

BOULDER-LHASA SISTER CITY PROJECT

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Lhungtse's Brain Surgery 6 August - 17 September 2013

Lhungtse is a teen-age Tibetan girl who lives in Kham on the Tibetan Plateau (Yajiang County in western Sichuan Province of China) with her mother and brother. Because her father passed away several years ago, her mother works as a farmer to support her family of three. In 2007, Lhungtse became totally blind in both eyes and also started suffering from headaches. Her mother took her for a diagnosis to a hospital in Kangding, where the doctors told them that Lhungtse probably would not live for more than 18 months.

Diagnosis In 2010, Dr. Li Tiaoying, Sichuan Institute of Parasitic Diseases (SIPD), Chengdu, Sichuan, was in Yajiang County conducting another of her research projects on screening for a very serious preventable parasitic disease called cysticercosis. When Dr. Li's research team went to Lhungtse's home to ask for volunteers to be screened, her mother was not at home. So they did not know about Lhungtse and moved on to the next home. Later a relative learned about the screening program and carried Lhungtse to the research team. Through blood serum testing and MRIs of her brain, Lhungtse was diagnosed with a serious case of neurocysticercosis. This disease results from fecal-oral contamination from human carriers of another very serious preventable parasitic disease called taeniasis. The risk factors for taeniasis include eating undercooked pork, the use of free-ranging pigs, lack of latrine facilities, lack of meat inspection, poor hygiene, and a poor economy.

The neurocysticercosis caused many cysts deep in Lhungtse's brain. The cysts caused hydrocephalus, for which there is an abnormal accumulation of cerebrospinal fluid (CSF) in the ventricles of the brain. The hydrocephalus caused increased intracranial pressure inside Lhungtse's skull. This increased intracranial pressure caused Lhungtse's headaches and damaged her optic nerves. This damage caused Lhungtse's blindness.



Lhungtse in 2010 in her home village with Dr. Li Tiaoying (right) and a village leader (left)

In 2011 and 2012, Lhungtse was taken to hospitals in Chengdu and Shanghai for further evaluations. However, her mother could not afford any treatment.

In October 2012, I attended an International Symposium on Cestode Zoonoses Control in Shanghai, China. Cestode zoonoses are tapeworm diseases that can be passed from animals, whether wild or domesticated, to humans. Dr. Li Tiaoying, SIPD, made a presentation on "Current status of taeniasis/cysticercosis in Tibetan communities of Sichuan Province, China." She described three Tibetan teen-agers with serious neurocysticercosis infection. I asked her, "Who is the girl in your photo for whom the infection caused blindness?" Dr. Li answered, "Lhungtse."

Surgery In early 2013, I asked Dr. Li many questions about the surgery that was indicated for Lhungtse. She said that she needed ventriculoperitoneal (VP) shunt brain surgery, that would drain excess cerebrospinal fluid from a ventricle in her brain and be absorbed by her abdomen. This drainage would relieve the high intracranial pressure. If she did not receive this operation, the high intracranial pressure would cause other serious health issues in addition to the blindness and headaches, such as, nausea, vomiting, loss of bladder control, seizures, coma, or even death. Dr. Li indicated that the surgery could probably be performed in Chengdu at Huaxi Hospital. Based on estimates provided by the hospital, I concluded that \$13,000 should be enough to pay for the surgery and other related costs. Lhungtse and her mother told Dr. Li that they would accept the surgery in spite of its risks.



A disappointed Lhungtse on August 6 outside Huaxi Hospital with her mother (right) and me (left)

Thanks to kind donations from many of you and others, BLSCP raised \$13,000 for Lhungtse's brain surgery before I departed Boulder for Chengdu on August 3. On August 6, Dr. Li and I met Lhungtse and her mother at Huaxi Hospital for a medical evaluation by the Chief of the Neurosurgery Department. We were accompanied by Tsomo, a Tibetan Village Project intern, whom BLSCP hired to provide language interpretation & translation and support. Tsomo speaks Mandarin Chinese, English, and Lhungtse's local Tibetan dialect and helped Lhungtse and her mother relax as much as possible. To our surprise, the Neurosurgery Chief told us that he believed that surgery was not indicated, based upon Lhungtse's symptoms and recent MRIs! This news disappointed Lhungtse, who then thought that she would not receive the surgery that she needed.

As soon as we were outside of the hospital, Dr. Li told us that Huaxi Hospital does not have much experience with hydrocephalus caused by neurocysticercosis. She then called her colleague Dr. Liu in Dali, Yunnan, who has considerable experience with neurocysticercosis and VP shunt surgery. He said that surgery was indicated and that we should bring Lhungtse to Dali University Hospital for surgery.

Due to my prior commitments in Chengdu and Lhasa and Dr. Liu's prior travel commitments, I arranged to take Lhungtse and her mother to Dali on August 26. The flight from Chengdu to Dali was the first air travel for Lhungtse and her mother! Lhungtse loved pushing the baggage carts in the airports and laughed when she experienced the bump of landings and the action of the jet's brakes. We were accompanied by Delek, a Tibetan Village Project tour guide, whom BLSCP hired to provide language interpretation & translation and support. Delek speaks Mandarin Chinese, English, and Lhungtse's local Tibetan dialect and helped Lhungtse and her mother relax as much as possible.

After their thorough examination of Lhungtse and her MRIs, the neurosurgeons in Dali advised us that Lhungtse needed double VP shunt surgery (both left and right sides of the brain) and that their hospital is not equipped to perform it. They discussed this evaluation by phone with Dr. Li, who told us that she would then try to arrange an evaluation by the Neurosurgery Department at Sichuan Provincial People's Hospital (SPPH) in Chengdu. So we returned to Chengdu on August 29.



Lhungtse on August 27 in Dali modeling my cowboy hat



Sichuan Provincial People's Hospital in Chengdu



Lhungtse on September 6 chatting with Delek during her recovery in SPPH

Because of Dr. Li's long-time friendship with a high-level SPPH physician, we were able to meet the SPPH neurosurgeons on August 30! After their thorough examination of Lhungtse and her MRIs, they advised us that single VP shunt surgery should be sufficient because the MRIs showed no blockage between the left and right ventricles. Over the weekend Lhungtse and her mother concluded that they wanted to proceed with this surgery, in spite of the risks, even though restoration of any of her vision appeared to be highly unlikely. The neurosurgeons at all three hospitals told us that the six years of high intracranial pressure had been too long for her damaged optic nerves to recover. During the last week of August, I witnessed two of six mini-seizures suffered by Lhungtse. Even though I was quite anxious about the risks of surgery, I knew that without the surgery, Lhungtse's long-term risks would be higher.

On September 2, Lhungtse was admitted to SPPH. After she passed various physical examinations, her surgery was scheduled for September 5. During the three-hour surgery Lhungtse's mother, Delek, and I waited outside of the operating rooms with relatives and friends of other patients undergoing surgery. Our only information on Lhungtse's status was provided by updates on an electronic display on the wall. Finally Delek told me that the status indicated that we could go to Lhungtse's room. Because we had been told by the neurosurgeons that Lhungtse would typically spend one or two days in the Intensive Care Unit (ICU) after surgery, I did not know what to expect in Lhungtse's room.

To my surprise Lhungtse had just arrived in her room on a gurney (wheeled stretcher). She had tolerated the surgery so well that she did not need the ICU!

During Lhungtse's week-long recovery, Delek and I supported her and her mother by spending many hours each day in Lhungtse's hospital room.

On the day after surgery, Lhungtse was feeling good enough to be featured on a live 20-minute news interview on Sichuan Television (SCTV4)!

Post-Surgery Chemotherapy

Lhungtse was released from SPPH on September 13. Dr. Liao, the neurosurgeon, indicated that the surgery was successful. He cautioned us that he can not predict whether there will be any post-surgery complications. Following the surgery, Lhungtse has not suffered any of the headaches and mini-seizures like she experienced in Chengdu and Dali during August.

On September 12, Lhungtse began the first of several two-week courses of albendazole to kill the parasitic cysts in her brain. Because she experienced only minor side-effects from this chemotherapy, she was able to complete the first course as an out-patient in Chengdu. On September 17, I departed Chengdu and returned to my home in Boulder. Lhungtse and her mother returned to SPPH on October 7 for the first of three check-ups by Dr. Liao. He indicated that Lhungtse was making good progress with her recovery and that she could return to her home to continue her chemotherapy as an out-patient. Because each course of albendazole is separated by three months, she will begin her second course in

December. Dr. Liao told her to return to SPPH in January 2014 and July 2014 for further check-ups.

On October 8, Lhungtse and her mother went to SIPD to see Dr. Li and show her the latest MRIs. Dr. Li's e-mail to me: "Lhungtse is now in much better condition, always smiling. More importantly, she now can feel sunshine when it is strong, and she feels that her head became smaller, compared to the past. Anyway, all of the message is good news."



Lhungtse's new shoes!

On October 9, Lhungtse and her mother safely returned to their home in Yajiang County by bus (typically a 10-hour trip). Before they departed Chengdu, they went shopping for some new clothes for Losar (Tibetan New Year), which will occur on March 2.



Lhungtse on October 8 talking with Dr. Li Tiaoying at SIPD

Future Activities

Several doctors and nurses have said that Lhungtse is very lucky to have met me and BLSCP. I know that I am very lucky to have met her! She is such a brave, resourceful, smart, appreciative, and lovable girl. Even though none of her vision has been restored, Lhungtse is happy these days. Her spirit and passion for life are strong. She now has hope for a better future.

Using WeChat on our mobile phones, I am communicating with Lhungtse and her mother several times each week via audio clips and photos. I hope to be able to visit them during 2014. From time to time, Tsomo and I have a 3-way conference call with them.

Lhungtse is one of many Tibetans in western Sichuan who suffer from headaches, and/or seizures, and/or blindness, due to neurocysticercosis. Based on preliminary results, Dr. Li has recently established a laboratory method for diagnosing cysticercosis. In the future she hopes to use this method to confirm suspected neurocysticercosis cases in western Sichuan. If the cases are identified in their early stages, treatments can be less costly and less complicated than Lhungtse's treatment.



Tsomo (right) and Lhungtse's mother (left) preparing dumplings in Chengdu

Dr. Li is also continuing her field research to identify human carriers of taeniasis. Remember that neurocysticercosis results from fecal-oral contamination from human carriers of taeniasis. Because the human carriers usually have no symptoms, Dr. Li has found that rural Tibetans are reluctant to take their time to volunteer for testing. Dr. Li thinks that one way to improve the testing would be to offer some high-quality cooking oil as a reward. She suggested that BLSCP could take an active role in her field work by raising funds to purchase the cooking oil.

Dr. Li is also conducting training classes on preventing taeniasis and cysticercosis for local health care leaders in western Sichuan. BLSCP could enhance this training and take an active role by raising funds to cover some of the costs.

Lhungtse's Brain Surgery Now 88% Funded

For many circumstances, \$13,000 would have covered the costs of Lhungtse's surgery and related expenses. However, because of the unforeseen delays and the side trip to Dali, Yunnan, the total expenses were \$19,091.71. To pay the bills in Chengdu, BLSCP borrowed \$5,000.00 from a Tibetan friend in Lhasa, and I paid the remaining bills with my personal credit card. One week ago, BLSCP received a \$5,000.00 loan from a Boulder lender so that BLSCP could pay back the \$5,000.00 to our friend in Lhasa.

In addition to the \$13,000.00 that BLSCP raised before I departed Boulder on August 3, we have received \$3,721.45 in donations for Lhungtse. Thanks again to all of you who contributed in any way!

So we now need to raise \$2,370.26. Of this amount, we need \$1,278.55 to pay off the balance of the \$5,000.00 loan and \$1,091.71 to reimburse me for other expenses which I paid with my credit card. Donations that exceed \$2,370.26 will be used for:

1. Any unforeseen future medical expenses that Lhungtse may incur
2. After Lhungtse's full recovery, vocational training for her
3. Active roles for BLSCP in Dr. Li's continuing efforts to prevent neurocysticercosis

BLSCP believes that Lhungtse deserved this effort and expense so that she could have a chance for a better future. Please forward this e-mail to others who may also be interested in helping Lhungtse.

Please send your donations, payable to BLSCP, to BLSCP, 776 Cottage Lane, Boulder, CO 80304-0758 U.S.A. BLSCP is a non-profit 501(c)(3) public charity. Our tax ID number is 74-2469070. All contributions are tax-deductible, to the extent allowed by law. BLSCP will acknowledge your donation with a letter.

For donors in China or other foreign countries, please contact me for suggestions on how you may transfer funds to BLSCP.

Bill Warnock, President
19 October 2013