Expensive Medicine Means Life for Palestinian Children

By Basem Awad

When ANERA pharmacist and medical program manager Dr. Yousef Hasan and I arrived in the West Bank village of Ya’bad, we saw relief on the faces of Mohammed and Tohsi. We were delivering vials of Cerezyme, the only effective medication for Gaucher’s (pronounced “go-shays), a rare disease affecting their two young children. ANERA’s Medical In-kind program distributes Cerezyme to clinics and hospitals treating twelve children with the disease in the West Bank and Gaza Strip. Cerezyme is donated to ANERA by the Genzyme Foundation.

Mohammed and Tohsi’s children, Tamer, age 5, and Lana, age 3, must take intravenous infusions of Cerezyme every two weeks, but their physician, Dr. Yusef Hamaashi, ran out of his supply. Mohammed and Tohsi were worried that Dr. Hasan and I were going to have trouble making it through the many checkpoints and bad roads of the West Bank. We were all relieved that, on this trip, we...

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Tamer, left, and Lana were diagnosed with Gaucher's Disease at a very early age, effectively saving their lives.
Scholarship Program Profile:
Nada from Dar El Tifl

Five year-old Nada is one of the youngest students in ANERA’s Scholarship Program. She attends kindergarten and lives in the boarding section at Dar El-Tifl, a school for girls in Jerusalem. Unlike many of the girls at Dar El-Tifl, Nada’s parents are living; however, they have no means to care for their five children.

When Nada first arrived at Dar El-Tifl, she showed signs of neglect. She was unkempt, withdrawn and sad. Now wearing her bright pink-checkered uniform and a smile that would melt any heart, Nada has a brighter future. She loves drawing and sports and her favorite food is macaroni.

Nada is just one of over 200 Palestinian, Lebanese and Jordanian children, ages 5-18, who benefit from ANERA’s Scholarship Program. Because of Scholarship Program donors, these children are able to attend schools or live in orphanages that meet their special needs and give them that extra bit of help.

ANERA’s Scholarship Program helps cover the costs of tuition, books, school supplies, food and medical expenses for students in seven schools in the Middle East. For more information about how you can help a child in the Scholarship Program, contact Nancy Nye, Scholarship Program Coordinator, at 202-842-2766, ext. 20 or nnye@anera.org.

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experienced few setbacks and made it to Ya’bad on time.

“Gaucher’s is a metabolic disease characterized by a deficiency in producing an enzyme needed to break down a compound called glucocerebroside, which accumulates and calcifies in the heart valves,” explained Dr. Hasan. If not treated, the disease is fatal.

“We discovered that Tamer had the disease when he was one and a half years old,” said Mohammed. “We are fortunate that he received the correct diagnosis. Otherwise, he would have died. We later discovered that our next child, Lana, also has the same condition.”

The annual cost of Cerezyme treatment is in the range of $100,000. Treatment must continue for the life of the patient. Annually treating 12 children in the West Bank and Gaza Strip costs more than one million dollars.

“Before the second intifadah, I used to do construction work in Israel, but since it broke out, I have not been able to find regular work. This has been the case for most residents of the village. Even when I had work, though, it would have been impossible for me to cover the cost of this medication,” said Mohammed.

Thanks to the donation of Cerezyme from the Genzyme Foundation, Tamer and Lana are alive, well, and smiling.
ANERA Benefit Concert Tour Reaches Broad Audiences

When politics are pulled down by circumstances, the people of letters, of art, and of music, appear and light up the way, and provide us with hope in the future and in humanity.

– Edward Said

Performing for packed audiences in Washington DC, Philadelphia, and New York, the four member faculty Oriental Music Ensemble of the Edward Said National Conservatory of Music received standing ovations at every concert in a benefit tour organized by ANERA during mid February 2006.

Introducing the Ensemble at their performances, Rima Tarazi, chair of the Conservatory’s Board of Directors, spoke about how music creates harmony in a dissonant world and of music education teaching students to be creative, while learning the discipline of a craft and how to cooperate with others. Suhail Khoury, Director of the Conservatory, referred to the critical role of music in sustaining hope during difficult times.

This premier US tour was made possible by contributions from individual ANERA donors, the Ford Foundation, and the Foundation for Middle East Peace. It was co-sponsored by the Center for Contemporary Arab Studies of Georgetown University, the Smithsonian Freer/ Sackler Galleries, Swarthmore College and Alwan for the Arts in New York.

The Edward Said National Conservatory of Music has been an ANERA education partner since 1999 and is a major player in the cultural and educational scene in Palestine. Proceeds of the tour will go towards the Conservatory’s Palestine Youth Orchestra.

The annual enrollment of the Conservatory numbers about 550 students; additional students attend workshops in refugee camps in the West Bank. The Conservatory’s community concert series features local and internationally known musicians reaching annual West Bank audiences of thousands. ANERA is one of its major US supporters.
The three villages of Al-Nasariyah, Beit Hassan, and Aqrabaniyah are situated in a beautiful valley near Nablus. During the winter, the area’s rainfall collects in the valley, causing the streams to flood and making them difficult and dangerous to cross. With ANERA’s help, now the residents of the three villages each have their own bridge which allows them to cross the floodwaters easily and safely.

“The bridge has helped us in a hundred thousand ways,” said Abu Mithkaal, a local farmer, who friends address in the traditional way (Abu means “father of”; the second name is that of his eldest son) “We used to have to cross by foot. The water would get very deep and cold. We also had to worry about getting our livestock across safely. Cars and tractors couldn’t make it across or got stuck. It’s much better now.”

Abu Hafedth, a village council member who oversaw the building of the bridge in Al-Nasariyah, said “There have been many improvements in the lives of these villagers because of the building of the bridge. While most of the villagers live on the northern side of the stream, we have twenty-four families on the southern side. It was hard for them to cross when the stream was flooded. The children couldn’t get to school. The sick couldn’t get to the hospital. There’s also farming land that couldn’t be tended to. Some of the water that mixed into the stream is waste, and that was a health concern for people and animals having to cross by foot.”

“The village council of Beit Hassan had already started the bridge but were not able to complete it due to financial difficulties” said Nasser Qaddous, ANERA’s agricultural specialist. “We read about the incomplete bridge in the newspaper and realized we could help. We came and met with village council members and agreed to complete it.”

“For years, this village has been hoping to have a bridge,” said Abu Mithkaal. “Neither the British, nor the Jordanians, nor the Israelis helped us. But finally, thanks to ANERA’s help, we finally have a bridge.”
ANERA REMEMBERS...

Jim Sams

Mr. James F. Sams, a founder and long-time board member of ANERA, passed away on December 21, 2005. He is survived by his wonderful wife of 48 years, Betty, son James, daughter-in-law Lisa, and grandchildren Claire and James of London, England, and daughters Alicia of New York, NY, and Victoria of Carlisle, PA.

Mr. Sams, a devoted family man, with his equally active spouse Betty, was a successful lawyer and businessman.

We at ANERA knew him as a great contributor to our mission: creating opportunity and hope in the Middle East. Along with equally devoted colleagues, and the strong partnership of his wife, Mr. Sams founded ANERA in 1967-1968. As ANERA began its operations, Mr. Sams served on the board, helping steer the young organization.

Mr. Sams also gave his time to building other institutions to help people’s welfare and contribute to intercultural understanding, especially with respect to the Middle East. Among these were: Grameen Foundation USA, Center for Contemporary Arab Studies of Georgetown University, Center for Global South Studies of American University, American Task Force for Lebanon, and the US Inter-Religious Committee for Peace in the Middle East.

Mr. Sams’ honors and awards included the Order of the Cedar from the Lebanese government, the Distinguished Community Service Award from the Rene Moawad Foundation, the Arab American of the Year award from ACCESS, and the Alex Odeh Activist Award from American-Arab Anti-Discrimination Committee.

Mr. Sams was truly a great person and servant of mankind. We join his family in mourning his passing.
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