

Hope Happens Here

Battle with the consequences of severe neonatal gut infection

Theo Poulton¹ and *Prakash Mandhan²

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ثيوپولتون وبراكاش ماندان

This article is based on an interview with the parents of the child conducted in August 2010 by Theo Poulton, a Year 12 student at The British School Muscat, on placement at Sultan Qaboos University Hospital. It was edited by Dr Prakash Mandhan, his supervisor and the neonatal surgeon in charge of the patient.

“HAVING CHILDREN IS NOT ONLY A BLESSING, but also a joy for parents and grandparents” said Mrs. A. Her son AH, now an eight month-old boy, has spent almost 90% of his life in Sultan Qaboos University Hospital (SQUH). AH and his twin brother were to be the couple's first children so, naturally, they were very excited as they awaited the birth of their sons. However, this excitement was dampened when they learnt that their son, AH, would need an operation.

AH was born at SQUH in January 2010 and since then has undergone three major and several minor operations. He was born prematurely as the second twin; this meant that he not only weighed less than a normal newborn, but was also more susceptible to infections. Any procedures he underwent would be higher risk to him compared to a full-term baby.

When he was 12 days-old and in the incubator in the Neonatal Intensive Care Unit (NICU), the nurse noted that his abdomen was enlarged and soon green coloured bile started pouring from his mouth. A quick assessment by doctors in the NICU together with X-ray and blood test findings suggested that he had an intestinal infection. The neonatal surgeon on duty was called and AH immediately underwent an emergency operation to

save his intestine. “When the neonatal surgeon told us about AH's condition, the necessity of urgent operation and the expected outcome, we were very worried and prayed to Almighty God to save his life” said AH's parents. “I was so worried because as it was such a big operation for such a small baby (1.4 kg). I wondered, how can surgeon operate on such a small baby?”, added AH's mother. While the senior neonatal surgeon, two senior anaesthetists and a couple of senior nurses were trying hard to save AH's life, his parents and family members were praying and waiting for news about the baby. Nearly 95% of his small intestine was seriously infected and the germs had already affected his whole body. The neonatal surgeon had to remove his dead small intestine and then tried to save some of other affected parts of intestine in order to give AH a chance to live and grow unaided. After the operation, AH was given very strong antibiotics and full intensive care support to give him a chance to fight against the deadly infection. Unfortunately, within 48 hours, he deteriorated further and needed a second operation. During this procedure, all except the first ten centimetres of the small intestine was found to be dead. It was a very hard decision for the surgeons to make, as well as for the parents, but since this was the only option to save his life, his entire dead small intestine was removed in the hope that once he was cured of the infection, he could be offered other alternatives. This left AH with only a very small percentage of the 250 cms of intestine of an average full-term newborn. “I remember, my wife was shocked after she had this news about

¹The British School, Muscat, Oman; ²Department of Surgery, Sultan Qaboos University Hospital, Muscat, Oman.

*Corresponding Author email: kidsurg@squ.edu.om

AH and so was I, but since we had no other option and we wanted him to survive, we made this hard decision. It helped to hear that there would be some options afterwards for AH to get an intestine” said AH’s father, an employee in a private company.

Despite this second operation, AH’s health was not good in the following few days. His father said, “We feared that we were very close to losing him, but we had great confidence in the doctors in SQUH and also hope from Almighty God that he would be alright”. He also said, “It was through our hope and the efforts of the surgeons, doctors and nurses that he survived and within a week he was a different boy.”

During this difficult period, AH’s father said that they had great moral support from family and friends. AH’s mother agreed and added, “The most important thing was that my husband was there for me and that everyone in the Unit was trying his/her best for our son”. She continued, “When we looked at our twin sons in the neonatal unit, we always felt more protective of AH due to his condition. “I used to look at him, touch and cuddle him for hours to give him loads of support and love as he was my very tiny and cute baby,” said AH’s mother.

Due to the shortness of his small intestine, AH was now dependent on intravenous (IV) total parenteral nutrition for his supply of basic nutrients with the paediatric gastroenterologist taking over this special care. After a few weeks, it was time for the surgeon to restore AH’s intestine so that he could be started on oral feeds. “Based on our previous experience, this time we were more confident and less worried about the operation since we had great trust in AH’s surgeon, who had already operated on him twice”, AH’s father commented. “We had more hope now that AH would be able to have some feed and grow like his brother”. AH’s third operation successfully rejoined his 10 cm of small intestine to his large intestine and also made a temporary hole in his stomach for supplementary feeds.. “AH could be started on small feeds ten days after his third operation and we were very excited on that day” said his parents. “When I saw the nurse giving him his first feed, I was thrilled”, said AH’s mother. “I was imagining joyfully that soon I would be able to feed him myself”. After a few days, his feed was increased slowly and he was also removed from the incubator as he was improving and looking well.

Time flew by. At eight months-old, AH now

weighs 5.0 kg and receives nutrition from IV drips as well as from the tube into his stomach. “Although, he does have very minor problems with the tube in his stomach and with the central line for his IV feeding (which is very close to his heart), overall he is doing well”, said AH’s mother. By August 2010, AH had had four operations and his parents had more hope for his future health.

AH has spent most of his life in SQU Hospital, his mother almost constantly with him. She is a teacher, but unable to fulfil her professional commitments due to AH’s condition. Her husband has been a great support and they share the care of AH and his twin brother at hospital and home. AH’s mother said that although the care in the ward was good, she sometimes felt frustrated at not being given all the details about her son’s condition, “I like to know everything about my baby and his condition. Maybe more junior staff are not used to being asked about every little thing. It’s not only the doctor’s decision. As his mother, I would like to be involved in his care plan”. She felt that the consultants did understand her feelings and did provide the information she wanted. Her husband agreed, saying, “For us, we would like to make the decisions. If they decide to operate on him and we are not convinced, then we will say no. I remember, when the surgeon said AH needed one more operation (to connect AH’s small and large intestines). He explained the risks and benefits. It took us some time to decide, but finally we agreed with him. I think it is better to make the decisions yourself rather than leaving it to others”.

As for the overall care and support given to AH at SQUH, AH’s mother said, “I feel it is really very good especially from the consultants, such as the paediatric surgeon, the paediatric gastroenterologist, the neonatologist and the paediatrician”. It has been a great experience for us to see what a great team of doctors and nurses we have here. Everyone at different levels has been very helpful and supportive to us. The hospital administration has also been very cooperative for the supply of consumables, IV feeding and medicine for our son”.

AH is now at home on IV nutrition, but regularly comes to SQUH for evaluation. The hope is that AH can have an intestine transplant, using part of the small intestine from his twin brother or a parent, so that he can have a chance to grow and survive without IV nutrition. One of the major disadvantages of IV nutrition is that it affects the

liver functions and can eventually cause liver failure, and the need for a liver transplant. Up to now, there have been quite a few intestinal and liver transplants in children all over the world and the results are very encouraging. However, this treatment modality still needs more development before it becomes safe and easily available.

“Since there is no facility for intestine and liver transplant in Oman, we have been in touch with transplant teams in Europe and America for our son”, said AH’s parents. “The doctors from Europe have asked us to send the medical reports and soon, inshallah, we will go and see a transplant team in order to get an opinion for AH. “I have done a lot of research and reading on the Internet about intestine and liver transplant”, said AH’s mother. “Although, I am not very comfortable with the final results, I have

gradually become quite convinced about the need for it. Earlier, I was totally against the proposition when the consultants first suggested it. It is going to be a huge burden on both of us financially as well as socially as we are the only earning members in the family. Finally, we are a bit concerned about the care AH will need after the transplant. It is going to be very tough and hard on both of us to travel to Europe for post-transplant care hence we hope that transplant doctors in Europe will make a team with our surgeons and gastroenterologists in SQUH, so that we can get very similar care right here in SQUH. I have seen the hard work of our doctors and nurses in SQUH and we have a lot of confidence in all of them. We only wish this transplant could happen as soon as possible so that our son can have a more normal life”, concluded AH’s mother.