



burma children medical fund

**BCMF** | Operating to give Burma's kids a future

# April-June 2013

## Three Month Summary



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## Overview

A Personal Note from the Program Manager:

With the political and economic reforms that have taken place in Burma over the last few years, Burma and the international community have become increasingly focused on opportunities for economic development and international commerce. In June, Burma hosted the World Economic Forum on East Asia, and it will assume the chairmanship of the Association of Southeast Asian Nations (ASEAN) in 2014. These changes represent positive steps for the country's economic future, but without sustained effort by the Burmese government to significantly increase investment in areas such as healthcare and education, the daily lives of many Burmese people have changed very little. In June, the Bangkok Post published an article written by two of our BCMF staff detailing the critical condition of the Burmese health care system. (The article can be found [here](#)). The article demonstrates how our patients' perspectives provide valuable insight into the challenges facing the Burmese healthcare system and illuminate many of the barriers still faced today by Burmese citizens in need of medical care. In this issue of our quarterly report, we are presenting a selection of stories from our patients that illustrate the barriers and difficulties they continue to face seeking health care in Burma.



Thway is a 2 year-old baby boy who was born with an imperforate anus. As a result, he had been living with a colostomy since he was two days old. He came to BCMF in August 2012 to get anal reconstruction surgery and to reverse his colostomy. In June, after he had successfully completed his treatment, Thway and his mother returned to BCMF for a post-op interview and she discussed the differences in her experiences with the healthcare system in Thailand versus that in Burma. She told us that because her son was born without an anus, he underwent colostomy surgery in Rangoon two days after he was born. Following the surgery, he needed to go to follow-up appointments at the hospital every month for 3 months. At the last follow-up appointment, he had developed a severe skin rash all over his body and she said that the doctor scolded her, implying that that it was her fault that he had developed a rash. The doctor then examined Thway's stoma, and then recommended they buy medicine, without offering any further explanation about the cause of the rash or discussing next steps for surgery. She said, "In Burma, the nurses and doctors are not nice to the

patients and they do not communicate well. When they speak to patients, their faces and voices are hard." After being referred to BCMF, he had anal reconstruction surgery, physical therapy, and had his colostomy reversed in December 2012. Thway's mother contrasted her experience in Thailand with her experience in Burma. She said that the doctors, nurses and medical staff they encountered in Chiang Mai were very different from those in Burma. The medical staff were very patient and kind and were very thorough in communicating with them, explaining Thway's condition and treatment in detail. She was very happy with the treatment her son received in Chiang Mai and happy that the doctors and nurses treated both of them with such respect, kindness, and understanding.

Another patient, Myint Myint, is a 38-year-old woman from Mon State who has been struggling with cardiac disease for over a decade. She came to BCMF in July after trying unsuccessfully to obtain treatment at a variety of hospitals and clinics in Burma. Unable to afford the surgery she needed, Myint Myint would regularly self-medicate, purchasing heart medication for herself at a local drugstore. Despite her efforts to take care of herself, she still became very ill and ultimately had to be hospitalized in a government hospital for two weeks. During this time, her doctor told her that she needed a heart transplant. However, she said the costs of a transplant would be steep; in discussing her experience with BCMF staff, she said “I was told that I would have to bribe the doctor and other staff in Rangoon, giving them 200,000 kyat [200 USD] in addition to the cost of the surgery.” This was completely out of reach for her financially, so she did not pursue it further. While BCMF will fund the cost of her medical treatment going forward, Myint Myint says that she currently is 600,000 kyat (\$600 USD) in debt due to the medical bills she incurred in Burma. She says that she will ultimately have to sell her land and house in order to pay back her loans.



Aung is a 50-year-old man from Karen State suffering from kidney stones who came to BCMF for the first time in February 2013. Aung and his family have struggled to get him treatment since his symptoms began three years ago, seeking palliative care at a local clinic as they are unable to afford the surgery he needs to remove the kidney stones. When asked about the current state of the Burmese health system, Aung said that there is a medic in their town who treats local villagers, but they still have to pay for the costs of medication and treatment. He said that the average visit costs about 8,000 kyat (8 USD), depending on the type of medical problem being treated. He also said that in December 2012, the government distributed mosquito nets to people in his village, but did not provide any anti-malaria medication. Additionally, there are free polio vaccinations available to children in the village, but all other vaccinations cost about 3,000 kyat (3 USD) each. Because of this, parents that do not have money cannot afford to get their children vaccinated. Aung also noted that it is very common for patients to have to pay bribes when they

go to the hospital in order to get better quality treatment. Patients that do not pay bribes tend to be ignored by hospital staff, while those that do pay can expect more attention and a better quality of care.

Each of these stories represents some of the common barriers faced by many patients in Burma, where medical care is often unavailable, inaccessible, of poor quality, or cost-prohibitive. As Burma continues along the path of reform, it is vital that the government invest in services for the people as much as in commerce and economic development. Without such a commitment to health and human rights, individuals with complex medical conditions will continue to have few options for getting the medical care they so desperately need.

<b>Total number of new cases across the program</b>	<b>46</b>
- Children – Burma Children Medical Fund (BCMF)	14
- Children (under 12) funded by donor in Chiang Mai	13
- Special Adult Cases – Burma Adult Medical Fund (BAMF)	10
- Obstetric and Gynecological Cases—Burma Women Medical Fund (BWMF)	9

## APRIL PATIENT SPOTLIGHT: AYE THANDAR



Aye Thandar is a six-year-old girl with cardiac disease who came to BCMF this April. Her parents left Burma three years ago to find work and they have been living in Thailand ever since. Her father works as a day laborer at a rose garden in Pho Phra, earning 550 baht (18 USD) per week cutting flowers. Her mother used to work at the garden as well, but when she became pregnant with her second child, she had to stop working. Her father says that when both he and his wife were working, they were able to get by, but now that he is the only one working, they are struggling to make ends meet.

Aye Thandar's parents first noticed her symptoms when she was only a year old and they were still living in Burma (Bago Division), and they have struggled to find her treatment ever since. She started running a fever, had heart palpitations, and was experiencing difficulty breathing. They went to the local clinic, where doctors told her parents they suspected she might have a heart problem. They said that it might resolve on its own as she got older, and did not advise her parents to pursue further treatment. However, her symptoms persisted, and so her parents took her to a local medic who had some medical training, but was uncertified. He gave her oral medications and injections to treat her symptoms, which provided only short-term relief. They then tried traditional medicines, which cost them 25,000 kyat (25 USD) per month and again provided Aye Thandar with only temporary relief. Despite these treatments, Aye Thandar's symptoms always returned and no one offered them more information or advice regarding next steps to treat her condition. When Aye Thandar's parents moved to Thailand to find work, she stayed behind with her grandparents until the age of four, at which point she joined her parents in Pho Phra. Over the last two years, her parents report that she has continued to have symptoms including fevers, difficulty breathing, and fatigue. Her parents took her to the local clinic in Pho Phra, where they gave her medication to help treat her shortness of breath—doctors there suspected she might have asthma. However, her symptoms continued, despite the medication.

When her mother became pregnant, she did not have enough money to deliver the baby at Pho Phra Hospital, so friends recommended she come to Mae Tao Clinic to give birth. The journey only took about two hours, but they had to pass through three police checkpoints and at each checkpoint, they had to pay police 100 baht (3.33 USD) before they were allowed to continue traveling. Once they arrived at Mae Tao Clinic, Aye Thandar's father asked medics to examine Aye Thandar as well, as she was continuing to have nosebleeds. When medics examined her, they diagnosed her with cardiac disease and referred her to BCMF.

When asked about her current symptoms, Aye Thandar's parents said that she still gets tired easily and she seems to get colds frequently. She can walk and play like most other kids, but is easily fatigued. Aye Thandar's parents said they have been stressed about her health for many years now; they have known something is wrong with their daughter, but have been unable to get her help. Aye Thandar says she wants to be a teacher when she grows up, but her parents are worried they cannot afford to send her to school. Right now, they say they cannot hope to dream about her education because they have so many financial difficulties. They hope to send her back to her grandparents so she can attend school in Burma, but say that she will have to wait to start school until after she gets treatment. Aye Thandar went to Chiang Mai and received an echocardiogram on May 9<sup>th</sup>. She is now waiting for her surgery to be scheduled.

## MAY PATIENT SPOTLIGHT: SAN SAN



San San is a 40 year-old woman who was referred to BCMF in March of this year with a uterine myoma (a benign tumor that grows within the muscle tissue of the uterus). San San had noticed a hard mass in her lower abdomen in October 2012. Thinking she was pregnant, she excitedly came to Mae Tao Clinic for confirmation. She was disappointed to learn from the ultrasound that the mass was not a pregnancy, but rather a uterine myoma. The staff at Mae Tao Clinic advised that she get a surgery that would cost 15,000 baht (500 USD), but knowing that she could not afford it, San San simply lived with her pain and symptoms, returning every month to Mae Tao Clinic to receive medication and an examination to measure the growth of the mass.

San San lived in Mon State until 8 years ago, when she and her family moved to Myawaddy to look for better job opportunities. Now, San San's husband works as a motorbike taxi driver, but their income is inconsistent. Their eldest son moved back to Mon State to work at his uncle's computer shop after he finished school, and their younger son attends first grade in Myawaddy. They do not always have enough money to make ends meet, and the fact that San San has not been able to work has been a stress on the entire family. Before coming to BCMF, San San considered selling her parents' house in Mon State to pay for her surgery, but reconsidered as she would like to save that money for her children's future.

She was referred to BCMF in March 2013 and enrolled in the Burma Women Medical Fund (BWMF). She then went to Mae Sot Hospital for surgery to remove the myoma on May 16, 2013. Now, she no longer has any pain from the myoma. San San said that before the treatment, she was in so much pain that she had difficulty walking. She said she also could not do her daily tasks due to the size and sensitivity of the mass. Following the surgery, she says she can now walk normally, no longer has any tension or abdominal pain and has a good appetite and sleeps well. She has much more energy and is happier than before.

San San said that her overall experience in Mae Sot Hospital was good; everything went well and the doctors and nurses were kind to her and made sure to explain her treatment. She said that compared to hospitals in Burma, hospitals in Thailand have much better quality of care, expertise, and technology. She had no difficulties at the hospital and the staff were very caring and assisted her with all of her needs.

San San's family, friends, and even her landlord were all very happy to see that she returned home so happy and healthy! She said that BCMF funding her surgery has been very helpful to her and her family. She no longer feels any stress regarding her health and how it will affect her ability to care for her loved ones. When she fully recovers, she hopes to return to work and earn money to support her family, and if she can earn enough, she wishes to donate to BCMF and the Mae Tao Clinic. San San said she is very grateful and she will remember the staff and donors of BCMF for the rest of her life, and that she prays for the donors who helped to support her treatment. She hopes that she will continue to be healthy and be able to in turn help people who are less fortunate than herself.

## JUNE PATIENT SPOTLIGHT: KYAW

Kyaw is a 25 year-old man who came to BCMF from Karen State. He works as an agricultural day laborer to help support his elderly parents, but his income is not always enough to make ends meet and sometimes he must borrow money with interest from a broker in their village. Kyaw has been suffering from chronic kidney disease since he was 8 or 9 years old, living with severe pain, numbness in his back, and other associated urinary symptoms.

He never went to the village clinic for his problem, as he has always been shy and embarrassed about it. He used traditional medicine instead, which helped him to feel a little better. However, he has an aunt in Myawaddy, who took him to see a visiting foreign doctor that was providing free medical consultations in his village. At the time, the doctor diagnosed him with a urinary tract infection and gave him medication for it. Kyaw says this medication made him feel a little bit better, though when he urinated, he still had a lot of pain.

Kyaw's aunt knew about the Mae Tao Clinic because she had been treated for malaria there. She didn't know if Mae Tao Clinic could treat kidney problems or not, but since they had run out of options in Burma, they decided it was worth seeing if the clinic could treat Kyaw. At Mae Tao Clinic, he had another urine test and was given more medication. Medics diagnosed him with chronic kidney disease, severe hydronephrosis, and a urinary tract infection. Hydronephrosis literally means "water inside the kidney" and is caused by the obstruction of the flow of urine inside the kidney. Untreated, it can lead to progressive kidney atrophy. The medic explained that they couldn't treat him at Mae Tao Clinic and they referred him to BCMF. He was enrolled in the Burma Adult Medical Fund (BAMF) and is currently awaiting transfer to Chiang Mai for treatment.

Kyaw says that he feels very stressed about his condition. He wants to work to support his family, but his condition makes it difficult for him. He says that sometimes he feels sad and that his condition makes him shy and self-conscious. Throughout his interview with BCMF, however, he asked how to say phrases in English, including "Hello my name is Kyaw" and "Thank you." After treatment, he plans to go home to his village in Burma and stay with his parents. In the future, he hopes that he can work to support his family and wants to marry his girlfriend.

With the political reforms taking place in Burma, Kyaw says that has noticed some changes. In addition to the foreign doctor providing health care to the people in his village, he said there is also now free primary education, though it is not funded by the government, but by an international NGO.



## URGENT SUPPORT NEEDED: NAY TOE



Nay Toe is a one year-old baby boy who has been diagnosed with a brain tumor that is impacting his vision. Since he was born, his mother says that he has always been a healthy baby, eating, sleeping, playing, and growing normally. However, at the end of May 2013, his parents started noticing that he was having vision problems. He began using his hands and feet to feel his way around when he is walking and must listen to sounds in order to navigate. When his parents call him, he hears and tries to go to them, but often goes the wrong way. He still sleeps and eats well, but he is frightened all of the time because he cannot see. He calls to his parents and wants them beside him constantly, and cries often.

Nay Toe's parents moved to Mae Ku Lum in the Tak Province of Thailand four years ago. Before coming to Thailand, they lived in Bago Division in Burma. They came to Thailand so that his father could get a job in a corn processing plant. Currently, they stay on their employer's land in a small house. They have been unable to save money; seeking treatment for Nay Toe has been expensive and they earn just enough to meet the family's basic needs. Sometimes they borrow money from Nay Toe's uncle, especially for emergency healthcare.

When Nay Toe's vision problems started, his parents brought him to the Mae Tao Clinic to seek treatment. They went to the eye clinic, where the eye doctor told his parents that he might still have a little bit of eyesight remaining, but suspected that his eyes were not the source of his vision loss. He suggested that Nay Toe be checked for a potential neurological problem and referred them to Mae Sot Hospital. The next day, when they went to Mae Sot Hospital, Nay Toe was admitted for five days and given a CT scan. The scan verified that he has a brain tumor pressing on his optic nerve and that he will need to have brain surgery in Chiang Mai. After his diagnosis was confirmed, he was referred to BCMF.

There is still some question about the degree to which Nay Toe's vision has been affected by the tumor and it is unclear if he is totally blind. The CT scan shows a tumor pressing on his optic nerve, which the eye doctor at Mae Tao Clinic believes is most likely a benign Craniopharyngioma. Craniopharyngioma refers to a slow-growing tumor that typically occurs in children. The doctor believes there is a possibility that if the tumor is removed, Nay Toe could regain some vision.

Nay Toe's parents said that Mae Sot Hospital told them not to worry about their baby's blindness and said that he will see again. However, they believe that he is completely blind and are very upset about his diagnosis. They are very worried and stressed because he is their first and only child. Furthermore, his father has not been working since Nay Toe's problems began, and as a result, the family currently has no income. Now that they have come to MTC and he has been referred to BCMF, they say they have a little hope for the future and that it makes them a little happier to know that their baby might have a chance to see again.

In the future, Nay Toe's parents hope that he will be able to go to school and get a good education. Before he got sick, they planned for his father to work in Bangkok and send money back home for Nay Toe to attend school. They hope that if he recovers from his blindness, they can carry out this plan. Please consider making a donation to BCMF to support Nay Toe's surgery in Chiang Mai.

## 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.*

### AUNG MIN



Aung Min was a three-year-old boy from Mon State whose mother brought him to BCMF in early June with a severely swollen abdomen. Earlier this year, his mother noticed a small mass in his lower abdomen and when he started to complain of pain, she brought him to a local clinic that referred them to Mawlamyine Hospital, an hour and a half away. There, Aung Min was hospitalized for four days. While he was in the hospital, his mother left Aung Min in the hospital with his aunt while she went home to get money for food. When she returned, she found Aung Min and his aunt outside of the hospital with all of their belongings. The doctors had told them that his kidney was enlarged and he could stay in the hospital for three more days, but must leave after that because his only treatment option was in Rangoon. Knowing that his mother could not afford to go to Rangoon, Aung Min's aunt had packed them up to go home.

When they returned home to tell Aung Min's father of the situation, he responded harshly, saying that all humans die and it was simply Aung Min's time. However, Aung Min's mother responded that she only has one child, and she would not let her son die. A neighbor told her about the Mae Tao Clinic, and although she had never been to the border before and did not know how to cross into Thailand, she sold some of her belongings to raise money for the trip. When she told her husband that she was taking Aung Min to get medical treatment no matter what he thought, he told her that if she went, she could not return. She went anyway, making the journey across the border for her son's sake.

When she arrived in Myawaddy on the Burma side of the border, she received help from a driver and a boat operator to cross the border and reach Mae Tao Clinic, explaining that her son was very ill. Upon reaching the clinic, Aung Min was referred to BCMF. BCMF send him to Chiang Mai immediately where he underwent exploratory surgery. In the course of the surgery, doctors discovered a large tumor attached to multiple organs. Unfortunately, the cancer had spread too far and he could not be treated. Aung Min's mother made the difficult decision to take him off of the respirator, and he passed away shortly after. BCMF would like to remember this little boy and his fight, and his brave mother, who was so determined to get her son the care he needed no matter what.

## WANNI

Wanni was a two-year-old girl who suffered from cardiac disease. Her parents are from Burma but have lived in Mae Sot as migrant workers for 15 years, making an inconsistent income through day labor and selling vegetables. Wanni's struggle began when she was six months old; she became very sick and a doctor at a Thai clinic determined that she had a heart problem and told her parents that she would need to be treated in Chiang Mai. However, her parents could not afford to go to Chiang Mai for treatment, and for the next several months, Wanni was frequently sick, suffering from a fever, cough and vomiting every few weeks. Her parents brought her to multiple clinics despite their financial challenges, but their daughter's condition did not improve.

When she was 11 months old, Wanni became very sick and her parents brought her to Mae Sot Hospital, where she was hospitalized for 8 days. Following her hospitalization, Wanni returned to Mae Sot Hospital multiple times. When doctors confirmed her diagnosis of cardiac disease, they explained that her only treatment option was in Chiang Mai and referred her to BCMF.

BCMF transferred Wanni to Chiang Mai for investigation in April, where she was put on medication for her heart condition while she awaited her next appointment. Doctors will frequently put new patients on heart medication in an attempt to stabilize their condition enough that it is safe to proceed with surgery. She was due to have an angiogram in Chiang Mai in June, but before this could occur, she became ill again and had difficulty breathing. Her mother brought her to Mae Sot Hospital where they tried to stabilize her, but sadly she passed away. BCMF would like to respectfully remember Wanni's struggle and express our sincere condolences to her family.



## April-June 2013: Summary Data

<b>Total number of new cases across the program</b>	<b>46</b>
-Cardiac Disease	13
-Other	8
-Urological/Kidney Condition	5
-Gynecological Condition	9
-Cancer	3
-Gastrointestinal Condition	3
-Burn	1
-Neurological condition	1
-Orthopedic Condition	2
-Blood Disorder	1
<b>Patient's Home State/Division</b>	
-Karen State	24
-Tak Province	16
-Mon State	4
-Magway Division	1
-Mandalay Division	1
<b>Total number of patients taken to Chiang Mai for treatment</b>	<b>116</b>
<b>Total number of follow-up visits at BCMF (prior patients)</b>	<b>300</b>
<b>Total number of patient deaths</b>	<b>2</b>

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