

## Towards Effective Ponseti Clubfoot Care

### The Uganda Sustainable Clubfoot Care Project

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**Abstract** Neglected clubfoot is common, disabling, and contributes to poverty in developing nations. The Ponseti clubfoot treatment has high efficacy in correcting the clubfoot deformity in ideal conditions but is demanding on parents and on developing nations' healthcare systems. Its effectiveness and the best method of care delivery remain unknown in this context. The 6-year Uganda Sustainable Clubfoot Care Project (USCCP) aims to build the Ugandan

healthcare system's capacity to treat children with the Ponseti method and assess its effectiveness. We describe the Project and its achievements to date (March 2008). The Ugandan Ministry of Health has approved the Ponseti method as the preferred treatment for congenital clubfoot in all its hospitals. USCCP has trained 798 healthcare professionals to identify and treat foot deformities at birth. Ponseti clubfoot care is now available in 21 hospitals; in 2006–2007, 872 children with clubfeet were seen. USCCP-designed teaching modules on clubfoot and the Ponseti method are in use at two medical and three paramedical schools. 1152 students in various health disciplines have benefited. USCCP surveys have (1) determined the incidence of clubfoot in Uganda as 1.2 per 1000 live births, (2) gained knowledge surrounding attitudes, beliefs, and practices about clubfoot across different regions, and (3) identified barriers to adherence to Ponseti treatment protocols. USCCP is now following a cohort of treated children to evaluate its effectiveness in the Ugandan context.

**Level of Evidence:** Level IV, therapeutic study. See Guidelines for Authors for a complete description of levels of evidence.

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All of the electronic supplementary materials have been reprinted with permission of their respective sources (Dr. George William Lutwama, "Prevalence of Physical Movement Disabilities Among Children in Rukungiri District, Uganda"; Dr. Joseph Theuri Macharia "The Idiopathic Clubfoot: Short-term Results of Treatment with the Ponseti Method at Mulago Hospital"; and Dr. Sam Zaramba, Director General of Health Services of the Uganda Ministry of Health, educational materials).

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## Introduction

An estimated 1400 infants are born every year in Uganda with congenital clubfoot. Usually the deformity is not diagnosed, or if diagnosed it is neglected, as the conventional treatment of surgical correction is simply not possible with the resources available. In 1994, there were an estimated 10,000 children in Uganda with neglected clubfeet [2]. Congenital deformities (mostly clubfeet) are responsible for 30% of musculoskeletal ill health and disability in children in Uganda (see Lutwama in supplemental materials available with the online version of CORR). Children with neglected clubfeet are destined to grow up with deformed and painful feet, leading to physical disability. Untreated, this disability affects an individual's mobility and threatens their potential productivity [1]. The neglected clubfoot deformity results in disability for the individual, a reduced standard of living for the entire family, and a burden to the community.

In the 1940s Professor Ignacio Ponseti from the University of Iowa developed a noninvasive method of correcting the clubfoot deformity with a high rate of painless, functional feet in adulthood [17]. It is an appealing method in areas where surgical resources are scarce. In 1999, a Canadian-led, Rotary-funded pilot project introduced the Ponseti method of treating clubfoot into selected areas of Uganda by increasing awareness of the deformity and training suitable health professionals in the method. Macharia performed a descriptive followup study to

determine the early results of Ponseti treatment of clubfeet at Mulago Hospital by orthopaedic officers (paramedical healthcare professionals) specially trained in the method. He found 52 of 67 clubfeet corrected with an average of 6.2 casts and concluded the Ponseti method could substantially reduce the disability burden caused by idiopathic clubfeet in Uganda (see Macharia in supplemental materials available with the online version of CORR).

Realizing the potential impact of a Ugandan national clubfoot management strategy based on the Ponseti method, the authors designed and obtained funding for the Uganda Sustainable Clubfoot Care Project (USCCP). The project's purpose is to make available a sustainable universal, effective, and safe treatment of the congenital clubfoot deformity in Uganda using the Ponseti method. We provide a brief overview of USCCP, its strategies, activities, and achievements to date (as of March 2008).

## The Uganda Sustainable Clubfoot Care Project (USCCP)

USCCP is a Canadian International Development Agency (CIDA) [4] funded University Partnerships in Cooperation and Development (UPCD) [22] 6-year (2004–2010) collaborative project. Project partners include the University of British Columbia (lead partner), the Makerere University Medical School, the Makerere University School of Public Health, the Ugandan Ministry of Health (MoH), and CBM International [6]. USCCP's intended outcomes are to institutionalize the Ponseti method of clubfoot treatment throughout the Ugandan healthcare system and to upgrade healthcare curricula of all Uganda's schools of higher education to include the treatment of clubfeet by the Ponseti method. By the end of the project: (1) there should be high awareness of the deformity with healthcare workers and the population; (2) the deformity should be routinely recognized; (3) infants should be taken for available and effective treatment; and (4) there should routinely be high awareness and ability in newly trained healthcare professionals, who see children, to detect and treat clubfeet by the Ponseti method. (See Narrative Summary and Logical Framework Analysis in supplemental materials available with the online version of CORR.)

CIDA is one of many governmental organizations interested in alleviating poverty, promoting human rights, and supporting sustainable development. CIDA works in concert with its development partners, fragile states and countries in crisis, selected countries and regions, and the Canadian population and institutions. The UPCD program is a CIDA program that funds knowledge partnerships between Canadian universities and higher education organizations in developing countries in Africa and elsewhere.

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## Project Strategies and Activities

In 1997, the Ugandan MoH released a set of standards to help districts in Uganda develop services that meet the needs of people with disabilities [14]. This document describes disability and rehabilitation health services to be available at the district level consistent with national health policy [16]. Strategies for strengthening these services include decentralization, raising public awareness, capacity building of medical personnel to new approaches, and incorporating rehabilitation into the basic and in-service curricula for health workers. USCCP has adopted and adapted these strategies to guide its activities, outputs, and intended outcomes. These are detailed in the project's logical framework analysis. USCCP activities by strategy are summarized below. USCCP also has an evaluation component as detailed below.

### Decentralization

Lack of physical access to facilities has been identified as a barrier to seeking healthcare in an African setting [18]. To improve physical access, clubfoot detection and treatment is being decentralized. There is a renewed emphasis on MoH guidelines for routine screening for foot deformity as part of the first examination after birth (see below), leading to referral to a local clubfoot clinic if abnormal. Uganda's national healthcare system has 56 public hospitals (two national referral, 11 regional referral, and 43 general). Within the Ugandan healthcare system, the orthopaedic officer (a paramedical with 3 years of postsecondary training) is the frontline hospital healthcare professional for musculoskeletal conditions. USCCP is assisting the MoH to: (1) Sensitize health administrators at the district and subdistrict levels to changes patterns of practice in regard to the treatment of clubfeet so they may allocate appropriate resources; (2) Help 40 hospitals across Uganda establish weekly clubfoot clinics. Each clinic acts as the area's resource for children with clubfeet. Two orthopaedic officers staff each clinic with access to a medical officer or surgeon for tenotomies. Materials and braces are accessed by individual hospitals from government stores. (3) Coordinate quality assurance mechanisms with onsite visits (quality of care, availability of casting supplies/braces, etc.). USCCP will pass this quality assurance responsibility to the MoH as the project matures.

### Raising Public Awareness

There is a lack of awareness within the general public that the clubfoot deformity is correctible. To raise public

awareness, USCCP has assisted the MoH to design and distribute awareness-raising posters and pamphlets to village health teams, healthcare centers, churches, and schools. These materials explain the importance of screening for foot deformities at the time of first examination after birth and the need to seek timely care at a clubfoot clinic if findings are abnormal. USCCP and MoH have also created FM radio public health messages to inform the public at large of the same messages (see Ministry of Health poster, pamphlet, appointment card, and Radio Public Awareness Message 1 and 2 in supplemental materials available with the online version of CORR).

### Capacity Building of Healthcare Professionals to New Approaches

Screening for foot deformity at the first examination after birth and the use of the Ponseti method for clubfoot treatment are new or re-emphasized approaches for Ugandan healthcare professionals. In-service training is the USCCP mainstay of building capacity in these areas.

#### *Screening for Foot Deformity*

For children born in a healthcare facility, screening for foot deformity will ideally occur at or soon after birth by the midwife or nurse. For births outside a health facility, MoH guidelines are for newborns to be taken to a healthcare facility for a well-baby check (to include screening for foot deformity), first immunization, and birth registration. USCCP is working with MoH to provide in-service training and educational materials for nurses, midwives, and health professionals in the community that first see the at-risk population in how to screen for foot deformities and in the importance of the referral of children with abnormal screening results to the nearest clubfoot clinic.

#### *Treatment with the Ponseti Method*

At clubfoot clinics, orthopaedic officers will examine children with abnormal screens to confirm or exclude the diagnosis of clubfoot. When indicated, orthopaedic officers will administer all components of Ponseti treatment for the clubfoot except for the tenotomy, as it is outside their usual scope of practice. Medical officers and surgeons will perform Achilles tenotomies when indicated. Orthopaedic technicians at designated workshops will make Steenbeek foot abduction braces.

All orthopaedic officers in Uganda are being trained (with a series of Ponseti method hands-on workshops) to

implement Ponseti clubfoot treatment. Where medical officers and surgeons supervise orthopaedic officers in clubfoot clinics, they have been trained in the method and their role in the tenotomy. Technicians at government and other orthopaedic workshops have been trained in making Steenbeek foot abduction braces [9]. These workshops can now make sufficient braces to meet Uganda's needs.

#### Incorporating New Information on Clubfoot Care in the Curricula for Healthcare Professionals

Uganda has four medical schools (two with postgraduate surgical training programs), 32 schools of nursing and midwifery, a school for orthopaedic officers, and a school for orthopaedic technology. These schools all have curriculum content on the detection and care of children with congenital musculoskeletal abnormalities. All schools are amending their curriculum content to include, as appropriate, USCCP-designed modules and supporting training materials on clubfoot detection and Ponseti clubfoot treatment as well as the Production Manual for the Steenbeek Foot Abduction Brace [9]. Several schools (Makerere University Medical School, Mbarara University of Science and Technology School of Medicine, Mulago Paramedical School of Orthopaedic Officers, Mulago Paramedical School of Orthopaedic Technology, and Mulago School of Midwifery & Nursing) have already implemented these changes, which include lectures, tutorials and hands-on practical teaching in clubfoot clinics.

#### Evaluation

A large endeavor such as USCCP offers many opportunities for studies and surveys. Selected examples are presented.

##### Survey of Incidence of Clubfoot in Uganda

Clubfoot is a common foot deformity recorded in Uganda, but the incidence or gender ratio of the condition has never been measured in the country. The main objective of the *Survey of Incidence of Clubfoot in Uganda* was to measure the overall incidence and gender ratio of clubfoot deformity in a Ugandan national sample. At eight regional hospitals with clubfoot clinics, delivery room staff were in-serviced by USCCP staff on how to screen for foot deformities at birth. From March 2006 to December 2007, all babies with foot deformities detected by delivery room staff at birth were referred to the hospitals' clubfoot clinics, where orthopaedic officers examined the referred children

and recorded the specific deformity and gender. The denominator was all live births at these hospitals in the same period.

##### Understanding Clubfoot in Uganda: A Rapid Ethnographic Study

USCCP is endeavoring to implement a culturally appropriate and relevant awareness and treatment program for clubfoot. As cultural perceptions of the deformity, disability, and gender may affect not only the initial presentation for assessment but also the tolerance to the treatment regimen, it is vital to have an in-depth understanding of how Ugandans view the condition of clubfoot. An ethnocultural survey was designed to study knowledge, attitudes, beliefs, and practices about clubfoot across different regions in Uganda. The intent was to use the knowledge gained to better understand treatment-seeking behavior around clubfoot and the potential barriers to adherence to treatment protocols. A cross-sectional, descriptive study was conducted in eight districts of Uganda using qualitative methodology, employing 48 focus group discussions, 156 interviews, and participant observation. The study addressed local terminology, theories of causation, knowledge dissemination, treatment-seeking behavior, gender differences, and potential barriers to adherence to treatment.

##### The Barriers to Adherence to Ponseti Clubfoot Treatment Protocols in Uganda. A Case-control Study

Loss to followup during Ponseti treatment of clubfeet in Uganda is not uncommon. *Understanding Clubfoot in Uganda: A Rapid Ethnographic Study* identified a number of factors that may potentially act as barriers to adherence to treatment protocols. The purpose of the barriers to adherence to Ponseti study was to clarify which of these factors were most likely to be associated with inability to adhere to Ponseti treatment protocols. The variables studied included: (1) sociodemographic characteristics of name, age, gender, marital status of caregiver, number of siblings, address; (2) socioeconomic characteristics of occupation of the father/mother, education level of father/mother, family disposable income, properties owned by family (car, radio, TV, land, home); (3) characteristics affecting access to the clinic such as distance to clinic, travel time to clinic, cost of travel, means of transport; and (4) challenges to clubfoot treatment relating to the family (ie, care of other siblings), and to treatment (ie, costs of treatment). We performed a community-based case control study based in Kampala, Masaka, and Jinja from May 2007



to November 2007. By questionnaire, we determined study variables in two groups of caregivers of children with clubfeet, those who adhered to treatment protocols (attended the clinic as scheduled) and those who did not (failed to attend for at least two scheduled visits). Those who adhered were interviewed in the clinic. Those who did not adhere were interviewed during a home visit conducted for the purpose of the study. The data were analyzed to determine which variables were most likely to be associated with inability to adhere to Ponseti treatment protocols.

**Congenital Clubfoot in Uganda Treated by the Ponseti Method—Outcome at Age 4**

Ponseti clubfoot treatment has high efficacy in correcting the clubfoot deformity in ideal conditions. However, it is demanding on parents and on developing nations' healthcare systems. Its effectiveness and the best method of care delivery remain unknown in these systems. The purpose of the *Congenital Clubfoot in Uganda Treated by the Ponseti Method—Outcome at Age 4* study is to determine the outcome of Ponseti treatment on a sample of Ugandan children with clubfeet treated by the Ugandan healthcare system. This can be viewed as a measure of the effectiveness [8, 10] of the Ponseti method in the treatment of the congenital clubfoot in the context of the Ugandan healthcare system. USCCP has recruited a random sample of 345 children that presented with clubfeet at seven clubfoot clinics across Uganda. The children's clubfeet have been treated with the Ponseti method within the

Ugandan healthcare system. The children will be followed to project end in 2010 to determine the outcome at a mean 4 years of age.

**Key Achievements to Date**

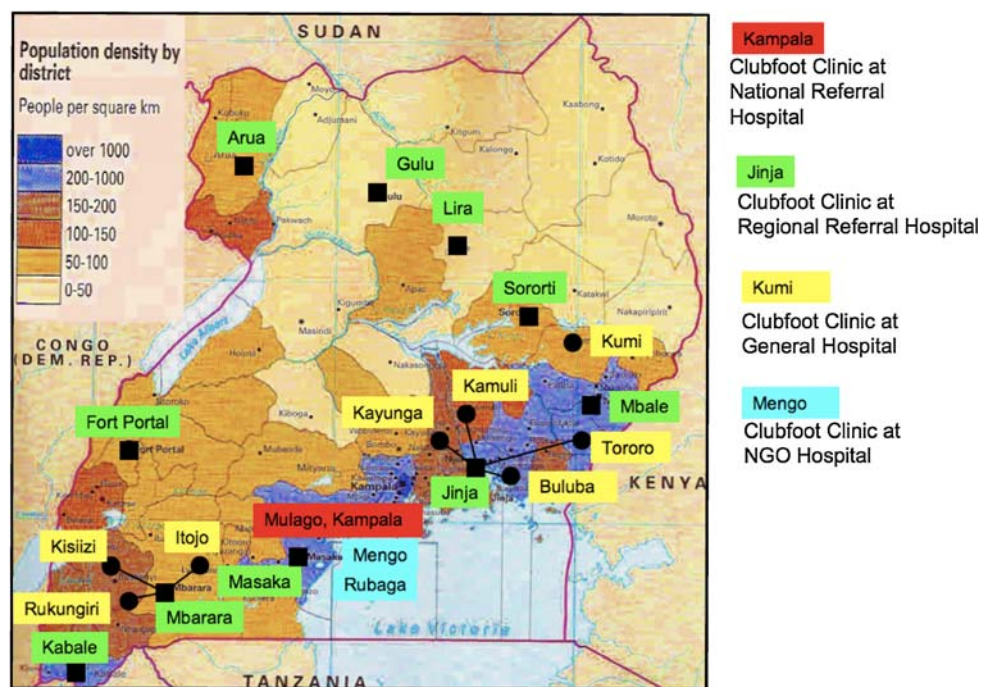
**Decentralization and Raising Public Awareness**

The MoH has approved the Ponseti method as the preferred treatment for the congenital clubfoot in all its hospitals. Twenty-one hospitals in Uganda are using the Ponseti method as the treatment of choice for clubfeet (Fig. 1, Table 1). A total of 872 children with clubfeet were seen at these clinics in 2006–2007 (Table 2). Also shown are the estimated births (using incidence data) and actual numbers seen by the region. USCCP and MoH designed awareness raising materials and FM radio messages are being widely

**Table 1.** 21 Hospitals by region in Uganda using Ponseti method for treating congenital clubfoot

Eastern (7)	Western (6)	Central (5)	Northern (3)
Mbale	Mbarara	Mulago	Lira
Jinja	Itojo	Rubaga	Gulu
Soroti	Kisiizi	Mengo	Arua
Kumi	Rukungiri	Kayunga	
Buluba	Kabale	Masaka	
Kamuli	Fort Portal		
Tororo			

**Fig. 1** Twenty-one hospitals have a clubfoot clinic where Ponseti treatment is available for clubfeet—note their location in the more populated areas.



**Table 2.** Children with clubfeet: estimated births and actually seen in the 2-year period 2006–2007 by region

Region	Estimated births*	Actually seen	Percentage
Central	754	326	43.2%
Eastern	710	260	36.6%
Northern	602	67	11.1%
Western	724	219	30.2%
Total for Uganda	2790	872	31.3%

\* Calculated as  $2 \times$  incidence of clubfoot (1.2 per thousand – US-CCP data)  $\times$  population  $\times$  crude birth rate (47 per thousand)—Uganda Census 2002 [20].

**Table 3.** Healthcare professionals benefiting from in-service training in clubfoot detection and Ponseti clubfoot management

Profession	Number of people
Nurses and midwives	634
Paramedical—orthopaedic officers	100
Paramedical—orthopaedic technicians/technologists	25
Medical—surgeons and medical officers	39

distributed and broadcasted to raise awareness in health professionals and civil society about clubfoot.

#### Capacity Building of Healthcare Professionals to New Approaches

Within Uganda's healthcare system many health disciplines are involved in clubfoot care. To date 39 medical officers and surgeons and 100 orthopaedic officers have been trained in the Ponseti method, 25 government and NGO technicians have been trained in the making of Steenbeek foot abduction braces, and 634 nurses and midwives have acquired new knowledge and skills in screening for foot deformity (Table 3). At every hospital with a clubfoot clinic, project staff members regularly inform and update hospital administrators about clinic activities to strengthen the case for local resources for clubfoot clinic supplies and manpower.

#### Incorporating Clubfoot Care in the Curricula for Health Professionals

In association with Global HELP Organization, USCCP has produced a 48-page full-color training manual entitled "Ponseti Clubfoot Care—A Training Manual for Healthcare Providers in Uganda" [9]. This provides one easily

**Table 4.** Students in health disciplines benefiting from USCCP-designed syllabus in clubfoot detection and Ponseti clubfoot management

Discipline	Number of students
Undergraduate medical	299
Postgraduate surgical residents	26
Paramedical—orthopaedic officers	340
Paramedical—orthopaedic technologists	68
Nursing and midwifery	419

digestible source for all core material on clubfoot detection and treatment by the Ponseti method for students in Uganda's medical, nursing, and paramedical schools, as well as for healthcare professionals looking after infants in Uganda's healthcare institutions. USCCP has printed 10,000 copies in Uganda for free distribution to all students at all Uganda's healthcare schools and institutions (see Ponseti Clubfoot Management: Teaching Manual for Healthcare Providers in Uganda in supplemental materials available with the online version of CORR).

Five healthcare schools (Makerere University Medical School, Mbarara University of Science and Technology School of Medicine, Mulago Paramedical School of Orthopaedic Officers, Mulago Paramedical School of Orthopaedic Technology, and Mulago School of Midwifery & Nursing) have approved the USCCP clubfoot modules, amended their curricula content, and are using the new modules and training manual. A total of 1152 students have benefited from upgraded training (Table 4). To date, this includes 299 medical students, 11 postgraduate orthopaedic and 15 postgraduate general residents at Makerere University Medical School and Mbarara University of Science and Technology School of Medicine; 340 student orthopaedic officers at the Mulago Paramedical School of Orthopaedic Officers; 68 orthopaedic technology students at the Mulago Paramedical School of Orthopaedic Technology; and 419 student nurses/midwives at Mulago and other schools of midwifery and nursing.

#### Evaluation—Results

##### Survey of Incidence of Clubfoot in Uganda

The total number of live births at study hospitals during the study period was 110,336. The total number of children with any foot deformity detected by study hospital maternity units was 290, of which 131 had a congenital clubfoot deformity. The incidence of clubfoot was therefore 1.2 per 1000 live births. The male-to-female ratio for clubfoot was 2.4:1.

## Understanding Clubfoot in Uganda: A Rapid Ethnographic Study

Across all ethnic groups, there was no single local term for what biomedicine describes as clubfoot. Rather, we uncovered multiple terms that fell into three loose groupings. (1) Descriptive terms for the shape of the foot (eg, zamfula—twisted). (2) Traditional beliefs: Children born with clubfoot are at times named after traditional gods who are believed to cause deformities (eg *Kadu wanema*, a name given to children with clubfoot, is one of the gods in Buganda. This god is believed to be crippled and hence often associated with lameness among the Buganda). (3) Ethnic origin: Persons with clubfoot are given a variety of nicknames depending on their ethnic origin (eg, *Ngige tiende* by the Japadhola implies that a person who walks on the dorsal part of the foot, which is tender, prefers to walk on soft/smooth surfaces).

Respondents were often not certain about cause but presented a number of theories they believed were likely or probable. Analysis of the causes of clubfoot from the lay and biomedical paradigms shows that both share some similar views on the explanations. Biomedical practitioners tend to refer to these as theories of cause as opposed to true cause. The two groups express similar views with hereditary, family planning pills, polio, reduced uterine space, use of drugs, poor nutrition of mother during pregnancy, and lack of antenatal care. However, the lay community explanations hinge more on supernatural causes such as witchcraft, spirits, sent by God, curses, and twin births. Knowledge of both the community and biomedical beliefs allows for greater understanding between practitioners and patients, and provides clues about the underlying motivation of some treatment-seeking behavior.

Respondents favored radio as a method of receiving health information. Ugandans use both biomedical and traditional care. The potential barriers to adherence were classified into six themes: (1) problems with programmatic resource availability and regional differences; (2) distance to treatment site; (3) poverty; (4) lack of paternal support; (5) caregiver's other responsibilities; and (6) challenges of the treatment process [12]. Gender preference did not appear to substantially influence treatment seeking for clubfoot.

## The Barriers to Adherence to Ponseti Clubfoot Treatment Protocols in Uganda. A Case-control Study

The caregivers of 73 children with clubfeet were interviewed. Twenty-nine (21 men and eight women) were caregivers of children who had not adhered to treatment. Forty-four (26 men and 18 women) were caregivers of

children who had adhered. Analysis revealed no differences in adherence to treatment rates between the two groups based on gender of patient, age at start of treatment, age of female caregiver, family history of clubfeet, siblings with clubfeet, caregiver education level, caregiver marital status, belief clubfoot is a curse, and treatment challenges. Analysis, however, revealed differences in adherence to treatment rates between the two groups based on travel factors (cost greater than 4000 shillings per visit, distance to clinic greater than 20 km, and travel time greater than 1 hour were all barriers) and socioeconomic factors (indicators of poverty such as a house floor made of mud and absence of TV were barriers). These data suggest that travel and poverty factors are the major barriers to adherence to Ponseti treatment protocols in Uganda.

## Congenital Clubfoot in Uganda Treated by the Ponseti Method—Outcome at Age 4

Three hundred and forty-five children with clubfeet seen at seven clubfoot clinics across Uganda from January 1, 2006, to December 31, 2007, form a cohort that will be followed until end of bracing at age 4 years. All were treated with the Ponseti method by the Ugandan healthcare system. Of the 324 idiopathic cases, 188 were bilateral, 84 were on the right, and 52 on the left, giving a total of 512 clubfeet in the cohort. Data collection is continuing and a report of outcome will be published at a later time.

## Discussion

In an agrarian society, disability is a major cause of ill health and poverty. The disabled are socially and economically disadvantaged with reduced educational and employment opportunities. Disabled females are further disadvantaged as they are less likely to marry and more likely to suffer abuse. The burden of care of the disabled child falls on the mother, who then has less time for other children, domestic, agricultural, and economic activity. The Uganda Poverty Eradication Plan [13] states, "households continue to name ill health as a cause of poverty more often than any single factor." It further states "the presence of good health is necessary not just to improve the quality of life of an individual in terms of his or her well being, but is an essential input for raising the ability of people to increase their incomes at a micro level, thereby contributing to poverty alleviation, and to facilitate a productive and growing economy at the macro level." Uganda is one of the least developed nations and has one of the highest birth rates (47 per 1000) [20]. 31% of the Ugandan population lives below US\$1 a day [21].

Improving health indicators for the disabled is an issue of relevance for the MoH. In 1997, the MoH in Uganda released an information booklet “Making A Difference For Persons With Disabilities: Learn More About Disability & Rehabilitation” [15] to provide more information on disability and rehabilitation of persons with disability in Uganda so that “all Ugandans including the disabled participate in the goal of health for all.” After Macharia concluded that the Ponseti method could substantially reduce the disability burden caused by idiopathic clubfoot in Uganda (see Macharia in supplemental materials available with the online version of CORR), the authors desired to bring to fruition the potential impact of a Ugandan national clubfoot management strategy based on the Ponseti method. Therefore, they designed and obtained funding for USCCP with a goal to make available a sustainable, universal, effective, and safe treatment of the congenital clubfoot deformity in Uganda based on the Ponseti method. The purpose of this article is to present a brief overview of USCCP, its strategies, activities, and achievements to date (March 2008).

USCCP is testing an innovative threefold strategy to overcome the problem of the neglected clubfoot in Uganda. First, USCCP is building capacity within Uganda’s healthcare system to detect children born with clubfeet and then use Ponseti treatment to correct the deformity. Project achievements to date include the following. The MoH has approved the Ponseti method as the preferred treatment for the congenital clubfoot in all its hospitals. A total of 798 healthcare workers have received training in the detection of foot deformities and Ponseti clubfoot management (Table 3). Twenty-one hospitals are offering Ponseti clubfoot care (Fig. 1, Table 1). In 2006–2007, 872 children with clubfeet were seen, representing an estimated 31% of the expected number of children born with clubfeet during the same time period in Uganda (Table 2). This seemingly small percentage becomes more meaningful put into appropriate context. In 2005, only 41% of all births occurred in a healthcare center whereas 59% occurred at home [20]. By the end of the Project, the target is that there should be high awareness of the deformity with healthcare workers and the population, the deformity should be routinely recognized, infants should be taken for treatment, and treatment should be available and effective.

Second, USCCP is building capacity within Uganda’s schools of higher learning (that are training Uganda’s future healthcare professionals) how to teach clubfoot detection and treatment by the Ponseti method. Project achievements include the following. USCCP has designed Ponseti clubfoot teaching modules for the curricula of all medical and paramedical schools in Uganda. Currently they are in use at two medical and three paramedical schools. To date, 1152 healthcare students have benefited

(Table 4). By the end of the Project, there should routinely be high awareness and ability in newly trained healthcare professionals seeing children to perform their specific roles in detecting clubfeet and treating clubfeet by the Ponseti method.

Third, USCCP has an evaluative component with two mandates. The first mandate is to perform studies that would facilitate the Project to build capacity to deliver care for children with clubfeet. USCCP has performed three studies towards this mandate: (1) Survey of Incidence of Clubfoot in Uganda, (2) Understanding Clubfoot in Uganda—A Rapid Ethnographic Study, and (3) The Barriers to Adherence to Ponseti Clubfoot Treatment Protocols in Uganda—A Case-control Study.

#### Survey of Incidence of Clubfoot in Uganda

The incidence of clubfoot varies widely among different populations, from 0.6 and 2.57 per 1000 live births in the UK and US, with males more affected than females in a ratio of 2:1 [5] to 6.8 per 1000 births among the natives Hawaii [3], and 6 to 7 per 1000 births among the Maori population in New Zealand [7]. There is limited information on the incidence of clubfoot in African countries. One study conducted in Zimbabwe in 2002 [11] reported the incidence of clubfoot to be 0.9 per 1000 births. In another study conducted in Malawi the incidence of clubfoot was estimated to be 2 to 3 per 1000 births [19]. A recent study conducted in Uganda, estimated the incidence of clubfoot to be up to 4 per 1000 births [12]. Based on the findings of our multicenter study, the cumulative incidence of clubfoot was 1.2 per 1000 births with a male/female ratio of 2.4:1. Combined with the Ugandan census and birthrate data, our incidence survey data permits not only accurate estimation of children born with clubfeet by district and for the country (Table 2), but also allows healthcare administrators to budget resources, and clinic staff to compare actual versus expected numbers seen.

#### Understanding Clubfoot in Uganda—A Rapid Ethnographic Study

A literature review revealed no articles published on how Ugandans view the clubfoot deformity. Our study explored perceptions about clubfoot (including terminology, causation, gender differences, knowledge dissemination, treatment-seeking behavior, and potential barriers to treatment) in different tribal groups. It was the first phase of USCCP, and served to inform the subsequent phases of the project. Several recommendations flowed from this survey, and project partners are implementing many. For example,



“because there is no single local term in any of the local languages for what biomedicine calls a clubfoot, awareness campaigns and education should rely heavily on visual aids such as models, pictures, and hands-on practical experience,” and “due to the stigma attached to disability, it is advisable to give strong visual messages that children with clubfoot may be returned to full function following treatment.” The identification of potential barriers to adherence has led to a second study to elucidate which barriers are most influential. Space restrictions limit a fuller discussion on other recommendations (see Konde Lule in supplemental materials available with the online version of CORR).

#### The Barriers to Adherence to Ponseti Clubfoot Treatment Protocols in Uganda: A Case-control Study

The data suggest travel and poverty factors are major barriers to adherence to Ponseti treatment protocols in Uganda. We found no studies in the literature discussing caregivers' perceptions and experiences with adherence to the Ponseti method of clubfoot treatment in an African setting. However, other studies have identified poverty and lack of physical access to facilities as barriers to seeking healthcare in an African setting [18]. Failure to address these barriers can lead to the failure of healthcare programs and blaming of patients. The study supports decentralizing clubfoot care to permit easier physical access by parents and caregivers.

The British pioneer clinical epidemiologist Archie Cochrane defined two concepts related to testing healthcare interventions: efficacy and effectiveness [8, 10]. Efficacy is the extent to which an intervention does more good than harm under ideal circumstances (“Can it work?”). Effectiveness assesses whether an intervention does more good than harm when provided under usual circumstances of healthcare practice (“Does it work in practice?”). There remains little doubt about the efficacy of the Ponseti method in correcting congenital clubfoot deformity when conditions are ideal. In contrast, the effectiveness of the Ponseti method in real-world situations remains unknown. It can be evaluated through observational studies of real practice. USCCP's second evaluation mandate is to perform studies that would help assess the effectiveness of the Ponseti method in the treatment of congenital clubfeet in Uganda. The study *Congenital Clubfoot in Uganda Treated by the Ponseti Method—Outcome at Age 4* will measure outcomes at age 4 on a cohort of children born in Uganda with clubfeet treated by the Ponseti method by Ugandan healthcare professionals within the Ugandan healthcare system. Outcomes at age 4 in this cohort will be used as a measure of the effectiveness of the Ponseti method in the Ugandan context and will be the subject of another publication after completion of the study. This information will

be of relevance for healthcare administrations interested in developing national strategies and programs for clubfoot care by the Ponseti method in other settings and countries.

The 6-year Uganda Sustainable Clubfoot Care Project aims to build the Ugandan healthcare system's capacity to treat children born in Uganda with clubfeet with the Ponseti method and to measure the treatment's effectiveness. The Ugandan Ministry of Health has approved the Ponseti method as the preferred treatment for the congenital clubfoot in all its hospitals. USCCP has trained 798 healthcare professionals in detection of foot deformities at birth and Ponseti clubfoot management. Ponseti clubfoot care is now available in 21 hospitals across Uganda and in 2006–2007, 872 children with clubfeet were seen. USCCP-designed teaching modules on clubfoot and the Ponseti method are in use at two medical and three paramedical schools in Uganda. A total of 1152 students in various health disciplines have benefited. USCCP surveys have (1) determined the incidence of clubfoot in Uganda as 1.2 per 1000 live births, (2) gained knowledge surrounding attitudes, beliefs, and practices about clubfoot across different regions in Uganda, and (3) identified factors that are barriers to adherence to Ponseti treatment protocols.

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