

When the pieces of the puzzle fit

Dar es Salaam, June 2017

In June I travelled to Dar es Salaam with friends who made the House of Hope financially possible. With Dr. Pam Follett, the American neuro-paediatrician who was one of the founders of this initiative, I took an international flight to Mwanza, where we visited the hospital that requests us for 600 shunts each year. The surgeon there was trained by neurosurgeon Dr. Shabani from MOI, our partner in Dar es Salaam. There I met Janet and Walter, a Tanzanian couple, who, in addition to helping children with cancer, are also committed to supporting our children. They have set up FOCC, an organisation that really wants to make a difference. Along with the Tanzanian parent group ASBATH, they were the chief architects of the project in Mwanza. FOCC works with volunteers who are present everyday in the hospital wards. They have a hospital badge and have access everywhere just like other staff members. Two bus stops away from the House of Hope, FOCC started a day centre where parents with very sick children can come for physiotherapy and support. An exceptionally positive and moving initiative that also works with volunteers. Sipa, who currently does the administration for ASBATH, also gives up her free time here during the weekend. While the children receive physiotherapy the parents receive training to make saleable products so that they can start up a small business to meet their financial needs. Beautiful design items. I bought out their entire little shop!



Parents at FOCC



The shop in FOCC



In MOI Shabani seeks solutions

Once again, it was a beautiful tale of highs and lows in our fight for our children. There were lows too. Because in all that one does, there is a great risk of undesirable side effects and corruption. For a long time, I thought that I could help by merely donating shunts. You can't make a hash of things with a shunt, I thought then. But it is not as harmless as that. A shunt is a wonderful remedy when a child has acute overpressure in the brain, but to operate a child unnecessarily is criminal and, above all, bad medical practice. What requirements can we demand from surgeons who use our shunts? Quality standards and selection criteria... Yes, the minimum is that the shunts may not be sold to the parents. In Dar, this appears to be difficult to check up on. Fifty of our shunts were stolen in MOI and sold to desperate parents in the black market

Even worse was the fact that one of Shabani's assistants forced parents to buy expensive American shunts impregnated with antibiotics in order to operate the child. While parents and volunteers went about fundraising to raise these astronomical sums, the children were left un-operated and went blind as a result.



Parents and their children receive training while they wait in the MOI neurosurgery clinic.

I fear that the surgeon receives a lot of money from the shunt dealer for each impregnated shunt that he places. I have reported all this to Dr. Shabani and, together with him, we are looking for ways to prevent this happening in the future. We have already informed the parents in the hospital wing, the FOCC volunteers in the wards, ASBATH and the new Cure coordinator that postponing surgery is not an option and that our Chhabra shunts are good and have proved their efficiency. It is not the shunt that determines success but the quality of selection, the sterile conditions in the operation theatre, preparation and performance by the surgeon. Therefore, the doctor is more important than the type of shunt.

Haydom, July 2017

Now I am going to Haydom and back to attend a seminar on spina bifida and hydrocephaly. Haydom is a small town in the middle of Tanzania that has been built around a hospital with 400 beds. Norwegian missionaries have planted it there in the middle of nowhere in the 60s. I have been there before, more than 15 years ago. I especially remember the 6 to 7-hour long route along bad and dusty roads. The hospital had a good reputation and a promising website. They had a surgeon who could place shunts. A European nurse who had been working there for several months already discouraged me to start something there for our children. She told me that because of the lack of nursing the most basic care wasn't available and that children die of infections on overcrowded wards. This is why I decided to start in a very modest way. I gave them a number of shunts and organised a continence training from CCBRT Moshi, our project at the foot of the Kilimanjaro. Our small project in Haydom worked for a while but I didn't hear more about it. The cooperation was supposed to have ended as CCBRT didn't think that the people in Haydom were still interested.



Most of the children look well

Until, out of the blue, I was contacted a few months ago by Theresa Harbauer, a young German paediatrician who ended up in Haydom 5 years ago and worked there for 2 years. At the request of the then Norwegian director she started to work with our children. And if I am to believe her, she started a real spina bifida team there. When I ask her why she has a special interest in children with spina bifida and hydrocephaly she answers straight away: for the parents, they are fantastic. It is her project that I want to visit now, 3 years after she left Haydom. Exciting as sometimes these initiatives stop quite abruptly when the central person leaves or a new management team enters.



Dr Theresa Harbauer started a Spina Bifida team in Haydom



More than 40 families attend the conference.

I see this initiative from Theresa as an unexpected gift from god in the sometimes lonely battle for our children. It makes me happy. And, Haydom works! More than 40 parents have turned up and a lot of their children are doing very well.

Colleagues from our projects from Moshi, Arusha and ASBATH are also present and impress me by their engagement and enthusiasm. The whole ALMC Team that supports Child-Help is there and CCBRT Moshi supported the parents financially by paying back their transport costs.

They sent Shedrack Domingo, a physiotherapist and paid the ALMC people to provide training and care here.

What a fantastic bundling of forces. Henry, the physiotherapist of Haydom animates and organises all this. He knows all the parents and children by name. He knows their history and their worries. The parents attend lectures, training courses and are divided into discussion groups. Shedrack provides advice on technical aids like braces, custom made chairs, shoes. He performs accurate measurements for devices and writes it all down in his book. He also knows some nice techniques to get the parents actively involved in the group discussions.



Shedrack has nice in house techniques to get the parents actively involved in group discussions

In the meantime, Theresa examines the children one by one. If necessary, she examines the kidneys with an ultrasound. Most children are doing well. One has to be circumcised as the catheterization doesn't work well. A 16-year-old boy is dizzy without obvious reasons. Another has had two shunts implanted but one isn't working. Catherine performs 4 operations on the second day. Here the iron is forged when it's hot as these very poor parents can't get to Arusha. What can be done now, what can be implanted now, is done straight away.



Dr. Theresa and Henry examin a boy with Spina Bifida

Theresa has become a real tropical doctor who when it is a matter of life and death performs surgical interventions herself. Dr. Catherine has taught her how to place shunts as when Theresa was in Haydom, there was nobody who could or would do it. Theresa also performs ultrasounds on a small machine that she brought from Germany and which she left behind for the hospital. She has printed all our protocols and documents and studied the continence management programme.



Theresa and Henry have put a soul into the project

comes together. And this puzzle in Haydom fits. A spina bifida project at 6-7 hours from Arusha, initiated by a young German doctor. Not obvious as shortly after she left Haydom, a Dutch doctor tried to bury the whole project but luckily failed. Henry, supported by two nurses, the paediatrician and the surgeon continued regardless.

Theresa asks me to address the parents. I made a photo presentation of a number of adults with spina bifida. I want to bring these parents hope and love as the main elements in the care for their children. I tell them about Margo, my successor as president of IF, who has spina bifida herself and is now in her fifties and is not only a paediatrician but also a geneticist. I introduce them to Franscesca who looks after 80 children with Spina Bidifa

A lot has changed in Haydom. The Norwegian parents of their deceased child, Leena, have financed the building of a beautiful and spacious children's ward "the Leena ward". The hospital now has, besides Henry, their own paediatrician and a surgeon who are involved in the care for our children. They might be missing a social worker and an occupational therapist, but this could become a complete spina bifida and hydrocephaly team.

Theresa is enthusiastic and intelligent, modest but bold. She listens and believes in the potential of children and their parents. Has enough doubts to not be too sure, because that can also be dangerous in the medical world. It is a lively combination which I secretly enjoy as we, together with IF and Child-Help have sown some of these seeds in the distant past. CCBRT, ALMC together with Child-Help have started spina bifida and hydrocephaly here. They have partly made possible the beautiful work of Theresa here in Haydom. Through ALMC they received the shunts and the necessary incontinence material.

I feel like one of the missing pieces of the puzzle that now comes together. And this puzzle in Haydom fits. A spina bifida project at 6-7 hours from Arusha, initiated



In between the examinations and discussions, the children play

in a boarding house. How Olga, after finishing her psychology degree successfully has become a rehabilitation doctor and is now married with two children. On a photo I show the director Jeffrey Tate of the opera of Naples and tell about Amina who has become youth leader within ASBATH ... all people with spina bifida who despite their severe disability lead a full life. To finish off I show the beautiful drawing that Bert Dombrecht made for our SHIP work, in which all important partners in care are in the same boat. I ask the parents who they think is the captain of the ship. They answer immediately: the mother and when the child grows up I ask ... then they also give the right answer. It is all about the captain, not the surgeon, who opens the door to a worthy life. A good paediatrician or spina bifida nurse will coach that mother and later also the child in



Hidaya and her daughter Amina, the first girl we helped in Tanzania. She now leads the ASBATH youth project



Dr Theresa Harbauer started "The Friends of Haydom" to assist the young team.

that role. This is how care should be. This is how care in Haydom can become.

When I am alone with Theresa she keeps on asking new people to join us. She seems scared to be alone with me but this is not the case. She connects people in an enthusiastic way. She has done that here for two years and this is probably how she has created the work that the Dutch doctor couldn't destroy. She leaves behind a beautiful but fragile project. Not a baby anymore but a growing child that thinks it can do anything but is still a bit dependent.

This is why Theresa founded "the friends of Haydom" and sends them the missing medical equipment. She also finances a fund to pay the costs for parents if they can't pay the bill themselves. She tries to visit once a year when she organises a parent meeting like this one.

She also wanted FOCC and Cure Hydrocephaly to attend. However, the car of FOCC has broken down and Colin from Cure has just become a father this week. She realises that

the Haydom team needs the support of lots of people and organisations and that is why she wants to bring them all together. And she manages. ASBATH has also sent Hidaya and Kilumba, two faithful employees who have been there since the beginning. They started a new ASBATH department and organise the elections for a new local leader. They speak very enthusiastically to the sometimes disconcerted parents. I am proud of them and feel that all of us here in Haydom contribute to a beautiful unity.

The director agrees to a local network meeting and we all gather around the table: the Haydom team, the Arusha team, CCBRT, ASBATH, Theresa and myself. Theresa shows us in a power point presentation her safari for our target audience. From nothing to 7 children, to now more than 50 children.

The director, maybe a bit political, says that Theresa especially has brought structure to the desperate attempts of her predecessors. For myself, she has together with Henry put a soul into this project and because of this the destructive attempts of the Dutch doctor didn't stand a chance.

The paediatrician emphasises the need for preventative measures as recently a lot of new patients turn up. I reply that more children turn up as there is now care available at Haydom. When an ice-cream tastes good, is available and affordable you will get more and more customers. We see this everywhere.



The Haydom director addresses the public warmly

Theresa emphasises the need for a permanent spina bifida and hydrocephaly team and clinics where parents can turn to. She asks for our children to be given a place in the Haydom outreach team so that parents can get care closer to home. Good plans for the future but a spina bifida and hydrocephaly clinic can be started straight away. From September onwards, every first Thursday of the month parents can go there and the whole team will be available for them. The team will be officially recognised and will get meeting time at least once a month.

Dr. Catherine makes a plea for the systematic signing up of the children in the National health insurance system. In that way the costs will be paid back. For the moment the ice-cream remains too expensive for many and the project is dependent on foreign donors. It is ASBATH's task to lobby for this cause politically. They are already doing this as some insurance companies refuse our children.

On the last day the director addresses the parents in a very warm and human way. He repeats all the points of action that have been decided upon in our meeting. This gives me hope as in this way he shows that the management embraces the project.

After the group photo has been taken the parents and their children start their journey home in uncomfortable buses. However, they have hope, their belief in their child has been fed. This is what they need to coach their children to a life which is as independent as possible.

I stay behind with Theresa and have a meeting with the financial department. It is mid-July and their whole budget for 2017 from the fund of Theresa has been used up. What to do now? It slightly overshadows the festive atmosphere of this week as the fund is really empty. Henry asks how they can afford to pay the costs for the parents now?



Dr Theresa examines a child. She provides the team with equipment like this ultrasound machine

When more children will make an appeal to Haydom, more money will be needed unless they they make savings in the cost of the care. For example, at the moment too much money is spend on unnecessary scans on babies where a cheap or free ultrasound would be a good alternative.

I am going to ask the board of governors of Child-Help to match the fund for this year. It gives them the time to sort out with Theresa something more consistent.

However, I am happy with this puzzle where the pieces come together nicely. I want to start investigating with Theresa how we can help this project to grow and let it survive in a more consistent way.

Pierre Mertens, July 2017