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Vol. No.4

June 2011

Keeping Children Healthy

Message from Father Shea

Kate is scrambling to print this latest newsletter before the end of the month. She asked me to write up something about caring for HIV children. As old folk are wont to do, my mind wandered

back eleven years to the beginnings of our work with children with AIDS.

And, in the beginning, all we could do was to stand helplessly watching a poor child struggle desperately in pain; trying to regain health and life. Little guys like Dutch Michael and Kirk; girls like Nam Fon died from lack of medicine and lack of knowledge. Then Fr Ron Nissen of the Marists of Australia wrote me to tell me that he had a nurse named Kate Introna, who wanted to volunteer for a

year. It was with Kate's knowledge and persistence that we were finally able to get anti-retroviral (ARV) medicine from first Doctors Without Borders (MSF) and then the Thai government.

The AIDS virus can become resistant to some of the ARV medicine and is still deadly despite advances in knowledge. We lost two teenagers last year from complications from AIDS. Now however we have dedicated doctors and nurses in the hospitals in northeast of Thailand who quickly treat anyone who has HIV/AIDS. Specialists from the Srinakarin University Hospital in Khon Kaen are of immense help with the various illnesses that creep into these children's lives.

God has been good to us, and although we are not yet able to cure AIDS, we have the wherewithal to deal with the virus and its terrible effect on young lives.

God bless you all Fr Michael Shea C.S.s.R

In the photo to the left of this paragraph, Fr Shea is standing with Ying and her mother Fai. Ying's father died from AIDS and she and her mother had been ostracised to live at the edge of their village with no running water or electricity, in a tin shack. Ying was unable to go to school as she was HIV positive and her mother was unable to pay for her education. Ying came to live at Sarnelli House when she was 9 years old and she was started on her ARV medicines

at Sarnelli House in 2003.

She was one of the older girls who at 11 years used to help the smaller ones with meals and baths. Fai, Ying's mother developed TB but with the help of Sarnelli House she was treated successfully and was also started on her ARV medicine. When Ying was 13 years old and her mother was well again they were reunited and Ying went back to live with her mother, after Fr Shea built them a new house. Ying completed her education at Rosario School with the financial support of her sponsor. Fai found work with the Good Shepherd Sisters in Nongkhai making handicrafts.

Ying is now 19 years old and is in her final year of senior high school and academically she is doing extremely well, she is bright, personable and enthusiastic. When she finishes senior high school she wants to go

on to study nursing and eventually come back and work at Sarnelli House.

For the 81 children living with HIV/AIDS at Sarnelli House

maintaining their health is one of the top priorities. Ensuring that they have access to medical care and treatment from the time they arrive at Sarnelli House can keep them healthy, and give them opportunities like Ying, in the future. Over the years children have arrived at Sarnelli House in varying states of ill health, some dumped at the doorstep by fearful or uncaring relatives, others referred by hospitals or welfare workers. staff have seen and cared



for children severely malnourished, racked by TB, covered in skin infections, unable to walk and scarred by shingles. Treating these children and returning their health back to them has been a long struggle. It has only and is still only achieved with a team effort.



Medicine rack for 6am and 6pm ARV medicine

From the beginning, Sarnelli House has worked with the doctors and nurses from the Nongkhai Provincial Hospital which is the closest hospital to Sarnelli House. Professional relationships have been developed over the years with the hospital staff and awareness of the treatment for HIV/ AIDS has improved and strengthened. When the Sarnelli House van pulls up at Nongkhai Hospital and disgorges a motley bunch of kids they are welcomed and directed to the outpatient clinic, the pathology department, the dental department or the emergency department (ED) depending on the problem. If a child's illness is severe and requiring specialist assessment and treatment then the more comprehensive services of the Paediatric Infectious Diseases Team at Srinakarin Hospital, Khon Kaen University are used. Despite a 2 hour drive to get there this team has provided much support to the children and staff of Sarnelli House and many sick children are now well and attending school thanks to them.

The caring staff at Sarnelli House

The staff who currently manage the health of the children are K.Noi, Nurse Eeu and Ms Jeap. Both K. Noi and Ms Jeap have been working at Sarnelli House for the last 10 years and have no formal nursing qualifications. They have been trained on the job from the beginning when we first set up the system for giving out the ARV medications. Their roles have evolved to become more than giving out tablets and they can now navigate themselves and the children around the Thai health care system with ease. Nurse Eeu has been working at Sarnelli House for the last 7 years and is about to go on maternity leave for 3 months with her first baby.

Together they manage all the different appointments for the 81 children with HIV/AIDS who attend 2 hospitals and varying outpatient departments. All the children must be correctly registered at each hospital and appointment cards and registrations kept up to date. Each child visiting the hospital to attend the ear nose and throat department, the dental, rehabilitation, or counselling clinics has to be individually registered at that hospital visit so their file can be retrieved. The girls keep a track of all the new medications prescribed on each visit. They store it in the child's individual medication box with their ARV medicine, and put it into little containers that are specially marked with the times of the day so the children get their medicine at the correct times.

Along with managing hospital and doctor visits the health staff at Sarnelli House load up the ARV medications every Friday morning into a morning and evening dosette box for each child for the week ahead. Updating the labels on individual storage boxes and on the wooden rack in the medicine room where the ARV medication is placed before the 6am and 6pm dose is given, is also an important task. The evening staff can then check the medicine against the label to ensure there is no mistake or mix up with the ARV medicines. Taking an incorrect dose or someone else's tablets can increase the risk of the virus becoming resistant to that particular ARV and affect the child's lifelong treatment.



Individual health care folders are maintained at Sarnelli House. On the front of the file is a photo of the child, the kids want it updated every few months to keep themselves looking good and they especially want the old photo of when they were sick to be removed. Inside the folder a record of childhood vaccinations, monthly recordings of weight and height, documentations of visits to the doctor, referral letters, and blood results are filed. Most importantly there is a record of the current drugs the child is taking and the most recent CD4 blood test. This file accompanies the child to any visit to the hospital.

A day at the hospital

To monitor the children's health they have regular 3 monthly hospital visits and they have been divided into 3 groups. Group 1 and 2 go to Nongkhai Hospital for their blood



tests, physical examinations and collection of their ARV medicines, Group 3 travels to Udon Thani to a government orphanage mid way between Nongkhai and Khon Kaen. For the children in each group this means a day off school.

The trip to Nongkhai Hospital for Group 1 and 2 starts with boarding the van at 7am without eating breakfast and going straight to the pathology lab and being jabbed in the arm for a blood test. Their resilience to pain is inspiring and the children rarely cry despite having faced more than their fair share of needle jabs. A breakfast of fried rice in one of the hospital meeting rooms follows and then begins the wait until the ARV medicine is ready for collection. Keeping the children occupied in a meeting room with only tables and



chairs and limited staff is a challenge. K.Noi and Ms Jeap have to retrieve blood results and document and check the 3 months worth of medicine given to them by the hospital. Older children are left to supervise the younger ones. Some of the children have a very limited attention span and by the time they have thoroughly explored the room and pressed and opened everything that can be pressed and opened they are bored. Numerous trips to the bathroom follow and detours are frequently taken around the large and very crowded outpatients department. Some kids doze on the table, the girls do each other's hair and the little boys are constantly followed out of the room as they make their escape and appraise the patients and the nurses doing their work. Boy Lek invariable hides under a nurse's desk and no one can find him, another little boy comes back from the toilet with wet hair and wet clothes; the temptation of running water too much to resist. Finally after sometimes 3 hours, the wait is over and the doctor's examination is next. Everyone is given their medical folder and marched in single file into the examination room and one by one they sit in front of the doctor who listens to their chest and signs the chart. The medicine is picked up and it's off to lunch to eat as many bowls of noodle soup as they can.

Group 3 have a longer day as they have further to travel but they have a shopping trip at Big C shopping mall in Udon Thani at the end, which is a big treat. For some of the newer children it is the first time they have been on an escalator and when they walk past the automated kids' rides their eyes are round and their mouths open. Everyone travels down in the school truck where the sun beats in through the open sides and the winds dries us all out in the hot season. In the rainy season the plastic is pulled down to prevent the rain getting in and everyone wilts with the increasing humidity. Despite these discomforts Group 3 is the most coveted group to be in, as a whole day travelling and a trip to the mall is on the top of everyone's list of the best things to do.

Hope for the future

Dtan is one of the sickest children living with HIV/AIDS at Sarnelli House now. She came in August 2010 and she is 13 years old. Her mother had died from AIDS and her father was caring for her, she has no siblings. However her father remarried and as is often the case, the newly formed family



did not want Dtan. She was sent to live with her aunt who was poor and had 3 children of her own. Her aunt could not care for her particularly as Dtan was getting sicker. Dtan has had meningitis and her cranial nerves supplying movement to her eye and her mouth and her swallowing reflexes have been damaged, perhaps permanently.

She has difficulty opening her eyes and her right eye is gradually losing sight, her speech is mumbled and her swallowing is slow. Dtan is now on ARV medications and she has had many hospital admissions since coming to Sarnelli House. It is difficult to see whether Dtan is happy because she has trouble smiling as one side of her mouth is pulled down. As well as the physical problems Dtan is going through, coping with the psychological ones must be at times overwhelming for a 13 year old girl. Adjusting to the noise and mayhem that is Sarnelli House after coming from a family environment is difficult for any child. Becoming accepted into the little cliques that are present and making friends is a rite of passage but for a child who is sick and cannot speak and see normally it becomes a huge hurdle. However, Dtan is fast becoming independent despite her look of frailty, she is at home alone with the housemothers who do the laundry, cleaning and the cooking during the week, and she has been taught how to make paper origami swans and hearts and to crotchet. She is also quick to take advantage of any trip into Nongkhai. Dtan is taking two steps forward and one step back and regaining her health is a slow and precarious process. We hope that she will be afforded the same opportunities as Ying in the future as we nurture her towards health and happiness with everyone's help.

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Written by Kate Introna, June 2011

Sarnelli House