



**Burma Children**  
*Medical Fund* operating to give  
Burma's kids a future

## October-December 2013

## BCMF Quarterly Report



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## Overview

As 2013 ends, we reflect on the changes we have seen in the last 12 months and what those changes mean for BCMF. Most striking is that we have seen a marked increase in patient enrollment. In 2013, we enrolled a total of 261 patients, up from 189 in 2012. This represents a 38% increase in patient enrollment. We have also seen a significant increase in patients with complex diagnoses such as cardiac disease and cancer. The majority of those patients have first attempted to access treatment in Burma before coming to Thailand in search of medical care. The ceasefires in Karen State and increased freedom of movement have made it easier for patients to travel in order to get treatment. Treatment that was not previously accessible in Burma may now be within reach as it is easier for patients and their families to travel to hospitals in larger townships and cities. However, Burma still faces significant resource constraints in its health care system, including a lack of advanced medical equipment and a limited number of specialists—cardiologists, neurologists, and oncologists—even in the larger cities of Rangoon and Mandalay. For patients attempting to get treatment for complex medical conditions, this can mean traveling long distances in search of treatment as well as long waits once they reach their destination. For those patients that do travel to Rangoon or Mandalay in search of treatment, many find that they cannot afford the costs of needed surgery or advanced medical care once they arrive.

In April 2013, Eleven Media Group reported on observations made by cancer specialist, Dr. Soe Aung, at a knowledge sharing seminar on cancer prevention. He noted that death rates from cancer have been rising every year in Burma and that only three hospitals treat the majority of cancer patients in Burma. In an article published by the Asian Pacific Journal of Cancer Prevention in 2012, researchers found that Burma's cancer burden was one of the highest in Southeast Asia. Researchers measured cancer burden by using a combined measure of mortality and morbidity, calculated as the sum of years of life lost due to premature mortality and years lived with a disability. One Burmese oncologist stated that he believes that cancer causes unnecessary deaths in Burma because many people only seek treatment after the cancer was well developed. "In Myanmar, cancer patients often only come to hospitals when the cancer is at a late stage," he said. However, the reason why so many people in Burma wait to seek treatment is no mystery. In Burma, hospital staff tell patients if they do not have money, there is no point in seeking treatment. In 2012, the World Bank reported that 67% of Burma's population lived in rural areas and international humanitarian reports estimate that up to 70% of the population in rural areas in Burma face significantly increased rates of poverty, making it impossible for many to pay for even basic health care expenses, let alone advanced investigative procedures or treatment.

Even those that can afford to follow-through with treatment find that options are limited. In Rangoon, patients sometimes face long waiting lists for chemotherapy. In other cases, the needed medical equipment is simply inadequate. A patient told BCMF that his oncologist advised him to go to Thailand for treatment. The oncologist was concerned about the safety risks the patient would face if he underwent radiation therapy with the aging equipment being used at the hospital and felt he had a better chance of receiving proper treatment in Thailand. In 2013, the charity "Cure Child Cancer" visited the oncology department in Yangon Children's Hospital. In a report prepared for a fundraising campaign sponsored by the Financial Times, the charity found that the oncology department does not have the expertise or equipment to conduct the specialized tests required to identify the most effective chemotherapy treatments for patients. Patients' records are kept in notebooks, there is no pharmacy, and parents have formed their own group to track down blood donors since the hospital's supply is unreliable. The hospital currently lists 250 vacancies for needed doctors, nurses and technicians.

Like many other organizations operating on the border, BCMF finds that many donors are shifting their priorities to funding programs working inside of Burma. Many international donors have stated that their funding to organizations on the Thai-Burma border will likely end or be significantly reduced after 2015. It will be a challenge to convince donors to continue funding organizations working on the border that are providing a vital service. Until Burma has the expertise, physicians, and equipment to serve people in need of complex medical care, it is essential that BCMF continue to help patients access treatment in the Thai hospital system.

## UPDATE: FUNDRAISING APPEAL BCMF PATIENT HOUSE

*Thank you to all BCMF supporters*

In addition to funding patients' medical treatment and providing support services, BCMF also provides patients with food and accommodation for as long as they are undergoing treatment. BCMF previously paid per patient for food and accommodation provided by a partner organization in Chiang Mai. However, given the significant and continuous increase in BCMF's patient caseload in recent years, our needs have expanded beyond what our partner organization is able to provide.

This year, BCMF reached a point where it became essential to establish a house exclusively for BCMF patients, allowing us to better serve our patients' needs and stabilize our costs. In October 2013, BCMF launched a fundraising campaign that aimed to raise \$5,000 in funds in support of a portion of our start-up costs.

**We are happy to announce that the campaign was a success and as of January 28<sup>th</sup>, we exceeded our goal, raising a total of \$5,285.**

The house officially opened in December and patients receiving treatment in Chiang Mai have already moved in. Many thanks to all who contributed and helped to spread the word about the campaign. BCMF could not exist without supporters like you!

Thanks to the following individuals who donated to the BCMF online campaign: Joanne Pawlak, Kazu, Henry Zwart, LVX Installation and Maintenance, Louise Cooke, Claire Habel, Maxine Ross, Patricia McLean, Jason P, Mick, Sean, Marie Golden, Nick Russell, Estrella Kemp, Frank Farrington, Emma and Rachel, Patricia Barber, Michael, John Kearney, Shauna O. Dunton, D & M Bling Sale, Byron Hornby, Jessica, B.N., Bernadette Whelan, Charles Watson, Friends of Alex Zachilow in Bangkok, AT & YT, RF, Sweet Dreams, and several donors who wished to remain anonymous.

<http://www.youcaring.com/bcmf>



*Patients and staff put the finishing touches on the BCMF logo at the patient house*

In addition to the online fundraising campaign, BCMF was fortunate to have many other supporters that helped to get the patient house up and running:

- Debbie Singh launched her own fundraising campaign in Australia and raised a total of \$10,000 in support of the patient house. Yvonne Ziegler and Gail Bailey also made a big effort to help with fundraising efforts in Australia.
- Debbie, Yvonne, and Gail all made visits to the patient house as it was being renovated and even rolled up their sleeves to do some of the work, shopping for supplies and helping the patients and staff to plant a garden.
- The Internews team in Chiang Mai donated many items - furniture, appliances, bedding and kitchen supplies.
- John Manning donated fans, a washing machine, clothes, toys, water filters, cribs, mattresses, bedding, and many other items. John came with BCMF supporters, Helen Overing and her daughter, to deliver these much needed items in person.



*From top left: Debbie Singh, Yvonne Ziegler, and Gail Bailey with BCMF patients; John Manning; BCMF patients and staff with new donations; BCMF staff Chan and Waan with their baby daughter.*

## OCTOBER SPOTLIGHT: DAW THIDAR



Daw Thidar is a 52 year-old woman who came to BWMF suffering from a uterine myoma (benign uterine mass). She lives in Myawaddy with her husband and two grown children on the Burmese side of the Thai-Burma border. She and her husband escaped to Thailand following the 1988 uprising in Burma and then returned to Burma one year later. She said that she and her husband's livelihoods have been affected by the unstable political situation in Burma as they have had to relocate several times over the years to escape the conflict. In her opinion, not much has changed in Burma with the recent political reforms with the exception that telecommunications and freedom of movement have both improved.

When Daw Thidar came to BCMF, she had been suffering from back pain and stiffness on the right side of her body for over a year. She

later began experiencing dizziness, abdominal pain, and her menstrual cycle lasted longer than usual. When her menstrual cycle lasted for ten days, she knew something must be wrong. She decided to cross the border to Thailand to visit the Mae Tao Clinic in October 2013. There, medics performed an ultrasound test that revealed she had a large uterine mass that would require surgical treatment. Medics referred her to BCMF and she was transferred to Mae Sot Hospital on October 14<sup>th</sup>. Due to the size of the mass, she underwent a total hysterectomy. She was discharged from the hospital five days later. Daw Thidar says her overall experience in Mae Sot Hospital was good. She was very impressed that the doctors and nurses were kind to her and she told BCMF staff that she was happy that she was given the same level of quality care as all of the other patients. She told BCMF staff that in Burma, poor people frequently do not receive the same quality of care as wealthy people. She said the discrimination against poor people in Burmese hospitals is noticeable and she was very pleased that she did not experience the same discrimination in Mae Sot Hospital. She says the only difficulty she encountered at Mae Sot Hospital was the language barrier; however, a fellow patient in the bed next to her spoke both Burmese and Thai and was able to translate for her.

When Daw Thidar came to BCMF for her post-operative interview, she had just been released from the hospital and was still in recovery. However, she said that she already noticed a decrease in her back pain and told us that the tenderness in her lower abdomen is completely gone. She has had no more problems with dizziness or headaches since the surgery and says that she already feels like she has more energy. She said she is very happy to have gotten treatment and relieved to have no more worries about her health. When she returned home, her husband and children were very happy that she had received treatment and was feeling better.

Daw Thidar told us that she is very grateful to the donors and staff of BCMF. She said she has a new life because of their help. She says that she never would have been able to afford treatment on her own, even if she had borrowed money from her relatives who themselves have very limited incomes. Her husband is also very happy for her and says that one day when he can save enough money from his salary, he would like to donate to the BCMF program. When asked about her future, Daw Thidar says she plans to find work to help support her family and hopes she can also find a way to "pay forward" the assistance she received from BCMF by helping other people in need.

## NOVEMBER SPOTLIGHT: YAN PAI



Yan Pai is a 5 year-old boy who came to BCMF after being diagnosed with Thalassemia. Thalassemia major is a life-threatening condition which causes severe anemia that requires regular blood transfusions. He was born in a small village in Karen State, just outside of the capital of Hpa-An.

telling his mother that he needed a blood transfusion. Following the transfusion, the doctor told his mother that he would need to return for regular blood transfusions every month. However, his mother decided not to return for follow-up appointments. She was not convinced the transfusions would help since she thought Yan Pai looked worse after the first transfusion.

After Yan Pai turned two years old, his mother noticed that his symptoms had returned – again he was very tired and wasn't eating well. She took him back to the government hospital in Hpa-an where he was again given a blood transfusion and once again told that he would need to return for transfusions every month. However, the doctor didn't explain his condition or why he would require regular transfusions. When we asked his mother why she didn't try to get more answers about her son's condition from the doctor, she replied that she was scared of the medical staff. She says that they would often scold patients and yell at them when they asked questions so she was too nervous to ask for more information about her son's condition.

This time, Yan Pai's mother followed the doctors' advice and took him back to Hpa-An Hospital where he continued to get monthly blood transfusions for the next three years. He was given medication as well and his mother was told that he would need to continue taking it his entire life (however, she is unsure what kind of medication it was and she was once again afraid to ask). The family was spending 80,000 kyat (\$82 USD) every month on his treatment. At the time, Yan Pai's family was running a dried food shop and were able to cover his medical bills. However, they would occasionally have to ask monks at the local monastery to donate blood as the hospital was frequently in short supply. In exchange, the family would pay for the monk's transportation costs and give them food.

One day, a neighbor told them about Mae Tao Clinic and suggested that they try to seek treatment for Yan Pai there. They came to the clinic in December 2012 and Yan Pai began receiving blood transfusions twice a month. His family decided to relocate to Myawaddy, on the Burmese side of the Thai-Burma border so that it would be easier for him to receive free treatment at Mae Tao Clinic. Yan Pai attends kindergarten in Myawaddy. His mother says that he loves school and he insists on going to school every day, even when he is not feeling well. Despite the regular transfusions, he still continues to suffer from severe fatigue. Immediately following the transfusions, he seems to feel better and has a good appetite, but after a few days, he goes back to being tired and not wanting to eat. Medics at Mae Tao Clinic explained Yan Pai's condition to his mother and discussed the fact that Thalassemia is often genetic. Though he was never diagnosed, his uncle suffered the same symptoms and died when he was 8 years old as he was unable to get treatment.

In October 2013, Yan Pai had reached the point that he needed transfusions every week. Clinic staff referred him to BCMF so that he could undergo a splenectomy at Mae Sot Hospital. Normally, the spleen recycles red blood cells. However, in patients with Thalassemia, red blood cells can accumulate in the spleen, causing it to become enlarged. An enlarged spleen can then become overactive and start destroying even the healthy blood cells the patient receives during transfusions. Removing the spleen can interrupt this cycle and reduce the need for transfusions.

His mother told BCMF staff that she is worried that her son's life will be cut short because of his condition.

Neighbors in Burma told her that having this disease means that he will die young. She is hopeful that the

surgery will help to prolong Yan Pai's life. She hopes that following treatment he will continue school and pursue whatever he wants to be when he grows up. She joked with BCMF staff that she hopes he has a long life so that he will be able to take care of his mother when he grows up.



## DECEMBER SPOTLIGHT: ZIN ZIN



Zin Zin is a sixteen year-old girl who came to BCMF after being diagnosed with non-Hodgkin lymphoma of the nasal cavity. Her family is from Bago Division in the south central part of Burma. Her father is the sole income earner in the family; he earns 4,500 kyat (\$4.50 USD) per day working as a porter at the train station. According to Zin Zin's mother, the money he earns is usually just enough to cover the family's day-to-day expenses.

Zin Zin is in the 10<sup>th</sup> grade; however, she stopped attending school in September when she started to lose her eyesight as a result of the tumor.

Zin Zin says she first noticed a problem with her eye in early September 2013 when her eye became swollen and red. However, she did not have any other symptoms at that time. Her mother took her to see a private optometrist in Bago City. At first, he suspected she had hyperthyroidism and referred her to Rangoon for further testing and treatment.

(Hyperthyroidism can cause the eye muscles to swell and bulge). On the doctor's advice, Zin Zin and her mother went to a government hospital in Rangoon for thyroid testing. However, her thyroid test was normal. They returned with the test results to the optometrist in Bago City. He again examined her eye, but could not see an obvious cause for the swelling. He again referred her to Rangoon, but this time recommended she see an ophthalmologist. During this time, the swelling in Zin Zin's eye had gotten much worse and she started to experience pain, tearing, and her vision started to become blurred.

The ophthalmologist in Rangoon examined her eye and told Zin Zin and her mother that there was no obvious problem with her eye and that he suspected that something behind the eye was causing the swelling. He referred her to a private health clinic in Rangoon where she had a CT scan. The CT scan revealed a mass in her nasal cavity that extended into her orbital cavity causing the swelling and displacement of her eye. The CT scan cost 90,000 kyat (\$90 USD) which Zin Zin's family paid with a loan from a friend.

Between September and November 2013, the swelling in Zin Zin's eye became increasingly worse until all of the tissue of her eye eventually prolapsed, displacing her eye entirely from the orbit. Zin Zin is very self-conscious about the appearance of her eye and wears a scarf over it when she is in public.

After the CT scan, the clinic referred Zin Zin to another hospital in Rangoon which specializes in ear, nose, and throat problems. There, they did an x-ray, a blood test, and a biopsy. The results of the biopsy revealed that she had non-Hodgkin lymphoma. They suggested the results of the biopsy be confirmed by a leukocyte common antigen (LCA) test, which is used to distinguish cases of non-Hodgkin's Lymphoma. The results of the LCA test were positive, confirming the diagnosis. The test cost 20,000 kyat (\$20 USD). When the doctor explained the results of the test to her, he told her that would have to go to a hospital in Rangoon that specialized in cancer treatment.

Zin Zin and her mother returned to Rangoon on December 3<sup>rd</sup>, 2013. This time, they went to the Medical Oncology Department at Yangon General Hospital. Zin Zin's mother had to first purchase all of the medication, including Zin Zin's chemotherapy medication at a pharmacy outside of the hospital. The medication cost a total of 40,000 kyat (\$40 USD) for her first five days of treatment. Her mother then took the medication back to the hospital where staff administered the chemotherapy to Zin Zin. After she completed her first round of chemotherapy, she was supposed to return to the hospital for a consultation and a second round of chemotherapy. However, after paying for all of her initial investigation and testing, her family had run out of money. Up to that point, friends and neighbors had lent the family money to help cover the costs of travel, food, testing, and medication for Zin Zin. However, her mother knew she could not continue to borrow money at the same rates since she knew she would never be able to pay it all back.

Out of options and money, Zin Zin's father asked for assistance for his daughter from monks at a monastery in Bago. There, the monks told him about Mae Tao Clinic. The family again borrowed money from a friend—50,000 kyat (\$50 USD)—to cover their traveling costs to Mae Sot. Medics at Mae Tao Clinic then referred Zin Zin to BCMF.

Zin Zin said that she does not currently have any pain, but she cannot see out of her right eye at all. Her mother was tearful during the interview, expressing her desperation to get treatment for her daughter. She says the family exhausted their options for their treatment in Burma and she feels like BCMF is her last hope to get her daughter the treatment she needs. She cried when she told BCMF staff that she is very worried about her daughter and says her only hope is for her daughter to get well. Zin Zin put on a brave face during the interview and when asked about her future, she told us she wants to be an engineer when she grows up.

BCMF has sent Zin Zin to Chiang Mai where she underwent a CT scan and a spinal tap which confirmed that the cancer has not spread beyond her nasal cavity and eye. She is scheduled to start chemotherapy.

**Please consider making a donation in support of Zin Zin's treatment:**

<http://burmачhildren.com/get-involved/how-to-donate/>

## October-December 2013: Summary Data

### BCMF Program Statistics October -December 2013

**Total number of new cases across the program** 70

-Children – Burma Children Medical Fund (BCMF)	15
-Children (under 12) funded by donor in Chiang Mai (CDF)	16
-Adults – Burma Adult Medical Fund (BAMF)	23
-Gynecological Cases - Burma Women Medical Fund (BWMF)	16

### Diagnoses

-Cardiac Disease	20
-Obstetric/Gynecological Condition	17
-Congenital Musculoskeletal Deformity	7
-Urological/Kidney Condition	6
-Cancer	4
-Blood Disorder	3
-Gastrointestinal Condition	3
-Other	3
-Severe Burns	2
-Orthopedic Condition	2
-Eye Condition	2
-Neurological Condition	1

### Patient's home state/division

-Karen State	30
-Mon State	10
-Tak Province	14
-Bago Division	7
-Refugee Camp (Thailand)	3
-Yangon Division	2
-Shan State	2
-Mandalay	1
-Bangkok	1

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