Sarmelli Ho

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Message from Fr. Shea

In this issue, our intrepid nurse Kate, is going to write about our children with HIV-AIDS. and how the antiretroviral drugs (ARV) has affected them. The first few years of our work with adults with AIDS and their children, was fraught with frustration. There were no ARV drugs available for people suffering with AIDS. Countless adults and children whom we tried to help, died of T.B. meningitis, and intestinal diseases. In the early 2000's, we had 17 women drawing and painting artwork in batik to sell as a means of livelihood. Only 4 have survived. At Sarnelli House young children and babies died as we watched helplessly. Finally, we heard that the Minister of Health for all of Thailand was visiting Nongkhai. Our young children wrote her a letter, asking for medicine and toys. The next day, we sent a van full of children and some house mothers to see her at the main government building. One of our housemothers, then a husky young lass, plowed through the phalanx of body guards, and the oldest girl gave the Minister of Health their letter. The next day, politicians were showing up with candy, clothes and games for the children. It seems that there was a warehouse in KhonKaen (a city in the northeast of Thailand) filled with ARV medicine, ready to be used, only the medical people had no idea how to prescribe the stuff. Kate got in touch with Doctors without Borders who came to give us useful knowledge about treatment for AIDS. I will let Kate continue the story.

May God Bless you all Fr Mike

Growing Up Positive

So much has changed since Fr Mike started accepting sick and abandoned children in 1999, many of them thin, ill and weak with AIDS. Not least is the improved state of health care in Thailand and the breakthrough of sustainable treatment for HIV throughout the world. What was once a death sentence has been turned around to become a chronic disease in most first world countries. With the advent of AntiRetroViral (ARV) medications and the advances in preparations and effectiveness, one tablet a day for many people is adequate to keep the virus suppressed. At Sarnelli House, children with HIV first started treatment in 2002. Before 2002, four children died horrific deaths as ARV medications were not freely available in Thailand. At one stage, 70 children with HIV were living together in one house in DonWai. They were given their ARV medications by the house mothers and it eventually became an inescapable routine in their lives. The children were woken at 5am and by 6am they were in line to take their handful of tablets. In the evening at 6pm it was the same - they were called in from playing and quickly gulped their tablets down to return to their interrupted play time. Initially the pill burden for these children was very high - some taking as many as 10 tablets morning and evening. Trying to coax the children to swallow them was a real difficulty. Over time, thanks to the diligence of the housemothers, the availability of the drugs, and the access to the doctors and nurses at the hospitals in Nongkhai and Khon Kaen, the children's health began to improve. The terrible fear that they would die before they reached young adulthood was lifted. The focus of care started to change to education and preparing them for the outside world.



Sarnelli House

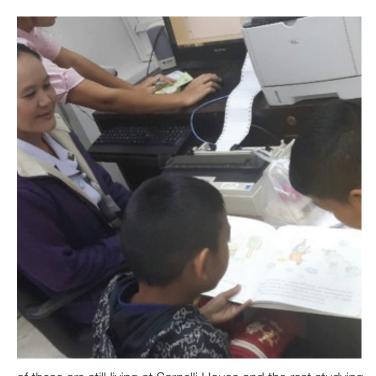


However, one of the main challenges was, and still is, to educate the children living with HIV about their illness and to try to reduce the stigma associated with it. They have to learn how to prepare their own medications for the week ahead, how to recognize their particular set of tablets and to check each time they take them. They also have to understand the reason they were taking the medication, why they are going to the hospital regularly and having blood tests. CD4 and Viral Count results are talked about frequently – these blood tests are used to monitor the effectiveness of HIV treatment – and for the children to understand their treatment, they must understand these test results. There are additional tests like IQ measurement, eye sight checks and extra blood tests for cholesterol and organ function all of which have to

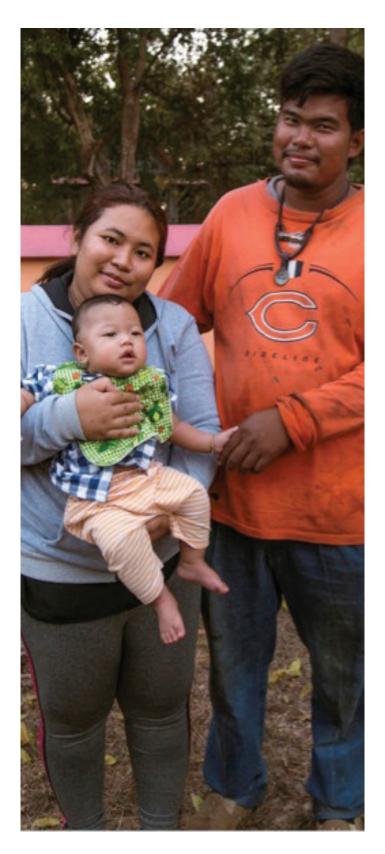
THE EYE

be explained. Many of the children have to be revaccinated or their vaccinations updated so there are always more injections for them to endure.

Between 2002 and 2010, the number of new children living with HIV referred to Sarnelli House was 81. Sadly nine have already died, and only one was unrelated to HIV. Poor access and poor adherence to ARV medication are among the reasons why the HIV virus becomes resistant. It is sometimes a struggle to persuade teenagers and young adults to continue taking their ARV medications once they have left home. At Sarnelli House there are now a number of young adults who have left and are studying or working in different cities away from the support structure of the Sarnelli family and who have poor adherence to taking their medicine. The resurgence of tuberculosis (TB), shingles and other AIDS related illnesses is a definite possibility and in some cases they have already been treated for these illnesses. It seems, for some that it is only having been critically ill and surviving that they become more committed to taking their ARV medication properly. Eighteen teenagers (20% of the overall number of children with HIV who have come through Sarnelli House) are not taking their ARV medications properly. Five



of these are still living at Sarnelli House and the rest studying or working outside of Nongkhai. Eleven are boys. It is hard to understand their reasoning and some of them are unable to articulate it themselves. Many have their past stacked against them. Due to brain infections from AIDS, possible side effects of early forms of ARV medications, a delayed start of school due to ill health and the constraints of living in an orphanage their intellectual capabilities have been diminished. When they grow into their teenage years these problems often manifest as low self esteem, increased risk taking and poor communication skills. Research also shows that some of the reasons for poor adherence include a lack of knowledge about the drugs, boredom with the pill taking, denial, fear of



disclosure and not managing the medication i.e. forgetting to carry it with them and not taking it on time.

These young people are huge concerns to the staff at Sarnelli House. The dilemma is how much to continue helping them if they will not help themselves. The staff at Sarnelli House keep in contact with those who have left and continue to encourage them to return to the doctor and to re-commit to their treatment.

It is with added urgency that we try and prepare the next batch of young children with HIV to equip them for their futures. Compared to the eight year time frame of 2002 to 2010 when 81 new children were living with HIV, from 2010 to 2018 only sixteen new children living with HIV were referred for care at Sarnelli House. This is a huge decrease and reflects Thailand's goal of meeting the WHO (World Health Organization) target of reducing mother to child transmission of HIV to less than 2%. Thailand is the first Asian country to surpass this WHO target by reducing rates. Hospitals throughout Thailand now test all pregnant mothers for HIV as part of their prenatal care and if they are positive for HIV they can begin treatment during pregnancy and also treat the baby on delivery.

Despite this success rate in Thailand, Sarnelli House still has young lives that need to be strengthened and educated about living with HIV. Currently twice a year in the school holidays at Sarnelli House expert groups attached to the hospitals come and give two days of seminars and workshops to the young adults living with HIV and address all these issues with them. There is role playing, group work and videos used to engage their attention. Often times there are courageous young adults with HIV who come and disclose their HIV status and talk to the teenagers about how they have coped with the illness and the treatment. These are big lessons to learn. Reducing the stigma of living with HIV and acknowledging the shame and sorrow of abandonment is just the beginning. There is also the precarious nature of potential relationships and for some teenagers the future is still difficult to face.

For all these challenges some young adults are able to successfully navigate these turbulent years and the future looks bright. In 2003, a little girl of ten years old came to Sarnelli House from another orphanage because the staff and village people were afraid of HIV. She developed two severe cases of shingles and she still bears the awful burn like scars on her body. She also had TB and was treated and eventually started on her ARV tablets in 2003 with the other children at Sarnelli House. She had learning difficulties as she started school very late because of illnesses and today she can only read and write minimal Thai. During her hospital visits, she was nominated to be a peer educator for other teens living with HIV. Despite her poor academic record her love and compassion and kind nature shone through. After finishing Grade 12 in 2014 she completed a 3 month cooking and Thai massage course and moved to the south of Thailand for work. Now she is married with a baby. Neither her husband nor her baby are infected with HIV, and the little family have moved back to be with their bigger family at Sarnelli House where they both work. They provide a wonderful example of moving beyond the stigma of HIV.

Moving on...

In May 2018, 15 students met to discuss their academic futures at Sarnelli House. They were all young adults who had grown up there. The meeting was developed by Br Keng and Brian O'Riordan as part of the education team along with Ms Dtim. Five of the students are already studying in University but ten of them are entering into third level education for the first time. Of these 15 students, seven of them are living with HIV. They have been nurtured, cajoled and encouraged to where they are today - about to leave the nest and test their future. This year the range of topics the students are studying cover Nursing, Business Management and Tourism. There will undoubtedly be some slip ups along the way, but this is to be expected. However the students have had their responsibilities made clear to them and they will visit Sarnelli House regularly for their monthly expenses ie, rent, food, tuition fees and they will in return bring their receipts back to be cleared at the office. In addition to those students in the accompanying photo there are two young women starting their internship through Pimali Hospitality School at 4 and 5 star hotels in Phuket and Buiram. Two other young men from Sarnelli House have just completed their internship, again through Pimali Hospitality School, and both have been offered jobs at a hotel in Bangkok. We wish them well and are so proud of them. It is with gratitude to their sponsors, donors and benefactors that they are able to pursue their dreams and to the staff of Sarnelli House who have walked with them.



Building update

Many thanks to all those who have generously helped with our new building for the girls of Vienghuk. The building now has a roof and is progressing but the unexpected rain in the last month has put us behind schedule. School has started back and the girls are disappointed they are not safely ensconsed. All going well the expected completion is for the end of June.



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If you would prefer to receive this and future quarterly newsletters by email or be removed

from the mailing list please email to volunteer@sarnelliorphanage.org

To protect the privacy of our children we have not used their real names or identified them in photos.

Written by Kate Introna, May 2018