Uganda Sustainable Clubfoot Care Project

UPDATE 2007

Makerere University

University of British Columbia

Canadian International Development Agency

Association of Universities and Colleges of Canada

Children's Orthopaedic Rehabilitation Unit (CORU)

Ministry of Health, Government of Uganda

Christian Blind Mission International

THE REPUBLIC OF UGANDA

CBMI Christian Blind Mission International HELPING THE WORLD TO SEE

Agence canadienne de développement international

Canadian International Development Agency

Association of Universities and Colleges of Canada

Association des universités et collèges du Canada

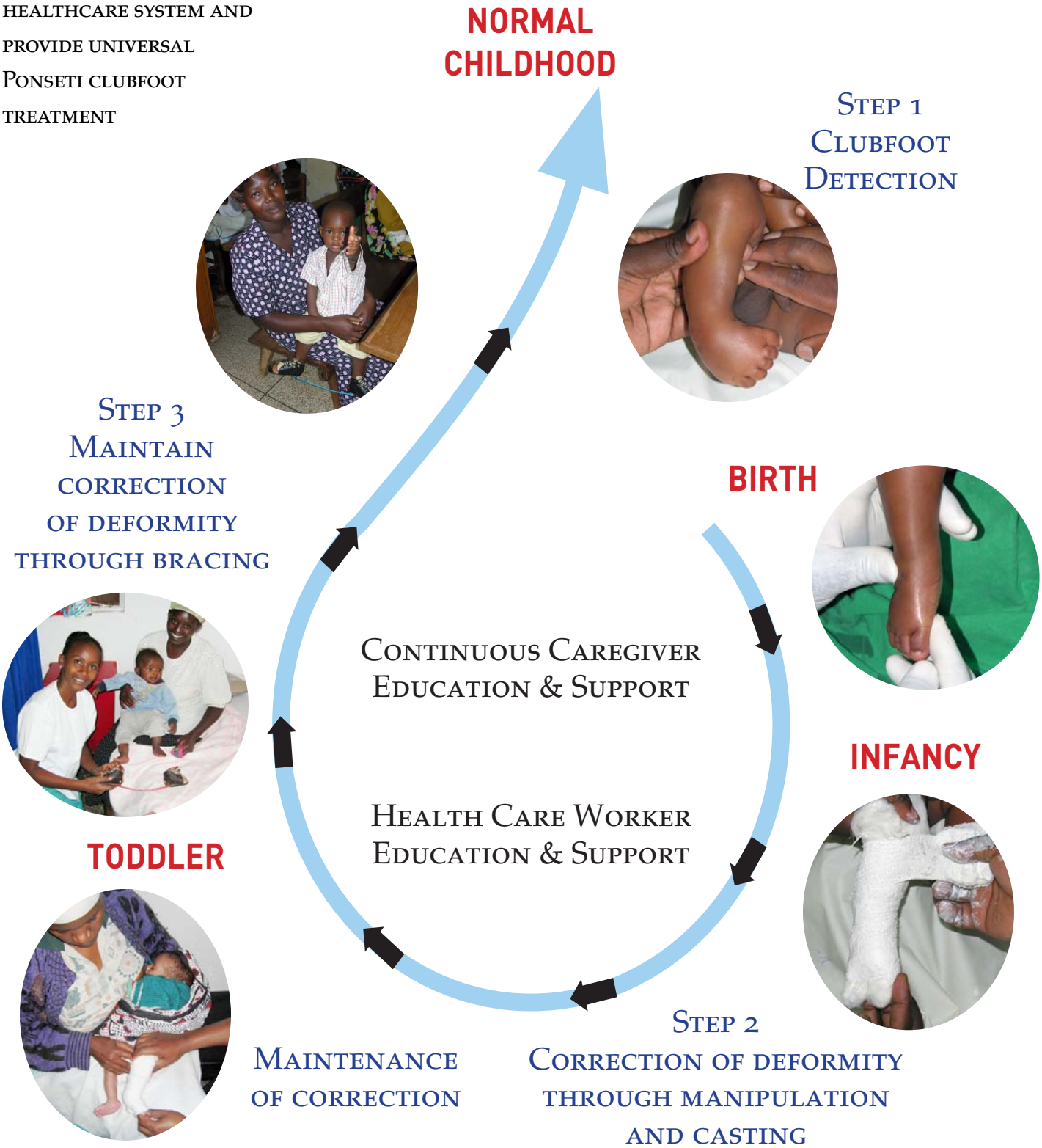
Makerere University we build for the future

UBC

Uganda Sustainable Clubfoot Care Project

The Project's mission is to reduce the consequences of disability from neglected clubfeet in Uganda by institutionalizing the Ponseti Method of clubfoot treatment throughout the Ugandan healthcare system and provide universal Ponseti clubfoot treatment

Steps towards a normal childhood for children born with clubfeet



Uganda Sustainable Clubfoot Care Project

April 1, 2004 – September 30, 2010

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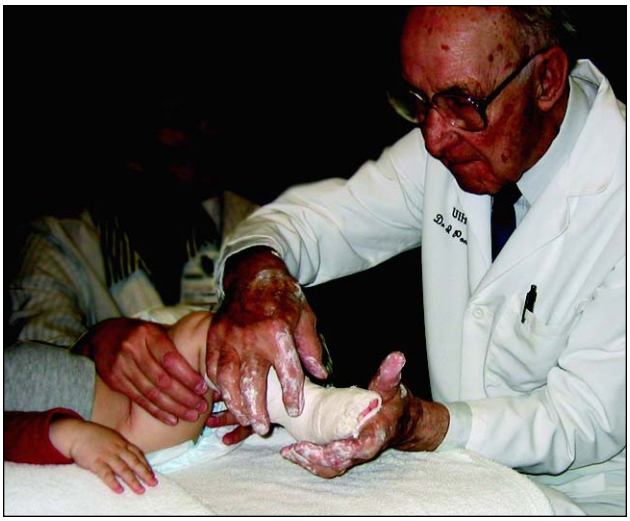
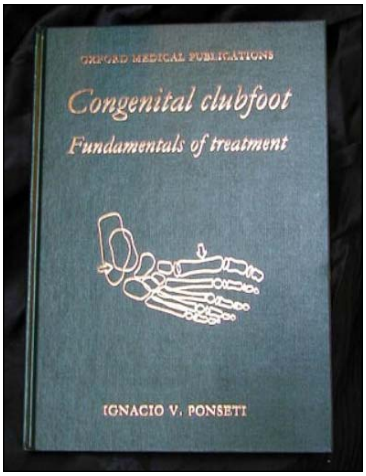
"The 50-year personal experience of Ignacio V. Ponseti, MD, indicates that most clubfeet, when treated shortly after birth, can be easily corrected by manipulation and application of five or six plaster casts."

Zlatko Anguelov
Ponseti Method of Idiopathic Clubfoot Treatment
Currents: Winter 2000, Volume1, Number 1
CURRENTS is published by University of Iowa Health Care

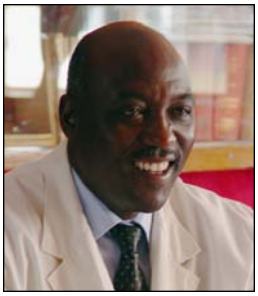




"We believe that at this moment in time it is important to pull together all the energy and momentum of the Ponseti method and to coordinate and concentrate its future programs and training so we can be a highly effective Association that brings about change to eradicate neglected clubfoot in the world. In this chaotic world of war, strife, terrorism, natural disasters and events over which we have no control, we need to pause and give thanks that the field of endeavor we are engaged in can change forever the life of a child. Together we can make it happen sooner rather than later".

- *From the Ponseti International Association for Clubfoot Treatment, University of Iowa Hospitals and Clinics, Department of Orthopedics, Iowa City, Iowa*

Report from the Project Directors



MR. Edward Naddumba

Senior Consultant
Ministry of Health
Orthopaedic Surgeon
Mulago Hospital

Prof. Shafique Pirani

Project Director
Department of Orthopaedics
University of British Columbia

Each year, over 1,000 children are born in Uganda with clubfeet. Most remain untreated and are subject to the downward spiral of deformity, disability, depression and despair.

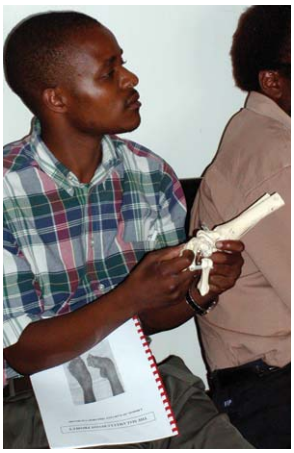
USCCP's goal is to reduce the consequences of the disability from neglected clubfoot in Uganda by institutionalizing the Ponseti Method of clubfoot treatment throughout the Ugandan healthcare system and to provide universal Ponseti clubfoot treatment.

We are approaching the mid-point of the six and a half year effort. How are we doing and what can we do better?

To answer these questions, USCCP commissioned a team of Canadian and Ugandan experts to perform a comprehensive Midterm Evaluation in March of 2007. We would like to quote three paragraphs from the evaluation's executive summary. The first two highlight our strengths and achievements. The third shows us the way forward.

"There is no question as to the relevance of this Project to the people of Uganda. Left untreated, the clubfoot disorder results in significant physical impairment that impedes mobility and has life-long functional implications. Children with clubfeet grow up with painful, deformed feet and as a result are severely restricted in their life-courses. The Project intervention, the Ponseti method, is incredibly effective if initiated early, performed well, and if families can comply with the full, lengthy course of treatment. Successfully treated, a child born with clubfoot can assume a life without functional deficits."

"... some remarkable achievements have been made towards building capacities for clubfoot detection and treatment. A strong and dedicated Project team has been assembled. They are currently overseeing the treatment of clubfoot at twenty clubfoot clinics at regional and general hospitals across seventeen districts. Annually, approximately 400 cases of clubfoot are being detected, and treatment initiated. Various cadres of health care workers are being sensitized to the detection and treatment of clubfoot. At the Ministry of Health, the Project has actively engaged and educated health policy makers. This has helped to facilitate the availability of regular supplies; plaster of Paris, cotton bandages and braces at clubfoot clinics."



Report from the Project Director

There have been constraints and setbacks.

First, thanks in part to research and careful monitoring being carried out under the Project, it is becoming increasingly clear that adherence to the Ponseti method of treatment is difficult for poor households. Barriers to compliance include: low levels of awareness about the long-term sequelae of clubfoot and the effectiveness of treatment; lack of regular supplies at clubfoot clinics; under-the-table fees charged at some clinics; distance to the nearest clubfoot clinic and associated travel costs; the perception that casts or braces are painful to the child, etc. Second, one of the central activities planned under the Project—towards early detection of the clubfoot deformity—was the training of community-based nurses in birthing and immunization centers. This sensitization has not yet begun, largely due to Ministry of Health delays. Also delay in the official approval of the role of nurses in clubfoot management by the nursing and midwifery council of Uganda has also slowed progress. Third, there are a number of factors that will threaten the sustainability of Project activities beyond 2010. Chief among these factors are: disproportionate "ownership" of the Project by Canadian viz. a viz Ugandan Project managers, failure to integrate Project activities within the Department of Orthopedics, lack of commitment (within the MOH) to maintaining the support supervision roles, recurrent problems with the delivery of key supplies (notably, plaster of Paris and braces) through the government supply chain.

Building sustainable capacity is challenging even when conditions are ideal. Yet the rewards are more than worth the effort. Stories of individual children - as told in the DVD accompanying this report, and in the CP1, a letter from a Uganda father - are perhaps the most evocative way of understanding the profound potential benefits of this project. Take a moment to have a look.

Respectfully Submitted,

MR. Edward Naddumba
Senior Consultant
Ministry of Health
Orthopaedic urgeon
Mulago Hospital

Respectfully Submitted,

Prof. Shafique Pirani
Project Director
Department of Orthopaedics
University of British Columbia

Project Profile

Lead Canadian Partner	Lead Developing Country Partner
The University of British Columbia	**Makerere University, Uganda**
Canadian Project Director: Dr. Shafique Pirani	**Uganda Project Director:** MR. Edward Naddumba
Professor, Department of Orthopaedics	Senior Consultant, Department of Orthopaedic Surgery
Phone number: (604) 522-2332 E-mail address: piras@aol.com	Phone number: 011-041-542332 E-mail address: enaddumba@yahoo.com

Link to Uganda's national development priorities

The Uganda Poverty Eradication Plan states that ill health is the most frequently cited cause and consequence of poverty in the country. Its four pillars of action include actions that directly improve the quality of life of the poor and actions that directly increase the ability of the poor to raise their incomes. The Uganda Ministry of Health has expressed the desire to incorporate the principles of clubfoot management espoused by this project within its next five-year strategic plan (2005-2010).

Project purpose

The project purpose is to make available in a sustainable fashion a universal, effective, efficient, and safe treatment of the congenital clubfoot deformity in Uganda.

Expected outcomes

The project will reduce the consequences of disability from neglected clubfeet by institutionalizing the Ponseti Method of clubfoot treatment throughout the Ugandan health care system and will train health care personnel to detect and treat the deformity.

Project Profile

Beneficiaries

The main beneficiaries will be children affected by clubfoot and their families.

Key activities

Key activities include an ethno-cultural survey, an incidence survey, the development of an awareness program, clubfoot conferences in Uganda as well as workshops for orthopaedic officers, technicians and local health care personnel to provide treatment with a method that is socially acceptable and economically viable.

Key Results to Date

The Ministry of Health has approved the Ponseti Method as the preferred treatment for the congenital clubfoot in all its hospitals. Awareness and training activities have taken place at 20 hospitals in 19 districts. 19 hospitals are now providing Ponseti care including the Mulago National Referral Hospital and 6 Regional Referral Hospitals. A total of 664 Ugandan Health Care Workers have benefited from training and sensitization, (8 surgeons, 3 medical officers, 98 orthopaedic officers, 19 orthopaedic technicians, 6 physio therapists, 550 nurses, midwives and health care workers and senior level hospital administrators). In 2006, 409 children were cared for.

5 schools of higher learning, Medical/paramedical/Nursing and Midwifery, have adopted USCCP Clubfoot training modules and teaching materials in their curricula. A total of 815 students in Healthcare have benefited, (168 medical students, 16 postgraduate orthopaedic and general surgery residents, 175 orthopaedic officer students, 32 orthopaedic technology students, 424 nursing and midwifery students).

Research activities ongoing include incidence and outcome surveys. An ethno-cultural survey highlighted barriers to care, allowing development of picture based awareness materials that emphasize that the condition is readily treatable.

Partner Institutions

The Project Partners include:

Canadian International Development Agency (CIDA)

Agence canadienne de développement international
Canadian International Development Agency

The Canadian International Development Agency (CIDA) is Canada's lead development agency. It has a mandate to reduce poverty and to contribute to a more secure, equitable, and prosperous world. CIDA works in partnership around the world to support sustainable development in developing countries and to offer humanitarian assistance in areas of need. *ww.acdi-cida.gc.ca*

Children's Orthopaedic Rehabilitation Unit (CORU)

CORU is one of the departments of Mengo Hospital working in the field of paediatric orthopaedics and plastic sugery. CORU's mandate is to prevent disability and to restore ability, or at least decrease the limiting effects of disabling physical condition. The main focus of CORU is children with physical disabilities.

Christian Blind Mission

To rescue and restore people trapped in poverty by disability. These are the most forgotten people in the world.

Makerere University

Makerere University is Uganda's premier institution of higher learning. With a student population of over 30,000, it ranks as one of the largest in East and Central Africa.

THE REPUBLIC OF UGANDA

Mulago Hospital

Mulago Hospital is an urban, tertiary care facility located in Kampala, Uganda. It is the largest government referral hospital, the main teaching hospital of Makerere University and the site of the main Clubfoot Clinic of the USCCP.

THE REPUBLIC OF UGANDA

Ministry of Health, Government of Uganda

To provide the policies, guidance and standards; facilitate district health services and manage nationally based health services. To ensure the attainment of a good standard of health by all people in Uganda in order to promote a healthy and productive life.

The University of British Columbia

The University of British Columbia, aspiring to be one of the world's best universities, will prepare students to become exceptional global citizens, promote the values of a civil and sustainable society, and conduct outstanding research to serve the people of British Columbia, Canada, and the world.

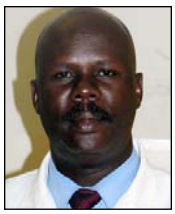
Key Team Members and Stakeholders

Team Member/Institution	Responsibilities
 Dr. Jackson Amone Assistant Commissioner Integrated Curative Division Ministry of Health, Uganda Plot 6 Lourdel Road, Wandegeya Kampala, Uganda	• Regular support supervision to the hospitals to ensure that: - all hospitals budget for and purchase supplies for clubfoot treatment - there is constant availability of Plaster of Paris and braces in the clubfoot clinics • Health workers sensitization on detection and referral of children with clubfoot
 Mrs. Susan Cutts Director of Administration Department of Orthopaedics University of British Columbia #3114-910 West 10th Avenue, Vancouver, BC V5Z 4E3 Tel: (604) 875-4156 Fax: (604) 875-4677 scutts@interchange.ubc.ca	• Program Administration in Canada
 Dr. Fulvio Franceschi Children's Orthopaedic Rehabilitation Unit, Uganda Mengo Hospital, P.O. Box 20146, Kampala, Uganda Tel: (256) 041273752 Mobile: 077 674098/553555	• Supervision of Ponseti Method Workshops • Financial Records/Budgets
 Professor Joseph Konde-Lule Institute of Public Health, Uganda  Professor Richard Mathias Department of Epidemiology University of British Columbia Canada	• Public health/primary care focus of the intervention within the Ugandan health care system • Research Supervisor • The design of the mid-term and final evaluation studies • Data input, analysis, interpretation and dissemination to the Project Directors • Quality assurance of the overall evaluation • Working with the Ministry of health re: screening of new-borns for clubfoot deformities and their referral for definitive diagnosis at the appropriate health center level focusing on the integration of this requirement into the existing health care system through the well baby visits, immunization programs and other primary health interventions in place in the Ugandan health care system
 Mr. Winston Miller Enable Canada Director Overseas Services Christian Blind Mission International 3844 Stouffville Road, Box 800, Stouffville, Ontario L4A 7Z9 Tel: (905) 640-6466 Fax: (905) 640-4332 E-mail wmiller@cbmicanada.org	• Member of Steering Committee • Assistance in capacity building issues related to the region as well as how the program can be expanded in Africa/elsewhere

Key Team Members and Stakeholders

Dr. Kenneth McGillivray
Associate Vice-President,
UBC International,
Canada

- Member of Steering Committee
- Assistance in capacity building issues related to the region as well as how the program can be expanded in Africa/elsewhere



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Mr. Ben Mbonye
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- Research Supervisors
- Curriculum content of Ponseti Method teaching modules for all the training institutions and Ponseti Workshops for orthopaedic officers in the community

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Dr. Norgrove Penny
Paediatric Orthopaedic Surgeon
Canada

- Uganda liaison
- Research Supervisors
- Curriculum content of Ponseti Method teaching modules for all the medical and paramedical training programs as well as the Ponseti Method Provider and Support Supervision Workshops for orthopaedic officers in the community
- Report preparation

Ms. Marieke Steenbeek-Dreise
Children's Orthopaedic Rehabilitation
Unit & Department of Orthopaedics
Makerere University
Medical School, Uganda

- Program Administration in Uganda

USCCP Web Sites:

http://oraweb.aucc.ca/pls/cupid/show_upcd_e?country_cd_in=158#Uganda%20Sustainable%20Clubfoot%20Care%20Project

http://ponseti.info/pia

Cumulative Results 2004-2007

These include the intended results, the performance indicators and the cumulative results achieved for the Project to date.

Intended Results	Indicators	Cumulative outcome & outputs achieved (use indicators)
Outcome 1 (institutional) By 2010, 80% schools of Higher Learning in Uganda (Medical Schools, Nursing schools, Paramedical Training Schools – that educate & train Uganda's future healthcare workers) will have strengthened capacities to teach how to detect and treat the congenital clubfoot deformity in a sustainable manner within the Ugandan social, cultural & economic context.	**Outcome Indicators 1** Indicator 1.1: Number of institutions in Uganda having improved capacities in the teaching of the care of the congenital clubfoot deformity. Indicator 1.2: Level of success in the teaching of the treatment of clubfoot deformity of practitioners trained through the targeted institutions.	1. Makerere University Medical School 2. Mbarara University of Science & Technology 3. School of Orthopaedic Officers - Mulago 4. Orthopaedic Technology Training School - Mulago 5. School of Midwifery & Nursing - Mulago Survey tool under development
Outputs 1 Outputs 1.1: Makerere University Medical School (MUMS)and Mbarara University of Science and Technology (MUST) School of Medicine undergraduate syllabus in Musculoskeletal health upgraded to include module for the Ponseti method of treating the congenital clubfoot deformity by 2005.	Output indicators 1 Indicator 1.1: Number of medical students benefiting each year from the upgraded syllabus. Assessment of quality of teaching module by survey.	Output 1.1: 168 (113 M,55 F) Makerere University Medical School and Mbarara University of Science & Technology medical students have benefitted from the upgraded syllabus. *| See Appendix 1 |* Survey under development.
Output 1.2: Makerere Medical School postgraduate syllabus in orthopaedic surgery and general surgery upgraded to include module for the Ponseti method of treating the congenital clubfoot deformity by 2005.	Output Indicator 1.2: Number of postgraduate students in general and orthopaedic surgery benefiting each year from upgraded syllabus. Assessment of quality of teaching module by survey.	Output 1.2: 8(M) postgraduate ortho resident and 8(M) postgraduate general residents have benefited from the upgraded syllabus. *| See Appendix 1 |* Survey under development.
Output 1.3: Mulago Paramedical School of Orthopaedic Officers syllabus upgraded to include a module for the Ponseti method of treating the congenital clubfoot deformity by 2005.	Output Indicator 1.3: Number of student orthopaedic officers benefiting from new modules each year. Assessment of quality of teaching module by survey.	Output 1.3: 175 (128 M, 47 F) student orthopaedic officers benefiting from new modules. *| See Appendix 1 |* Survey under development.
Output 1.4: Mulago Paramedical School of Orthopaedic Technologists training upgraded to include a module on Steenbeek Foot Abduction Brace by 2005.	Output Indicator 1.4: Number of student orthopaedic technologists benefiting from new modules each year. Assessment of quality of teaching module by survey.	Output 1.4: 32 (31 M, 1 F) student orthopaedic technologists benefited from new module. *| See Appendix 1 |* Survey under development.
Output 1.5: By 2006 80% of technicians currently in government and NGO have been trained in the Ponseti Method with a specific focus on the role of the Orthopaedic Technician through workshops in Uganda.	Output Indicator 1.5: Number of government and NGO technicians trained in the making of foot abduction braces.	Output 1.5: 19 (18 M, 1 F) government and NGO technicians trained in the making of foot abduction braces. *| See Appendix 1 |*

Cumulative Results 2004-2007

These include the intended results, the performance indicators and the cumulative results achieved for the Project to date.

Intended Results	Indicators	Cumulative outcome & outputs achieved (use indicators)
Output 1.6: Clubfoot screening module designed, introduced and taught by 80% of nursing and midwifery schools by 2006.	Output Indicator 1.6.1: Clubfoot screening module approved by nursing and midwifery council of Uganda for all nursing and midwifery schools by 2005.	Output 1.6.1: Clubfoot Screening Module approved by Nursing/Midwifery Council of Uganda.	*See Appendix 3* |
	Output Indicator 1.6.2: 80% of nursing and midwifery students benefiting from new module by 2006. Assessment of quality of teaching module by survey.	Output 1.6.2: 424 student nurses/midwifes (69 M, 220 F, Sex not indicated 120) benefiting from the new module. | *See Appendix 1* | Survey under development.
Output 1.7: By 2010, 720 medical students (80 at MUMS and 40 at UMMS each year for six years will benefit from new knowledge and skills in the detection and management of congenital clubfoot in Uganda with a specific focus on the role of the Medical Officer in the District Hospital.	Output Indicator 1.7: Number of medical students having acquired new knowledge and skills in detection and management of congenital clubfoot in Uganda.	Output 1.7: See Output 1.1
Output 1.8: By 2010, 48 residents (4 surgeons and 4 general residents each year for six years) have acquired new knowledge and skills in the detection and management of congenital clubfoot in Uganda with a specific focus on the role of the General and Orthopaedic Surgeon in the District and Referral Hospital.	Output Indicator 1.8: Number of residents having acquired new knowledge and skills and number that are using their new knowledge and skills in their practice.	Output 1.8: See Output 1.2
Output 1.9: By 2010, 120 orthopaedic officers in training (20 each year for six years) have acquired new knowledge and skills in the detection and management of congenital clubfoot in Uganda with a specific focus on the role of the Orthopaedic Officer in the District Hospital.	Output Indicator 1.9: Number of orthopaedic officers having acquired new knowledge.	Output 1.9; See Output 1.3
Output 1.10: By 2010, 80% of nurses (in Uganda seeing infants) will benefit from new knowledge and skills in the screening and detection of congenital clubfoot in Uganda with a specific focus on the role of the nurse at the time of issuance of the "child health card".	Output Indicator 1.10: Number of nurses having acquired new knowledge and skills.	Output 1.10; 530 (76 M, 454 F) Nurses and Midwifes acquired new knowledge and skills in detection and management of congenital clubfoot in Uganda. | *See Appendix 1* |

Cumulative Results 2004-2007

These include the intended results, the performance indicators and the cumulative results achieved for the Project to date.

Intended Results	Indicators	Cumulative outcome & outputs achieved (use indicators)

Outcome 2 (community)
By 2010, the Ponseti method of treating the congenital clubfoot is integrated within the Ugandan healthcare system such that there will be increased capacity within each of Uganda's 56 districts for detection and treatment. By the end of the project there should be high awareness of the deformity within health care workers and the population, the deformity should be routinely recognized, the infants should be taken for treatment, and the treatment be available and effective with improved treatment for up to of one thousand infants per year.

Outcome Indicators 2
Output Indicator 2.1: Actual compared to expected rates of referral to District Hospitals based on incidence data by sex.

Output 2.1 Uganda Population 2002

Region	Pop 000	Expected	Actual
Central	6684	434	155
Eastern	6302	410	116
Northern	5346	347	32
Western	6417	417	106
Total	24,748	1,608	409

Output Indicator 2.2: Number of District Hospitals using Ponseti Method as treatment of choice for clubfeet.

Output 2.2 19 Hospitals by District, Region in Uganda using Ponseti Method for treating Congenital Clubfoot

REGION			
Eastern (7)	Western (6)	Central (5)	Northern (1)
Mbale, Mbale	Mbarara, Mbarara	Mulago, Kampala	Lira, Lira
Jinja, Jinja	Itojo, Iganga	Rubaga, Kampala	
Soroti, Soroti	Kisiizi, Rukungiri	Mengo, Kampala	
Kumi, Kumi	Rukingiri, Rukingiri	Kayunga, Kayunga	
Buluba, Mayuge	Fort Portal, Kabarole	Masaka, Masaka	
Kamuli, Kamuli	Kabale, Kabale		
Tororo, Tororo			

Outputs 2
Output 2.1: Ministry of Health approval of Clubfoot Treatment Protocol for Uganda by 2005, with necessary resources for District Hospital Clubfoot care.

Output 2 indicators
Output Indicator 2.1: Official approval of Clubfoot treatment protocol by MoH with satisfactory arrangement for necessary resources for District Hospital clubfoot care by 2005.

Output 2.1: Official approval of clubfoot treatment protocol

1. Speech of Vice President and Professor Gilbert Bukenya's speech at the official launch of the USCCP on Tuesday, February 22, 2005.
2. Satisfactory arrangements for necessary resources approved in letter of Director General of Health Services Uganda, Dr. Sam Zaramba | *See Appendix 4* |

Output 2.2: By 2006, all of Uganda's 56 Districts to have at least one Orthopaedic Clinical Officer trained in the Ponseti Method of Treating the Congenital Clubfoot.

Output Indicator 2.2: Number of Uganda's Districts with Orthopaedic Officer trained in managing clubfoot by the method of Ponseti over time (by end of 2006).

Output 2.2: There are 19 hospitals and clinics in 16 districts | see list as per Output 2 | and 98 (83 M, 15 F) orthopaedic officers acquired new knowledge and skills in detection and management of congenital clubfoot in Uganda | *See Appendix 1* | | *See Appendix 6* |

Output 2.3: By 2006, a manual for District Hospitals for the management of the congenital clubfoot deformity has been produced and distributed to all hospitals in Uganda.

Output Indicator 2.3: The number of hospitals that have received the manual.

Output 2.3: The manual is expected to be printed the second quarter 2007-08 | *See Appendix 5* |

Output 2.4: By 2007, all of Uganda's 56 Districts' birthing clinics and immunization centers to be sensitized in clubfoot detection

Output Indicator 2.4: Percentage of Uganda's birthing clinics and immunization clinics sensitized in clubfoot detection over time by end of year 2007.

Output 2.4: See Output 1.10

Cumulative Results 2004-2007

These include the intended results, the performance indicators and the cumulative results achieved for the Project to date.

Intended Results	Indicators	Cumulative outcome & outputs achieved (use indicators)
Output 2.5: Over the life of the project, a variety of studies (Outcome Evaluations) and surveys (Incidence Survey, Ethno-Cultural Survey) are planned. This output focuses on data collection and interpretation (Incidence Survey-2005, Ethno-Cultural Survey-2005, Outcome Evaluation-2007 & 2010) presentation at conferences (24 presentations anticipated by end of project) and publications in peer-reviewed academic journals (12 anticipated by end of project). In addition 2 conferences are planned in Uganda (in 2008 & 2010) to disseminate the results of the Project.	Output Indicators 2.5: 1. Incidence Survey completed-2005 2. Ethno-Cultural Survey completed-2005 3. First Outcome Evaluation completed-2007 4. Final Outcome Evaluation completed-2010 5. Clubfoot Conference 2007 (full day workshop and details) 6. Clubfoot Conference 2010 7. 24 Conference Presentations 8. 12 Peer Reviewed Publications	Output 2.5: 1. Incidence Survey completed in 2007. The report will be available in Fiscal Year 4. 2. Ethno-Cultural Survey-completed, report distributed to stakeholders. 3. First Outcome evaluation is planned for FY4. 4. Conference on "Management of the Clubfoot Deformity - Working Toward Building National Capacity in the Developing World" November 2005. 5 Clubfoot Conference Dec. 2006 and March 2007. 6.1 4th Annual Bethune Round Table on International Surgery – The Neglected Clubfoot – From Quandary to Opportunity – Gordon Murray Lecture as part of Gallie Days (Dr. S. Pirani) University of Toronto 2004 6.2 Orthopaedic Update May 2005, University of British Columbia, Department of Orthopaedics – The Neglected Clubfoot – From Quandary to Opportunity (Dr. S. Pirani) 6.3 James Wiley Lecture, Children's Hospital of Eastern Ontario, Ottawa, 2005 – The Neglected Clubfoot – From Quandary to Opportunity (Dr. S. Pirani) 6.4 The Uganda Sustainable Clubfoot Care Project – Pacific Island Ssurgical Association, 2006. 6.5 The Uganda Sustainable Clubfoot Care Project – Nairobi Orthopaedic Club, 2006 (Dr. S. Pirani). 6.6 The Uganda Sustainable Clubfoot Care Project – Ponseti Method Workshop at University Teaching Hospital, Lusaka, Zambia, 2006. 6.7 The Uganda Sustainable Clubfoot Care Project – International Forum on Universities and Participatory Development at University of British Columbia 2006 (Dr. E. Naddumba). – see Communication Product 7 6.8 The Uganda Sustainable Clubfoot Care Project at Mansoura University, Egypt, Clubfoot Conference 2007 (Dr. S. Pirani). 6.9 The Ponseti Method in Uganda – First South African Ponseti Workshop – 2006 Johannesburg, South Africa

Project Context

Social, cultural, economic and political forces continue to influence the project activities and outputs.

Social/Cultural

The project's Ethno-cultural Survey has highlighted barriers to healthcare (such as beliefs about cause of the deformity, and the presence of many names in many local languages for one condition). The project has developed adaptive measures such as picture based awareness materials to emphasize that the condition is readily treatable. |See Appendix 8 & 9 | A "Barriers to Care" study has been commissioned and is underway to identify specific barriers to clubfoot care. The intention is for the results of this study to guide further adaptive measures.

Economic/Political

Uganda was the 2007 host for the Commonwealth Heads of Government meeting. This has placed a significant financial burden on the Uganda Government, resulting in constraints on budgets for many ministries including the Ministry of Health. As a result, the Ministry of Health moved ahead at a slower pace than anticipated in its desire to implement political and policy decisions to support clubfoot treatment universally in Uganda. Though most materials for care are now available on "credit-line" through the National Medical Stores, systemic issues persist resulting in inadequate staffing at hospitals and inadequate protection of resources. These will necessitate a realignment of the project outputs, to be determined by the Post Mid-Term Evaluation Action Plan.

Key Results 2006 - 2007

Key Activities	Outputs Achieved	Outcomes Achieved
Conferences – to raise awareness of the new approach in Uganda to manage the clubfoot deformity. 2 Conferences held: The first was in Nov 2005 at Makerere University Department of Orthopaedics on "Management of the Clubfoot Deformity - Working Toward Building National Capacity in the Developing World" December 2006, in conjunction with the Annual General Meeting of the Uganda Medical Association. March 2007, in conjunction with the East African Community Health and Scientific Conference. |See Appendix 7	|See CD		These conferences contributed towards all outputs by informing attendees (healthcare professionals of different types from all over Uganda and beyond) of the change in approach to clubfoot management in Uganda	These conferences contributed towards both project outcomes (Community and Institutional) by informing attendees (healthcare professionals of different types from all over Uganda and beyond) of the change in approach to clubfoot management in Uganda

Key Activities 2006-2007

Key Activities	Outputs Achieved	Outcomes Achieved
Training Workshops - Community A variety of health care professionals in Uganda focusing on their roles in the detection, referral and management of children born with clubfeet in Uganda in the community	Indicator 1.5: Number of government and NGO technicians trained in the making of foot abduction braces.	Output 1.5: 1 (1 M) government and NGO technician trained in the making of foot abduction braces. |See Appendix 1 |
	Indicator 1.10: Number of nurses having acquired new knowledge and skills	Output 1.10: 234 (45 M, 189 F) Nurses and Midwifes acquired new knowledge and skills in detection and management of congenital clubfoot in Uganda. |See Appendix 1 |
	Indicator 2.2: Number of Uganda's Districts with Orthopaedic Officer trained in managing clubfoot by the method of Ponseti over time (by end of 2006)	Output 2.2: 55 (47 M, 8 F) orthopaedic officers in 22 Districts have acquired new knowledge and skills in detection and management of congenital clubfoot in Uganda. |See Appendix 1 |
Regular Training Workshops, Teaching Sessions and Continuing Professional Education Seminars - Institutional A variety of health care professionals in Uganda focusing on their roles in the detection, referral and management of children born with clubfeet in Uganda.	Indicator 1.1: Number of medical students benefiting each year from the upgraded syllabus.	Output 1.1: 119 (82 M, 37 F) Makerere University, Medical School and Mbarara University of Science & Technology medical students have benefited from the upgraded syllabus. |See Appendix 1 |
	Indicator 1.2: Number of postgraduate students in general and orthopaedic surgery benefiting each year from upgraded syllabus.	Output 1.2: 4 (M) Postgraduate Ortho Resident and 4 (M) Postgraduate General Residents have benefited from the upgraded syllabus. |See Appendix 1 |
	Indicator 1.3: Number of student orthopaedic officers benefiting from new modules each year.	Output 1.3: 75 (56 M, 19 F) Student orthopaedic officers benefiting from new modules. |See Appendix 1 |
	Indicator 1.4: Number of student orthopaedic technologist benefiting from new modules each year.	Output 1.4: 32 (31 M, 1 F) Student orthopaedic technologists benefited from new module. |See Appendix 1 |
	Indicator 1.6.2: 80% of nursing and midwifery students benefiting from new module by 2006.	Output 1.6.2: 289 student nurses/midwifes (69 M, 220 F) benefiting from the new module. |See Appendix 1 |

Key Activities 2006-2007

Key Activities	Outputs Achieved	Outcomes Achieved
Clubfoot Clinics		Outcome 2: By 2010, the Ponseti method of treating the congenital clubfoot is integrated within the Ugandan healthcare system such that such that there will be increased capacity within each of Uganda's districts for detection and treatment.
Manual for Management of Clubfoot Deformity	Outputs 1.1, 1.2, 1.3, 1.4, 1.7, 1.8, 1.9, 2.2, 2.3: This 48 page manual has been written to include all necessary written training materials for clubfoot detection and treatment for medical, paramedical and nursing schools in Uganda. It will also be the main reference material made available to each hospital in Uganda treating children with clubfeet.	Contribution to both outcomes 1 and 2.. |See Appendix 5 |
Incidence Survey	Output 2.5: Incidence Survey is completed with 80,000 Ugandan babies being evaluated for foot deformities and eight of Uganda's largest hospitals found incidence of clubfoot 1.2 per 1,000 live births with a 3 to 1 male to female ratio. This will allow for more accurate planning by the Ministry of Health for resource allocation.	Outcome 2

Output 2.2 Additional hospitals in Uganda using Ponseti Method for treating Congenital Clubfoot (March 2007)

REGION			
Eastern (5)	Western (6)	Central (1)	Northern (1)
Soroti, Soroti	Itojo, Iganga	Kayunga, Kayunga	Lira, Lira
Kumi, Kumi	Kisiizi, Rukungiria		
Buluba, Mayuge	Rukingiri, Rukingiri		
Kamuli, Kamuli	Fort Portal, Kabarole		
Tororo, Tororo	Kabale, Kabale		
	Ibanda, Ibanda		

Results Variance

Results Variance - Difference between results expected and actual results achieved to date.

Expected Results	Results Achieved	Explanation
1. Conferences Two conferences to promote clubfoot care by the Ponseti Method to be organized; 1 in 2007, and a second in 2010.	3 Conferences held: The first was in Nov 2005 at Makerere University Department of Orthopaedics on "Management of the Clubfoot Deformity - Working Toward Building National Capacity in the Developing World" The second was in December 2006, in conjunction with the Annual General Meeting of the Uganda Medical Association. The third was in March 2007, in conjunction with the East African Community Health and Scientific Conference	Three conferences, (one more than the two originally planned) have already been due to perceived demand for information and knowledge on the work of the project.
2. Awareness Program Awareness in all Uganda districts by paper based materials.	Awareness module taught at continuing professional education sessions at 19 hospitals in 16 districts in Uganda	Delay in formal approval by the Nurses & Midwifery Council of Uganda of the role of midwives in detection of clubfeet led to delay in awareness raising program's full implementation. More awareness activities are scheduled for FY4.
3. Module Production a. Clubfoot screening module designed, introduced and taught by 80% of nursing and midwifery schools by 2006.	a. Clubfoot screening module designed	a. Delay in formal approval by the Nurses & Midwifery Council of Uganda of the role of midwives in detection of clubfeet led to delay in completion of the manual.
b. By 2006, a manual for Hospitals for the management of the congenital clubfoot deformity has been produced and distributed to all hospitals in Uganda.	b. A Manual for Healthcare Providers in Uganda for the management of the congenital clubfoot deformity has been written and is awaiting printing.	b. Technical problems in final copy, but now resolved printing expected to be done in the 2nd Qtr of FY4.
4. Orthopaedic Officer & Technician Workshops Workshops for the training of government and NGO orthopaedic technicians to manufacture foot abduction braces	Three workshops held for government and NGO orthopaedic technicians to manufacture foot abduction braces – 19 technicians trained	Training of Orthopaedic in-service technicians is due to the limited number of Orthopaedic in-service technicians available
Workshops for the training of orthopaedic officers in detection and management of congenital clubfoot in Uganda	8 Workshops held for orthopaedic officers in detection and management of congenital clubfoot – 98 Officers trained	No variance

Results Variance

Results Variance - Difference between results expected and actual results achieved to date.

Expected Results	Results Achieved	Explanation
5. Rural Support Supervision Rural Support-Supervision activities for all Uganda's Clubfoot Clinics	79 Support Supervision visits to 16 Clubfoot Clinics in 14 Districts	No variance
6. District FPD & Nursing Trainers Workshops Workshops to train trainers at all of Uganda's Schools of Nursing and Midwifery in screening for clubfoot	-Module prepared -Training materials are prepared -Training delayed	Delay in formal approval by the Nurses & Midwifery Council of Uganda of the role of midwives in detection of clubfeet led to delay in introduction of module into nursing and midwifery schools. Now approved Training expected in the second half of FY4.
7. Outcome Evaluation Data collection for outcome evaluation	Ongoing	No variance
8. Incidence Survey Data collection for incidence survey	Ongoing	No variance
9. Canadian Public Engagement Video - DVD Included Public awareness video for Ugandan communities and Canadian communities	Completed	No variance

Implementation Variance

Implementation Variance - Difference between the types of activities that were planned and those completed, including adjustments made as a result of the mid-term evaluation.

Activities Planned	Activities Performed	Explanation of Variance
Awareness Program		
By 2007, all of Uganda's 56 Districts' birthing clinics and immunization centers to be sensitized in clubfoot detection	Awareness activities centered on 19 hospitals in 16 Districts	Delay in formal approval by the Nurses & Midwifery Council of Uganda of the role of midwives in detection of clubfeet led to delay in awareness raising program implementation. Awareness activities are scheduled for FY4.
Orthopaedic Officer & Technician Workshops		
Workshops for the training of government and NGO orthopaedic technicians to manufacture foot abduction braces	Three workshops held for government and NGO orthopaedic technicians to manufacture foot abduction braces – 19 technicians trained	Training of government and NGO technicians to manufacture foot abduction braces is limited by the small number of technicians available in the country.
Workshops for the training of orthopaedic officers in detection and management of congenital clubfoot in Uganda	8 Workshops held for orthopaedic officers in detection and management of congenital clubfoot – 98 Orthopaedic Officers trained	No variance
Rural Support Supervision		
Rural Support-Supervision activities for all Uganda's Clubfoot Clinics	79 Support Supervision visits to 19 Clubfoot Clinics in 16 Districts	No variance
District FPD & Nursing Trainers Workshops		
Workshops to train trainers at all of Uganda's Schools of Nursing and Midwifery in screening for clubfoot	-Module prepared -Training materials are prepared -Training delayed	Delay in formal approval by the Nurses & Midwifery Council of Uganda of the role of midwives in detection of clubfeet led to delay in introduction of module into nursing and midwifery schools. Now approved Training expected in the second half of FY4.
Outcome Evaluation		
Data collection for outcome evaluation	Ongoing	No variance
Incidence Survey		
Data collection for incidence survey	Ongoing	No variance

Spin Off Activities and Unexpected Results

Spin Off Activities and Unexpected Results

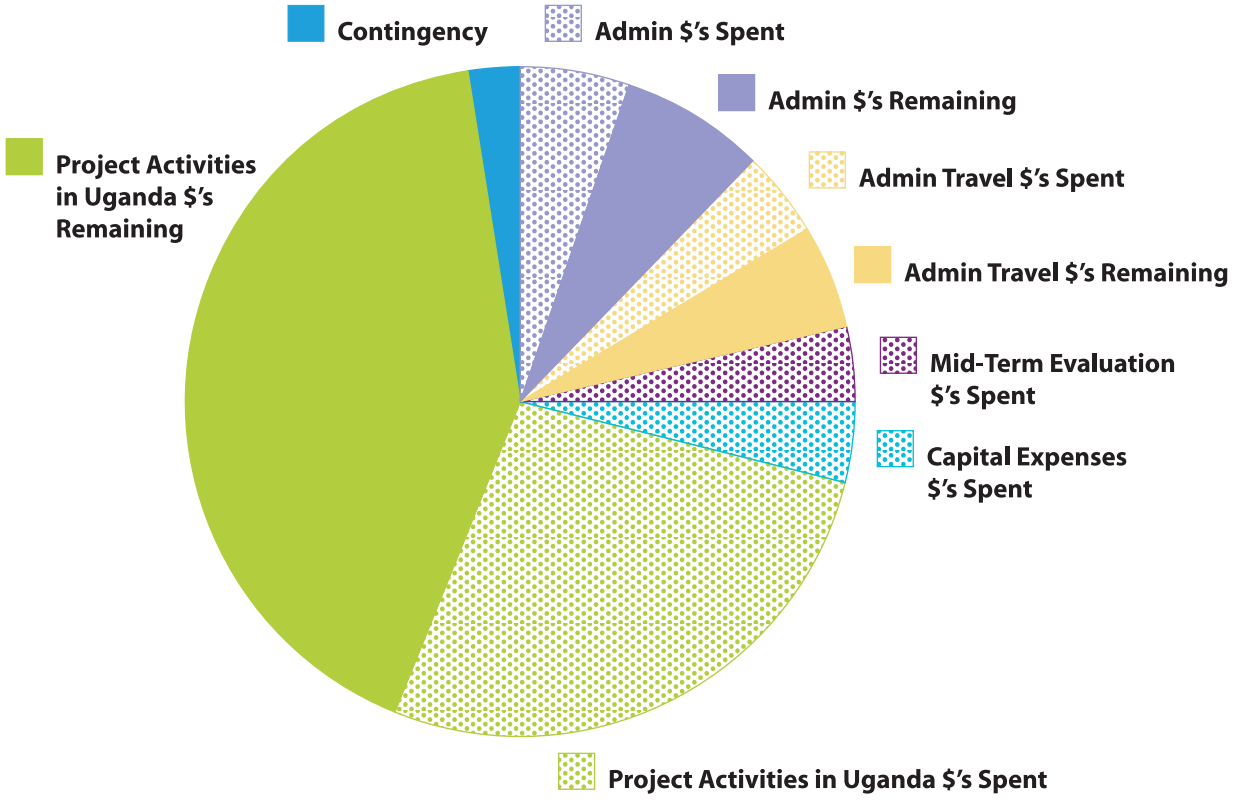
Spin Off Activities	Unexpected Results
Project Members invited to conduct Ponseti Method Workshop in Zambia at the University Teaching Hospital in Lukasa, July 2006.	Start of Ponseti Method of Clubfoot treatment in Zambia, with a target of providing a national program similar to the program in Uganda.
Project Members invited to conduct Ponseti Method Workshop at Wits Medical School, Johannesburg, South Africa, July 2006.	Start of Ponseti Method of Clubfoot treatment in South Africa, with a target of providing a national program similar to the program in Uganda.
	Visit to The Clubfoot Clinic at Mulago Hospital from Rotary International President, Bill Boyd. – see Communication Product 4
An NGO Group from Mali/Austria visited Uganda for a site visit to learn how to start a clubfoot program.	Start of Ponseti Method of Clubfoot treatment in Mali, with a target of providing a national program similar to the program in Uganda. – see Communication Product 6
3 week visit to USCCP in Uganda by a Churchill Fellow (a physiotherapist managing all clubfeet for a large part of North West Territory, Western Australia) to learn more about application of the Ponseti Method in rural areas, March 2007.	11 physio therapists taught the Ponseti Method.
1 week visit from "Parents Association of Children with Clubfoot in the Netherlands" to learn more about clubfoot treatment with the Ponseti Method.	Embassy, Canada's Foreign Policy weekly featured a story on USCCP. (See Communication Product 2)
The Ugandan and Canadian Project directors were invited to participate by presenting the work of USCCP to the International Forum on Universities and Participatory Development – UBC Robson Square , Vancouver, BC November 2006. – see Communication Product 7	The Record, New Westminster, BC's local weekly also featured the USCCP - an indicator of local interest in the Project. (See Communication Product 5)
As part of the Incidence Survey, senior administrators, at all involved hospitals were informed of the USSCCP activities and goals. |See Appendix 10 |	

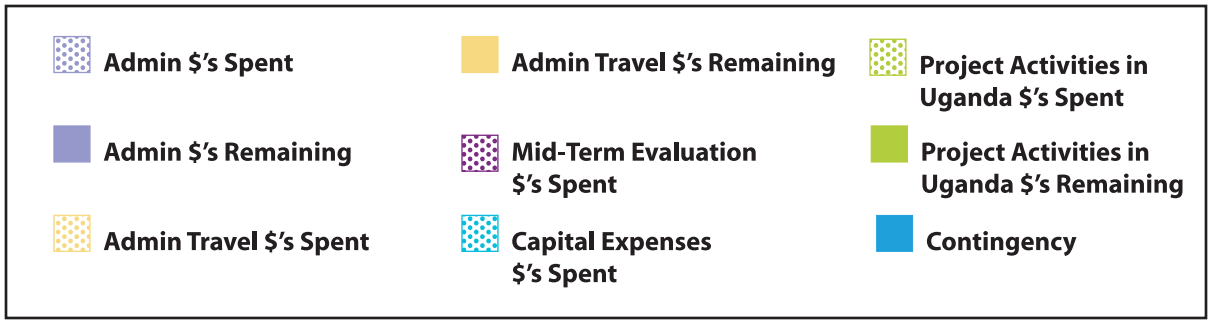
Funding Sources & Expenditures

Funding Sources (Total = CDN $1.8 million)

- Association of Universities and Colleges of Canada (AUCC) $980,000
- Enable Canada $90,000
- University of British Columbia (in kind) $630,000
- Makerere University (in kind) $100,000

Expenditures (cash)



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3
2
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DVD, CD, Communication Products and Appendices

DVD - Public Engagement and Educational Information
(inside front cover)

Movies:
- USCCP Movie
- USCCP Public Service Announcement
- The Ponseti Message - Treatment of Congenital Clubfoot in a 3 day old baby

CD (inside front cover)

Background to USCCP
- Narrative Project Summary
- Logical Framework Analysis
- Budget
- Making a Difference for Persons with Disabilities - Lean more about disability and rehabilitation
- Essential Services for Rehabilitative Health Care for persons with Disabilities in the District

Teaching Materials
- Clubfoot Management - Teaching Manual for Health Care Providers in Uganda
- Production Manual for Steenbeek Foot Abduction Brace
- PowerPoint Shows:
  - How Much Clubfoot Is There
  - What's So Different about the Ponseti Method
  - What Actually Happens
  - USCCP
  - Ponseti Method Workshop

Research Understanding Clubfoot in Uganda - A Rapid Ethnographic Study

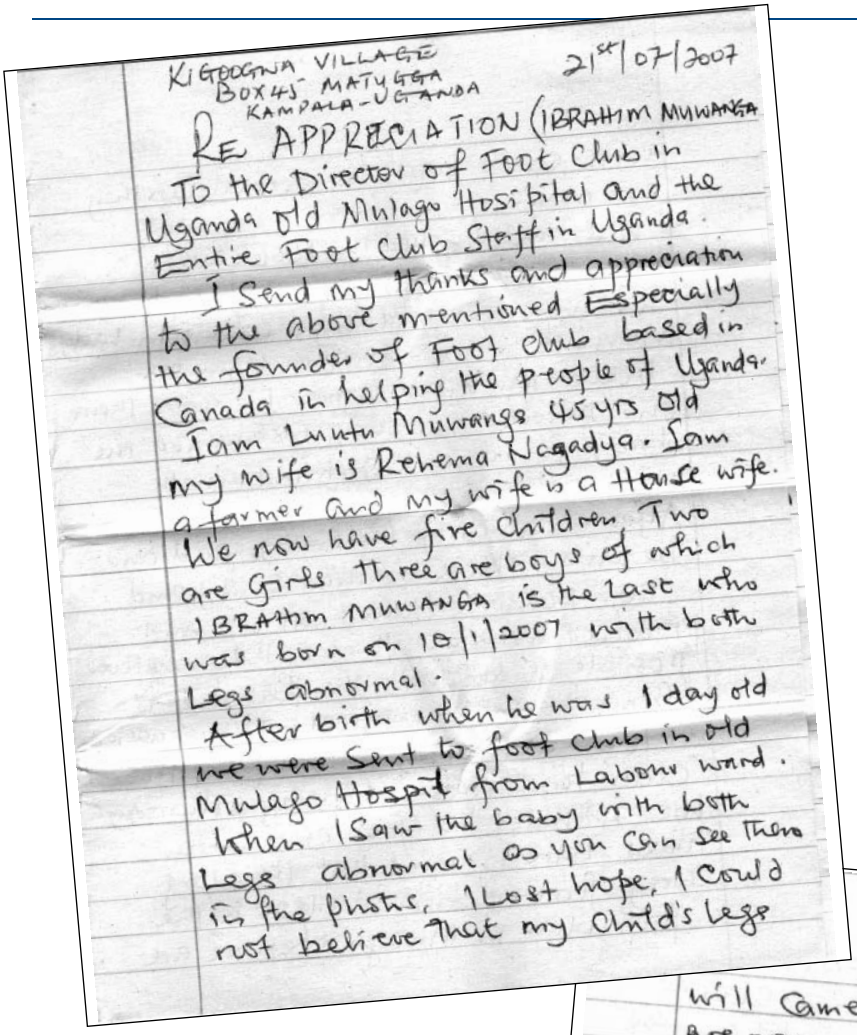
Communication Products

Product 1	Letter from father of Ibrahim Muwanga
Product 2	*Embassy* Newspaper Article
Product 3	*Daily Monitor* Article
Product 4	*New Vision* Article
Product 5	*The Record* Article
Product 6	Mali Report
Product 7	Internation Forum on Universities and Participatory Development

Appendices

Appendix 1	Cummulative Figures to Support the Annual Progress Report
Appendix 2	Mid-Term Evaluation
Appendix 3	Uganda Nurses and Midwives letter of acceptance to commence a module on clubfoot
Appendix 4	Letter from Director General Health Services re: Supplies for Rehabilitation of Clubfoot in Children
Appendix 5	Ponseti Clubfoot Management – Teaching Manual for Health Care Providers in Uganda. Complete Manual on CD
Appendix 6	Uganda Map of Population Density and Clubfoot Clinics
Appendix 7	East Africa Community Conference Program
Appendix 8	Clubfoot Clinic Appointment Card
Appendix 9	A Clubfoot Can Be Treated – A brochure for Health Workers who are in contact with newborn babies. Published by Uganda Sustainable Clubfoot Care Project in cooperation with the Ministry of Health
Appendix 10	Report of Meetings Held at USCCP Regional Hospitals for the Launch of the Incidence Survery of The Congenital Clubfoot Deformity in Uganda, Feb 2006

Communication Products - 1



KIGOOBWA VILLAGE
BOX 45 MATYGGA
KAMPALA-UGANDA

21st/07/2007

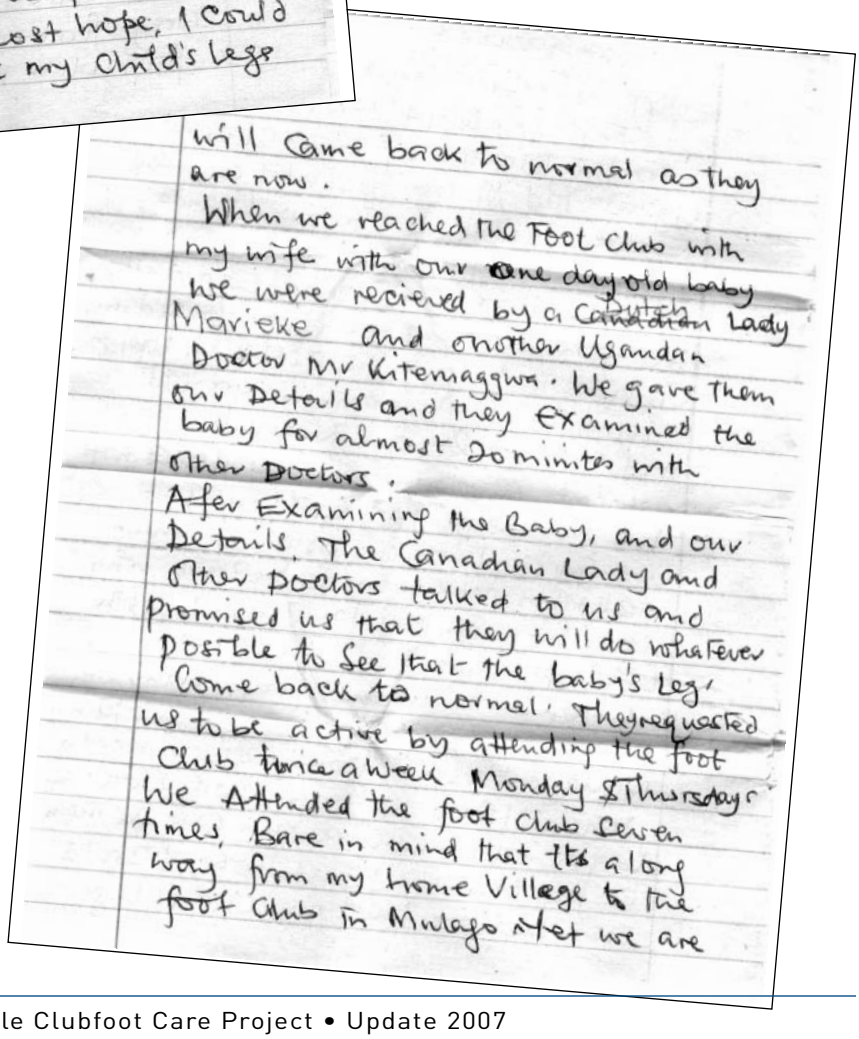
RE APPRECIATION (IBRAHIM MUWANGA

To the Director of Foot Club in Uganda old Mulago Hosipital and the Entire Foot Club Staff in Uganda.

I Send my thanks and appreciation to the above mentioned Especially the founder of Foot club based in Canada in helping the people of Uganda.

I am Lunta Muwanga 45 yrs old my wife is Rehema Nagadya. I am a farmer and my wife is a House wife. We now have fire Children Two are Girls three are boys of which IBRAHIM MUWANGA is the Last who was born on 10/1/2007 with both Legs abnormal.

After birth when he was 1 day old we were Sent to foot club in old Mulago Hospit from Labour ward. When I Saw the baby with both Legs abnormal as you can see them in the photos, I Lost hope, I could not believe that my Child's Legs



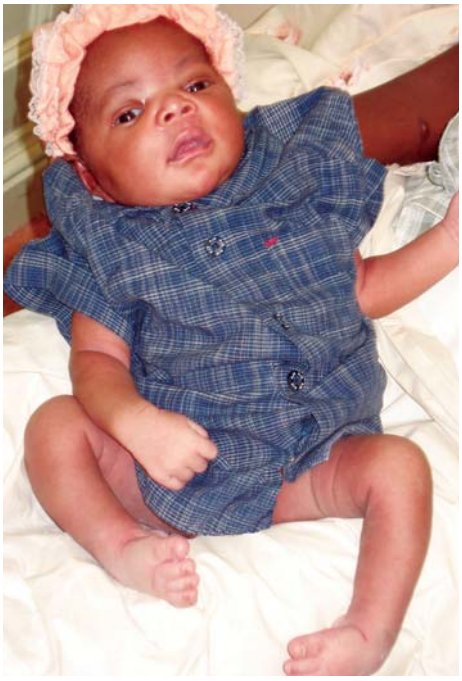
will Came back to normal as they are now.

When we reached the Foot Club with my wife with our one day old baby we were recieved by a Canadian Dutch Lady Marieke and another Ugandan Doctor Mr Kitemaggwa. We gave them our Details and they Examined the baby for almost 20 minites with other Doctors.

Afer Examining the Baby, and our Details. The Canadian Lady and Other Doctors talked to us and promised us that they will do whatever posible to See that the baby's Legs Come back to normal. They requested us to be active by attending the foot Club twice a Week Monday & Thursdays. We Attended the foot club Seven times, Bare in mind that its along way from my home Village to the foot Club in Mulago yet we are

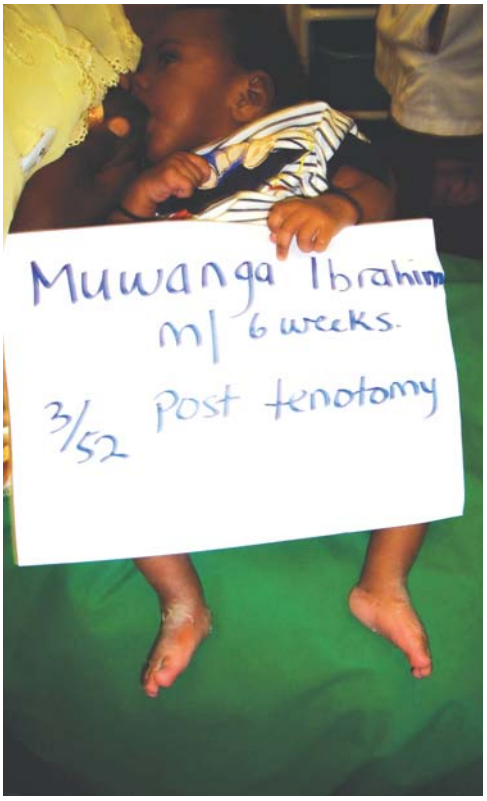
This letter was written by the father of Ibrahim Muwanga, a child from Kigoobwa Village, Matunga District, who was born with clubfeet and treated successfully at the Mulago Hospital Clubfoot Clinic. The pictures are of Ibrahim at various stages of his treatment.

Successfully treated, a child born with clubfoot can assume a life without functional deficits.



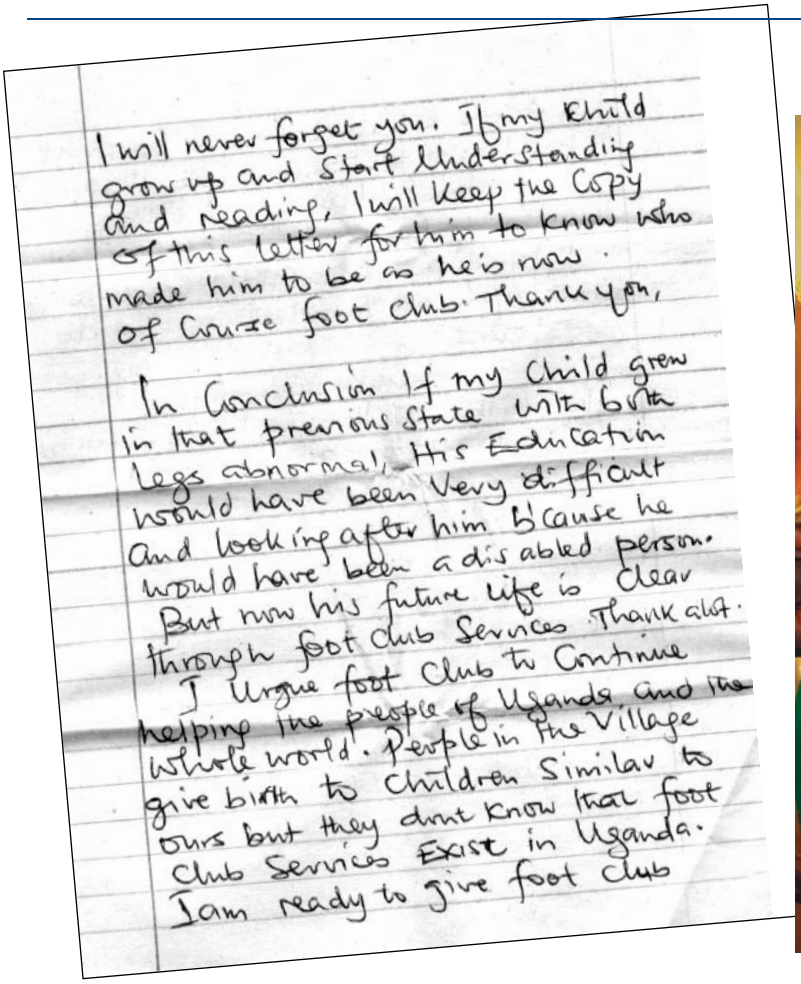
Communication Products - 1

poor financially but we tried to
bring the baby.
On the fourth time the Doctors told
us that the baby was going to be
operated both legs.
After operation we went back home
for three weeks and came back on
the day they requested to bring the
baby back. On that day I saw
the legs were coming back to normal
I was very happy ~~with~~ and my wife aswell
We couldnt believe it.
On the Seventh Visit to the Club, the
baby was given shoes to put on day &
night to a certain period. After
a couple of weeks we went and we got
another shoes to put on this time
they told us to put the shoes on
during night time only.
Now the baby is okey. It is!-
Unbelieavable but true.



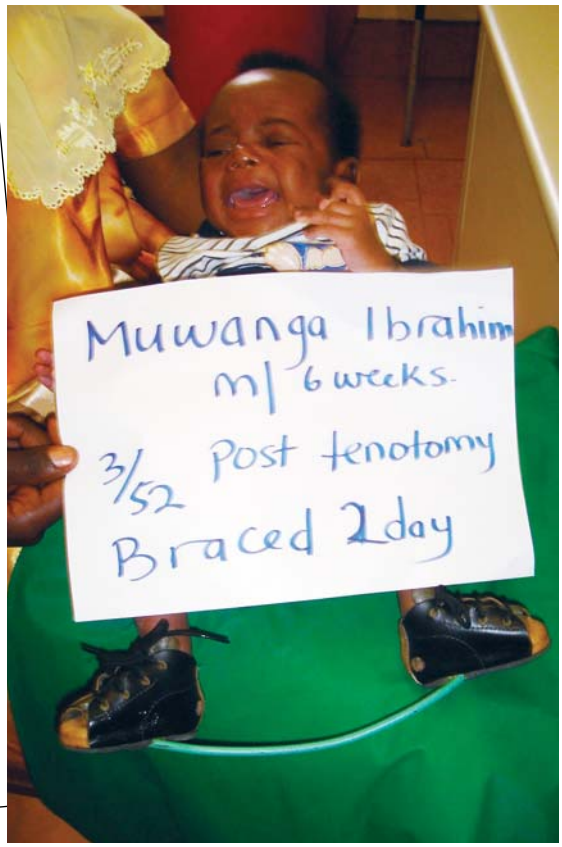
The Cardinal aim of writing this
letter is to send our thanks and
appreciation to the founder of foot club
and the Entire foot club staff in Uganda
Thank you very much. The service is
free Thank you. thank you.
I have no way I can show my appreciation
and thanks to you. I pray The Almighty
God to reward you.
Had I been well off financially, I would
have come to Canada with my wife
and the baby to say thank you to
~~the f~~ by shaking hands with the founder
of foot club and getting some photos
with him as a token of remembering.
I thank the Canadian Lady (
for her displine and the way she
handles patients and the whole staff
for their good service Thank you
Thank you, Every thing is free. where
Can you find this Expensive Service to
be free as it is in foot club.

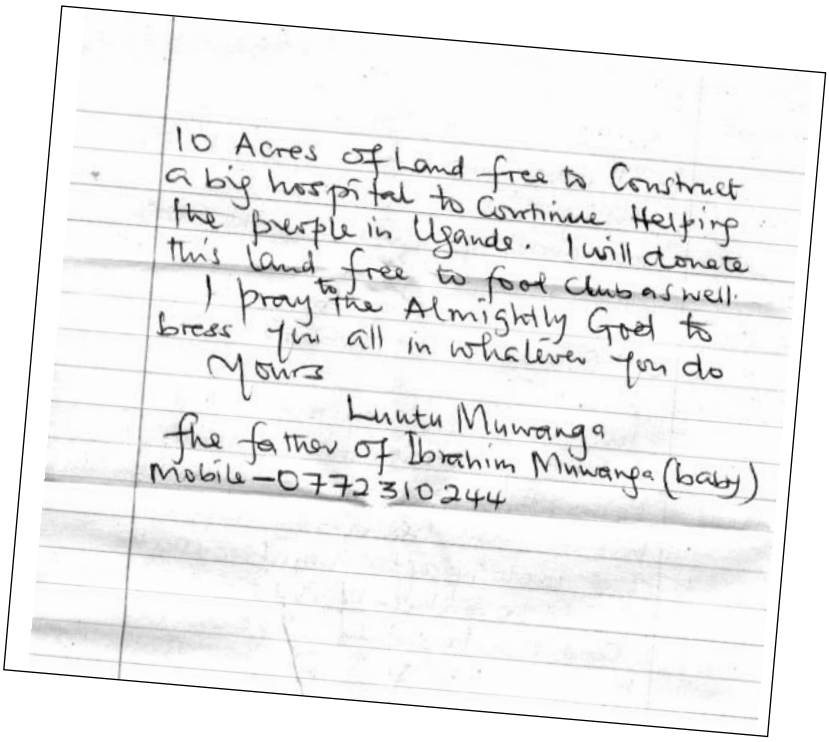
Communication Products - 1



I will never forget you. If my Child grow up and Start Understanding and reading, I will keep the Copy of this letter for him to know who made him to be as he's now. of Course foot club. Thank you,

In Conclusion If my Child grew in that previous State with birth legs abnormal, His Education would have been Very difficult and looking after him b'cause he would have been a disabled person. But now his future life is clear through foot club Services. Thank alot. I Urgue foot Club to Continue helping the people of Uganda and the whole world. People in the Village give birth to Children Similar to ours but they dont know that foot Club Services Exist in Uganda. Iam ready to give foot Club





10 Acres of Land free to Construct a big hospital to Continue Helping the people in Uganda. I will donate this land free to foot club as well. I pray to the Almighty God to bress you all in whatever you do

Yours

Luutu Muwanga
the father of Ibrahim Muwanga (baby)
Mobile – 0772 310244

Ibrahim Muwanga is an example of the potential of this project. He was born with clubfeet in a village fifty miles from Kampala. His feet were corrected at the Mulago Clubfoot Clinic.

"Some remarkable achievements have been made towards building capacities for clubfoot!"
- Midterm Evaluation

LATVIA
President Vike-Freiburga returns to Canada with her bid to be the next UN chief.
Page 4

EDUCATION
Report on program cuts, the dangers of private funding, and the benefit of overseas exchanges.
Pages 11-21

SATIRE
"We don't trust humour enough anymore," says Randy Boyagoda.
Page 23

EMBASSY
CANADA'S FOREIGN POLICY NEWSWEEKLY
OTTAWA, WEDNESDAY, SEPTEMBER 27, 2006 ISSUE 123 • $3.00

FALL EDUCATION REPORT

PHOTOGRAPH COURTESY OF DR. PIRANI

Canadian doctor Shafique Pirani (centre, wearing tie) and a group of health care workers in Uganda. Dr. Pirani returned to his native land to help fix foot deformities.

Canadian Doctor Changing Stance of Ugandan Health

■ Canadian university partnership helps Ugandan-born doctor return home to help treat clubfoot without surgery.

By Brian Adeba

Eight years ago, Shafique Pirani, an orthopedic surgeon in British Columbia, decided to visit Uganda to see his family's old house and the school he attended as a child. It was the first time he had set foot in the east African country after his family, together with other Asians, was kicked out in 1972 by Idi Amin, a brutal dictator whose rule of terror ended in the late 1970s when Tanzania troops ousted him from power.

While in Uganda, Dr. Pirani took the opportunity to talk to orthopedic doctors about some of the common ailments found in the country. He found out that congenital clubfoot deformity, a birth defect that affects the feet, was common in Uganda. People who suffer from the deformity have feet that are twisted in and down, in some cases the soles face their bodies. There are two ways to treat the deformity: In a surgical manner, which is more expensive, or through the Ponseti Method, a less expensive non-surgical way.

For Dr. Pirani, who was familiar with treating the deformity using the Ponseti Method, it was a turning point. He decided to establish a project in Uganda using the method.

A number of factors propelled him to act. First, there were only 20 orthopedic surgeons in the whole country with a population of 30 million.

"There were simply not enough to take charge of the situation," Dr. Pirani remembers.

cont'


LATVIA
President Vike-Freiburga returns to Canada with her bid to be the next UN chief.
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EDUCATION
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OTTAWA, WEDNESDAY, SEPTEMBER 27, 2006 ISSUE 123 • $3.00

Secondly, Uganda has a high fertility rate. "That means the average number of children in a family is seven, and that's about 50 births per thousand or 1.3 million births per year," says Dr. Pirani. Each year about 1,300 children are born with the deformity and doctors only knew how to treat it the surgical way, which is expensive and beyond the means of most Ugandans.

"It was also the most ignored disease by doctors," says Dr. Pirani.

In 1999, with some funding from Rotary International, Dr. Pirani started a project in Uganda to treat the deformity using the Ponseti Method, which he says never took off in North America "even though there is evidence that it is a good idea."

In 2004, through a program called University Partnerships in Cooperation and Development, managed by the Association of Universities and Colleges of Canada, with funding from the Canadian International Development Agency, the project began a process to build capacities to treat clubfoot deformity in every hospital in Uganda. Dr. Pirani's clubfoot project is one of the many examples of the types of international programs that the UPCD sponsors.

The UPCD establishes partnerships between Canadian universities and educational institutions in the developing world to strengthen academic departments and training, improve curricula and develop educational and professional opportunities. The partnership has helped train an estimated 300,000 people in the developing world.

Currently a national clubfoot clinic has been established in Mulago Hospital, Uganda's largest hospital in the capital Kampala. Five regional hospitals located throughout the country now have programs to treat clubfoot deformity using the Ponseti Method. Mr. Pirani says staff from these hospitals are also training health care workers in smaller clinics in small towns and villages. In addition, Dr. Pirani says the Ponseti Method can be taught to paramedics and other non-medical staff because it is easy to use.

"By 2010, hopefully, there will be a mature system of treating clubfoot deformity in the whole country," says Dr. Pirani, who added that the motivating factor for him was the feeling that he wanted to "give back to the country he was born in."

"It's an excellent opportunity to shake hands across the oceans," he says.

Dr. Pirani says now Uganda is one of the few countries in the world that has a policy on managing clubfoot deformity. Other countries in Africa are considering adopting the Ugandan method, says Dr. Pirani.

"I have just come back from Zambia and their government has expressed an interest in the Ugandan method."

Elsewhere in Africa, the same method has taken off in Malawi. The West African state of Mali is also keen to learn from Uganda.

"It's a positive effect of South-South cooperation," says Dr. Pirani.

brian@embassymag.ca

Article from: Daily Monitor Online, February 17th, 2007

TRUTH EVERY DAY
Daily MONITOR

News | February 17, 2007

Uganda's health funding not sufficient - UN expert

SOLOMON MUYITA & GRACE NATABAALO

KAMPALA

THE United Nation's Special Rapporteur on the Right to Health has said Uganda's health sector is seriously under-funded. Prof. Paul Hunt said the under funding offends international human rights obligations.

He quoted a May 2006 commitment by African Heads of State in Abuja, Nigeria, that 15 per cent of their national budgets would go to health.

"In Uganda, less than 9 per cent is devoted to the health sector," Prof. Hunt told journalists at the Grand Imperial Hotel in Kampala on Friday. "In his last budget speech, the Minister of Finance Ezra Suruma listed nine priority actions requiring the most urgent attention, I regret to say health was not amongst them," Prof. Hunt (right) said.

He said Uganda's national minimum health package is costed at US$28 per person per year yet the public expenditure for the government and donors is only US$9 per person per year. Prof. Hunt came to Uganda early this month to examine the government's efforts to combat neglected diseases. Flanked by Maarit Kohonen, the representative of the UN Commissioner for Human Rights in Uganda, he said Uganda's maternal mortality rate is among the worst in the world.

On the number of women who die during pregnancy, Prof. Hunt said: "The great majority of maternal mortality cases are entirely avoidable. Many Ugandan women are dying entirely unnecessarily." He said although the international community had agreed to a target of reducing maternal mortality by three quarters by 2015, it was unlikely for Uganda to reach the target.

Maternal death figures

Every year, between 505 and 880 maternal deaths are registered per 100,000 live births in Uganda. In some parts of the country, the rate is believed to be as high as 1,200 deaths per 100,000 live births.

"The scale of avoidable maternal mortality constitutes a very grave human rights issue. It is imperative that the government renews its commitment to reduce maternal mortality and gives this enormous human rights problem the attention and resources it deserves," Prof. Hunt said.

He said the government has not taken enough preventive measures in dealing with diseases such as sleeping sickness. "Preventive measures for sleeping sickness have not been scaled up and a number of cases are increasing. Sleeping sickness has even been reported in districts such as Kalangala, which have not experienced the disease for some years," Prof. Hunt said. He said the planned establishment of the Uganda National Health Research Organisation is long over-due. "I am disappointed to learn that the draft legislation to establish the Uganda National Health Research Organisation has still not been passed. This very important initiative to promote and strengthen national health research must be enacted and implemented as soon as possible," he said He, however, commended the government's intervention against neglected diseases such as Bilharzia and worms which have now been eliminated through the Child Days 'Plus' system.

Prof. Hunt said it is important for the government and donors to give the people of northern Uganda the highest priority in terms of health protection. "In some places, meaningful health related services are virtually non-existent," he said. "The health situation remains exceedingly grave, as most recently evidenced by the outbreak of cholera. In Kitgum, over 70 per cent of water sources are contaminated and less than 40 per cent of households have latrines."

Article from: The New Vision, August 28, 2007

THE New Vision
UGANDA'S LEADING WEBSITE

Rotary International President visits Uganda

Rotary International President, Mr Bill Boyd, (R) casting the leg of baby Nanyonjo Viola at Mulago Hospital yesterday. Left is the baby's mother Ms Agness Nakazi. According to Mr Dirisa Kitemagwa, an orthopaedics officer at the hospital, between 1000 and 2000 children in Uganda are born with deformed limbs annually. Bill is on a two day visit in the country to see to the progress of the activities of rotarians. Photo by Wandera w'Ouma

8 BUGANDA NEWS — The New Vision, Monday, August 28, 2006

Rotary president visits foot clinic

By Carol Natukunda

"I never believed that!" That was an exclamation of visiting Rotary International president, Bill Boyd, hours after his maiden tour of the Uganda Club Foot Clinic, Mulago Hospital on Wednesday.

The clinic is one of the humanitarian projects supported by Rotary Foundation, to ensure that children born with clubfoot deformities are identified at birth and have access to corrective treatment. Boyd is in Uganda to recognise Rotarians for providing humanitarian needs over the years.

"I did not realise that if you get a little baby, born in such a state, you would have their feet corrected back to normal," Boyd told the press at Serena Kampala Hotel. His wife Lorna, Rotary district governor 9200, Francis Tusubira among other Rotarians, accompanied him.

He commended District 9200, where Uganda belongs, saying it had made remarkable achievements in community service over the years.

"Rotary is not political. If there is need, it can address, then we do it regardless of your background," he said.

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PATIENT
An Ugandan child with club feet - the feet turn inward and upward.

Helping hands for Uganda

Project to help children with club feet made possible with Rotary funding

By Lori Pappajohn - THE RECORD

Looking out the window of the breakfast room of the Kampala Sheraton Hotel in Uganda, Shafique Pirani's gaze fell on the lush tropical gardens. But he hardly noticed them, or the succulent, fresh pineapple that had just been placed on the white tablecloth beside him.

All Pirani was aware of was a tingling in the tips of his fingers - that feeling one gets when life unexpectedly opens a door of vast opportunity.

At that moment, the surgeon realized he could help thousands of crippled Ugandans. Should he walk through the door - or walk away?

If one believes in fate, it was almost as if Pirani's entire life, from childhood on, was carved and moulded for this moment. Born in Uganda, Pirani had a degree in medicine from the University of London, England. His passion was treating club foot. Babies with the birth defect, if untreated, are often reduced to a life of pain and, in developing countries, poverty.

Pirani was schooled in the most advanced treatment method - four months of casting and recasting the feet and several hours of surgery. He'd used it successfully on babies for six years.

Then Pirani learned of a rarely used, radically different method.

American orthopedic surgeon Ignacio Ponseti had developed a technique that didn't require surgery.

"You had to manipulate the foot in exactly the right way when you were putting a cast on it," said Pirani.

"So I just changed how I placed my fingers on the child's foot. I suddenly realized it's taken 50 years for the orthopedic thumb to move a centimetre - and that's the centimetre that makes the difference. It was incredible."

Pirani wanted to know why Ponseti's method worked.

"It was 1998, Royal Columbian Hospital had just acquired an MRI and it struck me that we may be able to see what we were doing. X-rays didn't show the intricacies of how the little bones move in the cartilage. I wanted to know what the heck was going on. I was taught the only way you could fix a club foot was through surgery. The Ponseti method said the opposite.

"It was like reading, 'You can lose 50 pounds by just taking this pill.'"

Pirani reviewed the MRI images and was amazed - and convinced.

"It was an epiphany," he recalls. "I wanted to do something about it. Here I was in my own little world in New Westminster realizing that the implications of this study were amazing. And hardly any surgeons were using it."

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And that's where the breakfast at the Sheraton comes in.

LEARNING
Dr. Shafique Pirani, right, presents a training certificate to Otim Alfred at a Ugandan school. Thanks to funding from Rotary clubs, orthopedic officers in Uganda are being trained to teach other officers how to treat club feet.

It had been 26 years since Pirani had visited the country of his birth.

In 1972, a 15-year-old Pirani and his parents fled their homeland when then-leader Idi Amin ordered the expulsion of residents of Asian decent. Leave or face death.

Amin's ruthless reign plunged the once prosperous country, along with its health-care system, into chaos.

But in 1998, when the country had stabilized, the Pirani family returned for a brief, five-day visit. They wanted to see their friends, their home, their school.

That visit changed Pirani's life.

Stepping off the aircraft, Pirani glimpsed the familiar red soil, inhaled the aromatic Ugandan air and knew he was home.

The last day of his visit, Pirani breakfasted at the elegant Sheraton Hotel in Uganda's capital Kampala. Pirani was curious about the work of his breakfast companion, Zimbabwe-born Dr. Norgrove Penny of Victoria, B.C.

Pirani recalls Penny explaining that he was operating on hundreds of children with club foot every year.

Each year, 1,000 Ugandan children are born with club foot. The country of 28 million people has fewer than 20 orthopedic surgeons.

"It suddenly struck me," recalls Pirani. "The real importance of the Ponseti treatment is not that you can do it without surgery but that you can do it without surgeons. I said to Dr. Penny, 'You have to do the Ponseti method.' But he replied: 'I'm too busy - you have to.'"

And that's when Pirani felt the tingling in the ends of his fingers. In that moment, the future of thousands of children was in his hands.

Consider how fate had moulded this moment: Pirani was one of only a handful of surgeons in the world using the Ponseti method. And he happened to be having breakfast with Norgrove, whom he'd never met before, during a five-day visit to a place he hadn't seen in 26 years.

The stage was set, the door opened and Pirani strode through.

Then, the work began.

Club foot is a birth defect where the foot turns inward and can be so deformed that the sole faces upward. In a country based on agriculture, those born with club foot will likely never be able to work or marry and will live a life of poverty.

A child with club foot may not get to school because it hurts to walk. They can't help look after other children, fetch firewood and water or work in the fields.

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Says Pirani: "It's a painful deformity that leads to disability, demoralization, depression and despair."

When Pirani walked through fate's door, he was overwhelmed. Where would he find the ongoing funding needed for a project in a country with some 40 different languages and in which most of those he needed to reach were poor?

Despite having a full-time orthopedic practice in New Westminster, Pirani devoted hours to seeking funds. In 1999, he wrote 100 funding requests. No one responded.

But Pirani pressed on.

And then his big break came. The Burnaby Rotary Club pledged $10,000. That $10,000 brought in $70,000 in matching grants from Rotary International and the Canadian International Development Agency (CIDA).

The Royal City Rotary Club soon joined in and, since then, Rotary funding has totalled $250,000 for the Uganda Sustainable Clubfoot Care Project.

Two years ago, CIDA granted $1 million for the University of B.C. and Makerere University in Uganda to work together to ensure the program's success.

"The Rotary played a pivotal role in this project," said a grateful Pirani. "They were the first funders and the only funders for several years."

Pirani's first goal was to train orthopedic officers (similar to highly specialized nurses) in clinics throughout Uganda how to manipulate infants' feet and put casts and braces on them.

The second goal, which is ongoing, is to have most of Uganda's health-care schools teaching the Ponseti method by 2010.

But Pirani was discouraged to learn that, after teaching more than 100 orthopedic officers how to cast feet, one out of 10 of the club foot clinics weren't functioning properly.

"Maybe the baby was there, but the clinic was out of plaster for the cast. Maybe the technician was at home sick with AIDS or at the market selling fish because he hadn't been paid. Or the parents couldn't bring the baby because it was harvest time, or they didn't have the money for transportation."

"We realized all the pieces had to be in place for this to work. At that point you either walk away from it all and say, 'I've done what I can, I'll go play golf.' Or you try to understand the problem."

Pirani chose to understand. Since 1999, he has been to Uganda 18 times.

So successful is the club foot program now that it has spread to neighbouring Malawi and Zambia.

Meanwhile, Pirani's expertise has been sought in India and Brazil.

As a member of a small international group of Ponseti disciples, Pirani will travel this year to Egypt, Uganda, Israel and Germany, explaining a technique that is now being used to help infants in South America, Cambodia, China, Eastern Europe and the United Kingdom.

Pirani doesn't make money doing this. It is his passion.

He leans forward and quietly says, "When did I do a surgery that could allow someone to join their rightful place in the community, to go to school and get married?"

"It's enormous," he says about the difference the club foot program is making around the world. "I'm profoundly thankful to be given an opportunity to do something like this - and to know that one person can do something."

"If I didn't know the Ponseti method, at that breakfast in the Sheraton Hotel, I might have said: 'I can't help.'"

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Clubfoot Project Mali, West Africa

Update April 2007

Local executive: Gaoussou Traoré
Project executive: Martin Salzer, MD
Ponseti program: Christof Radler, MD
Surgical program: Klaus Zhuber, MD

Active Project Team:
Anita Kux; Matthias Kux, MD; Christof Radler, MD; Martin Salzer, MD; Karin Waschak, MD; Klaus Zhuber, MD

Update report by C. Radler, April 22nd 2007

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Austrian Society for medical Developmentcooperation

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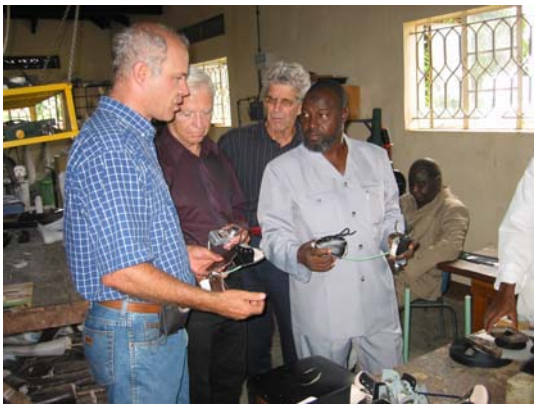
October 2006

Anita Kux; Matthias Kux; Christof Radler; Martin Salzer

We met in Kampala to visit the Uganda Sustainable Clubfoot Care Project with a group of four from Mali. The Mali group consisted of the head of the biggest orthopaedic department in Bamako and one of his surgical officers, our local project executive and one orthopaedic techniquian/physical therapist. In the next days Marieke and Michiel Steenbeek, Dr. Waiswa and the others gave us a very good overview of their program. I think that the most important part of our visit was to present our "stake holders" (orthopaedic chief and project executive) what is the goal of our efforts and how such a program can work.

For us it was important to see how the Ponseti method works in such a setting and what problems we will have to face in the near future. We visited Katalemwa and saw the really fantastic work Mr. Steenbeek is doing with the braces.



In Mali we started a 8 ½ -days workshop with 14 participants. We trained two orthopaedic surgeons, 3 doctors, 6 physical therapists and 3 orthopaedic techniquians. We met with officials from the ministry of health and social affairs who were very positive about our project and indicated that a financial support may be possible (as part of the poverty reduction plan). The teaching course and our project were on television two times. We were afraid that this might bring us a many patients who have everything except a clubfoot, but this did not happen as transportation in Mali seems to be as big a problem as it is in Uganda.

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In the 8 days we treated 29 children with 41 affected feet (only 9 were younger than 6 months, 2 were nearly 3 years old). Altogether we made 66 Ponseti casts. On the last day I performed/assisted 4 tenotomies. I think that our course was a success and that we met our criteria for the first phase of our project. We will be in Bamako again in January and will evaluate the babies treated in the meantime. We will also find (I hope) around 5 willing and capable local doctors/health officers, who can be trainers in the future.

January 2007

Anita Kux; Matthias Kux; Christof Radler; Martin Salzer

For January we planned a re-evaluation of the cases treated so far, a short advanced workshop for the last group of trainees and a second basic workshop for trainees coming from centers outside of Bamako. We wanted to find about three trainees who would be able to train the second group under our supervision.

After our arrival in Bamako in January we had to learn that the surgeon did not follow the protocol regarding the timing of the tenotomy. He was the orthopaedic surgeon who was part of the small group that visited the Uganda Sustainable Clubfoot Care Project in October and took part in the 10 days course in Bamako. Most tenotomies were performed too early, before the full abduction and subsequently before the derotation of the calcaneus were achieved. In many cases the post-tenotomy cast was not sufficiently dorsiflexed and abducted and they ran out of braces. We were confronted with quite a number of residual and recurrent clubfeet and so we had to re-cast many and re-tenotomize some. We were able to examine 77 feet as many came for the scheduled follow-up visit. A relapse/residuum was seen in 16 feet which were all re-casted. Three of those feet needed a second tenotomy.

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We concluded that there were two main obstacles: First, there were no orthopaedic officers in Mali (in contrast to Uganda) and only very few paramedical or medical personal had at least some experience with casting. Second, despite the 10 days intensive workshop we had not been able to train 14 people sufficiently. As a result we informed the second group that they will be given an introduction workshop on the Ponseti method by Martin Salzer and Mathias Kux but that they will not be able to cast patients in this first workshop.

From the first group we identified 7 trainees who seemed skilled, interested and who had casted the most patients since October. This small group was then intensively trained by me and additionally to the new patients many of the old patients were re-casted.

One three year old girl with a very rigid clubfoot was operated on by me and Martin Salzer in a local hospital. The cost of the operation was about 300 USD for DfD and we found the instruments quite insufficient, though the anesthesia was very effective and professional. Hospital Kathi is outside of Bamako and as the schedule for the OR is very non-specific a lot of time was lost waiting.

The “poor patient fund” initiated in October to support transportation and treatment cost for the poorest worked well and our social worker did a great job selecting patients for funding.

Before leaving we had instructed one of the trainees, a surgical resident, to do the tenotomies and asked him to perform the tenotomies together with another colleague. When we left, we had mixed feelings and were not sure if the treatment would be performed sufficiently.

At the end of January we had a patient database with 100 clubfeet with 44 feet in casting, 34 feet in Steenbeek braces after casting and tenotomy, 8 patients in Steenbeek braces after casting only, 9 feet abandoned treatment before tenotomy, 5 awaiting surgical correction.

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March 2007

Anita Kux; Matthias Kux, MD; Christof Radler, MD; Martin Salzer, MD; Karin Waschak, MD, Klaus Zhuber, MD

For this mission our aim was to further improve the quality of treatment in the treatment centre CNAOM and to finally select five to seven trainees to become trainers. Simultaneously, Martin Salzer and Klaus Zhuber made attempts to implement a surgical clubfoot program running parallel to the Ponseti program.
We decided that especially the organization and the work flow had to be discussed and explored intensively. Karin Waschak, resident at the paediatric orthopaedic department of Speising hospital, agreed to accompany us to Mali to help with casting and thereby gave me the opportunity to dedicate more time to organization.
In the first two days we have asked the trainees to schedule as many follow up visits as possible and we were able to see a lot of patients. To our big relieve the results were much better compared with January and we were able to identify five future trainers including two young doctors. Two of our trainees working outside of Bamako reported good results with casting but problems in having the tenotomy performed.

Karin Waschak supervised much of the casting while a lot of one on one talks and also discussion session were held to find structures that would work for us and would work for the centre and all involved staff. Certain trainers were assigned certain responsibilities like documentation, public relations and awareness and the workflow from the first presentation of the patient to the bracing period was discussed.
We found that one of the problems was supply as it was not reported early enough when the leather for braces or cast was used up and nobody knew exactly who should report to whom.

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Another problem was the frustration of the local staff with treating older and syndromic clubfeet. The Steenbeek braces which are manufactured in CNAOM are of sufficient quality, although the bar is a little thicker which makes bending of the brace to adjust the 70 degree abduction harder. Several levels of alert were introduced to make sure that shortage of material (cast, leather, scalpels, lidocain…) will be reported early. It was agreed on, that older children should not be treated in this stage of the program. Our social worker recommended having more social workers to be able to visit the patients at home, for assessment of eligibility for the patient fund, to ensure follow-up and especially to increase brace compliance. One of the trainers agreed on giving talks in nursing and mid-wife schools to heighten awareness.

A short hands-on workshop for seven participants who already came for the course in January was held by the trainers and supervised by us. We were happy to find that our selected trainers gave fantastic talks, had full understanding of the anatomy and the biomechanics and overall gave a very good course.

Cooperation with the regional hospital #V was started. This hospital is right next to CNAOM and will be used for operation in this stage of the project. A rehabilitation unit in CNAOM is planned, and although nothing really has been finished at the time of our arrival, the rooms have already been assigned. The agreed structure of the Ponseti program in CNAOM should allow a continuous treatment of patients. The criteria for treatment were set to include infants up to the age of two years.

In the next two visits which are planned for July and October the quality of treatment and the workflow in CNAOM should be augmented. We think it is important to have a running clinic in the capital before reaching out to more peripheral locations. The surgical part of the project, especially the rehabilitation center in CNAOM must be established.

A detailed evaluation of the initial results and further outreach to will be made in December 07 or January 08.

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Main unsolved problems:

The government is making many promises and is emphasizing their enthusiasm but has not made any financial contributions yet.

There are only 5 orthopaedic surgeons in Mali, many older and not very interested in treating clubfeet.

There are no surgeons to perform the tenotomy. General surgeons could be trained to do so, but they are rare, busy and not really interested.

There is no one to operate patients in whom the Ponseti method failed. These patients endured casting, had personal and financial expenses and should not be sent away with an uncorrected clubfoot.

To teach young doctors how to properly perform open release surgery would take years. Having patients being operated on by members of DfD is not sustainable.

Many patients are presented at a very late age, most patients between one and two years of age. Additionally, many of the feet are secondary clubfeet.

None of us is able to stay for a longer time period to act as a local coordinator and to help building capacity and logistics.

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International Forum on Universities and Participatory Development

November 20-22, 2006

Location

UBC Robson Square (downtown Vancouver) campus, 800 Robson Street

Purpose

The purpose of the Forum is to initiate institutional action-research and an ongoing dialogue among universities, development agencies, and others, on ways that Northern universities can enhance support for, and learning from, Southern action and thinking oriented to social inclusion and sustainability.

Background

Experiences around the world indicate that universities can make significant contributions to participatory development, the process that leads to sustainable poverty reduction with empowerment, gender equality, social inclusion, and respect for human rights. These same experiences also indicate that direct engagement with development can help universities better serve their teaching and research missions. For these reasons, many universities encourage students to engage in "service-learning" with their local communities.

Unfortunately, the potential for linking universities in the global North to participatory development in the South, directly and/or in co-operation with Southern university counterparts, has received little systematic attention from international development agencies, governments, or universities themselves. Academics in a number of countries are now proposing that the potential be explored through an ongoing program of collaborative, action-oriented research.[1]

[1] See, for example: P. Boothroyd and L. Angeles (eds.), Canadian Journal of Development Studies, XXIV:1 (2003), Special Issue on *Canadian Universities and International Development*; and, P. Boothroyd and M. Fryer, "Mainstreaming Social Engagement in Higher Education," Colloquium on Research and Higher Education Policy, UNESCO, Paris http://portal.unesco.org/education/en/ev.php- URL_ID=36308&URL_DO=DO_TOPIC&URL_SECTION=201.html

Outputs

The Forum will produce the following outputs:

- A scholarly *book* on "Universities and Participatory Development" which incorporates the best of the papers presented at the Forum.
- Establishment of the *Conquiry*— i.e., a network to support institutional action-research on possibilities for strengthening Northern universities' support to, and learning from, participatory development in the South, plus a four-year program of international forums to plan, report and build on the action-research (Experimental actions could relate to curriculum change that incorporates overseas project experience, or to development-oriented student/faculty/staff/alumni international exchanges, or to bringing information on Southern innovations that might have application in the North, etc.).
- *Commitments* by institutions and individuals to kick-start the Conquiry by undertaking collaborative or institution-specific action-research projects. This could include establishment of an international association to promote closer connections between universities and participatory development.
- *Recommendations*

  a) to interested universities in the North and in the South on steps that could be taken, by individual institutions and through international partnerships, to enhance support for and learning from participatory development in the South;

  b) to international development agencies (e.g., CIDA), research-support agencies (e.g., SSHRC, IDRC), and universities (e.g., through AUCC) on steps that could be taken to create more effective relationships between agencies and universities, i.e., relationships that go beyond funding and delivery of projects;

  c) to the World Urban Forum IV, Nanjing 2008, and other international symposia, on steps that could be taken to connect universities more closely to participatory development through North-South partnerships.

Expected Participation

The Forum will involve about 50 participants—academics, and officials representing agencies with international development and/or research funding mandates. About one-third of the participants will be from overseas.

Format

- Presentations and discussions:

  a) case studies of Northern universities directly engaging with, and facilitating Northern learning from, participatory development in the South;

  b) case studies of Southern and Northern universities collaborating on participatory development projects;

c) case studies of Southern and Northern universities learning from each other about university engagement in participatory development;

d) case studies of Southern university engagement with participatory development that could be instructive for Northern universities

e) overview analyses of the benefits and costs, and opportunities and constraints, to Northern universities engaging with and facilitating learning participatory development in the South.

- An "Open-space" meeting to plan the Conquiry and draft recommendations (as listed above).
- Final deliberations on recommendations.

Questions to be Addressed

Q1. The theoretical questions: How are we framing our understandings of participatory development in terms of principles, approaches and possible outcomes? In what ways can universities contribute to, and learn from, the theory and the practice of participatory development in both the North and the South? And, in what ways is university engagement in participatory development informing or gaining from the wider debate about engagement of the university with society and social change?

Q2. The empirical questions: What are some case studies of universities contributing to and learning from PD that inform the answers to Q1? In what ways did these cases involve domestic and/or international networking (South-South and South-North) among universities and supportive agencies? What are the lessons to be learned from these cases about opportunities, constraints, and about effective strategies?

Q3. The action questions: What local, national and international institutions can you identify that could play leading roles in more closely linking universities to PD? What specific actions might these institutions try and how might they learn from them? With whom might they collaborate domestically and internationally in these actions and resesarch? What forthcoming forums (e.g., WUF 2008) and other events might be appropriate venues for promoting collaboration and disseminating results?

- ## Agenda

Each presentation to be 15 minutes, followed by 5 minutes for questions.

Monday, 20 November 2006

9:00 *Opening:* Chair: **Craig Klafter**, Assoc. V.P. International, UBC
Welcome: **Dennis Pavlich**, VP External and Legal Affairs, UBC
Tim Dottridge, Director, Special Initiatives Division IDRC
Catherine Kiszkiel, Sr. Policy Analyst, CIDA
Jen Avaz, Manager, UPCD Program, AUCC
Overview of Forum—history, purpose, agenda: **Peter Boothroyd**

9:30 *The theoretical questions:*
Lead Panel Chair: **Nora Angeles**, Women's Studies, UBC
Uthai Dulyakasem, Dean of Liberal Arts, Walailak University, Thailand
Peter Taylor, Head of Graduate Programmes, Institute of Development Studies, Sussex

10:00 break

10:20 *The empirical questions:.*

Session A:

Chair: **Tony Dorcey**, UBC School of Community and Regional Planning

10:20 Localized Poverty Reduction Vietnam (LPRV) program— **Trinh Duy Luan**, Director, Institute of Sociology, Vietnam Academy of Social Sciences, and **Dang Anh Phuong**, Centre for Family and Women's Studies and International Relations, VASS, with discussant **Leonora Angeles**, UBC Centre for Human Settlements, and Women''s Studies

10:40 Thailand's Graduate Volunteer Centre at Thammasat, and Buddhist Midnight Universities— **Pirom Chantaworn**, Faculty of Economics, Thammasat, with discussant **Arti Khanderia**, UBC School of Community and Regional Planning

11:00 UQAM and Dom Bosco U project in Brazil— **Marcelo Marinho**, Dom Bosco U, Campo Grande, Brazil, with **Gaetan Tremblay**, Director, Centre for Studies and Research on Brazil (CREB), U. du Québec à Montréal

11:20 Universities, community-based watershed management, participatory waste management, and economic development in metropolitan Sao Paulo— **Jeroen Klink**, Pro-rector, Extension, Federal University, ABC Region of Sao Paulo; **Jutta Gutberlet**, Community-based Research laboratory, Geography, Uof Victoria

11:40 Water resource management in Central America— **Valeria Delgado**, Universidad Nacional Autonoma de Nicaragua, with **David Bethune**, U of Calgary

12:00 Community Learning Project— **Andrew Mott**, Director, Community Learning Project, Washington, D,C. with discussant **Margo Fryer**, Director UBC Learning Exchange, and School of Community and Regional Planning

12:20 Discussion

Session B:

Chair: **Jim Gaskell**, Assoc. Dean, UBC Faculty of Education

10:20 Building an international social work and community development program—- **Nguyen Huu Tan**, Ass't Dean, Faculty of Social Work and Community Development, Dalat U., Vietnam, with **Graham Riches**, Director, and **Brian O'Neil**l, UBC School of Social Work and Family Studies, and **Jitti Mongkolnchaiarunya**, Faculty of Social Administration, Thammasat U., Thailand

10:40 Community museums in Thailand— **Jitti Mongkolnchaiarunya**, Faculty of Social Administration, Thammasat U

10:50 Renforcement des capacités en intervention auprès des enfants et des adolescents— **Beatriz Vizcarra**, Universidad de la Frontera, Chile, with **Jacques Dionne**, U. du Québec en Outaouais

11:10 Brazil;s university-based co-ops to develop the Solidary Economy— **Fernando Kleiman**, Brazil National Secretariat for Solidary Economy

11:25 Simon Fraser U and Mexico— **Debbie Bell**, Simon Fraser U

11:40 U. of Ottawa and community-based learning methods in Kenya— **Joshua Ramisch**, UO

11:55 UBC Faculty of Education and Africa— **Yvone Brown, Harriet Mutonyi, Juliet Tembe, Shelley Jones, Maureen Kendrick**, and **Bonny Norton**

12:20 Discussion

Session C:

Chair: **Shafik Dharamsi**, UBC Faculty of Dentistry

10:20 Faculties of Medicine and social responsibility— **Charles Boelen**, former Coordinator of WHO program on human resources for health, and **Bob Woollard**, Head, Family Practice, Faculty of Medicine, UBC

10:40 Ecuador and UBC— **Patricio Velasquez**, Professor, U. of Machala, Ecuador, with **Jerry Spiegel** UBC Liu Institute for Global Issues and Centre for International Health, and **Annalee Yassi, William Bowie**, and **Margot Parkes**, UBC Faculty of Medicine

11:00 Uganda Sustainable Clubfoot Care Project— **Edward Naddumba**, Makerere University, with **Shafique Pirani**, UBC Faculty of Medicine

11:20 Reducing HIV Stigma by Education— **Ruben Aggor**, U of Ghana, with **Colin Yerbury**, Simon Fraser

11:40 New health sciences university, Nepal— **Arjun Karki**, with **Bob Woollard**, UBC

12:00 Discussion

13:00 lunch

Public session: Colloquium on Universities and Participatory Development

14:30 Chair: Margo Fryer, UBC Learning Exchange
"Universities, Global Citizenship, and Participatory Development"
– **Stephen Toope**, President, UBC

15:00 Chair: Tony Dorcey, School of Community and Regional Planning
"Universities and Participatory Development:
Lessons from International Experience, Prospects for the Future"
– **Sheldon Shaeffer**, Director, UNESCO Asia and Pacific Regional Bureau for Educa'n
– **Jingjai Hanchanlash,** Chairman, Research Cttee, National Educ'n Council, Thailand
– **Heinrich von Baer,** Executive Director, Red Sinergi@Regional, Chile
– **Kealeboga Nkebo Bojosi**, Lecturer, Department of Law, U. of Botswana
-- **H. Peter Oberlander**, Founder, Centre for Human Settlements, UBC

16:30 adjourn

Tuesday, 21 November 2006

9:00 The action questions
Plenary Panel Chair: Bob Woollard, Family Practice, Medicine, UBC

Charles Boelen, former Coordinator of WHO program on human resources for health
Jeroen Klink, Pro-rector, Extension, Federal University, ABC Region, Sao Paulo
Bud Hall, past Dean of Education, U. of Victoria
Representative of Aga Khan U.

10:15 break

10:30 *Plenary panel:* Chair: Graham Riches, Social Work and Family Studies UBC
"Perspectives on existing and potential relationships among agencies, universities, and participatory development "
IDRC, **Tim Dottridge**, and Luc Mougeot, Sr. Program Specialist
CIDA, **Catherine Kiszkiel**
AUCC, **Jen Avaz**

11:15 *Plenary discussion*

12:00 lunch

14:00 *"Open Space" workshop*

Facilitator: **Vince Verlaan**

In this time block, Forum participants are invited to join with others with similar interests to develop ideas for continuing the dialogue that has taken place at this Forum. Small groups will form around ideas put forward by various participants, and these ideas will be developed into commitments to act.

The major focus in all small groups will be on developing and launching the Conquiry. Sub-topic examples could include:

- effective dissemination of the knowledge presented and gained at the Forum;
- recommending to interested universities, international development and research-funding agencies, and other international forums (e.g. WUF 2008), steps that could be taken to enhance international academic support for and learning from participatory development.

17:00 adjourn

Wednesday, 22 November 2006

9:00 *Open Space workshop* continues.

10:15 break

10:30 *Closing Meeting*: Chairs: **Sheldon Shaeffer, Peter Taylor, Peter Boothroyd**

Review of the outputs of the Open Space Workshop.
Identification of emergent themes, and of linking actions that have high priority for follow-up.
Agreement on who will do what to follow up this Forum with publications, events, and processes.

12:30 Farewell Lunch

Appendix 1: Cummulative Figures to Support the Annual Progress Report

Cummulative Figures to Support the Annual Progress Report

Output	Description	FY1		FY2		FY3		Cumulative Total
		M	F	M	F	M	F	
Output 1.1	Makerere University Medical School (35 M, 22 F) and Mbarara University of Science & Technology (47 M, 15 F) medical students have benefited from the upgraded syllabus	0	0	31	18	82	37	168
Output 1.2	Postgraduate orthopaedic (8M) and postgraduate general residents (8) have benefited from the upgraded syllabus		0	8	0	8	0	16
Output 1.3	Student orthopaedic officers benefiting from new module	0	0	72	28	56	19	175
Output 1.4	Student orthopaedic technologists benefiting from new module					31	1	32
Output 1.5	Government and NGO technicians that were trained in the making of foot abduction braces	0		17	1	1	0	19
Output 1.6.2	Student nurses/midwives benefiting from the new module	0	0	3	12	69	220	424
Output 1.7	See Output 1.1							
Output 1.8	See Output 1.2							
Output 1.9	See Output 1.3							
Output 1.10	Nurses/midwives acquired new knowledge and skills in detection and management of congenital clubfoot in Uganda	0	0	31	265	45	189	530
Output 2.1	How many infants seen at all clubfoot clinics						409	409
Output 2.2	How many clinics were opened and where (2 clinics opened in 2006 were closed, new number for 2006 is 6)				6		13	19
Output 2.2b	How many orthopaedic officers in the community were trained in the Ponseti Method	0	0	36	7	47	8	98

Mid-Term Evaluation:

Tier 2 Project, "Uganda Sustainable Clubfoot Care Project"

For submission to:

Dr. Shafique Pirani
University of British Columbia
&
Association of Universities and Colleges of Canada

August 31st, 2007

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Executive summary

Terms of Reference

This is a formative, mid-term evaluation of the Uganda Sustainable Clubfoot Care Project (USCCP), a six-and-a-half year collaboration of the University of British Columbia (UBC) and Makerere University (MU). The Project is funded under Tier 2 of the University Partnerships in Cooperation and Development Program (UPCD), a financing agreement between the Association of Universities and Colleges of Canada (AUCC) and the Canadian International Development Agency (CIDA). The intent of the evaluation is to observe project activities and results after almost three years of implementation and to provide feedback to the project management committees at MU, UBC as well as to the AUCC.

Main Observations

There is no question as to the relevance of this Project to the people of Uganda. The clubfoot disorder is relatively rare (compared, for example, with diseases like malaria or severe gastro-enteritis), with an incidence of incidence of 1.3 in 1000 newborn infants. Left untreated, however, the clubfoot disorder results in significant physical impairment that impedes mobility and has life-long functional implications. Children with clubfeet grow up with painful, deformed feet and as a result are severely restricted in their life-courses. The Project intervention, the Ponseti method, is incredibly effective if: initiated early; manipulation, casting and tenotomy are performed well; and families comply with the full, lengthy course of treatment. Successfully treated, a child born with clubfoot can assume a life without functional deficits.

In just two years, since the official Project launch in February, 2005, some remarkable achievements have been made towards building capacities for clubfoot detection and treatment. A strong and dedicated Project team has been assembled. They are currently overseeing the treatment of clubfoot at twenty clubfoot clinics at regional and general hospitals across seventeen districts. Annually, approximately 400[1] cases of clubfoot are being detected, and treatment initiated. Various cadres of health care workers, including doctors, general and orthopedic surgeons, and orthopedic officers, are being sensitized to the detection and treatment of clubfoot. At the Ministry of Health, the Project has actively engaged and educated health policy makers. This has helped to facilitate the availability of regular supplies—plaster of Paris, cotton bandages and braces—at clubfoot clinics.

There have been constraints and setbacks.

First, thanks in part to research and careful monitoring being carried out under the Project, it is becoming increasingly clear that adherence to the Ponseti method of treatment is difficult for poor households.

[1] At the time of this evaluator's visit to Uganda (March, 2007), the evaluator was informed that between 200 and 250 cases were being detected per year, and treated in Project CFCs. The evaluator was later informed that the number of clubfeet babies recorded as presenting to all CFCs in 2006 was in fact much higher, numbering 409.

• Mid-term Evaluation: USCCP

Barriers to compliance include: low levels of awareness about the long-term sequelae of clubfoot and the effectiveness of treatment; lack of regular supplies at clubfoot clinics; under-the-table fees charged at some clinics; distance to the nearest clubfoot clinic and associated travel costs; the perception that casts or braces are painful to the child, etc.

Second, one of the central activities planned under the Project—towards early detection of the clubfoot deformity—was the training of community-based nurses in birthing and immunization centers. This sensitization has not yet begun, largely because of delays in getting a "check box" for clubfoot included on the Child Health Card. Though MOH has agreed to add check box for foot deformity on new child health card, production of the new card has been delayed due to ministry issues. Delay in the official approval of the role of nurses in clubfoot management by the nursing and midwifery council of Uganda has also slowed progress (see Appendix 5, point 1, for update).

Third, there are a number of factors that will threaten the sustainability of Project activities beyond 2010. Chief among these factors are: disproportionate 'ownership' of the Project by Canadian *viz.* a *viz.* Ugandan Project managers (see Appendix 5, point 2, for update); failure to integrate Project activities within the Department of Orthopedics; lack of commitment (within the MOH) to maintaining the support supervision roles; and recurrent problems with the delivery of key supplies (notably, plaster of Paris and braces) through the government supply chain.

These setbacks are not critical to the overall success of the Project. Given the drive and dedication of the Project team, it seems likely that the Project will continue to build momentum, and achieve many of the stated outcomes and outputs, between now and the end of the Project, in September, 2010.

Main Conclusions

If the Project is to achieve the desired rates of effectiveness, its design must be refined to address these 'demand-side' constraints, and barriers to complying with treatment, in particular. This will involve: renewed efforts to foster awareness, particularly among parents of children with clubfoot; new partners who can reach remote communities, and active pursuit of children who do not follow-up in clubfoot clinics. As per the outcomes and outputs set for the Project, there needs to be a focus on community- and district-level detection and referral. The Project should continue with its emphasis on the education of medical and para-medical professionals (albeit a rationalized approach that focuses on the knowledge and skills essential to the various functions in the health system). Sustainability issues are perhaps the most difficult to address. In general, the MOH, Department of Orthopedics and local management committee members need to take greater responsibility for the Project, and work to incorporate Project activities into existing systems and programs.

• Mid-term Evaluation: USCCP

Recommendations

A list of recommendations are made in the body of the report. Those most relevant to the key constraints facing the Project are:

Training of community-based nurses

- The Project team should continue to pursue module approval by the nursing and midwifery council of Uganda (see Appendix 5, point 1).

- Representatives of the MC should pursue, with renewed vigor, getting a clubfoot check-box included on the Child Health Card. It was proposed that the Project Directors (Canadian and Ugandan) go directly to the Director General at the MOH with this request. (The evaluator understands from recent communications that a meeting was to be held on June 12th, 2007, between USCCP team members and the Director General to discuss this and other issues.)

- With or without the check-box, the Project should begin to sensitize the community-based nurses. Given that the central Project team is already overwhelmed (and given that the MOH has indicated that this activity can not be performed through existing training mechanisms) additional human resources may need to be added to the Project team, dedicated to this activity.

- The evaluation endorses the decision of the MC to involve traditional birth attendants (TBAs) in sensitization.

Enhancing adherence

(See Appendix 5, point 4, for update.)

- A priority of the OO visiting for support supervision should be to carefully review outcome evaluation forms (with the local OOs) to detect cases of non-compliance / loss to follow-up / clubfoot resistant to treatment.

- Consider adding Project outcome indicators that include acceptance of the intervention (among those detected as having clubfoot) and compliance with the full course of intervention (among those who started it).

- Some portion of the budget that would otherwise have been spent in developing general hospital-based CFCs should be shifted to demand-side interventions.

- As a first priority, the focus should be on interventions to facilitate compliance / follow-up among those who have initiated treatment. These activities might include:
  - Careful counseling in CFCs.
  - Develop standardized messages that can be used to motivate parents. The messages should clearly state the dangers of defaulting, and both the biological and social consequences of neglected clubfoot.

• Mid-term Evaluation: USCCP

- Give each parent a card (pictures, not text) that indicates what will be done at each visit.
- Active case follow-up (by ortho officer vs. public health dept vs. LC1).
- Monitor charging of fees.
- Develop a strategy for active support (subsidies if needed) to help remote patients keep in touch with their nearest CFC.
- Encourage parents of children with clubfoot to form associations.

- When clubfoot is detected in maternity wards, there must be systems to ensure that the afflicted infant is examined by an OO (and treatment initiated) prior to the infant's discharge from hospital. The family should not be discharged to home, and then asked to return to the hospital on a CFC day.

Fostering sustainability

- The MC, together with the Canadian Project Director, should develop a step-wise plan, describing how major responsibilities and decisions will gradually be ceded to the Ugandan Project Director. By the end of the Project, administration of the Project should be entirely local.

- The Head of the Department of Orthopaedics at MU should be more pro-active in terms of getting residents to attend CFCs at Mulago, and getting orthopaedic surgeons to provide support supervision (or more specifically, tenotomies) when they are traveling to regional hospitals. The latter is particularly important if the position of orthopaedic coordinator is gradually to be phased out.

- The Project MC and Administrator are already actively interfacing with the MOH, towards increasing the Projectís profile. Additionally, the Project should:
  - Work at publishing papers in international, peer-reviewed journals. Raising the profile of the Project internationally is one sure way of catching the attention of representatives of the Ugandan MOH.
  - Commission an economic analysis, for example, comparing the cost per case of clubfoot treated by the Ponseti method vs. conventional surgical methods. Get a health economist involved. A solid economic argument is likely to help in "winning minds" at the MOH.

- NGO and for-profit hospitals should be increasingly involved, in order to enhance Project sustainability. Not-for profit hospitals in particular are great for specific niches. Hospitals that specialize in disabilities or rehabilitation, for example, might be willing partners.

The evaluation document proceeds as follows. Chapter 1 briefly describes the project and its context. Chapter 2 introduces the evaluation methodology. Chapter 3 comments on key project results achieved, and provides recommendations related to these. Chapter 4 reviews key findings in regard to the evaluation issues, and again provides related recommendations. Chapter 5 brings the report to a close with overall conclusion.

Appendix V: Update, August 2007

The appendix describes some of the progress achieved after the Evaluator's visit to Uganda (March 2007) and finalization of this evaluation (August 2007).

1/ The Nursing and Midwifery Council has finally officially approved the module on clubfoot in the curriculum on Nursing/Midwifery Schools. (E-mail of Marieke Dreise, dated 19 July 07.) The project can start implementing the plan for training tutors to teach the module to their students, as soon as the Staheli book is ready.

2/ The Ugandan Project Director suggests that the "disproportionate ownership" issue reflects departmental (MU, Department of Orthopedics) inexperience in managing this type of activity rather than lack of commitment or unwillingness to integrate activities within the department. The Ugandan PD has produced a report in response to the MTE. It is the first step in correcting the issue of disproportionate ownership. It is recognized a primary objective must be to clear the notion that this is a "Project" with external funding for all "Project Activities". The emphasis from now on will be that clubfoot work in Uganda will now be part and parcel of regular activities of the Department, will all members of the Department participating. The Ugandan PDís Report includes the strategies developed for the second half of the project. It will serve as the basis for an Action Plan and Budget Allocation and Response to AUCC to be presented at the MCM August/Sept 2007. (E-mail of Shafique Pirani, dated 2 August 07.)

3/ Indeed a meeting took place on the 12th of June at the MOH, but unfortunately only three out of the 25 invited people from within the MOH came. However, one of them was Mr. Isabirye, who does see some possibilities to add an item about clubfeet to the CME program (for nurses and midwives) country wide, with possible funds from the European Union. (E-mail of Marieke Dreise, dated 19 July 07.)

4/ During the research about compliance, which took place in May/June 07, we found that indeed many children dropped out. In Masaka for example, half of the babies did not come back regularly in the bracing phase. We also found that it is very difficult to find the parents who dropped out of treatment. Even with the outcome evaluation forms filled in, with address, etc., many parents were untraceable. Also LC's were not really willing to assist in tracing patients. In the last few months one of the young OO's regularly has joined the SS team to go through the outcome evaluation forms and it is clear that something needs to be done to improve filling in the forms and also compliance by the parents. It seems that one of the reasons that people do not come back is that they do not understand the importance of the bracing. So we really will have to work on that in the training of OO's so that they give good health education and counseling. I am, for example, thinking of a refresher course for all trained OO's in which we have a special topic on this and on the importance to fill out forms, etc. Also issues like charging money to parents could then be touched on in a very sensitive way. (E-mail of Marieke Dreise, dated 19 July 07.)

5/ There was a workshop in March, 2007, for the tutors of the School for OO's in how to teach and how to assess the students. Unfortunately the main driving force in the School of OO's, Mr. Otim, has been transferred to the School for Health Tutors. He has not been replaced. This is a big loss for the school and for the Project. (E-mail of Marieke Dreise, dated 19 July 07.)

• Mid-term Evaluation: USCCP

6/ The Orthopedic Workshop in Mulago Hospital has now produced 300 braces of decent quality. However, there are managerial and organizational problems in the workshop and an investigation has taken place recently. A report of this investigation is to be out soon. So far USCCP has not been able to organize a system whereby the Project buys the braces that the workshop produces, as the workshop is not allowed to have its own account. If the project pays for the braces via the Mulago Hospital accounts, the money will very likely not be available for the workshop. (E-mail of Marieke Dreise, dated 19 July 07.)

7/ The Head of Department promised to organize things so that students from Orthopedic Technician Training School (OTTS) would be allowed to learn how to make braces in the orthopaedic workshop. Unfortunately, the HOD is on sick leave. (E-mail of Marieke Dreise, dated 19 July 07.)

8/ The success of the incidence survey reflects the diligence with which the central team approached the task – seeking to identify missed cases and then to resolve the problem with further support and training of midwives. As of the end of May 2007, the study includes 80,000 babies and is already the largest survey of its kind anywhere. The incidence numbers remain steady at 1.3 per thousand live births with a male to female ratio of 3:1. (E-mail of Shafique Pirani, dated 2 August 07.)

9/ A young OO has joined the SS team to assist in going through the outcome evaluation forms and filling in gaps and finding drop outs. We need to find a system so that the forms are used to monitor the children under treatment, not only for the outcome evaluation. (E-mail of Marieke Dreise, dated 19 July 07.)

10/ We have a new orthopedic coordinator, who unfortunately cannot travel upcountry due to family reasons. It is hoped, however, that he can organize/coordinate teaching/attendance in CFC for the medical school and for the general surgery and orthopedic surgery residency programs, as coordination for these students is seriously lacking.

11/ The General Surgery Residents have rotated through the CFC at Mulago Hospital. Two residents rotated through in March 07, and two more are rotating through now. The first two will be posted in rural areas and are keen on using their skills in their practice. One will be posted to Lira, and the other to Juba in Southern Sudan. (E-mail of Shafique Pirani, dated 2 August 07.)

12/ The fellowship for the first orthopaedic coordinator is now being organized in Egypt. The Coordinator has expressed a strong interest in pursuing a PhD – focusing on the economics of clubfoot treatment. There were several reasons for delay in organizing a fellowship – not least being indecision on behalf of the coordinator regarding the nature and location of desired training. For instance, specific introductions were made as far back as fall of 2006 to a member of World Orthopaedic Concern and fellowship opportunities in India. The Project Directors are recommending to the MC that a further sum of $6000 be made available to each OC for fellowship studies.

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13/ Mulago Hospital Administration has commissioned a committee to look at the problems affecting the Mulago Orthopaedic Workshop. The Committee is to report very shortly. USCCP awaits this report— NGO produced braces cost almost twice what Mulago Workshop produced braces cost. The Management Committee and CAT will continue to seek methods to empower the Mulago Workshop to become more and more productive in the interest of long term affordability and sustainability (E-mail of Shafique Pirani, dated 2 August 07.)

14/ Staheli Manual Printing is now scheduled for Sept 2007. (E-mail of Shafique Pirani, dated 2 August 07.)

15/ USCCP submitted 4 abstracts to the Third World Congress of Birth defects held in Rio, Brazil, June 2007. All four were accepted, with substantial funding for travel and accommodation provided by the conference organizers (NIH and March of Dimes). Dr Waiswa, Prof Konde Lule and Dr Jackson Amone traveled from Uganda to present. (E-mail of Shafique Pirani, dated 2 August 07.)

16/ Discussions for an economic analysis started in Early March 2007. An economic analysis will be done but as adherence and completion rates and functional capabilities are an integral part of that analysis, it will be done when outcome data are available. (E-mail of Shafique Pirani, dated 2 August 07.)

17/ It is revealing to look at how the Support Supervision team actually score the clinics. The scoring as per May 2007 is appended (see e-mail of Shafique Pirani, dated 2 August 07). From this scoring, it would seem that seventeen out of twenty clinics are scoring either average or good at scoring the clubfoot and technique. This suggests that the technical skills required are well within the capabilities of orthopedic officers clinics, and that after a variable period of project support supervision, the MoH can take over support supervision activities as part of their integrated plan for support supervision of their institutions as regularly and normally carried out and for which MoH has a budget.

It must be appreciated that there will always be some variability in technical abilities of healthcare workers as well as variability in the pathology of any clubfoot. The question that the project needs to determine is whether the strategy of placing the care of the child with a clubfoot in the hands of an orthopedic officer is sound. The data appended show ratings for the 20 clinics set up are Excellent 2, Good 5, Fair 7 and Poor 4. The 7 Excellent and good clinics now need less SS. It is revealing that the better clinics have been established the longest – suggesting that after a period of Intense SS, many if not most clinics can be raised to a certain standard. The Project Directors therefore feel that the original plan to establish CFC at most General Hospitals with appropriate facilities remains the best option. (E-mail of Shafique Pirani, dated 2 August 07.)

• Mid-term Evaluation: USCCP

Appendix 3: Uganda Nurses and Midwives letter of acceptance to commence a module on Clubfoot

Telephone: General Lines: 340874/231563/9
Registrar's Office 256-041-251862
Fax: 256-041-231572

IN ANY CORRESPONDENCE ON
THIS SUBJECT PLEASE QUOTE NO: UNMC/75

Uganda Nurses and Midwives Council
Ministry of Health
P. O. Box 4046
Kampala
Uganda

28th June 2007

The Director,
Club Foot Project,
MULAGO – UGANDA.

Dear Sir,

ACCEPTANCE TO COMMENCE A MODULE ON CLUBFOOT

Greetings from the Uganda Nurses and Midwives Council.

This is to acknowledge receipt of your letter dated 11th May 2007, concerning approval of acceptance of commencement of the module on Clubfeet.

The Nurses and Midwives are often the first Health Professionals who come in contact with newborn babies during delivery or immunization. They are essential in detecting the clubfoot deformity at an early stage and referring the babies appropriately to the nearest clubfoot health unit. By doing so, Disability can be prevented and the child can grow up to lead a normal and productive life.

The Nursing and Midwifery schools can, by teaching the modules to their students play an important role in the acquisition and sustainability of these skills.

The purpose of this letter is to inform you that, the module has been approved and accepted in the relevant curricula of nursing.

I thank you for all your efforts to make this programme a success.

THE UGANDA NURSES AND MIDWIVES COUNCIL
P. O. BOX 4046
28 JUN 2007
KAMPALA

Matte Florence Rita,
REGISTRAR – UNMC.

Telephone: General Lines: 340874 / 231563/9
Permanent Secretary's Office: 256 - 41 - 340872
Fax: 256 - 41 - 231584

THE REPUBLIC OF UGANDA

Ministry of Health
P.O. Box 7272
Kampala
Uganda

IN ANY CORRESPONDENCE ON
THIS SUBJECT PLEASE QUOTE No. **ADM.45/273/01**

The Medical Superintendent,

.....

.....

Re: Supplies for Rehabilitation of Clubfoot in Children.

The congenital clubfoot deformity is the most common major cause of muskulo skeletal disability for congenital defects. New methods of management can now correct this deformity without surgery in less than 2 months. To prevent recurrence, a brace is worn at night for 4 years
The Uganda Sustainable Clubfoot Care Project (USCCP) has been operating in Uganda since February 2005. The project is actively involved in building capacity in detection, and correction of the clubfoot at and shortly after birth. Currently a number of health facilities throughout the country from district hospitals to national referral hospitals are providing this service.
It is estimated that 1:1000 live births will have club foot treatment within the first two months of life and will require at least 36 rolls of bandage P.O.P 10cm and 6 braces to correct the defect.

The major set back is unavailability of adequate supplies for this service to be delivered at the health facility.

The purpose of this communication is therefore to remind you of the need to order adequate quantities of the bandage P.O.P to enable this service be delivered effectively in your facility. P.O.P is included and paid for under the Credit Line and can be obtained from the NMS for public institutions and JMS for NGO facilities, while the braces can be obtained from the nearest orthopedic workshop or advice can be got from the USCCP **Project Administrator, Marieke Steenbeek-Dreise on phone 0772465174**. It is planned that braces will soon be available from your nearest orthopedic workshop.
The Medicines and Therapeutic Committees (MTC) should actively be involved in the process of quantification and ordering of these supplies.
By this letter, the Medical Stores are also reminded to keep adequate quantities of the P.O.P to enable smooth delivery of this service.

Dr. Sam Zaramba
Director General of Health Services.

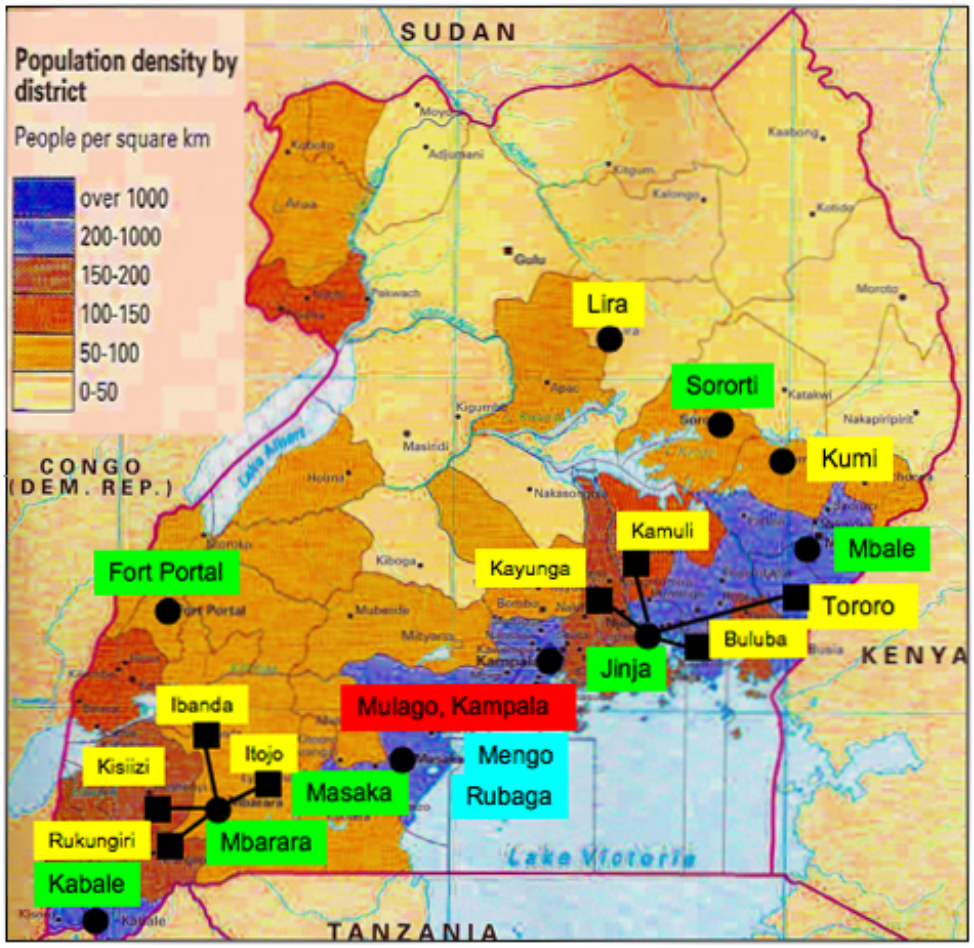
c.c. Commissioner Clinical Services
c.c. Assistant Commissioner Health Services (IC)
c.c. Principal Pharmacist
c.c. Ag. General Manager NMS
c.c. General Manager JMS
c.c. Project Administrator, USCCP

Ponseti Clubfoot Management

Contents

Teaching Manual for Health Care Providers in Uganda

Uganda:Population Density & Clubfoot Clinics



Kampala

Clubfoot Clinic National Referral Hospital

Jinja
Mbarara

Clubfoot Clinic Regional Referral Hospital

Kumi
Lira

Clubfoot Clinic District Referral Hospital

Mengo

Clubfoot Clinic Non Government Hospital

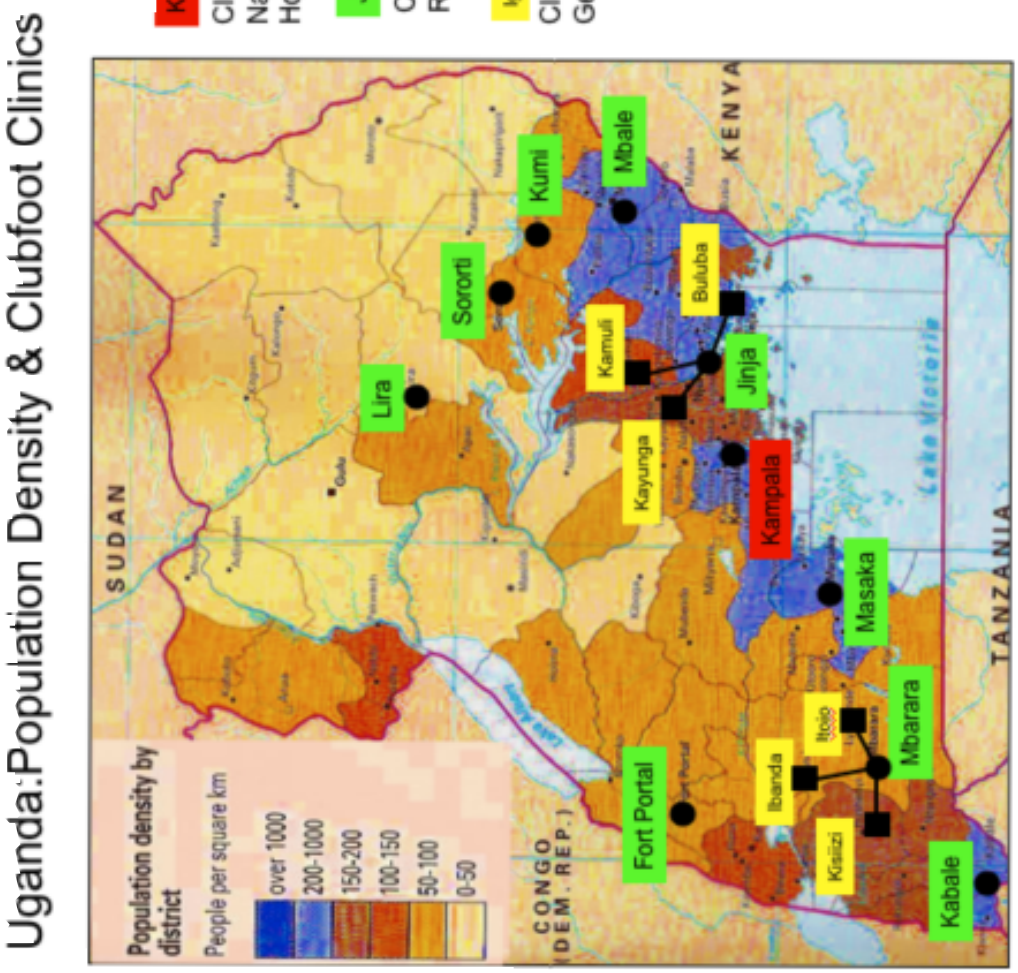
Appendix 7: East African Community Conference

The Uganda Sustainable Clubfoot Care Project (USCCP) Workshop at the 1st East African Health & Scientific Conference & 33rd Medic Africa International Exhibition

March 28 – 30, 2007

Attendees will have a better understanding of the clubfoot including:

- The burden of the neglected clubfoot to the individual and to society
- Diagnosis and management with the Ponseti Method
- The methods by which USCCP is building capacity within Uganda for clubfoot treatment
- Research on clubfoot in Uganda
- International Spread of USCCP Principals



THE UGANDA SUSTAINABLE CLUBFOOT CARE PROJECT PARTNERS INCLUDE:

Canadian International Development Agency (CIDA)

Association of Universities and Colleges of Canada

Association des universités et collèges du Canada

Christian Blind Mission International

CORU

Appendix 7: East African Community Conference

Thursday March 29, 2007

9:30 – 10:00 Plenary Session 3: Health Research in East Africa

10:00 – 10:30 Tea Break, Poster Viewing, Visit Exhibits

THE CLUBFOOT AND ITS TREATMENT

MODERATOR: Dr. Shafique Pirani

10:30 – 10:45 The Burden of The Neglected Clubfoot
– MR Edward Naddumba

10:45 – 11:15 The Ponseti Method of Clubfoot Treatment
– Dr. Shafique Pirani

11:15 – 11:30 The Roles of the Ministry of Health - Dr. Amandua

11:30 – 11;45 The Roles of the University in Clubfoot management
– MR. Titus Beyeza

11;45 – 12;15 Movies: i.Public Service Announcement
ii. Uganda Sustainable Clubfoot Care Project

12:15 – 12;30 Panel Discussion
-

12:30 – 13:30 Lunch Break, Poster Viewing, Visit Exhibits

USCCP Research

MODERATOR: Dr. Joseph Konde-Lule

13:30 – 13:45 Incidence Survey – MR. Gonzaga Waiswa

13:45 – 14:00 Ethno-Cultural Survey – Dr. Joseph Kondel-Lule

14:00 – 14:15 Focused Continuing Medical Education
– MR. Gonzaga Waiswa

14:15 – 14:30 Panel Discussion

Clubfoot Beyond Uganda

MODERATOR: MR. Edward Naddumba

14,30 – 14.45 Global Initiative - Dr. Shafique Pirani

14:45 – 15:00 Clubfoot Care in Kenya – Dr.Joseph Macharia

15:00- 15.15 The Ponseti Method in Egypt – Dr. Yasser Elbatrawy

15.15 – 15.30 Panel Discussion and Summarization

15:30 – 16:00 Tea Break, Poster Viewing, Visit Exhibits

Clubfoot (at twenty intervals) correct rapidly during Ponseti treatment – especially if started shortly after birth. After the 4th cast, a Tendon Achilles Tenotomy is done. When foot is corrected, braces are worn to maintain corrections, 3 months fulltime, 3-4 years at night.

The Uganda Sustainable Clubfoot Care Project Mission is

To make available in a sustainable fashion, universal, effective, affordable, and safe treatment of the congenital clubfoot deformity in Uganda.

Background: In 1994, there were an estimated 10,000 children in Uganda with neglected clubfeet, each growing up to face a life of deformity, disability, and despair. Affecting one baby in a thousand, another 1500 babies are born with clubfeet each year in Uganda.

Between 1999 and 2003 a pilot project introduced a non-surgical method of clubfoot correction (the Ponseti Method) to the clubfoot clinic at Mulago Hospital. Results showed that Ugandan Paramedical workers (orthopaedic officers) could correct the majority of clubfeet in newborns and infants in an economically and socially feasible way for society in Uganda.

Activities:

Building capacity to teach:

- ✓ Medical School and MMed Surgery & MMed Orthopaedic Surgery.
- ✓ Paramedical Schools for OO's and Orthopaedic Technology
- ✓ Schools for Nursing & Midwifery

Building capacity to detect & treat clubfeet:

- ✓ In service training workshops for Nurses/midwifes in labour wards and Immunization clinics.
- ✓ In-service training for OO's in district hospitals

Research and data collection:

- ✓ Ethno cultural survey: Knowledge, Attitudes, Beliefs and Practices in different regions in Uganda
- ✓ Incidence survey of clubfeet in 8 major hospitals, examining 100,000 newborns
- ✓ Outcome evaluation study

Intervention: The Uganda Sustainable Clubfoot Care Project (USCCP) is a 6 year CIDA funded project that desires to - 1.Build capacity throughout the Ugandan Healthcare System for the early detection and treatment of the congenital clubfoot. 2.Build capacity in Ugandan Healthcare Schools to teach detection and management of the clubfoot 3.Collect baseline and efficacy data of this method in Uganda.

Outputs: USCCP had successfully incorporated clubfoot detection and management by the Ponseti Method into the curriculum of all medical and paramedical (including nursing and midwifery) schools in Uganda. Clubfoot clinics have been established at twenty of Uganda's Hospitals. An Ethno-cultural Survey measured what Ugandans know, feel, and believe about the clubfoot deformity. An incidence at birth survey was completed. By 2010, USCCP's goal is for all children born in Uganda with clubfeet to have the deformity detected at birth, be referred for treatment and that effective treatment be available locally.

Expected outcomes:
The project will reduce the consequences of disability from neglected clubfeet by institutionalizing the Ponseti Method of clubfoot treatment throughout the Ugandan health care system and will train health care personnel to detect and treat the deformity.

INTERNATIONAL SPEAKERS:
Dr. Yasser Elbatrawy
Lecturer of Orthopaedics
Head of Unit of Limb Lengthening & Reconstruction Surgery
Nazahraa University Hospital, Al Azhar University, Cairo, Egypt

Dr. Joseph Theuri, Macharia, MBChB (Nbi), MMed Ortho (Mak)
Project Director
Clubfoot Care in Kenya
AIC CURE International Children's Hospital, Kijabe, Kenya

Professor Shafique Pirani
Project Director
Uganda Sustainable Clubfoot Care Project
University of British Columbia

NATIONAL SPEAKERS
Dr. Jacinto Amandua
Ministry of Health, Uganda

MR. Titus Beyeza
Head, Department of Orthopaedics
Makerere University, Uganda

Professor Joseph Konde-Lule
Institute of Public Health, Uganda

MR. Gonzaga Waiswa
Orthopaedic Surgeon
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Makerere Univeristy, Uganda

MR. Edward Naddumba
Uganda Project Director
Uganda Sustainable Clubfoot Care Project
Department of Orthopaedics
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Appendix 8: Clubfoot Clinic Appointment Card - Side One

Where are the clubfoot clinics:

- Mulago Hospital, Kampala
- Nsambya Hospital, Kampala
- Mengo Hospital, Kampala
- Rubaga Hospital, Kampala
- Katalemwa Cheshire Home, Kampala

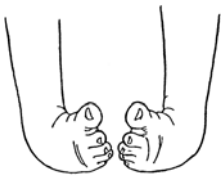
- Jinja Regional Referral Hospital
- Buluba Hospital
- Kamuli Hospital
- Kayunga Hospital

- Mbale Regional Referral Hospital
- Butiru Cheshire Home
- Tororo Hospital
- Kumi Hospital
- Soroti Hospital

- Masaka Regional Referral Hospital
- Mbarara Regional Referral Hospital
- OURS, Ruharo, Mbarara
- Itojo Hospital
- Kisiizi Hospital
- Kabale Hospital
- Fort Portal Hospital
- Kagando Hospital
- Namutamba Rehabilitation Centre

- Lira Hospital
- Gulu Hospital
- Arua Hospital

Clubfoot Clinic Appointment Card



Patient number: ……

Name of child…….

Date of birth……..

Name of mother……..

Name of father…….

Address:……...

…….

……

Please, bring this card every time you come to the clubfoot clinic

Appendix 8: Clubfoot Clinic Appointment Card - Side Two

Appointments

Date:

1st visit .....

2nd visit .....

3rd visit .....

4th visit .....

5th visit .....

6th visit .....

7th visit .....

8th visit .....

9th visit .....

10th visit .....

11th visit .....

12th visit .....

13th visit .....

14th visit .....

15th visit .....

16th visit .....

17th visit .....

18th visit .....

19th visit .....

20th visit .....

A CLUBFOOT CAN BE TREATED

Neglected clubfeet are disabling and painful to walk on.

PREVENT DISABILITY
REFER TIMELY

A brochure for Health Workers who are in contact with newborn babies.

Published by
Uganda Sustainable Clubfoot Care Project
in cooperation with the
Ministry of Health

THE REPUBLIC OF UGANDA

Some Foot Deformities

- Foot abnormalities in the newborn infant are not infrequent (1-3%)
- Many are benign, & will resolve without medical treatment
- Some however are not benign & the infant will grow up lame unless the deformity is corrected.
- Therefore all infants should be screened for foot deformities at birth. Those suspected as having a foot deformity should be referred to the orthopaedic officer for assessment & treatment

Appendix 9: A Clubfoot Can Be Treated Brochure

The Role of the Healthcare Worker

Clubfeet of newborn baby

Counsel the parents and show understanding for their fears. The cause is not known so nobody is to blame. The Ponseti method of treating the clubfoot deformity is very successful if children follow the whole treatment. Try to motivate the parents to come for all the appointments from the clubfoot clinic. The treatment is free of charge in govt. hospitals,

Some of the problems the parents may face in adhering to treatment are

- Poverty, no money for transport
- Fears, beliefs and social pressure
- No support from one parent,
- Other responsibilities, e.g. the mother has to take care of many children,
- They live far from the hospital,

Support the parents and help them to find solutions to their problems.

The Treatment of Clubfoot

Plaster of Paris casts during the treatment of bilateral clubfoot

The Ponseti Method consists of weekly manipulations and plaster cast treatment that usually take five to eight weeks.

In most cases a small surgical procedure, a percutaneous tenotomy under local anaesthesia is required to treat the residual equinus deformity. The last cast is then applied and left for 3 weeks.

The tenotmy is done in the clubfoot clinic

Bracing

Once the correction has been achieved the casts are replaced by the Steenbeek Foot Abduction Brace to hold the foot in the corrected position.
The brace is worn full time (except for bathing) for a period of three months. It is then worn at night and naptime only, until the child is three to four years old. This is of utmost importance because the clubfoot will recur without the use of the brace!!!
The child has to come back for checkup regularly to check for recurrence and bigger size brace.

90% of the clubfeet will recur if no brace is worn!

If the parents come in time and follw the whole treatment the child may never know it was born with clubfeet. It is just like any other child.

When To Refer A Child With Clubfoot

- Mulago National Referral Hospital, Kampala
- Nsambya Hospital, Kampala
- Mengo Hospital, Kampala
- Rubaga Hospital, Kampala
- Katalemwa Cheshire Home, Kampala
- Jinja Regional Referral Hospital
- Buluba Hospital
- Kamuli Hospital
- Kayunga Hospital
- Mbale Regional Referral Hospital
- Butiru Cheshire Home
- Kumi Hospital
- Soroti Regional ReferralHospital
- Masaka Regional Referral Hospital
- Mbarara Regional Referral Hospital
- OURS, Ruharo, Mbarara
- Itojo Hospital
- Kisiizi Hospital
- Kabale Hospital
- Fort Portal Regional ReferralHospital
- Namutamba Rehabilitation Centre
- Lira Regional Referral Hospital
- Gulu Regional Referral Hospital
- Arua Regional Referrral Hospital
- Hoima Regional Referral Hospital

For more information contact:
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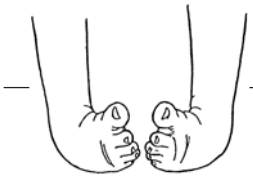

UGANDA SUSTAINABLE CLUBFOOT CARE PROJECT

Report of meetings held at USCCP Regional Hospitals for the Launch of the Incidence Survey of The Congenital Clubfoot Deformity in Uganda, Feb 2006

Introduction of the Uganda Sustainable Clubfoot Care Project.

Uganda is one of the least developed nations and has one of the highest birth rates on Earth (50 per thousand population). Its population is largely rural (90%) and dependent mostly on subsistence farming for their daily needs. In an agrarian society, disability is a major cause of the developmental challenges of ill health & poverty. An estimated one thousand infants are born every year in Uganda with one or both feet affected with a birth defect known as 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 (Atria). Congenital deformities (mostly clubfeet) are responsible for 30% of musculoskeletal ill health & disability in children in Uganda. (Lutwama, 2002). Children with neglected clubfeet are destined to grow up with deformed & painful feet, leading to physical disability. Untreated, this disability affects an individual's mobility and threatens their potential productivity. 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.

The Uganda Sustainable Clubfoot Care Project was launched one year ago. It aims to reduce disability as a cause of poverty by treating children with clubfeet at the earliest possible stage, preferably starting in the first weeks of life. Every child in Uganda with clubfeet should be able to be corrected and after treatment follow the same life trajectory as his peers. The Project is a partnership between the University of British Columbia (Canada), Makerere University, the Ministry of Health, Christian Blind Mission and the Children's Orthopaedic Rehabilitation Unit in Mengo hospital, supported by the Canadian International Development Agency.

A vital part of the Projects work is the generation, processing & analysis of data on various aspects of congenital clubfeet in Uganda. On Feb 15th 2006, the Project launched an Incidence Study, designed to find out the true burden of the congenital clubfoot in Uganda.

This is a report of our visits to all the participating hospitals.

The Visiting Team:

Prof. Shafique Pirani	USCCP Project Director, Orthopaedic Surgeon, UBC, Canada
Prof. Richard Mathias	Professor Health Care & Epidemiology, UBC, Canada
Dr Gonzaga Waiswa	Orthopaedic Surgeon Mulago, Orthopaedic Coordinator USCCP
Mr Dirissa Kitemagwa	Senior Orthopaedic Officer, Mulago
Mr. Henry Musoke	Senior Orthopaedic Officer, CORU, Mengo
Mrs Marieke Dreise	Project Administrator USCCP, Kampala

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Appendix 10: Report of Meetings Held at USCCP Regional Hospitals for the Launch of the Incidence Survery of The Congenital Clubfoot Deformity in Uganda, Feb 2006

Participants Rubaga Hospital, 1-2-2006:

Mr Turyabanika, Joseph	Surgeon
Mrs. Hellen Acola	Senior Nursing Officer, In charge Maternity
Dr Edward Lubuulwa	Senior Consultant Paediatrician
Dr. Hilda Kizito	Paediatrician
Dr. Jumba-Mukasa	Senior Consultant Obstetrician/Gynaecologist
Mr. Fred Mutyaba	Orthopaedic Surgeon
Mr Nkoto, Musa	Orthopaedic Officer

Participants Mengo Hospital, 1-2-2006:

Dr. G. Bukenya	Deputy Medical Director
Sr. Milly Nanteza	Senior Nursing officer, In Charge Maternity, Private Wing
Sr. Victoria	Senior Nursing Officer, In Charge Maternity
Mr. Musoke Henry	Orthopaedic Officer, Children's Orthopaedic Rehabilitation Unit

Participants Jinja Regional Referral Hospital, 2-2-2006

Dr Wanume, Benon	Medical Superintendent/Consultant Public Health
Mrs Naibale Robinah	Senior Nursing Officer, Maternity, Assistant in charge
Mrs Beatrice Amuge	Asst. Commissioner Nursing Services, Public Health Specialist
Dr Kisegerwa Enock	Medical Officer Special Grade, Obs/Gyn
Dr Ekwaro Lawrence	Senior Consultant, Surgery
Mrs Sempa Hellen Jennnifer	Orthopaedic Officer

Participants Mbale Regional Referral Hospital, 3-2-2006

Dr. Mike Kagawa	Ag. Med. Superintendent, Obs/Gyn
Dr. Geoffrey Madewo	Consultant Orthopaedic Surgeon
Mrs Nassuna, Edith	Senior Principal Nursing Officer
Mrs Ekido, Lossiro	In Charge Acute Care Unit
Mrs. Kenya, J	Ag. In Charge Maternity 1
Mr. Watenyeri Julius	Principal Orthopaedic Officer
Mrs Odong, Mary Pedun	Senior Nursing Officer, P.H.D
Mrs Jennifer Odong	Nursing Officer, Paediatric Ward
Mr Buyi Alex Bernard	Orthopaedic Officer
Mrs. Tuundbe, Regina	Area Manager OBS/Gyn
Mr. Nina, Sam	Orthopaedic Officer
Mrs Penninah Oola	Senior Nursing Officer, Masaba Wing
Mrs Atayo, Anne Mary	Nursing Officer, Maternity 2
Dr Mwaka, Erisa	Orthopaedic Surgeon

Participants Mbarara Regional Referral Hospital, 7-2-2006

Dr Mihayo, Placid	Medical Superintendent
Mrs. Ndiku, Odilla	Ag CNO
Mrs Nakalanzi, Assumpta	In charge Maternity
Mr. Fernando Perez	Head of Department Obs/Gyn
Mr. Louis Tugume	Head of Personnel
Mrs Jennifer Nabunya	Orthopaedic Officer
Mrs Jessica Tagobera	Nursing Officer, Paediatric Ward
Mr. Kazibwe, Herman	Physiotherapist
Mr. Mwesigwe Stephen	Orthopaedic Officer

Appendix 10: Report of Meetings Held at USCCP Regional Hospitals for the Launch of the Incidence Survery of The Congenital Clubfoot Deformity in Uganda, Feb 2006

Participants Nsambya Hospital, 8-2-2006

Dr. P.N.Kituuka	Deputy Medical Superintendent, Paediatrician
Mrs. Kiwanuka, Josephine	In Charge Private Maternity Ward
Mrs Nakkazi, Sarah	In Charge General Labour Ward
Mr. David Magala	Orthopaedic Officer
Mrs Asio Alice	In Charge Antenatal Clinic
Mrs A.D Namirembe	Principal Nursing Officer

Participants Mulago National Referral Hospital, 8-2-2006

Dr. Edward Naddumba	Ag. Director Mulago Hospital, Uganda Project Director USCCP
Dr Philippa Musoke	Head of Paediatric Department
Dr. Biryabarema, Christine	Head of Dept of Obs/Gyn
Mrs Rose Nakayiza	In Charge Labour Ward
Mrs Kabasonga, Mildred	In Charge Labour Ward

Participants Masaka Regional Referral Hospital 9-2-2006

Dr. Kenya Mugisha	Medical Superintendent
Mrs Anne. J. Wandera	Principal Nursing Officer
Mr Nuwamanya David	Hospital Administrator
Mrs Nakiganda Elizabeth P	Senior Nursing Officer, In Charge Maternity Ward
Mr. Muwonge John	Orthopaedic Officer
Mr. Asiimwe, Emmanuel	Orthopaedic Officer
Dr. Ssebaggala, Stephen	Orthopaedic Surgeon

At each visit, the visiting team initially met with Administration & then went on to see the Clubfoot Clinic, and the Maternity units. The following presentations were made and discussions undertaken on the best ways to implement the study.

1) The Problem of the Congenital Clubfoot in Uganda

In the past the clubfoot problem was seen as a surgical problem. The consequence was that in many developing nations with a scarcity of surgical resources, children with clubfeet were usually managed by benign neglect. Recent Ugandan trials of Professor Ponseti (an orthopaedic surgeon in Iowa, USA) non-surgical intervention of manipulation and casting gave very good results and was cost effective. The method can be applied by Orthopaedic Officers or Physiotherapists under the supervision of a doctor and is therefore quite suitable for use in developing countries. In a period of 8 weeks a foot can be fully corrected. A minor surgical procedure, a tendon Achilles tenotomy needs to be done under local anaesthesia and can be done by a medical officer in the outpatient clinic. A brace is worn as instructed post correction to prevent reccurence of deformity.

Once consensus was achieved among Academia, Ministry of Health and Ngo's in Uganda that the Ponseti Method is the preferred method of treatment, applicable in Uganda, the Uganda Sustainable Clubfoot Care Project (USCCP) was born. Funded largely by The Canadian International Development Agency (CIDA) it's mandate is to build capacity for clubfoot detection & treatment by the Ponseti throughout Uganda by 2010 by:

- Assisting all (para) medical schools to incorporate a module on the clubfoot & its treatment in their curriculum and by designing teaching materials for those schools
- Organizing in service training sessions for those (para) medicals who are already working in the field on screening for and the treatment of the congenital clubfoot.

The MOH has agreed to provide supplies like plaster, cotton wool and braces to the hospitals to make the treatment sustainable. Plaster and Cotton wool are now on the credit line. If hospitals face problems in receiving plaster and cotton wool, then they are requested to contact the project administrator, Mrs Marieke Dreise (e-mail mariekedreise@mac.com or phone: 077 2465174) so that she can follow it up with Dr Amandua, the Commissioner of Clinical Services at the MOH.

2) Incidence Study in Uganda Sustainable Clubfoot Care Project

USCCP investigators face a number of unknowns as they procede with the project. The project therefore has a third arm of data collection and analysis.

The Project's research activities started with an ethno cultural survey of the congenital clubfoot in Uganda. This is reported elsewhere.

The next major research undertaking is an incidence survey (number of children with congenital clubfeet per 1000 live births, aggregated by sex). It is to start on the 15th of February 2006. Worldwide the incidence of clubfeet is believed to be 1:1000, but the figures given for different countries vary. It has never been researched in Uganda on a wide scale. Power analysis suggests 100,000 babies need to be examined to establish a true incidence of clubfeet at birth in Uganda, along with a sex distribution. This will not only give planners data to plan for services, but also allow for prediction of anticipated referral rates by sex at each Didtrict Clubfoot Clinic. If these numbers are not met, local officials can be alerted to look for a cause.

Professor Mathias gave an introduction on the incidence survey. Uganda's 8 major hospitals in Uganda will be involved in the Incidence survey: Mbale, Jinja, Mulago, Mengo, Nsambya, Rubaga, Masaka and Mbarara (all hospitals that have orthopaedic surgeon/general surgeon a clubfoot clinic, and a maternity unit with reliable records).

1) Study Goals:
   a) Primary
      i) Determine the incidence of clubfoot deformities in Uganda
      ii) Determine the gender ratio of clubfoot deformities
   b) Secondary
      i) Determine the incidence of other musculoskeletal deformities that may involve the foot
      ii) Estimate the effectiveness of the module which trains birth attendants in the recognition of clubfoot deformities.

2) The Denominator:
   a) The denominator will be live births.
   b) The time periods must be predetermined so that a clubfoot deformity is not included from outside the period of the study.
   c) Assumptions

      Basic to the determination of any rate is the measurement of the population from which the cases are drawn. In the incidence study, this is to describe the number of births by gender from which the cases are drawn. As clubfoot does not contribute to fetal death, it would be reasonable to use the live births plus still births if the still births were equally examined for deformity. However, as this is not a very reasonable assumption the denominator will be live births.

      The assumptions underlying this measurement is that clubfoot is not being diagnosed antenatally. Although it is possible through antenatal ultrasound, this procedure is sufficiently rare in Uganda that few is any cases of clubfoot will be diagnosed prenatally and hence influence where the delivery will take place. This assumption is made so that we can assume that the number of clubfoot deformities are being drawn from the same population as the births and is not "enriched" by referral to the center for delivery specifically due to clubfoot.

      The recording of births is reasonably accurate. As the ratio of clubfoot deformities to births is expected to be low, slight under counting of births will not influence the rate very much.

3) The Numerator:
This is much more susceptible to error. With the expected ratio in the order of 1:1000 live births, even a few false positives of false negatives will greatly influence the rate.
   a) *Case definition:*
   Standard case definition as confirmed by either the attending orthopedic surgeon or by the orthopedic officer who has been trained in clubfoot diagnosis. A clubfoot will be defined, for this study, as a deformity that is eligible for correction by the Ponseti method.
   b) *Case detection:*
   Each live birth will be examined for the presence of a deformity of the foot. The person attending the birth will not be expected to diagnose the clubfoot deformity reliably. They will be asked to refer each child for diagnosed to the orthopedic officer, before the mother and infant are discharged from the ward. If this is not possible, the identifying information will be forwarded to the orthopedic officer. They will then determine if the child returns to the clubfoot clinic. If the infant does not come to the clinic, a home visit will be arranged to have the child examined and referred to the clinic. There are two possibilities for the home visit the public health nurse or the orthopedic officer. If it is to be the nurse and under the assumption that the child will not be brought for treatment, the orthopedic officer will review the diagnosis of clubfoot requiring treatment with the nurse to improve the diagnostic reliability.
   The orthopedic officer will visit the obstetrical ward on a weekly basis to inquire about possible cases. This is to maintain the interest of the birth attendants as this is a rare condition, if they are not encouraged to maintain surveillance, they may not have this as a routine examination.
   c) *Requirements for centers to be enrolled in the study:*
   Orthopedic officer present and expected to be present throughout the study period
   Not necessarily the same person
   Clubfoot clinic present on site or sufficiently near that referrals of cases are possible.
   Nursing sister in charge of the obstetrical ward consents to active surveillance project

3) Data collection:
   i) Weekly:
      - Number of live births in the facility by gender
      - Number of infants referred to the orthopedic officer by gender
      - Number of referred infants by gender and condition
   ii) Monthly
      - Report of each facility sent to the study center
      - Analysis of rates from each center by:
        - Gender rates by center
        - Number and Rates of Abnormalities of foot unilateral or bilateral
        - Number of detected infants who were not seen at the clinic within two weeks.
        - Number and Rates of Confirmed clubfoot by gender and by unilateral or bilateral
      - Summary of all centers
        - Total number of live births by gender
        - Rate of abnomalities referred by gender and by unilateral/bilateral
        - Rate of confirmed cases by gender and unilateral/bilateral
   iii) Notes:
   The weekly reports are confidential to the facility. While there will be feedback to each facility within in two weeks of the month end, the facilty specific data will be returned to that facility only. They will be compared to the rates for all facilities but the numbers from all facilities will not be used.
   This confidentiality of facility specific data is one of the requirements of the BC Perinatal database. They record a great deal of data but are very careful not to allow one facility to compare themselves to another. Rather one facility can only compare themselves to the overall. As the numbers increase, we will calculate the rates and the confidence limits about those rates. This will be our way of trying to determine of there are outliers in the reporting. For your interest, we will be using the Poisson distribution to calculate the confidence limits rather than the normal distribution as these are rare events.

iv) Data checks:

The birth numbers will be compared to the data which is submitted to the Ministry of Health.

The number of children presenting for the first time with clubfoot requiring treatment at Mulago and Mengo will be monitored monthly. The additional information required will include the place of birth so we can determine if it from a reporting facility and hence how good our detection rates are.

We need to regularly watch for cases detected by the birth attendants but who are not assessed by the orthopedic officers. This means that we need to collect the data from the orthopedic officers on how many they have assessed and what the results of the assessments were.

Assessment of the effectiveness of the module used for nurses/midwives/birth attendants in allowing the birth attendants in detecting abnormalities and in the rate of false positives. With a rare event, I think it will be exceptionally difficult to determine the false positive rate. We will assess this by looking at children referred to the clinics who were born at one of the surveillance centers but were not found by the nurses and hence not referred. From this rate we will adjust from the number who were detected but who did not come to the clinics to estimate those missed who did not come on their own. These numbers are expected to quite low. A qualitative assessment of the module will be done to determine how comfortable and confident the nurses are in detecting the abnormalities.

Discussion

Without exception a very warm welcome was given to the project team, and all the hospital administrations went out of their way to see how the project activities could be facilitated. All hospital Admistrations and Maternity Units agreed that they were ready to launch the Incidence Study on Feb 15th 2006. Regular follow up will be done by USCCP members.

Prof Mathias stressed that the project does not want to increase the workload of the nurses. Realizing, that they are already very busy, the work should be kept to a minimum and fit in the existing systems. The project does not want to burden the nurses/midwifes with the performing the diagnosis clubfeet, or extensive paperwork, - simply to screen for any foot deformity. This approach will encourage alertness for any foot deformity. It is much better to have many false positives then to miss any true positive

- The nurses will call the orthopaedic officer when they have detected a foot abnormality and the orthopaedic officer will come to diagnose. The mothers are normally staying for 24 hours
- To make sure no baby with a foot deformity is missed, the orthopaedic officers agreed to pass by at the maternity ward every morning before the discharge time to check if there is any case that needs to be seen by him/her.
- In the weekends there is usually an orthopaedic officer on call, who will pass by at the maternity ward. In the hospitals where there is only one orthopaedic officer, some officers agreed still to be called, or the nurses would try to convince the mother to come back on Monday with the baby.
- The nurses are asked to fill in only a brief referral form, which is be given to the orthopaedic officer. It's main purpose will be to find the mother/family if the infant does not come to the clubfoot clinic.

The midwifes/nurses in the delivery rooms/labour wards agreed, they are the right people to screen for foot deformities at birth. They already keep records already and count monthly how many babies have been born. In some hospitals there is a special column for abnormalities. All the involved hospitals have agreed to create a column for foot deformities in their record book. At the end of the month the midwifes will count how many babies were born and how many of those had a foot deformity. That will probably be around 1-3% of the babies. Of these ones few will be clubfeet. The midwifes will also count the sex of the babies born and the sex of the babies with the foot deformity, because there is a suspicion that there are more boys with clubfeet than girls.

4) Awareness/sensitization

To make sure that the nurses and midwifes know how to recognize a foot deformity the project will organize sensitization sessions for them. It was discussed that a team can come several times to the hospitals in the next few weeks to make sure that every nurse/midwife has an opportunity to attend. Many suggestions were done by the hospitals to include nurses working in the under five clinics or paediatric ward or in outreach for immunization. All those nurses are welcome to attend, the more the better. The Ministry of Health has requested to join forces and it will avail a nurse who will give a session on examination of the newborn. The sessions will probably take around 2 hours in total.
The project is in the process of making educational materials for the nurses e.g. some brochures and posters showing different foot deformities.
Dr Waiswa made a schedule, which hospital would be visited when and the nurses/midwifes in charge were going to organize that as many nurses/midwifes as possible would attend.

5) Outcome evaluation.

The children who are diagnosed with a clubfoot are going to be treated and followed for a period of 4-5 years to research the outcomes of the treatment and the bracing. After around 8 weeks the feet will be corrected by the manipulation and casting and then the correction has to be maintained.
The Steenbeek Foot Abduction Brace has been specifically designed for that purpose and has to be worn full time for 2 months and then for another 3-4 years at night.
If the brace is not used the deformity will recur in 90% of the cases.
The Project has designed forms for the outcome evaluation and the Orthopaedic officers will be taught how to use them.
The project also wants to find out what factors influence compliance/non compliance.
The Orthopaedic Coordinator of the USCCP will bring regular visits to the hospitals for data collection and support supervision. The Regional Orthopaedic Surgeons will also supervise the orthopaedic officers on a regular basis.

Respectfully Submitted
Marieke Steenbeek-Dreise
Uganda Project Administrator
March 31st 2006