

BOULDER-LHASA SISTER CITY PROJECT

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Fighting Cysticercosis in Kham (Sichuan) 14-30 October 2017

BLSCP members Bill Warnock and Shari Mayer traveled to Chengdu to continue fighting a parasitic disease called cysticercosis, which is highly prevalent in Kham (Sichuan Province of China). Bill and Shari used personal funds to pay for all of their travel costs.

In 2013 BLSCP raised \$19,000 to fund brain surgery for Lhungtse, who had lost her eyesight from neurocysticercosis. The brain surgery did not restore any of Lhungtse's eyesight but did relieve many of her other symptoms. For the past four years, BLSCP has funded her expenses for medical checkups and anti-epileptic medicines.

October 18-19 - Chengdu Our excellent tour guide, driver, and interpreter/translator was again Tenpa Tenzin. On October 18, our tour provided by Conscious Journeys began, and he drove Lhungtse, her mother, and Bill to Sichuan Provincial People's Hospital for Lhungtse's annual checkup by her neurologist, Dr. Zeng Xian Rong. Since taking Clonazepam (1 mg each night before bedtime), in addition to Oxcarbazepine (one 300-mg tablet, three times each day), starting on 2 November 2016, Lhungtse had reportedly suffered only around five short seizures. Her mother said that these occurred at times when Lhungtse was very tired. She also had a minor seizure as she was being examined by Dr. Zeng, apparently triggered by fatigue due to a very long day of travel on October 17 from her home in Yajiang County to Chengdu. Results from a CT brain scan, EEG (brain wave test), and later blood tests showed that Lhungtse's condition is stable. Dr. Zeng prescribed for Lhungtse to continue taking the same dosage of each medicine.

October 20-22 - Xichang On October 20, we drove to Xichang to conduct our Student MRI Project with Dr. Li Tiaoying. Starting early in 2017, BLSCP conducted a campaign to raise \$36,700 to provide an MRI brain scan for 56 Tibetan primary school students whose blood had tested positive for cysticercosis. The school is in Shuiluo Township, Muli County, Liangshan Prefecture, (southern) Sichuan Province. MRI brain scans are needed to determine treatment methods, which depend on the location, number, size, and stage of cysts in the brain. Without appropriate treatment, the brain cysts will probably lead to epileptic seizures and possibly other more severe, even life-threatening symptoms.



Shuiluo students on bus to Xichang
[courtesy: Jason Zhang, Xinhua News Agency]



MRI waiting room, Liangshan Prefecture
People's Hospital #1, Xichang
[courtesy: Jason Zhang, Xinhua News Agency]

On September 21, Bill had learned from Dr. Li that some of the 56 students would not be available to travel to Xichang, due to either relocation or graduation. On October 21, MRI brain scans were performed for 44 students and 3 adults. The adults were the wife of the school headmaster, the sister of the school deputy headmaster, and Lhosang Drolkar. Lhosang is a 19-year-old Tibetan woman whose blood had tested very positive for cysticercosis. Many years ago she lost the vision in her left eye and also started suffering from headaches. Bill made a request to Dr. Li for her to have an MRI brain scan. So her father and younger sister took her from their home in Donglang Township, Muli County, to Shuiluo Township to join the students for the trip to Xichang.



Shuiluo student receiving MRI brain scan
[courtesy: Jason Zhang, Xinhua News Agency]



Lhosang (green jacket) meeting Lungtse (pink jacket) and her mother (far right)

Cysticercosis is a preventable parasitic disease. However, the life cycle of the parasite is rather difficult to understand for many people. Dr. Li has an excellent pictorial diagram showing the life cycle and several intervention measures that can prevent the disease. Following Bill's request, Dr. Li prepared laminated copies of this diagram and brought them to Xichang. While the MRIs were being performed, we gave a copy of the life cycle diagram to each of the students and to each of the adults in the waiting room. We introduced Lungtse and her mother to everyone and explained that neurocysticercosis had destroyed her eyesight many years ago. Then Dr. Li and Bill each explained the diagram to everyone and stressed how important it is to keep the diagram in the home and share the information with others. The school deputy headmaster said, "We would not have taken the disease so seriously if Lungtse had not been in attendance today."



Bill Warnock teaching how to prevent cysticercosis
[courtesy: Jason Zhang, Xinhua News Agency]



Dr. Li teaching how to prevent cysticercosis
[courtesy: Jason Zhang, Xinhua News Agency]

Thanks to 79 different individuals, foundations, and corporations, we raised \$30,976 for our Student MRI Project. In a totally unexpected development, several factors caused our actual project costs to be significantly lower than the estimated costs included in our fundraising literature. Because 12 students were not available to travel to Xichang, only two buses were needed, rather than three. In addition, Dr. Li was able to negotiate a significantly lower daily rental fee for each bus. For each MRI, the hospital charged us only \$94, compared to the estimate of \$150. The total project cost was only \$21,269. Therefore, we had a surplus of \$9,707.

Prior to our Student MRI Project, Dr. Li did not have any method for knowing which of the students had cysts in the brain. She did know that anyone whose blood tests positive for cysticercosis is at risk for neurocysticercosis (cysts in the brain). She also knew that early treatment of neurocysticercosis is important for a better prognosis. The 47 MRI brain scans revealed 11 cases of neurocysticercosis. These cases include 9 of the students, the sister of the school deputy headmaster, and Lhosang Drolkar. The MRIs also showed that two of the other students have been cured of neurocysticercosis. Each of these two students had received an earlier MRI on an individual basis and then received drug therapy. No treatment is indicated for the other 34 whose MRI showed no brain cysts.

Dr. Li is planning to visit Shuiluo Township again in early December. She plans to meet with the parents of the 9 students and the sister of the school deputy headmaster to discuss appropriate treatment. Since most or all of these 10 patients have only a few brain cysts, Dr. Li hopes that they can also be cured with appropriate drug therapy. However, the drug therapy needs to be administered in a hospital under the care of a trained physician. If the families can not afford such treatment, Dr. Li will inform Bill regarding the funding needs.

Lhosang's MRI brain scan showed many cysts and severe hydrocephalus. Dr. Li concluded that she urgently needed ventriculoperitoneal (VP) shunt brain surgery, the same surgery that BLSCP provided for Lhungtse in 2013. The other BLSCP Directors agreed with my recommendation that we use our project surplus of \$9,707 toward the costs of the surgery. This surplus amount is similar to the total hospital costs for Lhungtse's surgery. At breakfast on the morning of October 23, Bill informed Dr. Li regarding BLSCP's decision. She then contacted Lhosang's father, who had not yet reached his very remote home with his two daughters. Upon learning of this good news, they headed to Chengdu for Lhosang's surgery.

October 23-24 - Kangding Shari Mayer joined us in Xichang on October 22. On October 23, Tenpa drove Shari, Lhungtse & her mother, and Bill to Kangding to visit some friends and hang out together.

October 25-26 - Tagong We had wonderful experiences at Angela Lankford's Khampa Nomad Arts Center and Ecolodge, located around six miles NW of Tagong. The beds were cozy, the food was delicious, and the conversation was engaging. When one of Angela's cats jumped onto the piano keys,



Khampa Nomad Arts Center and Ecolodge (lower right)
[courtesy: Angela Lankford]



Dinner at Angela's Ecolodge

the sound sparked Lhungtse's interest. She sat at the piano, exploring the sounds of the keys, perhaps for the first time in her life. The tactile-audio experience was fascinating to her. Since Angela no longer needed her electronic keyboard, she gave it to Lhungtse.

October 27 - Yajiang & Kangding Tenpa drove us to Lhungtse's home in Yajiang, where her mother treated us to homemade vegetarian momos and sweet tea for lunch. As soon as we plugged the electronic keyboard into an outlet, Lhungtse sat down and experimented with the sounds of the keys for around one hour! Shari and Bill were thrilled with this unforeseen development! If Lhungtse's mother and brother are not able to find a local keyboard tutor, Shari and Bill plan to find one elsewhere. Shari, Tenpa, and Bill spent the night in Kangding.



Lhungtse at Angela's piano



Lhungtse at her electronic keyboard

October 28-29 - Chengdu On October 28, Tenpa drove us back to Chengdu. Dr. Zeng, Lhungtse's neurologist, had already arranged for Lhosang to be admitted to Sichuan Provincial People's Hospital on October 27. She also had contacted Dr. Liao, Lhungtse's neurosurgeon, and arranged for him to perform Lhosang's brain surgery. On the afternoon of October 29, Dr. Li, Shari, and Bill visited Lhosang in her hospital room. Lhosang and her family were very appreciative of BLSCP's interest and financial commitment. We deposited the BLSCP surplus of \$9,707 in Lhosang's hospital account. Bill connected with Lhosang's younger sister Bima via WeChat, so that she could help him monitor Lhosang's condition from Boulder. On October 30, Shari and Bill returned to their homes in Colorado.



Shari, Lhosang's father, Dr. Li, Lhosang, Bill, Lhosang's sister Bima (left to right)

On November 6, Lhosang's brain surgery was successfully performed by Dr. Liao. Apparently she did not require any intensive care, and her recovery has been very good. Bima recently texted Bill that Lhosang would be released today, November 22, and then head for home. The BLSCP contribution of \$9,707 will be a major percentage of Lhosang's total hospital expenses. Dr. Li has explained to Bill that Lhosang's father should receive an insurance refund of most or all of the total hospital expenses within a few months from the Muli County government. This refund will be very timely and useful for Lhosang's post-surgery checkups and medicines.



**Lhosang on November 6,
recovering from brain surgery**



**Lhosang on November 18, with her father
and sister Bima**

During several discussions with Dr. Li, Bill learned that Lhosang's father, Tseten Dorje, is a hard-working farmer with limited income. The family could not afford the cost of Lhosang's surgery because of expenses for Lhosang's older sister, Tsering Youdon, who became paralyzed below her waist three years ago. Tsering was married and living with her husband but still volunteered to help a neighbor of her parents construct a new building. Apparently during the construction of the foundation, soil collapsed onto her and caused a severe spinal injury. Her father reportedly raised more than \$15,000 for some surgery, but it did not help with the paralysis. Dr. Li and Bill have made several inquiries with experts regarding whether rehabilitation medicine could help Tsering regain any use of her lower body. Three years of paralysis is thought to be too long for any hope of rehabilitation. However, the experts will help to identify some special equipment, such as an appropriate wheelchair, that can improve Tsering's daily life. If this equipment can not be provided by other sources, Dr. Li will inform Bill regarding the funding needs.



Tsering Youdon before her spinal injury



Tsering Youdon after her spinal injury

New BLSCP Project Now Under Development

Dr. Li and Bill have discussed a new collaborative project for 2018. It will be focused on prevention of cysticercosis through education of rural doctors working in prevalent areas of Sichuan Province (Kham). The current concept calls for BLSCP to bring two American physicians to Chengdu to help with the training of the rural doctors. Dr. Li's laboratory in Chengdu has specialized facilities for diagnosis of taeniasis/cysticercosis that will be very useful for the training curriculum. After we gather more information from Dr. Li, we will provide you with the details.

Bill Warnock, President
22 November 2017