mathieu, director of the medical humanitarian group, brought her daughter to meet the villagers suffering from a mysterious bone affliction called Kashin-Beck disease (KBD) also known by Tibetans as big-bone disease.

Flora is seven and stands as tall as a big bone disease patient who is 47-years old — her mother's age.

"The worst form of KBD is dwarfism," says Dr Mathieu. "This debilitating disease affects the growth and joint cartilage resulting in deformed joints, shortened limbs, and stunted growth. This permanent disorder can start as early as four years old and progresses until the age of 25. Patients experience a lifetime of pain and restricted mobility, which has social and economic consequences.

"In the rural villages where we provide assistance, you see children not able to play like normal and adults not able to do the heavy farming work," observes Dr Mathieu.

Thirty million people live in

KBD endemic areas in a crescent shaped region from southeast Siberia, sweeping through 13 provinces in Northwest China, and ending in a large swath of Tibet. Scientists have not yet found its cause, but some of the risk factors seem to be selenium and iodine deficiencies, fungal contamination of grains, and nutritional deficiencies due to poverty.

Dr Mathieu has spent 15 years treating and researching KBD. In 1992, she was working with Doctors Without Borders in Manila when she was asked to travel to the central Tibetan plateau to explore this unusual disease. As a physical therapist, she decided to start a training program, to teach the village doctors how to ease the excruciating daily pain and increase the mobility of the patients. Ninety village and community doctors were trained in about 60 villages. Intrigued intellectually about this neglected and still unknown disease, Dr Mathieu wrote a doctorate thesis on KBD.

In 2002, Doctors Without Borders handed over the program to Dr Mathieu, the team of volunteer scientists mainly from universities and other institutions in Belgium, and the

local staff to continue the work under a new organization called the Kashin-Beck Disease Foundation. Its mission is to research the cause of KBD in order to implement relevant and quality treatment and prevention programs with the goal of improving the health status of this population. Approximately two to three million Tibetans live in endemic areas.

"As far as we know, KBDF is the only international group working on this disease," says Dr Mathieu.

To date, experts believe that the cause is multi-factorial, including some linked to the environment. Currently, the program has three major integrated components addressing the major risk factors. Village doctors continue physical therapy to ease the pain and improve the mobility of KBD patients. Children are screened for KBD and given minerals and vitamins. Lactating mothers and pregnant women are also given vitamin D at the health clinics. In order to encourage the dressing of seeds just before planting season, KBDF designed a mobile seeds dressing machine and donated one to each of the 86 villages it serves. At harvest

time, KBDF's field technicians provide community training on proper grain storage, along with the distribution of shelves and storage bags. These measures help grain from becoming contaminated.

Owing to extreme poverty and a basic diet, the rural population is susceptible to chronic malnutrition and an increase risk of big bone disease. Long term progress depends on finding the cause of the disease, so research along with prevention programs continue. All these activities are done in collaboration with the Centers for Disease Control (CDC) and Prevention, Tibet Autonomous Region, led by Dr Shilo. KBDF and CDC renewed its partnership agreement last July.

"We will have the results of a three-year study covering 1,069 children in 51 Tibetan villages at the end of October," says Dr Mathieu. "Also, agricultural specialists and the local staff are finding more initiatives to diversify the poor diet." KBDF also explores other endemic areas to learn more about the disease.

"I have been to provinces of Heilongjiang and Gansu, and Inner Mongolia Autonomous



Dr Françoise Mathieu with her daughter and a KBD victim.

Region. This year we hope to go to another endemic area. But all of this takes time and sustainable funding, which is what we are looking for now."

Kashin-Beck Disease Foundation is an international non-profit organization that provides medical and humanitarian assistance to 50,000 Tibetans living in endemic areas and those suffering from Kashin-Beck disease. For more information and to make a donation, please visit www.kbdfoundation.org.

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