



A child receives treatment for clubfoot at the Mulago Hospital Clubfoot Clinic in Kampala, Uganda

Photo: Association of Universities and Colleges of Canada

Stepping up: Help for disabled children in Uganda

A model aid project offers a simple non-surgical treatment for clubfoot that is transforming the lives of thousands of children in Uganda

By Moira Farr

Since she was three months old, Nicole Kebirunji, now just over two years old, has been coming for treatments of her clubfoot at the Mulago National Referral Hospital in Kampala, Uganda. At this age, the prospects for correcting her deformity are excellent. Nicole's mother, Emily, has carefully followed instructions for managing her infant

daughter's casts and was willing to travel to a regional clinic nearly 100 km from her Kampala home to buy fitted braces that weren't available at the time through the Mulago Hospital. The goal is to make sure that Nicole will be walking normally, without braces, canes or crutches, by the time she's ready to go to school.

Emily Kebirunji has reason to be determined about her child's treatment. Nicole's future, and her family's, literally is at stake. With a severe deformity such as clubfoot—a congenital defect seen in 200,000 babies worldwide each year; 80 percent of them in the developing world—Nicole would face a life of poverty,

shame and social isolation. But with a successfully corrected foot, she can join her peers in receiving an education, gaining employment and leading as normal and happy a life as anyone else in her community.

Nicole is just one of more than 3,400 children in Uganda who have benefitted from an innovative and relatively inexpensive non-surgical treatment for clubfoot known as the Ponseti Method. It is now taught to thousands of Ugandan surgeons, nurses, paramedics, orthopedic technicians and other professionals in training modules at 38 schools of health-care across the country, and is available at low cost across a country-wide network of 40 clinics, thanks to the pioneering efforts of Shafique Pirani, an orthopedic surgeon and clinical professor at the University of British Columbia (UBC), as well as the public health approach, advocated and led by Professor Richard Mathias at the School for Public Health at UBC.

In 2004, Dr. Pirani and his Makerere University partners in Uganda, in partnership with Christian Blind Mission International and the Ugandan Ministry of Health, presented a proposal and received a C\$980,000 commitment from the Canadian International Development Agency (CIDA) and an \$820,000 in-kind contribution from the Ugandan and Canadian project partners to launch a project that would bring this cost-effective method to the country, train a range of health-care professionals to detect and treat clubfoot, and provide the support required to make it sustainable. "Now these children are able to go to school and mix with the other children without stigmatization," says Edward Naddumba, Ugandan project director and Head of the Department of Orthopedic Surgery at Makerere University, who continues to lecture on the project at conferences around the world and who sees about 20 clubfoot patients per day in his busy clinic. In addition, the Mulago Hospital Clubfoot Clinic is open twice a week with an average of 50 visits each week. It's the parents, as well, who benefit from de-

stigmatization, relieved the moment they arrive to find that help they can afford is available to their children.

An important ingredient to the project's success has been the partners' strategic decision to target sustainability in project design. The role of the Canadian partners and the use of funds were targeted at building in-country capacity for Ponseti clubfoot management and teaching. The Ugandan Ministry of Health accepted

"Now these children are able to go to school and mix with the other children without stigmatization."

**Edward Naddumba,
Head of the Department
of Orthopedic Surgery,
Makerere University**

the responsibility of providing the resources and materials needed for the care of children (clinic space/staff and treatment materials in its hospitals.) For the most part the ministry has managed to do this. They have had constraints in the provision of an uninterrupted supply of plaster and braces. Hence parents can be faced with the problem of having to purchase these items. The project has always supported the desire of the ministry to provide the necessary resources, and therefore has avoided the temptation to fill the gap, except in very unusual circumstances. For the same reasons, the project has tended avoided subsidizing travel costs for parents.

The Uganda Sustainable Clubfoot Care Project has been so successful in raising public awareness, training professionals, providing parents with some financial help for casts, braces and transportation and ultimately correcting a life-altering disability that it was recognized by the World Health Organization (WHO), in its 2011 World

Report on Disability as a model for other developing countries to follow. Finding sustainable methods for treating childhood disabilities is recognized by CIDA as a key to reducing child poverty worldwide—ill health is the most commonly cited factor linked to poverty and unemployment in developing countries. At the invitation of the WHO, the project team is now developing guidelines for the management of clubfoot in developing nations that will inform the process for developing global standards for how disability should be taken into consideration in international development work. This formal process is similar to the one used to create standards for taking gender equality into account, a process now taken for granted as essential for effective development work.

Dr. Pirani knows what it's like to have a disability, having been left with a limp from polio suffered at age three. Born in Uganda, he moved to Canada with his family when he was 16. On a trip to his homeland in 1998, he was shocked and saddened to see both children and adults with untreated clubfoot lining the roads he travelled, social outcasts who lived in poverty and had no hope for their future. "I knew that unfortunately I couldn't do much for the adults, but I could help the children." Two years earlier, Dr. Pirani had become aware of a highly successful method for correcting clubfoot without surgery developed by Professor Ignacio Ponseti at the University of Iowa. The Ponseti Method uses a series of casts and braces from infancy, when the foot is mostly cartilage. Dr. Pirani commented that "had I made my trip back home five years earlier, I wouldn't have known about it, so it was a case of good timing."

Many other countries in Sub-Saharan Africa and elsewhere are in the process of implementing the project's training template themselves, and a scaled-up version of the model is about to be undertaken in Bangladesh. The treatment model piloted in Uganda is an unqualified success. More than anything, it's the children and their happy, reassured parents who know how critical the treatment will be to their quality of life. 