

## Sami's story

"Life doesn't make sense; we need to make sense of it" said a wise friend when the war was raving and I was devastated. Humans killing their fellow humans, killing animals, destroying mother earth and hurting innocent children. However, when you have a genuine will to help and make a difference, and mostly when you hit your lowest, an opportunity crosses your path and you give it your best. In early November 2023, this opportunity came into my life from the Netherlands, via my friend and fellow Pompe\* patient, Maryze Schoneveld van der Linde.



*Sami - 13 year old*

"Sami", a thirteen-year-old boy from Northern Gaza who was diagnosed with infantile Pompe disease - a very rare genetic and debilitating disorder - came into our lives seeking help. His very worried physician in Israel asked Maryze to help Sami. He needed to have his fortnightly lifesaving Enzyme replacement therapy to preserve his body's muscles from permanent damage and deterioration. The medication was not allowed to get through into Gaza and also couldn't be kept due to long term power cuts and Sami was not allowed out, for adults were angry at each other.

The journey began with trying to figure out the procedures and where to start. The frantic calls to friends and contacts in several countries started. Canada, USA, Australia, Egypt, Netherlands, Malaysia, Syria and the UAE. These contacts also spread the word trying to help.

Contacting Sami's family was extremely difficult due to the disconnection of electricity and internet in Gaza. In December we eventually managed to get photos of their identity cards and Sami's birth certificate and medical reports.

The first step was having to get Sami a referral signed by four doctors explaining his disease and the need to get out of Gaza for urgent treatment. Mrs S. Abo-Khalil in Sydney, provided us with a few numbers of doctors in Gaza who might be able to help. The doctors were overwhelmed with the huge numbers of injured and sick people, lacking the time and means to treat people yet to look after any paper work. They also struggled with the Internet disconnections and phone calls were almost impossible. One of them was very kind and graciously agreed to provide the referral, however the referral was lacking the signature of three more doctors. We had to do with what we had and not be "greedy".

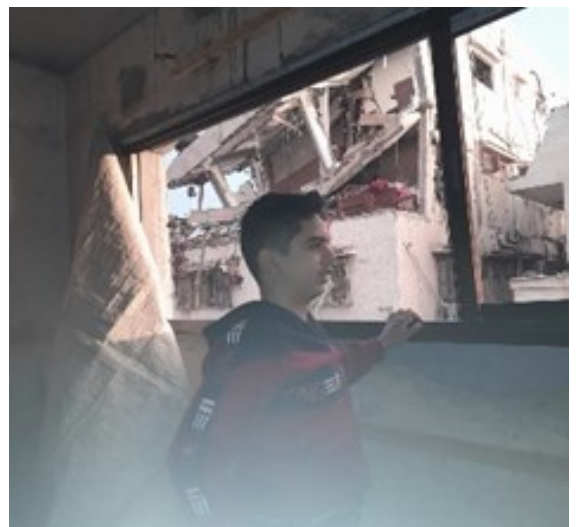
At that time, we learned about a humanitarian program run by the UAE, Turkey and Qatar. These countries volunteered to fly the injured and sick into their hospitals for treatment at their governments' cost. We started to send emails and make calls to so many organisations and contacts in all of the above countries. We needed names of individuals as contacting the organisation was not helpful. We tried the International, UAE and Egypt's Red Cross, UAE and Ramallah's Red Crescent, Doctors Without Borders and Sanofi (The company that makes the Enzyme Replacement Therapy). They all advised that they can't help with treatment if Sami is in the North, he must go South, but he was not able to do so due to the extreme dangers of the move and the fact that the North was under siege.

Meanwhile, the South of Gaza became too dangerous and treatment there was not an option anymore.

Our next step was to try to get him out to Cairo, which required having his name on the list of the Palestinian Ministry of Health. It is a list that has the names of the patients and injured who have a referral, but there were thousands of people waiting and the department was prioritising the severely injured. Since Sami had a chronic disease, his case was not as urgent as a person with several broken bones or with severe burns, but we knew that the damage that was happening to his muscles was irreversible, which meant that he was going to live for the rest of his life, if he survives, with a very disabled body and probably ventilation. Also, once a child with Pompe reaches the stage of not being able to walk, the next step would be difficulty breathing, which means slow painful death especially when there aren't any breathing machines or electricity in Gaza. By late December, Sami's walking was already very difficult.

We started to send direct messages to the doctors that we contacted before and some directed us to others, however the doctor in charge was receiving thousands of requests and he wasn't going to prioritise Sami. Our contact in Malaysia, Mr. M. Shehada knew about this and knew a close friend of that doctor and he contacted him personally to explain the seriousness of the case. The concerned doctor approved and within a few days Sami's name was on the list.

The doctor advised that Sami needs to go to Rafah within 3 days maximum or he will not be able to help him anymore, but Sami was unable to leave the North due to the ongoing shelling. The four-story building next to his was shelled in the middle of the night and put to the ground. The family's apartment's door flew and fell over Sami while he was sleeping due to the severity of the explosion, but luckily, he did not sustain any physical injuries. We received a photo of Sami standing near the window watching the neighbours remains being pulled out of the rubble and a voice message from the mother crying and pleading for help.



*Sami looking at the destroyed neighbouring home.*

An adult needed to accompany Sami, and his father was the best candidate, since Sami had four more siblings, three between the ages of 12 to 10 years old and a seven months old breastfeeding baby brother. The mother needed to be with the children. We needed to make sure that the father has the security clearance to leave Gaza from the Israeli Authorities. He already had a security clearance permit to move between Gaza and Israel for Sami's hospital checkups, however we later learned that this was not suitable to depart into Egypt. We needed to start a search to check if he was allowed to leave.

On the 20<sup>th</sup> of January 2024, Maryze received the Royal Decoration for all of the voluntary humanitarian work that she has done over the long years, helping and saving Pompe patients' lives all over the world. After her decoration she was interviewed by a Netherland's journalist and instead of speaking about herself, she selflessly chose to use this opportunity to reach out to the Dutch diplomat Sigrid Kaag, who on the 8<sup>th</sup> of January 2024, had resigned from her position as finance minister and deputy Prime Minister to take on the role of UN Senior Humanitarian and reconstruction Coordinator for Gaza. Maryze appealed to Sigrid Kaag to help Sami and that was the header of the article. Other Dutch politicians helped to get the contact details of Sigrid, who immediately came on board and we then had direct contact with the United Nations.



*The newspaper article with the plea for help.*

At the Beginning of February, the laws and regulations regarding leaving Gaza became very strict. No one can leave without a passport, and we needed to get Sami and his father passports, which required another long journey of research and seeking help. It was extremely difficult as they did not have passport photos and there was nowhere to go to be photographed. They sent us normal photos and we edited them to make them suitable for the applications. They were also unable to sign their applications because there was no electricity for the printers. We needed to resort to so many contacts and had a difficult time finding someone in Ramallah who could help, but it eventually happened. We sent photos of the passports to the family then the passports were dispatched to the Palestinian embassy in Cairo.

In February we worked relentlessly to organise an ambulance for Sami, via the Red Crescent and/or the United Nations cars. By the time Mr. M. Shehada managed to contact a manager at Red Crescent, two of their ambulance cars had been shelled. The paramedics and the patients died. The manager advised that they cannot transfer any patients, unless their names were given to them by the hospital as they do not want be held responsible for the patients' lives.

We tried to contact Al-Shifa hospital, where Sami used to have his infusions, to ask them to provide Sami's name to Red Crescent for the ambulance transfer, but to our surprise, they did not have his file. We attempted to contact several other hospitals, but Sami's file was nowhere to be found.

The ambulance cars would only go to the north to collect patients two or three times a week. We asked the family to go there and just wait, beg and ask, but they were not successful.

After all of these very difficult stages, we learned from three different reliable sources that the father was not allowed to leave.

We had to check if the mother was willing to go, which was a very difficult decision for the family to make, especially with a breastfeeding baby, but they wanted to save Sami's life. The mother begged to take the baby with her. Leaving him was a big concern because there were no suitable baby formulas or clean water and babies were dying of dehydration. We had to get the mother and the baby passports and we went through the whole process again with a lot of help from contacts in different countries.

By early March, the Egyptian Authorities made new rules regarding the companions of the sick and injured. They were not allowed to have any infants or children with them and no changes were allowed to be made to the companions' names that were originally on the ministry of health list. When we went back to check Sami's companion's name on the list, we couldn't find any, which was a "mistake" that worked in our favour. However, we were stuck with getting the baby out.

Mrs S. Abu Khalil informed several Palestinian/Australian doctors at a meeting held in Sydney about Sami's case and asked them to help with the permission for the baby. We also contacted "Sanofi" asking if they could please provide us with a letter advising that Sami's treatment is ready in Cairo at the University of Ain Shams Hospital along with the name of the treating doctor and that the company is paying for the cost of the treatment and friends and family will pay for the family's accommodation and their life expenses. Also to include that they would like to request Sami, his mother and baby brother. The company representatives were very kind and they provided the letter promptly, which was extremely helpful.



*Sami's baby brother.*

The passports were ready and dispatched to the embassy, but the family needed means of transport.



*The family going to Rafah carrying a white flag.*

We learnt that people from the north were going South via the sea. The family was reluctant because it was dangerous and people were being shot at while taking that route. At this stage Sami became almost unable to walk and started to have difficulty breathing, so the mother decided that she will just leave the following day. We quickly informed the UN as we were informing them about every step. The UN from their side were doing what they could in the silent diplomatic background.

Since nobody was able to assure the mother that the baby can cross the borders with her, she left without him and took only Sami and his 11-year-old sister so she can help her with Sami's mobility. That was shocking news to us, but she said in her very sad voice message that she was unable to carry the baby

and Sami's warm clothes while she and his sister were helping him to move with his arms around their necks. It was a long and difficult journey and they were shot at and escaped death by a miracle.



We lost direct contact with the mother and were only able to have updates via the father's voice messages, which were sometimes difficult to understand because he was sobbing. They finally arrived at their relative's home in Rafah after long hours, then the following early morning they went to Rafah borders' crossing.

While they were at the Rafah crossing, we worked with the wonderful contacts in Cairo who within hours organised accommodation for the family, which is located close to the hospital, and a wheelchair for Sami.

Several people from around the world were up all-night praying and waiting in anticipation to see if they will get through. After very long hours of procedures, waiting and interviews, they were allowed to go into Egypt.

The Egyptian Government provided medical attention to all three at the borders, then transferred them by ambulance to Nakhel hospital in Senai. Sami had a health check and blood tests and the mother was given medication to dry her milk. They had a rest and waited for the next step.

The hospital in Cairo was not able to request Sami's transfer until they receive his medication from Sanofi in Cairo, which required the approval of the Egyptian Ministry of Health. A few days were lost in the process, the mother became very unwell and over stressed. We were pushing via Sanofi in coordination with the doctor at Ain Shams Hospital for the medication to be delivered. Meanwhile, Sami was assessed by a neurologist at Senai who conveyed the information to the doctor in Cairo, since Sami would be a new patient to them.

The medication was finally received, however there was no news about when Sami will be transferred. A few days later, representatives from the Egyptian ministry of health visited the hospital in Senai and interviewed the family to check what exactly had to be organised. They understood that everything was ready and advised that they will go to Cairo soon.

Another few days passed and nothing happened. Sami was stuck in the bureaucracy of the system. We were contacting both hospitals to understand the procedures, but we could not get a clear answer. We had to push again through several contacts to transfer him by ambulance, as two weeks had already passed.

At 6am on the 1<sup>st</sup> of April, the family was picked up by a Red Cross ambulance from Nakhel Hospital in Sinai to the hospital in Cairo. After about seven hours, we received a photo of Sami resuming his infusion, which had stopped for six long months. That was another moment of deep gratitude and joy. Finally, our mission had been really accomplished. Sami was back on treatment again!



*Sami getting his first infusion in Egypt.*

Sami, his mother and sister are now supported by the many volunteers supporting Gazans in Cairo. They are residing in a safe place, the children will be enrolled in school and provided access to a children's psychologist for free counselling and mental support.

Another wise friend said: "If the intention is pure and you work through it, not on it, it will materialise." We wish to thank all the amazing people from all walks of life, different ethnicities, religions and backgrounds who helped and are still helping Sami through his journey with pure intentions. We are also very grateful to all the volunteers in Egypt who are now part of our journey to get treatment for Sami.

We could not have done it without your dedication, effort, information, prayers and guidance. We also wish to thank you for your financial donations that helped the family buy food.

Lama Al-Akhras (Australia)

Maryze Schoneveld van der Linde (The Netherlands)

\*Pompe disease a rare genetic condition that causes muscle weakness that gets worse over time. it is also called acid maltase deficiency disease and glycogen storage disease type II.