

Hope in the Desert

This story focuses on one part of the Gaucher Initiative in Egypt. It was written by Jim Daniels, a photo-journalist who traveled there on Genzyme's behalf to document the patients and their stories.

Expertly dodging the errant cars and masses of people who clog the streets, Nesma Hammad and her mother Fayzia walk through the chaotic Cairo traffic on their way to their bus stop. Everyone seems anxious to arrive home in time for Iftar, the much-awaited first meal of the day that is taken after sunset during the holy month of Ramadan. The mother, dressed in the traditional black robe of the Bedouin, and her daughter in a long denim dress, meld easily into the waiting crowd. Few of those around them would guess that only minutes before, 18-year-old Nesma was sitting with a needle in her arm, getting her bi-monthly dose of a drug that enables her to lead a meaningful life.



Gaucher patient Nesma Hammad (blue gown) and her mother Fayzia (black gown) walk through the streets of Cairo, Egypt.

Nesma has Gaucher Disease and is one of more than 60 people in Egypt who are part of the Gaucher Initiative, a Genzyme sponsored program that provides patients in the developing world with Cerezyme regardless of their ability to pay. The Initiative, which has a large program in China and smaller ones in Vietnam, Cuba, India and several other countries, is a partnership among Genzyme, the humanitarian organization Project HOPE, and local health officials.

A Remarkable Program for Patients

Henri Termeer began with the simple yet ambitious goal of providing enzyme replacement therapy to every patient with Gaucher Disease in the world. Tomye Tierney, vice president and general manager of emerging markets, embraced that goal and set out to create a vehicle to execute the vision, the Gaucher Initiative.

For Tomye and her group, launching the program in Egypt in 1999 was the culmination of months of effort to secure the participation of Project Hope, health professionals and officials of foreign governments to implement the organized delivery of Cerezyme to treat Gaucher patients in need.



Nesma, Fayzia and Dr. Reda Mansour, a pediatrician and Project Hope's Gaucher Initiative coordinator in Egypt.

"This is the most gratifying effort I've ever participated in," she said.

Her deep connection to the program is evidenced by the ongoing relationships she maintains with many patients around the world, like Nesma, whose photograph sits in her office. When asked about her dreams for the future, a grateful Nesma answered shyly, "I want to go to America someday and visit Tomye."

Most of the patients in the program are young (between 7 and 12 years old), come from a family

with extremely modest means, and live within Cairo's sprawling metropolis of almost 10 million people (with a few commuting from remote towns in other parts of the country). For most, the journey that led to the health clinic where they receive Cerezyme began as a difficult one, a voyage accented by countless visits to doctors and hospitals and underscored by the fearful unknown of a mysterious, incurable disease. Thankfully, these patients ultimately found the Gaucher Initiative, a program that provides hope for the future.

Doctors Join the Cause

After working in Pediatrics in one of Cairo's hospitals, Dr. Reda Mansour joined Project HOPE in 2000 as the first physician involved in the Gaucher Initiative in Egypt. Her roll as project coordinator calls upon her skills as both a doctor and an administrator, managing data and discussions regarding the program's patients, overseeing their care and planning for the orderly distribution of their medicine. Dr. Mansour regularly visits patients' families at their homes to monitor their treatments, maintain personal contact and educate parents on vigilantly observing their children's health so symptoms can be assessed at an early stage.

"When you work helping people, you see the results of your work right before your eyes," she said. "When I see my patients doing well, responding to treatments, this makes me very happy. I love my patients."

Answers to 16 Years of Questions

Nesma went to the doctor for the first time when she was a year and a half old, after her mother noticed her abdomen getting bigger and her overall health deteriorating. This began 16 years of frequent trips to a variety of doctors, including specialists in anemia and malnutrition, which became an increasing hardship for the single mother with little money.

"I suffered a lot with Nesma," Fayzia confided. "She needed blood transfusions every two weeks. We'd spend one week in the hospital and one week at home. In the beginning, she was too sick for me to take the bus so we had to use expensive taxis. Sometimes neighbors would help. It was very difficult."

Nesma's symptoms only got worse and her ever-expanding spleen was finally removed. As she got older, her liver began to enlarge, making her vulnerable to the taunts of neighborhood children who chided her for being pregnant.

Eventually, they found Dr. El Azim Khaled, a specialist in pediatrics and hematology at Cairo University, who had experience with cases like Nesma's and who became an important member of the team assembled by Tomye to implement the Gaucher Initiative.

Dr. Khaled diagnosed Nesma with Gaucher Disease and explained to her and her mother that it had no cure and that Nesma needed an expensive drug made in the United States to prevent the problems the disease could cause. Through the Gaucher Initiative the medicine would be donated to Nesma. She would have to come to Cairo University every two weeks for an infusion of the drug.

Four years later, Fayzia thanks Allah every day for bringing her daughter back to health and for "the American company" for providing the medicine that gives her daughter life. For her part, Nesma dreams of the future.

"Praise Allah, I am fine," she said. "I want to someday have sweet children and I will give them sweet names. Perhaps someday I will become a doctor."

Amr, Patient Number One

In another part of Cairo, 11-year-old Amr El Gohary walks through his neighborhood with his

father Maamon's arm over his shoulder. Maamon is an accountant and works in Aman, Jordan. Because of his work and the expense of travel he comes home to Cairo infrequently during the year, but manages to stay for the entire month of Ramadan.

Maamon and his family were living in Aman in 1997 when Amr's inexplicable decreasing health led them to look for answers anywhere they could. A Jordanian blood specialist confirmed that the mysterious illness afflicting their son was Gaucher and recommended that they seek the counsel of a doctor in Jerusalem who had experience with it. Dr. Zimran, one of Gaucher's early treaters, examined Amr and told the family that he needed the drug Ceredase, an expensive enzyme replacement therapy that was unavailable to them in Israel. The doctor did, however, hear about treatments being provided in Cairo through a fledgling program and helped Amr's family make contact with Genzyme to petition for help. Through the intervention of Tomye, Amr was referred to Dr. Khaled and became the first patient admitted into the program in Egypt.



Amr El Gohary walks through his neighborhood with his father Maamon.

"In the beginning, it was strange," said Somia, Amr's mother. "We started to call pharmacies to see if we could buy the drug but it was too expensive. Amr's father had a nice job but even with his job we could not afford this drug. I was afraid we wouldn't get the medicine in time." But once enrolled in the Gaucher program, Amr's strength returned and he was finally able to live a normal life.

"I remember that I had a big abdomen and there was a lot of pain," Amr said. "I went to the clinic at Cairo University for the infusions. I was a little afraid. But I liked the way Dr. Khaled treated me and I started to feel much better."

Amr now enjoys playing soccer, swimming and clowning around with his friends. "I thank everyone at Genzyme for their help," Maamon stated.

Mosbah's Brood

Not all patients who are part of the Initiative in Egypt live near Cairo. Mosbah Muhammed lives near the mouth of the Nile in Dumyat and travels six to eight hours by bus from the city for bi-monthly visits to the clinic. The length of the trip is only part of his challenge; all three of his children have Gaucher.

Because there are times when the family cannot make the journey to Cairo, doctors Khaled and Mansour often travel to them to deliver a supply of Cerezyme, which a local physician administers, and to do a physical examination of the children.

The oldest child, Asmaa, now 10 years old, started to show signs of an enlarged spleen and a pronounced squint when she was still a toddler. The parents sought medical advice in the village and took the child to Mansura University in the Delta. No one recognized her condition and she went undiagnosed for a number of years, eventually having her spleen



Mosbah Muhammed helps doctors Reda Mansour and El Azim Khaled unload their car as they deliver a supply of Cerezyme for Moshbah's three children.

removed. When the second daughter, Iman, was born she showed no abnormal signs until age of one and a half when she became severely cross-eyed, her abdomen became enlarged and she was unable to walk or crawl. It was at this point that the parents were advised to go to Cairo University.

"I was upset," Mosbah remembered. "I already did not know what the older sister had and to find out that the same problems were in the younger one... I was depressed."

While Mosbah's family believes in Allah and that it is some people's destiny to suffer, when their second child developed the symptoms of a still unknown cause, it tested their faith. He says he felt powerless at not being able to help his sick children.



Asmaa, Ahmad and Iman Muammer, who all suffer from Gaucher disease, play in their neighborhood in Domyat.

The children were finally diagnosed with Gaucher in 1997 and soon began receiving Ceredase through the Ministry of Health. The government-administered program was poorly funded and was ineffectual; the doses prescribed for them were a fraction of what they needed. In 1999, the same year that Asmaa and Iman were enrolled in the Gaucher Initiative where they finally received the correct dosage of the drug, the third child, Ahmad was born. Although he too was diagnosed with Gaucher, the 4-year-old still exhibits no symptoms of the disease.

The family has very few resources, even for their most basic needs. Mosbah works hard as a wood carver in a furniture factory in the city to make just enough money to feed his extended family of seven. On the days when they all go into Cairo for the infusions, they must travel in a crowded bus the day before. Once in the city they rely on the kindness of friends to put them up for the night. It is a financial burden just to take his three children on public transportation and the time it takes away from his work is an added expense. But Mosbah feels that the sacrifices they make for their children's health has more than paid off, it has been miraculous.

"The difference today is like the distance between the earth and the sky," he said.