



burma children medical fund

BCMF | Operating to give Burma's kids a future

# January-March 2013 Three Month Summary



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## Overview

A Personal Note from the Program Manager:

As we began 2013, we had initially projected a modest increase in patient enrollment based on the percentage increases we recorded in 2011 and 2012 respectively. However, we saw a significant increase in new patients in just the first month of 2013. As January came to a close, we speculated that this increase in patient enrollment was a temporary phenomenon and decided to wait and see if the trend continued. However, now that the first quarter of 2013 is complete, it is clear that our increased enrollment rates are not just a passing trend. We have enrolled record numbers of patients each month. In the first quarter of 2013, we have registered a total of 77 new patients in the program (up from 41 patients in the last quarter of 2012).

We believe that the increase in patient enrollment is due in part to the increased freedom of movement that has occurred along with the recent political reforms in Burma. This increased freedom of movement has occurred both within Karen State and across the border with Thailand. Sustained ceasefires in Karen State (which borders Mae Sot) means there are fewer areas of conflict and zones of control which our patients previously had to navigate in order to reach Mae Sot. Patients report that there are fewer checkpoints on the Burmese side of the border and when they do pass through checkpoints, they are subject to less scrutiny and questioning than they were in the past. Patients also report that previously, Burmese authorities treated those people who had traveled to Thailand as suspicious and some were even accused of being spies. However, patients now tell us that with the recent political reforms, tensions have eased significantly and it is now much easier to cross back into Burma without being subject to intense questioning or risking arrest. Further fueling the phenomenon, word has spread among Burmese people living on either side of the border about the increased freedom of movement and more people are now willing to attempt the trip to Mae Sot that they considered to be too risky before. Finally, patients report that improved roads and transportation have also made travel much easier. As Burma increasingly focuses on opportunities for economic development and increased commerce, the government has invested in improving roads that were previously in poor condition and sometimes impassable.

The recent political reforms in Burma are a good sign for the country's future and there is great hope that the positive changes will continue. However, it is important to remember that change will not happen overnight and some reforms will take longer than others. Rebuilding the infrastructure of the healthcare system will take years if not decades. The Burmese government made modest increases in healthcare spending in 2013 which is a positive step. However, overall healthcare spending remains relatively low when compared to more developed countries in Asia and the rest of the world. There are still few Burmese hospitals that are able to provide treatment for complex cases, and at those facilities that do offer care, treatment continues to be cost-prohibitive. Most of our patients have exhausted treatment options in Burma before they come to BCMF. A common story we frequently hear from our patients is that they first sought treatment at a local clinic or hospital in their village only to be referred to a larger hospital in Rangoon for treatment. Local clinics and hospitals in Burma do not typically have the expertise, resources, or equipment to treat complex medical conditions and refer patients to Rangoon for further investigation and treatment. Families often take out loans or sell personal belongings in order to make the trip to Rangoon only to find that their treatment options there are limited or that necessary surgeries will cost more than they can hope to earn in a lifetime. Coming to Mae Tao Clinic and BCMF is usually a last resort as they have exhausted options in Burma and decide to cross the border to Mae Sot in a last ditch effort to seek treatment that is completely out of reach in Burma.

It is important to remember that while the increased freedom of movement means that it is easier for patients to come to Thailand to seek treatment that is unavailable or unaffordable in Burma, the choice to come to Mae Sot has very real consequences for the families of BCMF patients. When parents come to Mae Sot with a sick

child, they may leave other children and grandparents behind in Burma. Families are split apart and many parents report that they must temporarily stop working or even quit their jobs in order to come to Thailand to seek treatment for their child. In some cases, parents may attempt to find temporary work in Mae Sot in order to help support their family while their child undergoes treatment. In other cases, parents may have to rely on friends and family back home to loan them money to help sustain the family during the course of their child's treatment. The choice to come to Mae Tao Clinic and BCMF has significant consequences for many families and shows the level of love, dedication, and desperation families feel in the course of their attempts to get treatment for a sick family member.

The increase in patient enrollment reflects a new reality for BCMF and we must make adjustments accordingly. Our enrollment criteria have not changed. BCMF strongly believes that everyone has a right to healthcare and we strive to provide this opportunity to people from Burma regardless of age, sex, race, religion or legal status. BCMF does not have any set criteria for admission to the program; however, funding constraints often mean that we cannot accept patients who have come to us late in their illness and who have a poor chance of survival. Nevertheless, BCMF aims to treat as many patients as we can who seek our help. This means that we will continue to try to serve as many patients as possible, even as our enrollment rates continue to increase.

Unfortunately, the increase in patient enrollment presents new financial challenges for BCMF. The reality for BCMF is that we rely heavily on the support of private donors and individuals to help meet our funding needs. Many of our donations come from private individuals and one-time fundraisers that we cannot rely on as recurrent sources of funding. As a result, we must appeal to our current donors as well as to take a strategic approach to look for new sources of funding in order to help meet the funding shortfall we will face as greater numbers of patients come to us for help.

<b>Total number of new cases across the program</b>	<b>77</b>
- Children – Burma Children Medical Fund (BCMF)	26
- Children (under 12) funded by donor in Chiang Mai	31
- Special Adult Cases – Burma Adult Medical Fund (BAMF)	18
- Obstetric and Gynecological Cases—Burma Women Medical Fund (BWMF)	2

## JANUARY PATIENT SPOTLIGHT: THI DAR



Thi Dar is a 3-year-old girl suffering from Thalassemia. Shortly after she was born, Thi Dar developed jaundice and was placed in incubation and given a blood transfusion. Her hospitalization cost the family a total of 100,000 kyat (\$116 USD) which her parents had to borrow from relatives. Thi Dar's condition improved, but after 3 months, she developed jaundice a second time and again had to return to the hospital for another blood transfusion. Doctors diagnosed her with Thalassemia and said she would continue to require blood transfusions every few months.

Thalassemia is a genetic blood disorder in which the body does not make enough healthy red blood cells and produces less hemoglobin than normal. Hemoglobin is an iron-rich protein in red blood cells which carries oxygen to all parts of the body. People

who have Thalassemia can have mild or severe anemia. People with Beta Thalassemia Major, or Cooley's Anemia, need regular blood transfusions (often every 2 to 4 weeks) in order to help maintain normal hemoglobin and red blood cell levels. Signs and symptoms occur within the first 2 years of life and may include poor appetite, dark urine, slowed growth and delayed puberty, jaundice, bone problems, and an enlarged spleen, liver, and heart.

After returning home to their village, Thi Dar was well for only about two months before she once again became jaundiced and had to have another blood transfusion, costing 30,000 kyat. Each subsequent transfusion lasted for shorter and shorter periods of time, until the family was returning to the hospital for blood transfusions every two weeks. After the third transfusion, the family could no longer afford the cost of the donated blood and asked a family friend to donate blood for their daughter.

Thi Dar's mother said she has lost count of how many times her daughter has had blood transfusions over the past 3 years. Each trip to the hospital cost them around 20,000- 25,000 kyat (about \$27 USD), and each time they had to personally search for a blood donor. Occasionally, they would be able to pay for the hospital visits themselves, but often they would borrow money from friends or family.

When Thi Dar was one and a half years old, her stomach began to bloat to an alarming size. Seeking answers at the hospital, the doctors told Thi Dar's mother that her daughter would need to undergo an operation in Rangoon since the local hospital did not have the resources to carry out the required surgery. As the family did not have the money to travel to Rangoon, let alone the money to cover the cost of the surgery, they did not pursue further treatment for her and her stomach continued to bloat. Upon seeing Thi Dar's condition, a cousin told the family about Mae Tao Clinic in Mae Sot and the free treatment Thi Dar could receive there. Her father sold his horse cart for 50,000 kyat (\$58 USD) and left the other two children with their grandmother while he, his wife, and Thi Dar made the journey to Mae Sot.

Upon arriving in Mae Sot, her father found work as a construction worker in order to be able to support the family while they travel back and forth to Mae Tao Clinic for Thi Dar's blood transfusions. However, he is working illegally as neither he nor his wife have legal documentation to live or work in Thailand.

Thi Dar's illness has caused a great deal of stress and hardship for their family. Her mother has been separated from her other two children for one year already, unable to take care of them whilst she is living in Mae Sot. The family is under huge financial stress from the healthcare expenses that have built up over the years. Her mother says she wishes her daughter's condition will improve so that she can work and help relieve some of the family's financial burdens.

After BCMF sent Thi Dar to Chiang Mai for consultation and treatment, doctors determined that her spleen was enlarged. The spleen helps the body fight infection and remove unwanted material. In patients with Thalassemia, the spleen has to work harder and may become enlarged as a result. The enlarged spleen can worsen the anemia. In the case of Thi Dar, doctors determined that she needed to have her spleen removed.

A neighbor in their village told Thi Dar's mother to leave her untreated because it was simply too difficult to look after her. However, Thi Dar's mother told us that she could not comprehend how a mother could ever think of doing such a thing. She said she wants to see her daughter healthy and happy once again; living and playing normally like other children.

## **FEBRUARY PATIENT SPOTLIGHT: POH POH**



Poh Poh is a 7-year-old girl who came to BCMF after being diagnosed with a congenital cataract. Her family noticed a small white spot developing in her left eye that eventually grew larger and blocked her vision. She also complained of pain in her left eye. Her family went to multiple clinics in Burma in search of treatment; several of the clinics prescribed medication but her condition did not improve. The family continued to pursue treatment hoping to find a clinic or hospital that would be able to help their daughter. In total, they spent 300,000 kyat (\$340 USD) attempting to get Poh Poh diagnosed and treated. However, none of the clinics offered any answers and Poh Poh's vision continued to deteriorate. After they had spent a great deal of money and run out of options for treatment in Burma, the family heard about the Mae Tao Clinic from a friend. At Mae Tao Clinic, Poh Poh was referred to BCMF.

After BCMF sent Poh Poh to Chiang Mai for an initial investigation, doctors told her family that the cataract was too far advanced and her eye could not be saved. Poh Poh's family says the doctors and nurses explained everything to them very clearly including the severity of her diagnosis. After her initial consultation in Chiang Mai, Poh Poh was then referred to Mae Sot Hospital where she was scheduled for surgery to remove her eye. When nurses wheeled her out of the operating room, she was covered with a white sheet and her grandmother initially feared she had died during the operation and started crying. However, doctors and nurses reassured her that the surgery went according to plan, and though it was necessary to remove Poh Poh's eye, she was perfectly fine otherwise.

Poh Poh told her grandmother that she is afraid to go to school because she is worried that the other kids will make fun of her. Poh Poh will eventually receive a prosthetic eye; while her eyesight cannot be restored, the prosthetic eye is a cosmetic solution that will help her to look like other children. BCMF staff told her family that they should encourage Poh Poh to go to school and to tell her that the fact that she has only one eye should not keep her from getting an education. BCMF staff then showed her family a picture of another BCMF patient—a little girl who also had her eye removed due to retinoblastoma (eye cancer). Poh Poh's grandmother

and father were very encouraged to hear about another child who had undergone a similar operation and was doing well.

One week after the surgery, Poh Poh was in good spirits and played with blocks and toys throughout the interview. She built a very tall tower of yellow and orange blocks while BCMF staff talked with her father and her grandmother. Her grandmother said that before the surgery, Poh Poh complained of pain in her eye; now there is no pain at all. Because of the cataract, Poh Poh was not able to see out of her left eye before the surgery so her vision has not changed—she still plays and does her chores just as she did before. Additionally, Poh Poh attended school regularly before the operation, but she missed her final exams because of the surgery so she will have to repeat the first grade. Poh Poh says she likes going to school and that her favorite subject is Burmese. When she is not in school, her favorite thing to do is to take care of the ducks on her family's farm. She says she wants to be a medic at Mae Tao Clinic when she grows up.

Before the surgery, her grandmother said she was constantly losing sleep because she was so worried about Poh Poh's health. Although Poh Poh lost her eye, her grandmother is now she is very relieved to know that her granddaughter is healthy and happy. Her grandmother says she never experienced this kind of service in Burma; she would like to thank the donors very much and is very glad to have this kind of support from the donors of BCMF.

## MARCH PATIENT SPOTLIGHT: PHYU THA ZIN



Phyu Tha Zin is a 14-year-old girl who has suffered from cardiac disease for the last four years. Her family lives in Myawaddy, Burma. Her father is a day laborer who helps to mill wood used in construction. He earns about 10,000 kyat (\$12) per day. His two elder sons work with him, but they each earn only about 3,000 kyat (\$3.50) per day. Because they are young, they do not get paid as much as more senior workers. However, their income is not consistent and is dependent on their rates of production. Phyu's mother cooks a local Indian dish that she sells to local people in their neighborhood. She earns 2,500 kyat (\$3) per day. Despite the fact that four of the family members are working, their total income is not enough to meet the family's basic needs. They have a large family (Phyu has seven other siblings) and their combined income is just not enough to cover all of their day-to-day expenses. Whenever there are unexpected expenses, Phyu's father has to take an advance on his wages and then pay his boss back later.

Phyu's mother first noticed her daughter's health condition when she was 10 years old. Phyu complained that she was tired and having trouble breathing, so her mother gave her traditional medicine purchased from a neighbor's shop.

However, after a week, Phyu's symptoms were getting worse, so she took Phyu to the local medical clinic. At the time, in addition to having difficulty breathing, Phyu was also coughing a lot so staff at the clinic gave her medication to help treat her congestion. Each visit to the clinic cost about 2,500 kyat, the equivalent of a day's labor for Phyu's mother. When Phyu's symptoms still did not improve, clinic staff suggested that she go to Myawaddy Hospital for further treatment and investigation. At Myawaddy Hospital, Phyu was diagnosed with Tuberculosis and given TB medication for one month.

However, despite taking the medication, her condition continued to deteriorate. She had no appetite, was losing weight, had difficulty sleeping, and was severely fatigued. Her mother initially wondered if these were side-effects of the TB medication. However, Phyu's mother ultimately sensed that something more serious was wrong with her daughter; in addition to her other symptoms, she also began to develop edema (swelling of her

arms and legs) and complained of heart palpitations. Her mother returned to the local medical clinic where nurses recommended she be hospitalized because her heart rate was elevated. Phyu and her mother again returned to Myawaddy Hospital where doctors admitted Phyu as an inpatient. They repeated blood tests and also did a chest x-ray to verify the TB diagnosis. Doctors told her mother that Phyu had been misdiagnosed and that she did not in fact have TB. Phyu's mother told BCMF staff that the family had to buy all of their own supplies including needles, cotton, and medication. Further, Phyu's mother said she encountered nurses at Myawaddy Hospital that told her point blank, "If you have money, you can stay in the hospital, but if you don't, you have to check out. Nothing comes for free."

Phyu was in the hospital a total of 9 days, which cost her family a total of 300,000 kyat (\$350), the equivalent of over a month's labor for her father. Phyu's father again had to take an advance on his salary in order to pay his daughter's hospital bill. After her stay in the hospital, Phyu's condition improved, but her heart rate still was not normal. Doctors suggested that Phyu's mother take her to Rangoon for further treatment because they did not have the equipment or expertise necessary to treat her in Myawaddy. When Phyu's mother told doctors that she could not afford the cost of the trip to Rangoon, they suggested bringing her across the border to Thailand where she could be seen at Mae Sot Hospital instead. However, when Phyu's mother and father discussed the options to get further treatment for Phyu, they came to the conclusion they did not have enough money to take her to either hospital.

When Phyu arrived home, her condition improved for a while, but after about 6 months, her symptoms returned. Phyu's parents decided to take her to a private clinic across the border in Mae Sot, where doctors again did blood and urine tests and took another chest x-ray. The doctor told Phyu's mother that the x-ray showed that one side of Phyu's heart is larger than the other and that she needed to be treated for cardiac disease. The doctor recommended that the family take Phyu to Mae Sot Hospital for further investigation and treatment. Despite their financial difficulties, Phyu's parents realized their daughter was not getting better and followed the doctor's advice to take her to Mae Sot Hospital. Phyu was hospitalized while doctors performed additional tests and prescribed heart medication. The total cost of her stay in Mae Sot Hospital was 13,000 Baht (\$450). Phyu's parents could only pay a small portion of the bill and they eventually decided to pawn their land in order to pay the remaining amount of the hospital charges.

Over the next 9 months, Phyu took medication for her heart disease and showed mild improvement, but continued to experience symptoms. When she went to Mae Sot Hospital for a follow-up appointment, doctors recommended that Phyu be hospitalized again. However, at that point, their previous bill from the hospital was still outstanding. Phyu's mother was worried that she still owed the hospital money and told staff she could not afford another hospitalization. The staff from Mae Sot Hospital understood the family's financial difficulties and suggested they bring her to Mae Tao Clinic to see what assistance they could give the family. At Mae Tao Clinic, medics referred her to BCMF. She is scheduled to be transferred to Chiang Mai for investigation and treatment on May 9<sup>th</sup>, 2013.

Today, Phyu continues to get tired easily and cannot walk long distances. She still has not returned to school. Phyu can't do her daily chores because she is too tired and weak. She cannot eat or sleep well because of coughing too much. She is extremely thin and cannot sit for long hours without having to lie down. Because of Phyu's condition, her mother is unable to work and her father says he constantly worries about her. The family is extremely worried about her health and stressed about the many debts they have to pay off as a result of trying to get her treatment. Phyu's mother says she hopes that one day her daughter will be healthy. Phyu says she used to want to be a teacher, but has stopped attending school since she became sick and now says she has lost hope to continue her education. But she told her mother that despite her illness, it is still her goal to one day take care of her parents. She says "Even if I can't be a teacher I will do sewing at home and use the money to help support my parents".

## IN MEMORIAM: OUR FIGHTERS

*In some cases, patients only come to Mae Tao Clinic and BCMF after they have been sick for a long time. Many seek treatment in Burma but are ultimately unable to afford the cost of medical care. With no other options, many patients simply live with their symptoms until they hear about the Mae Tao Clinic and BCMF from a friend or neighbor. BCMF would like to remember our fighters.*

### HTWE



Htwe first came to BCMF in 2007 after being diagnosed with cardiac disease. She was born with a heart condition known as Tetralogy of Fallot. It is caused by a combination of four heart defects that are present at birth. These defects, which affect the structure of the heart, cause oxygen-poor blood to flow out of the heart and into the rest of the body. Infants and children with Tetralogy of Fallot usually have blue-tinged skin because their blood doesn't carry enough oxygen. When Htwe first came to BCMF, her fingers, toes, and lips were blue. Her mother said she was frequently prone to infections and fevers.

In 2007, fighting in Karen State, where Htwe's family are from, meant that the journey to Mae Tao Clinic was dangerous. Additionally, their lack of legal documentation meant that they could be subject to detention and arrest while making the trip to Thailand. However, desperate for a solution, Htwe's family made the journey to Mae Sot and Mae Tao Clinic, where medics referred her to BCMF. (In subsequent visits to Mae Sot, Htwe's parents were arrested on three separate occasions and had to pay fines to local authorities in order to reach the clinic for follow-up appointments).

Htwe underwent three surgeries in Chiang Mai. Her father reported that, following the first surgery, she had a lot more energy and was much more talkative than before. Her mother said she felt lucky that Htwe's condition had improved. Following that surgery, she underwent two additional surgeries, but experienced complications. She again returned to Chiang Mai for treatment on January 31, 2013 after she stopped responding to medication. After a long battle, she passed away at 5am on March 29<sup>th</sup>.

When we interviewed her, Htwe told us that she wanted to be a doctor when she grows up. She played with her parents and pretended to give them injections as though they were her "patients".

BCMF would like to remember Htwe and her brave fight.

## MOE SANDAR



Moe Sandar was a six year old girl who came to BCMF suffering from a brain tumor.

In December 2012, her parents noticed that her right eye was pointed slightly in the other direction and that she was having difficulty seeing. Moe Sandar told her grandmother that things looked “crooked” to her. Her family first took her to a variety of local clinics in their home city of Pa’An before finally pursuing treatment in Rangoon. There, doctors tested her vision and determined the source of the problem was not her eye, but her brain. They referred her to the Asian Royal Medical Hospital where doctors took a CT scan which showed that Moe Sandar had a brain tumor. Neurologists did a biopsy which showed that the tumor was benign; however, swelling in the brain tissue around the brain meant that doctors could not safely remove the growth. Doctors recommended that as a next step, Moe Sandar have an MRI to get a better image of the growth in order to better determine its position and whether it could be safely removed. The hospital stay and biopsy had already cost her family 2 million kyat (\$2,000 USD). Her father had asked his employer for an advance on his salary to help pay for her medical expenses, putting the family deeply into debt. Without money to fund additional investigation and treatment, Moe Sandar’s parents were out of options. When Moe Sandar’s family told the doctor they could not afford the MRI or further surgery, he advised Moe Sandar’s family to check out of the hospital. Doctors offered no further advice

about where the family could seek treatment or whether they could get financial assistance to treat her condition.

A friend in Myawaddy recommended the family take Moe Sandar to Mae Sot Hospital for treatment. When doctors there reviewed her records from Rangoon and learned she had a brain tumor, they told the family they did not have means to treat her (no MRI and no neurosurgeon) and that she would need treatment in Bangkok or Chiang Mai. They advised the family that if they did not have money to pursue treatment themselves, they should come to Mae Tao Clinic and that clinic staff might be able to advise the family on how to pursue further treatment. The family brought Moe Sandar to Mae Tao Clinic where medics referred her to BCMF. By the time Moe Sandar came to us, her condition was rapidly deteriorating; she was having difficulty walking and could not bathe or dress herself; things she could previously do by herself.

BCMF sent Moe Sandar to Chiang Mai for treatment, but by that point, the tumor had grown significantly. She suffered severe hemorrhaging and died while in Chiang Mai.

Moe Sandar’s family spent a lot of time and money in their desperate search to get her treatment. As we interviewed the family, her grandmother broke down in tears when asked about her feelings about her granddaughter – she said she could not begin to express how worried she was about Moe Sandar. Moe Sandar told us that she wanted to become a nurse when she grows up. When she came to us, she had just started kindergarten and was able to say “My name is Moe Sandar” in English!

BCMF would like to remember this beautiful little girl and express our sincere condolences to all of her family members who fought so hard for her.

## January-March 2013: Summary Data

<b>Total number of new cases across the program</b>	<b>77</b>
-Cardiac Disease	28
-Congenital Musculoskeletal Deformity	9
-Other (landmine injury, Kawasaki Disease, tongue tie, etc.)	6
-Urological/Kidney Condition	4
-Eye Condition	4
-Meningocele	4
-Obstetric/Gynecological Condition	4
-Abnormal Growth/Benign Tumor	3
-Cancer	3
-Gastrointestinal Condition	3
-Burn	3
-Neurological condition	3
-Orthopedic Condition	2
-Blood Disorder	1
<b>Patient's Home State/Division</b>	
-Karen State	32
-Tak Province	23
-Mon State	7
-Bago Division	6
-Other (Thailand)	2
-Shan State	2
-Kachin State	1
-Chiang Mai	1
-Bangkok	1
-Kayah State	1
-Yangon Division	1
<b>Total number of patients taken to Chiang Mai for treatment</b>	<b>141</b>
<b>Total number of follow-up visits at BCMF (prior patients)</b>	<b>280</b>

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