



burma children medical fund

BCMF

| Operating to give Burma's kids a future

# Burma Children Medical Fund (BCMF)

## June 2011 Activity Report



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***“...a vast area of eastern Burma remains in a chronic health emergency, a continuing legacy of longstanding official disinvestment in health, coupled with protracted civil war and the abuse of civilians. This has left ethnic rural populations in the east with 41.2% of children under five acutely malnourished. 60% of deaths in children under the age of 5 are from preventable and treatable diseases...”<sup>1</sup>***

## **June 2011 Cases: An Overview**



Thin Thin Nwe came to Mae Tao Clinic suffering from severe burns

In June 2011, BCMF accepted 15 new patients onto the program. This included referrals to the Burma Children Medical Fund (**BCMF**) and [Burma Adult Medical Fund \(BAMF\)](#). The conditions our new cases presented with varied greatly and included:

- [Congenital heart disease](#)
- Unhealed fractures and broken bones
- A rare type of skin cancer (dermatofibrosarcoma)
- Severe burns (to 42% of body)
- Encephalocele (on bridge of nose)
- Old burn injury (resulting in contracture of skin)
- Throat cancer (*BAMF supporting logistics only*)

Also in June, BCMF facilitated the [movement of 48 patients](#) from the Mae Tao Clinic (in Mae Sot) to Chiang Mai (360kms) while 10 patients were scheduled for surgery.

A notable case this month was 18-year-old **Thin Thin Nwe** (see photo) who was bought to the Mae Tao Clinic by her family. She was in great pain and was suffering from extensive burns to 42% of her body (chest, arms, fingers, buttocks, thighs, legs, feet and toes). She was involved in an accident at the property her family work on. They moved to Thailand 18 months ago to find work and now manage the corn fields on a farm near the border. Thin Thin is the eldest of six children – the youngest being only eight months old.

In late May 2011, while trying to light the lantern for the evening, her sister realised that the propellant had been mixed up. By then it was too late and the lantern had caught on fire. In a panic, she threw the lit lantern out the door of their hut. Sadly, Thin Thin happened to be walking into the hut when the flaming fuel was in flight. She caught the full brunt of the burning fuel on her chest. She turned to protect herself and she was engulfed in flames. After a few days of being cared for by the medics in the [Mae Tao Clinic](#) surgical department, Thin Thin was referred to the [Burma Adult Medical Fund \(BAMF\)](#) as it became apparent that she would need to be sent for specialised care at the local Thai hospital. There she could have her burns monitored, cleaned and dressed daily in the operating theatre. Thin Thin continues to be cared for at Mae Sot Hospital and her family are never far away from her bedside.

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<sup>1</sup> [Diagnosis Critical: health and human rights in eastern Burma](#), October 2010

The [Burma Adult Medical Fund](#) (BAMF) also took on the case of a 44-year-old man presenting with a rare type of tumour (located near his rib cage). **Naing Kyaw** grew up in Karen state and was forcibly recruited into a break-away armed ethnic group when he was young. He escaped after one week. In 1995, his village was overthrown by that same group and Naing Kyaw and his family (along with many other villagers) crossed into Thailand to find safety. He has been living in a refugee camp along the Thai-Burma border since.

In 2001, Naing Kyaw noticed a growth on his chest and he had surgery in the refugee camp to remove it. Over the next decade, he had the growth cut out two more times but it became clear that his recurring growth was not able to be successfully treated at the clinic in the refugee camp (operated by Malteser International). In 2011, Naing Kyaw decided to travel to the [Mae Tao Clinic](#) to seek treatment (with the assistance of another organization based in the camp). A biopsy was taken for testing at Mae Sot Hospital which revealed that Naing Kyaw was suffering from a rare form of cancer in the fibrous tissue of the skin (dermatofibrosarcoma). BAMF was consulted and he was referred to Chiang Mai for treatment and radiation. Naing Kyaw returned to the refugee camp to see his family. BAMF negotiated with Malteser International for his transportation from the camp to Chiang Mai to be arranged while BAMF committed to funding his treatment costs and oversee his treatment plan. The prognosis for this type of tumour is good which makes Naing Kyaw a good candidate for the BAMF program. He is in a good state of health and has four children to care for.

BCMF continues to hear stories about the **ongoing fighting in Karen State** from patients who come to the [Mae Tao Clinic](#) seeking medical care. Conflict plays a large role in their inability to access basic health care as does the Burmese government's disinvestment in health, particularly in eastern Burma. 'Burma only spends 1.8% of total government expenditures on health, leaving Burma in 138<sup>th</sup> position in the UNDP's Human Development Report for 2009'<sup>2</sup>

Naing Kyaw at the Mae Tao Clinic surgical department



Maung Chit Lwin's father was killed in June 2011.

**Patients referred to BCMF are fighting for survival on a daily basis.** Many of them live in areas that are constantly under threat from different armed groups including the Burmese army. Villages continue to be attacked and civilians are forced to run. Entire families face displacement, psychological trauma, the loss of income-earning family members, personal injury and even death. Not to mention exacerbation of their medical condition from being exposed to preventable conditions such as malaria and malnutrition.

In June 2011, BCMF heard news that the father of one of our young patients was killed when the public vehicle he was travelling in drove into the crossfire of two armed groups. **Maung Chit Lwin** ([hydrocephalus](#)) was scheduled to travel to Chiang Mai for a follow-up but his appointment has now been re-scheduled.

<sup>2</sup> [Diagnosis Critical: health and human rights in eastern Burma](#), October 2010

# June 2011: Summary of New Cases

<b>Total number of new cases across the program</b>	<b>15</b>
- Children – Burma Children Medical Fund (BCMF)	5
- Children (under 12) with surgery funded by donor in Chiang Mai	5
- Special Adult Cases – <a href="#">Burma Adult Medical Fund</a> (BAMF)	5
- Gynaecological Surgery – Burma Women Medical Fund (BWMF)	0

NAME	SEX	AGE	PROGRAM	CONDITION
Tha Gan Nay Oo	F	6	BCMF	Burn
Htet Lay Aung	M	16	BCMF	Fractured femur (osteomyelitis)
Hnin Ei Phyu	F	14	BCMF	Congenital Heart Disease
<a href="#">Yan Naing Linn</a>	M	17	BCMF	Congenital Heart Disease
Maung Nyi Nyi	M	16	BCMF	Congenital Heart Disease
Zaw Htet Hlaing	M	5	BCMF/CDF	Congenital Heart Disease
Aye Thandar Oo	F	8	BCMF/CDF	Congenital Heart Disease
Maung Nay Linn	M	4	BCMF/CDF	Congenital Heart Disease
<a href="#">Ga Chor</a>	M	9	BCMF/CDF	Encephalocele
Htet Inzali	F	2	BCMF/CDF	Congenital Heart Disease
Ah Ngae Lay	M	25	BAMF	Cardiac condition
U Thaung Sein <sup>3</sup>	M	53	BAMF	Throat cancer (self-funding)
Naing Kyaw	M	44	BAMF	Dermatofibrosarcoma
Thin Thin Nwe	F	18	BAMF	Severe burns
Nai Na	M	33	BAMF	Unhealed fracture (left leg)



Maung Nay Linn and his mother at the Mae Tao Clinic (June 2011)

## Maung Nay Linn – 4 years old – congenital heart disease

*“...Maung Nay Linn’s mother says her youngest child’s illness causes her family great stress. She worries that his illness will be fatal and there is no money within the family to pursue ‘user pays’ medical treatment in Burma. Maung Nay Linn has advanced symptoms of heart disease - clubbed fingers and toes which are blue in colour (cyanotic). During his interview with BCMF, Maung Nay Linn wanted to run and play but he only lasted a minute before needing to rest to allow his breath to recover. Maung Nay Linn’s mother says that she wants her son to be able to play. Her hope is that he will get better so that he can be like other children his age...”*

**[Maung Nay Linn traveled to Chiang Mai in July 2011 for further medical investigation]**

<sup>3</sup> Please note this patient is funding his own surgery with the logistical support of BAMF

# June 2011: BCMF Patient Movement

In June 2011, BCMF organised the logistics for the [departure of five \(5\) vans](#) departing the Mae Tao Clinic. Forty eight (48) patients (plus their carers) were transported to Chiang Mai for surgery and follow-up (existing cases) and also for initial investigation and detailed diagnostics (new cases).

The departure dates and patient load were as follows:



7-month old Say Paw was born with a parasite in her eyes.

## BCMF PATIENT VAN - 2 JUNE 2011 (see [photos](#))

NAME	SEX	AGE	PROGRAM	CONDITION
Ah Htwe	F	3	BCMF/CDF	Congenital heart disease (heart surgery)
Pai Zin Linn Htet	M	6	BCMF	Renal condition
Zayar Linn	M	1	BCMF/CDF	Congenital heart disease
Di Di	M	2	BCMF/CDF	Meningocele
Kyay Lah Wah	M	1	BCMF/CDF	Congenital heart disease
Hla Pyit Win's baby	M	2m	BCMF/CDF	Meningocele
Paw Mu Paw (SMRU Case)	M	10	OTH/CDF	Meningocele
<a href="#">Mya Sandar Moe</a>	F	6	BCMF	Brain tumour (see <a href="#">video</a> )
Poe Kyaw Kyaw	M	13	BCMF	Bilateral eye condition (incl. cataract right eye)

## BCMF PATIENT VAN - 9 JUNE 2011

NAME	SEX	AGE	PROGRAM	CONDITION
Kyaw Zin Oo	M	13	BCMF	Lymphoma
Jun	M	14	BCMF/CDF	Congenital heart disease
Hnin Si Paw	F	5	BCMF	Ganglioneuroma (tumor of the nervous system)
Aung Htet Oo (SMRU case)	M	4	OTH/CDF	Congenital heart disease
Fa Ei Phyu (SMRU case)	F	7m	OTH/CDF	Congenital heart disease
Thant Zin Win	M	12	BCMF	Congenital heart disease (follow-up)
Cho Cho Mar	M	5m	BCMF/CDF	Congenital heart disease
Linn Let Kyaw	M	5m	BCMF/CDF	Heart disease and Hirschsprungs disease
Say Paw (see photo top right)	F	7m	BCMF/IRC	Detached retinas (due to parasites) & cataract
Ar Kar	M	7	BCMF/CDF	Imperforate anus

## BCMF PATIENT VAN - 16 JUNE 2011

NAME	SEX	AGE	PROGRAM	CONDITION
Myo Kyaw (see story next page)	M	7	BCMF	Acute Lymphoblastic Leukaemia (ALL)
Saw Bie	M	3	BCMF/CDF	Congenital heart disease (post-surgery)
Maung Chit Lwin	M	9m	BCMF/CDF	Hydrocephalus (post-op check-up)
Zayar Linn	M	1	BCMF/CDF	Congenital heart disease
Khant Linn Hein	M	8m	BCMF/CDF	Congenital heart disease
Tha Wah War (SMRU case)	F	2m	OTH/CDF	Congenital heart disease
Kaw Eh Tha Blay (SMRU case)	M	1	OTH/CDF	Congenital heart disease
Sandar Aye (SMRU case)	F	6m	OTH/CDF	Clubbed foot
Ngwe Yee Win Lae	F	2	BCMF	Soft tissue mass (right arm)
Tin Htun Naing	M	4	BCMF	Mass on neck

## BCMF PATIENT VAN – 23 JUNE 2011

NAME	SEX	AGE	PROGRAM	CONDITION
Naw Say Paw	F	6	BCMF/CDF	Congenital heart disease
Ye Ye	M	7	BCMF/CDF	Congenital heart disease/Downs Syndrome
Naw Kyi Win	F	15	BCMF	Neurofibromatosis (non-malignant)
Hnin Than Zin Thin	F	7	BCMF/CDF	Congenital heart disease (post-op)
Kyaw Eh Paw	M	18m	BCMF/CDF	Imperforate anus
Zin Tin Win	M	2	BCMF/CDF	Congenital heart disease
Zin Myat Noe Khaing	F	2	BCMF/CDF	Congenital heart disease/Downs Syndrome
Maung San San	M	1	BCMF/CDF	Congenital heart disease/Downs Syndrome
Myo Thi Dar Oo	F	4	BCMF	Eye condition (old case re-opened)
U Thaung Sein	M	55	BAMF	Throat cancer ( <i>BAMF logistical support only</i> )

## BCMF PATIENT VAN – 30 JUNE 2011

NAME	SEX	AGE	PROGRAM	CONDITION
Htoo Ku Paw	F	2	BCMF	Haemangioma
Mu Di Htoo	F	2	BCMF/CDF	Congenital heart disease
Than Htike Aung	M	2	BCMF/CDF	Gastrointestinal problem (colostomy)
Khin Mar	F	27	BAMF	Craniopharyngioma (non-malignant)
Zaw Htet Aung	M	16	BCMF	Bladder exstrophy (post-op)
Jue Jue Kyaw	F	26	BAMF	Rheumatic heart disease (post-op)
Phyo Maung Maung	M	4	BCMF	Acute Lymphoblastic Leukaemia (ALL)
U Kaw Week Da (monk)	M	27	BAMF	Heart disease
Mya Mya	F	14	BCMF	Congenital heart disease

May 2008



Jan 2009



Jun 2011



### Myo Kyaw Remembered...

*Myo Kyaw travelled to Chiang Mai for the last time in June 2011.*

*Sadly, he was given a terminal prognosis and he passed away at the Mae Tao Clinic 3 weeks later (in July 2011).*

In February 2008, 4-year-old Myo Kyaw was diagnosed with Acute Lymphoblastic Leukaemia (ALL). This form of leukaemia is common in childhood and has a cure rate of 85% in children. Myo Kyaw was referred to BCMF and commenced treatment in Chiang Mai soon after. Over the years, Myo Kyaw and his mother became part of the BCMF family as they regularly travelled to Chiang Mai for Myo Kyaw's chemotherapy and check-ups.

He was responding well to his treatment until 2011 when his condition deteriorated rapidly.

Despite her sadness, Myo Kyaw's mother says the time she spent together in Chiang Mai with Myo Kyaw was very special. There were periods when Myo Kyaw was well enough to play like other children his age. She also had the opportunity to learn how to speak Thai. Myo Kyaw's mother knows that everything possible was done for her son and she thanks BCMF supporters for giving her two and a half further years with her son that she would not have had otherwise.

At the end of June 2011, Myo Kyaw, pressed his hands together in front of him as a sign of gratitude and said...

**'kobkhun krap'** (thank you in the Thai language)

## June 2011: Meet some of our new cases...



Ga Chor – 9 years old - encephalocele

[Ga Chor](#) was born with a small mole-sized lump on his face. Now nine, Ga Chor's small lump has grown into a large facial deformity. His condition is known as 'encephalocele' - a congenital defect where the brain membranes protrude through a groove in the skull. Ga Chor's mother thought that his deformity made him unfit for education but he commenced school this year when a local migrant school told the family that he was welcome to attend.

When Ga Chor was 5 months old, his father died of suspected malaria. His mother has since remarried and has a total of six children. Ga Chor's family lease land to grow corn and they reside in a village on the Thai side of Thai-Burma border. Ga Chor's mother says she moved her family from Karen State for safety and improved prospects. She remembers times when she needed to run into the jungle to avoid fighting in her village in Burma.

Until recently, Ga Chor's mother was not aware that her son's condition could be treated. An NGO working in the area (*Help Without Frontiers*) noticed Ga Chor's condition and referred him to BCMF. Umphang Hospital (in western Thailand) facilitated his transportation to Mae Sot and Ga Chor went from there to Chiang Mai in July 2011 on the BCMF patient van.

Ga Chor is very shy but he tells BCMF that he doesn't get angry when other children tease him about looking like an elephant. He goes on to explain that he needs to be careful when playing because it is painful if he is hit in the face. Once his soft facial protrusion was knocked and he was rendered unconscious.

Ga Chor's mother shares that she had felt a sense of hopelessness regarding Ga Chor losing his father at such a young age and about his facial deformity. She explains that Ga Chor is a thoughtful boy who helps her cook and care for his younger siblings; the youngest is 10 months old. Ga Chor's mother hopes her son will be happy no matter what the outcome (of treatment) may be. She loves her son very much and this will not change if he remains the same or receives successful treatment.



**Yan Naing Linn – 17 years old – heart disease**

[Yan Naing Linn](#) has congenital heart disease. He dropped out of school this year because he could no longer cope with the walk which causes him severe shortness of breath.

Like his 4 younger siblings, Yan Naing Linn was born in Mon State, Burma. When he was 2 months old he experienced acute diarrhoea and his mother took him to see a doctor. The doctor told her that Yan Naing Linn had a [congenital heart condition](#) and they would need to save for corrective surgery.

Yan Naing Linn's father makes furniture from wood. He earns 5,000 Kyat (US\$5) a day but his earning capacity is seasonal (less in rainy season). There is not sufficient money coming in to meet all the family's needs let alone afford health care. Yan

Naing Linn's extended family help out with the cost of school for him and his siblings.

Yan Naing Linn says that he doesn't remember a time in his life when he did not feel tired. He recalls that he experienced shortness of breath when playing. By the age of 15 his symptoms deteriorated to include difficulty in breathing, palpitations and chest pain. This commenced a period of great financial outlay by his family to treat Yan Naing Linn's symptoms. The family was forced to sell their assets including the land they had inherited.

Yan Naing Linn's heart was failing and it was no longer working as an effective pump (congestive cardiac failure). This was causing his blood to become sluggish and thick requiring multiple blood-thinning medications to prevent clotting. The hospital treatments also involved performing regular venesection (blood-letting) to reduce the volume of fluid needing to be pumped by his overloaded heart. This obsolete technique for cardiac patients is not seen in developed world hospitals.

In May 2011, Yan Naing Linn was hospitalised after experiencing seizures. Seizures are a complication of advanced cardiac failure seen in the condition called [Tetralogy of Fallot](#). Seizures are caused when there is not enough oxygen circulating in the blood to reach the brain. His 8-day inpatient stay cost his family 550,000 Kyat (US\$550).

Yan Naing Linn's family despaired as they knew that he was in desperate need of life-saving surgery that they could not afford. His grandmother knew of a family whose child had received cardiac treatment through BCMF and she encouraged Yan Naing Linn's parents to take him over the border to the [Mae Tao Clinic](#) (MTC) in Thailand. Again, Yan Naing Linn's extended family came to the rescue and helped cover the cost involved in the journey to reach Thailand.

Yan Naing Linn's mother's greatest hope is that her son will get better. Yan Naing Linn is very shy, reserved and softly spoken. He is acutely aware of the great difficulty that his family has faced in trying to fund his medical costs. This leads Yan Naing Linn to explain that his only hope for the future is to one day pay back his family.

## JUNE 2011 ACTIVITY REPORT – MORE INFORMATION:

### PATIENT STORIES:

<b>Ga Chor</b>	<a href="http://www.burmachildren.net/our-cases/children/chor/">www.burmachildren.net/our-cases/children/chor/</a>
<b>Yan Naing Linn</b>	<a href="http://www.burmachildren.net/our-cases/children/yan-naing-heart-disease/">www.burmachildren.net/our-cases/children/yan-naing-heart-disease/</a>
<b>Mya Sandor Moe</b> (transferred 2/6/11)	<a href="http://www.burmachildren.net/our-cases/children/mya-sandor/">www.burmachildren.net/our-cases/children/mya-sandor/</a>
<b>Maung Chit Lwin's success story</b>	<a href="http://www.burmachildren.net/our-cases/success-stories/chit/">www.burmachildren.net/our-cases/success-stories/chit/</a>
<b>Field Update: Maung Chit Lwin's father killed</b>	<a href="http://www.burmachildren.net/2011/06/14/field-update/">www.burmachildren.net/2011/06/14/field-update/</a>
<b>Saw Bie's success story</b> (transferred 16/6/11)	<a href="http://www.burmachildren.net/our-cases/success-stories/saw-bie/">www.burmachildren.net/our-cases/success-stories/saw-bie/</a>

### VIDEOS/PHOTOS:

<b>BCMF Patient Van 2 June 2011</b>	<a href="http://www.burmachildren.net/2011/06/02/bcmf-patient-van-2-june-2011/">www.burmachildren.net/2011/06/02/bcmf-patient-van-2-june-2011/</a>
<b>Sandor &amp; Poe – a family journey (short video)</b>	<a href="http://www.youtube.com/watch?v=4Pxb4TfvZ2E&amp;feature=related">www.youtube.com/watch?v=4Pxb4TfvZ2E&amp;feature=related</a>
<b>What do we do - BCMF</b>	<a href="http://www.youtube.com/watch?v=6GntYMRq6PE&amp;feature=related">www.youtube.com/watch?v=6GntYMRq6PE&amp;feature=related</a>
<b>Hydrocephalus</b>	<a href="http://www.youtube.com/watch?v=b4drytAilms&amp;feature=related">http://www.youtube.com/watch?v=b4drytAilms&amp;feature=related</a>

### MORE INFORMATION

<b>About BCMF</b>	<a href="http://www.burmachildren.net/about-us/">www.burmachildren.net/about-us/</a>
<b>Sponsor a Van</b>	<a href="http://www.burmachildren.net/get-involved/sponsoravan_2011/">www.burmachildren.net/get-involved/sponsoravan_2011/</a>
<b>More links</b>	<a href="http://www.burmachildren.net/links/">www.burmachildren.net/links/</a>
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<b>BCMF Youtube</b>	<a href="http://www.youtube.com/burmachildren">www.youtube.com/burmachildren</a>
<b>Mae Tao Clinic</b>	<a href="http://www.maetaoclinic.com">www.maetaoclinic.com</a>
<b>Diagnosis Critical</b> (report in English)	<a href="http://bit.ly/pYDEDt">http://bit.ly/pYDEDt</a>
<b>Diagnosis Critical</b> (report in Thai)	<a href="http://bit.ly/piytch">http://bit.ly/piytch</a>

