Uganda Diary

On the Ground with the Global Diabetes Initiative

TEXT AND PHOTOS BY
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LAST SUMMER, three members of Einstein's Global Diabetes Initiative (GDI) traveled to Uganda to cosponsor a diabetes training conference for doctors and nurses from 22 regional clinics. The GDI has been active in Uganda since 2005, when it began collaborating with Mulago Hospital, the 1,500-bed teaching hospital of Makerere University College of Health Sciences, on ways to improve diabetes care through training and education. The GDI is also active in India, where it is conducting research into malnutrition-related, or type 3, diabetes.

I accompanied Einstein's GDI team on its trip to Uganda. The overriding take-home lesson from my week there: Mounting an effective global health program requires patience, persistence, ingenuity, cultural sensitivity and a hefty dose of humility. What follows are my reflections on the trip, in words and pictures.

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Mulago Hospital, Kampala

It takes only a few minutes at Mulago Hospital to see why outside help is so vital. Patients must provide their own food and bedding. Family members serve as nurses and cooks, sleeping on the floor beside their loved ones and doing laundry outside on the hospital grounds. It's sobering to think that this is the best public hospital in the country. "The government controls costs by discharging patients as soon as they smile," says one Mulago physician, only half-joking. The overall mortality rate is about 70 percent.

Over at the Endocrinology Unit, the situation is much the same. The staff appears highly dedicated, but with limited resources, there's only so much they can do. In Uganda, people with diabetes are typically diagnosed late, often after falling into a coma and being admitted for emergency care. Those who make it home must somehow survive on a diet rich in carbohydrates and poor in protein, and with intermittent access—at best—to glucose monitoring and medications.

Unfortunately, this scenario is not limited to Uganda. "Cases of diabetes worldwide are expected to exceed 370 million by 2030, and 90 percent of those will occur in developing countries," says GDI director Meredith Hawkins, M.D., professor of medicine at Einstein, who is making her fifth trip to Uganda.

Still, Dr. Hawkins remains positive. "It would be very easy to feel overwhelmed," she says. "But any time I wonder whether this work makes sense, I look at the phenomenal success in combating diabetes at Christian Medical College in Vellore [GDI's partner in India]. CMC was started by an American woman 100 years ago. She set an example for reaching across an enormous cultural divide and doing something sustainable. From the very beginning, she focused on education and training."

Hallway outside Endocrinology Unit, Mulago Hospital.

One Mulago physician said, only half-joking, that the government controls costs by discharging patients as soon as they smile.

Office of the Minister of State for Relief, Disaster Preparedness and Refugees

In global health, as in many other aspects of life, it's who you know.

Francis Musa Ecweru, Ugandan minister of state for relief, disaster preparedness and refugees.

Thanks to Dr. Hawkins' friends Don and Marty McLaughlin, a couple involved in humanitarian work in Uganda for several years, the GDI team secures a meeting with Francis Musa Ecweru, a charismatic and powerful government minister and a man who knows how to get things done. Years earlier, as an auxiliary army commander, he led a force that freed thousands of women and children held captive by Lord's Resistance Army rebels in eastern Uganda.

The hope is that the minister and others in the government can help spread the word about diabetes. "To improve outcomes, diabetes must become a national priority," remarks Dr. Hawkins.

Last-Minute Conference Preparations

The GDI team leaves the minister's office to run around Kampala in search of a shop to make copies of conference materials, including pre- and postconference tests for attendees. I wonder: Is this the best use of three diabetes specialists in a country with just a handful of endocrinologists and a million-plus people with diabetes? But Dr. Hawkins has a different perspective.

"I don't mind doing chores when, ultimately, it means saving lives," she says. "And it's important to get those tests ready for the conference—we need to measure outcomes so we and our Ugandan colleagues can be more effective."

Her thoughts echo those of Paul Farmer, M.D., Ph.D., the global health guru. As Tracy Kidder writes in *Mountains Beyond Mountains*: "Farmer [has] come to think that a willingness to do what he calls 'unglamorous scut work' is the secret to successful projects in places like Cange [Haiti] and Carabayllo [Peru]. 'And,' he says, 'another secret: a reluctance to do scut work is why a lot of my peers don't stick with this kind of work.'"

GDI team member Elizabeth Walker, Ph.D., R.N., professor of medicine and of epidemiology & population health at Einstein, also has an upbeat outlook. "So many people in global health have told us that you cannot accomplish anything in Uganda," she says. "That's one reason I want to help. We can help them accomplish small steps.… I don't feel like the problems here are overwhelming."

Participants attending the diabetes training conference step on the scale to calculate their body mass index.

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Nakyessa, 55 Miles North of Kampala

Four years earlier, in Nakyessa, Dr. Hawkins met a young boy named Ponsiano who had malnutrition diabetes, a little-understood form of the disease. Ponsiano died three months later, probably from too much insulin.

"This is a very familiar story in Uganda," says Dr. Hawkins. "We're now doing research in India to determine whether it might be better to manage malnutrition diabetes with diet and drugs, hopefully sparing many people from fatal insulin doses," she says.

Today's visit to Nakyessa carries a more encouraging message: Even in a country plagued by poverty, drought, corruption and political instability, things can still be accomplished. With modest resources and relatively little experience in development efforts, the McLaughlins—Dr. Hawkins' friends—have improved the lives of hundreds of children and their families by building a school, health clinic, library, cottage industry and model farm.

Downtown Kampala

Dr. Hawkins and GDI member Jason Baker, M.D.—a former fellow in diabetes, endocrinology and metabolism at Einstein, who is now an assistant professor of medicine at Weill Cornell Medical College—stroll into Casino Simba in downtown Kampala with a wad of greenbacks donated by an American pharmaceutical company. A tale of two good doctors gone bad? No, the casino reportedly is the best place in town for changing U.S. dollars into Ugandan shillings, which are needed to pay for tomorrow's conference.

But the casino tells the Einstein duo that it won't pay unless they play. "We were up a creek," recounts Dr. Hawkins. "It was Saturday night, the other exchange places were closed, and the next morning we were leaving for the rural conference center. So, I pulled out my Einstein business card and told them what we were doing—and they changed our money at a very good rate."

Mukono Agricultural Research and Development Center, Outskirts of Kampala

More than 80 doctors and nurses from diabetes clinics around the country gather for the three-day training conference, organized by Fred Nakwagala, M.D., and Agatha Nambuya, M.D., of Mulago Hospital, in conjunction with the GDI. Speakers include the GDI team as well as Silver Bahendeka, M.D., chief of the International Diabetes Federation, Africa region; Andrew Otim, M.D., chief of the Uganda Diabetes Association; and a half-dozen other Ugandan diabetes specialists. Among the topics covered are the cardiovascular complications of diabetes, diabetic foot care and hypoglycemic emergencies.

On day two, the attendees break into small groups to discuss how to encourage healthy behavioral changes in patients. The doctors and nurses are slow to start but soon warm to the task.

"Group learning is common in Western training but new to Uganda," says Dr. Walker, who leads this part of the conference. "We need to learn more about how they learn best, about their communication skills and about their health beliefs and priorities."

Other reminders of the cultural divide between Africa and America include a perplexing sign on a dormitory bathroom door: "Please do not urinate in the bathroom." It turns out that what they call bathrooms are what we call showers.

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Another reminder comes from Dr. Nambuya. "It is in the blood of the African to go to witches," meaning witch doctors, she notes during a discussion about patients' beliefs and behaviors.

"North American medicine may not necessarily be the best solution in Uganda," adds Dr. Hawkins. "The highly technological approaches we use here may not be affordable or culturally appropriate. We have to learn what will help—both from our Ugandan partners and from models that have proven successful in other developing nations."

Continuing-education programs are rare events in Uganda, so the doctors and nurses make the most of the opportunity. Each participant receives a detailed, 50-page manual on diabetes care. Not one copy is left behind. In many regions of the country, doctors and nurses have little access to the Internet or medical literature, so such materials are treasured.

The second day of the conference stretches until midnight, and nobody seems to mind. If anything, the pace picks up late in the evening, as the closing session evolves into brainstorming: How can Uganda's doctors and nurses

Attendees at the diabetes training conference.

Home visit (left to right): Mrs. Mutagamba, Elizabeth Walker, Ph.D., R.N., Meredith Hawkins, M.D., and KCCC nurse Clare Yiga.

change the public's understanding of diabetes, influence public policy and attract funding for diabetes care?

The conference ends in a celebratory mood with a mini-graduation, as participants are called to the front of the room to receive handshakes and certificates.

"Countries such as Uganda suffer an enormous brain-drain of health professionals, and for good reason," Dr. Hawkins tells me. "There is little support for them, and few resources. The ones who stay are heroes, and we need to treat them as such."

Making a House Call

A dusty drive to the outskirts of Kampala brings us to the one-room home of Mrs. Mutagamba (not her real name), a woman in her fifties who has been struggling with type 2 diabetes for some 25 years. She knows how to control her illness, but the harsh reality of everyday life intervenes.

When Mrs. Mutagamba has money for food, she feeds the grandchildren in her care first and eats what remains. Her small garden, a long walk away, yields a meager crop of sweet potatoes. She can't afford glucose monitoring or regular trips to the clinic. It's a wonder she has lived this long.

Mrs. Mutagamba exemplifies the difficulty of treating type 2 diabetes in a place like Uganda. That's why the GDI has placed more emphasis on prevention—which is where Dr. Walker, a specialist in behavioral change, comes in.

"Health-care providers in Uganda haven't yet been trained to solve problems or set goals, or in techniques that empower patients by offering them choices in self-care," says Dr. Walker. "Some Ugandan colleagues even tell us that you have to scare patients to make them change behaviors. Often that results in just short-term change."

Dr. Walker cites Western research showing that people are more likely to maintain a behavior that they choose themselves and feel confident performing. "Perhaps the doctor-patient relationship in Uganda is different, with neither party willing to relinquish the traditional doctor-patient roles," says Dr. Walker. "I'm going to investigate it further."

With the support of a pilot grant from the Global Health Center, Dr. Walker plans to collaborate with Ugandan providers to set up and evaluate a self-management training program for use in diabetes clinics.

Kamwokya Christian Caring Community (KCCC)

After a fond farewell from Mrs. Mutagamba, the team heads to KCCC, the faith- and community-based nongovernmental organization that had arranged the home visit with her.

The GDI team arrives and is invited to deliver impromptu lectures on diabetes for staff and patients. KCCC runs a series of clinics serving some 10,000 people in the slums of Kampala. And it's a marvel—clean, organized and efficient. If Dr. Walker can develop a behavioral change program for Uganda, places like KCCC could conceivably put it into practice.

A young patient waits to see a doctor at the Mulago Hospital's Pediatric Unit.

Pediatric Unit, Mulago Hospital

At the diabetes conference, the GDI team learned that many children with diabetes are seen at Mulago Hospital's pediatric unit. Dr. Baker investigates. At Mulago he meets 10-year-old Mike, a newly diagnosed type 1 diabetic with respiratory problems, malaria and a urinary tract infection.

For Dr. Baker, who himself has type 1 diabetes, Mike's case hits home.

"Even with the resources I have—the fancy insulins, the unlimited testing strips—I find it extremely challenging to manage my diabetes well. So imagine how hard it is for someone like Mike," says Dr. Baker.

He wants to help develop consistent methods for following patients with diabetes—in particular, providing them with testing supplies and monitoring systems.

Jason Baker, M.D., and nurse Florence Ayoo, Pediatrics Unit, Mulago Hospital.

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"Those things just don't exist here—patients can't afford them," says Dr. Baker. "They may be given insulin, which helps them survive but isn't enough to help them truly control their disease. It merely helps them survive. As they continue to live, they will have a lot of complications and a low quality of life. There's no reason that resources used to manage diabetes in the developed world can't be made available here."

Departure

Dr. Hawkins says that the trip—especially the conference—far exceeded her expectations and has paved the way for future visits.

"We're going to be involved in two meetings this year, both of them organized and run by Ugandans," she says. "One of them is another diabetes training conference. And we've been invited by the faculty from Mulago to deliver lectures at a research conference—the first scientific meeting of the Ugandan Endocrine Society."

Dr. Baker sees Uganda as a place with great needs and with solutions that are often quite simple, if only they can be implemented. "Looking into the eyes of patients who have so few resources and little hope for controlling their diabetes fortifies my drive to come back to Uganda," he says.

"We are just beginning to understand our partners here—their issues, their politics, their beliefs," says Dr. Walker. "Because of scarce resources, improving diabetes care in Uganda in a sustainable and meaningful way is certainly a challenge, but that is what we plan to do, with our Ugandan colleagues leading the way. It is our privilege to work here." E

Mike, newly diagnosed with type 1 diabetes.