

# Development of a Neonatal Intensive Care Unit in Uganda, Africa

Developing nations face tremendous challenges in providing care to mothers and children. Uganda has some of the highest maternal and infant mortality rates in the world. The Luwero triangle in central Uganda is one of the poorest areas of Uganda. In the late 1990s, the ISIS Foundation began developing a neonatal intensive care unit (NICU) in this area. The article describes NICU development and relates the author's experiences in working with the staff of Kiwoko Hospital. The overall goal of this effort has been to assist the hospital to be more self-sufficient using a train-the-trainer approach. Key words: *NICU, preterm infant, Uganda*

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**A**FRICA IS A continent rich in culture and history, with areas remote and untouched by the human hand; its beauty is breathtaking. Deep in the heart of the Luwero Triangle in central Uganda lies a place close to my heart – a place offering hope and healing to a community so deserving. This place is Kiwoko Hospital, located in the region's only functioning hospital. Once a local clinic, this hospital now treats over 25,000 people per year, and this number continues to grow. There are 149 beds for an approximate population of 500,000 people. These numbers have not always been so high.

Uganda is well known for the suffering faced under the dictatorships of Idi Amin and Milton Obote. During the reigns of terror, hundreds of thousands of Ugandans were murdered. Many killings occurred in the Buganda area known as the Luwero Triangle, which was completely depopulated. The fields in this area are still full of skeletons.<sup>i</sup> Under the current Museveni government, which took over in 1986, Uganda is more politically stable. A sense of civil society has been returning to much of the country. With this new-found peace has come economic growth, which has helped to make up for the past decline. Despite this new growth and feelings of hope, there is still cause for despair.

The increasing population taxes an already struggling health care system. Staggering numbers of people are infected with the human immunodeficiency virus (HIV). In the last decade Uganda lost over 1.8 million people (8% of its population) to acquired immune deficiency syndrome (AIDS). By the year 2000, roughly 1.7 million Ugandan children had been orphaned by this disease; nearly 1 million of these children are still alive.<sup>ii</sup> Currently, roughly 8.3% of Ugandans are HIV positive.<sup>ii</sup> Although the infant and maternal mortality rates have declined in recent years, the numbers are still some of the highest in the world (Table 1). Malaria, pneumonia, and diarrhea are among the main killers of children.<sup>iii</sup> Approximately half a million people live in the Luwero

district, one of the poorest districts in Uganda. The people are peaceful and hardworking, struggling to rebuild their homes against incredible odds. To do so, outside assistance was imperative.

Indicator	Uganda	United Kingdom	United States
Gross national income per capita (US dollars)	310	24,500	34,260
Infant mortality (no. of child deaths per 1,000 live births)	81	6	7
Under 5 mortality (no. of child deaths per 1,000 live births)	127	6	8
Maternal mortality (no. of mothers who die per 100,000 live births)	510	7	8
Access to safe water (% of population)			
Rural	47	100	100
Urban	80	100	100
Adult literacy (% of population)			
Male	78	NA	NA
Female	57	NA	NA
% of children who are underweight (moderately or severely so)	26	NA	1
Children who are stunted (height)	38	NA	2
% of 1-year-old children immunized against			
Tuberculosis	83	NA	NA
Diphtheria, whooping cough, tetanus	55	93	96
Polio	55	93	91
Measles	53	91	92

NA, not available. *Source:* Data from UNICEF 2002, *Statistical Data by Country*, <http://www.unicef.org>, Accessed June 2002.

### THE ISIS FOUNDATION

Half way across the work Audette Exel and Sharon Beesley, two businesswomen who decided to change their lives and make a difference in the developing world, had a vision. They would use their expertise in the business world to develop a finance business, ISIS Limited, to fund the ISIS Foundation. The ISIS Foundation would initiate and manage primary health care projects in the developing world. In 1997, the ISIS Limited was incorporated, with its head office located in Bermuda. The doors to the business and foundation opened in spring 1998. A dream was about to come true.

Since mothers and their children have a long history of being disadvantaged in third world nations, the health care of these two groups became a main focus. After much research, two areas were chosen: Nepal and the Luwero Triangle. The overall goal was not to be a long-term solution but to assist villages and hospitals in becoming more self-sufficient. Training the trainer is the best approach to achieve this end.

Upon researching areas within the Luwero Triangle, the foundation came in contact with Kiwoko Hospital. Initially, the foundation sponsored community-based primary health care projects at the hospital. These projects concentrated on nutrition, clean water, essential drugs, immunizations, and maternal care. A four-wheel drive vehicle was purchased and used as a mobile clinic to facilitate outreach. A valued employee of the hospital who is known and well-respected throughout the community,

conducted his teaching under a tree. It was here that immunizations were administered. ISIS and Kiwoko Hospital thereby began a partnership that would last for years.

## **FOUNDATION PROJECTS**

The first major foundation-funded project was building the Community-Based Health Care (CBHC) hall for meetings and training. CBHC staff continue to run a wide range of programs in the Luwero area. They provide direct assistance to people in this region and also train local members of the community to volunteer in the health field, including volunteering to become traditional birth attendants. More recently, the program has added AIDS counseling, sanitation training, school visits, disability services, and dental care to the training. With the ability to transport mothers within the growing community, the hospital was treating difficult deliveries of sick and premature infants, many weighing less than 1 kg. The hospital and foundation soon realized that more was needed to care for these infants. The idea for the neonatal intensive care unit (NICU) was born.

Meanwhile, I had been working in Bermuda in neonatal intensive care nursing. This experience, along with involvement in projects with the Bermuda Department of Health, increased my interest in working in development with members of the ISIS Foundation who had just returned from Kiwoko with accounts of sick babies, mothers who were dying, and a hospital struggling to save them. My relationship with ISIS would be life changing.

ISIS began working on strategies to rectify the challenges faced in Kiwoko on the maternity ward. Chronically understaffed and close to maximum capacity, it became evident that sick infants would need to be cared for in a separate structure. A donation was received that allowed ISIS to begin planning for a NICU. The development of this NICU would open up an entire new phase for the ISIS Foundation in Kiwoko.

The early assessment and planning stage for the NICU in Kiwoko began in 1999. At this time I had relocated to Seattle, Washington, where I worked in a NICU and continued my involvement with the ISIS Foundation. Arrangements were made for me to visit the site in February 2000. At the request of the staff, initial training would address neonatal resuscitation. Staff possessed no formal training in the resuscitation and care of sick infants and were learning on the job. It was thought that training all staff involved in the maternal/child area to resuscitate infants would lay a firm foundation. Care of the premature and low-birth-weight infant also would be a main focus.

## **PREPARING FOR THE JOURNEY**

In the meantime, I had started to spread the work in the Pacific Northwest area about Kiwoko Hospital and its need for supplies and equipment. The first equipment donated consisted of six cardiorespiratory monitors. Then boxes of supplies started to accumulate, all saved by the staff. The NICU was starting to become a reality. During this time we communicated with Kiwoko and used every discipline of the NICU team to help troubleshoot any care-related problems. The unit was completed in October 1999, wired with both 110/240 voltages in order to accommodate any medical equipment that could be found.

In February 2000, I left for Uganda. Thirty-three hours of travelling and an 11-hour time difference brought me to one of the most beautiful, yet shocking, places I had ever seen. Traveling down the red dirt road into Kiwoko from Kampala propelled my senses into overdrive as clay huts, lush forests, and beautiful children running along the side of the truck came into view. We entered the gates of Kiwoko, and the hospital came into view. Each ward of the hospital is a one-level building that surrounds a central grassy courtyard. Circling the hospital are the homes in which many hospital employees live. The car park consists mainly of bicycles, one of the main modes of transportation, and a Toyota four-wheel drive. It serves as the ambulance for this remote area.

The labor room consisted of four rusted metal beds with ropes for stirrups. The cement floor was stained and pooled with blood from a previous delivery. No linen was available unless provided by the family. The resuscitation table was a wood table that was 3 feet high and positioned at a severe tilt; there were no heat sources available. Scarce supplies stocked the old wood shelves. The only emergency supplies for the entire hospital consisted of one adult ambubag and mask, one laryngoscope, one suction machine operated on a bicycle-type mechanism, and an oxygen supply that worked only when the power was on. There was an old metal crib; the only infant bed was a 30-year-old incubator with a heater that worked at times. The adjacent maternity ward room, full of post-partum mothers nursing their babies, consisted of rows of metal beds. All doors and windows were open to the outside in an attempt to cool the room from the tremendous heat.

Entering the NICU, it was clear to me that this was a newer structure, but a shell at that. Not yet in use, a fine layer of dust covered the room. It was empty except for a few sinks and a central nursing station. As I looked around the room, I envisioned how it would come alive in the days ahead, with hopes that many little lives could be saved here. I knew that more need existed here than in any place I had seen in the Western World.

## **TRAINING**

The first stage in training was the neonatal resuscitation program (NRP). Having been an instructor in Seattle, I knew we would need to conduct the training sessions differently in Kiwoko. We divided staff into groups of 8 to 10. Because English is a primary language, second to Buganda and Swahili, complete translation of the program was not necessary. The groups consisted of midwives, doctors, anesthetists, and medical officers (physician's assistants). These were the hardest working groups I have ever encountered. All six theory lessons were covered in 1 day using shared education materials. The second day was spent practicing skills. I worked individually with each person to ensure that his or her technique was correct. The remainder of the day was spent running through mock resuscitations to pull the new skills together.

With no ventilators, very little equipment, and few medications, I was uncertain if the intubation and medication portion of the program would be of much use. I had not planned to test staff on this area since I could not provide them with all the resources normally used in the program. The staff requested that we cover all lessons regardless and that I test them as I would at home. This was the first of many testaments to their determination and commitment. Thirty people went through the program. Many sat

through classes after working a 12-hour night shift; others requested classes in the evenings so they could attend after a long day of work.

The University of Washington had donated resuscitation dolls and equipment. Curious onlookers often watched through the windows during training. I learned later that the resuscitation dolls were of great interest. The staff often commented they did not know that training materials such as this existed. They appeared hungry for the education and expressed gratitude to have theory to relate to the practice.

Testing would take place on my last days at Kiwoko in order to give the staff ample time to review the content. Late in the evenings I would see the lights on in the NICU as the groups practiced their skills together. Twenty people participated in the testing and all passed. The excitement was palpable as they recognized their achievements. The same format of NRP training is used currently, with over 50 people trained to date.

### **The Earliest Cases and Equipment Needs**

To maximize the assessment of needs, I encouraged staff to use my assistance, which they did. The acuity of sick infants treated at Kiwoko Hospital was and remains high. One time, while I was away from the site, premature twins were born; they weighed approximately 1 kg each. I learned later that one of the twins died during a power outage that affected the electrically run oxygen concentrator. This is not an uncommon event. Every night, at varied times, there is a shortage of electrical power. In fact, most of the night passes without electricity. Lanterns, flashlights, and an oil-fueled generator are used.

I decided that we should postpone further NRP training at that time and focus on the basic of premature baby care with the remaining twin. Maintaining thermoregulation was a challenge due to the many obstacles encountered. The heating system in the incubator was unreliable. Hot water bottles were used for heat, causing repeated episodes of hypothermia and hyperthermia. These instances were not the staff's fault; rather, they could be traced to the lack of funds that caused low staffing levels and no functioning equipment. The only linen available was what the mother could provide, which was usually limited. Kangaroo skin care was encouraged during hospitalization of low-birth-weight infants.

Delivering adequate fluids and nutrition was another challenge. The mother of the twins was hand expressing milk and obtaining approximately 2 mL. The cost of formula, if available, is beyond what the average Ugandan family can afford. Starting an intravenous (IV) on a baby of this size was not common practice. Dextrose concentrations were delivered in as high as 50% concentrations, and there were no means for central IV access. There were no IV pumps in the hospital; therefore, an attempt was made to regulate flow. It was not uncommon for 1 L of fluid to be delivered over a short period of time to a low-birth-weight infant. At times, a childless mother would be seen nursing an orphaned baby in an effort to provide nutrition (four mothers died in labor in the 2 weeks I was at Kiwoko). If an infant required gastric feeds, the mother often gave these feedings. Aspiration of milk was not uncommon.

Another day, an emergent situation arose that again reinforced the need for a NICU. A 5-day-old infant was rushed to the hospital blue and choking. I had been

testing for NRP at the time, so emergency equipment was readily available. After stabilizing the infant, it became apparent that she might have Trisomy 21. The parents had suspected this, but they had been told at another clinic that she did not have this condition after a visual examination. They were concerned because her feedings had not been established and she seemed to have occasional dusky spells.

The infant was dehydrated, extremely jaundiced, and had a loud heart murmur. Due to malfunctioning equipment, the laboratory was not operating that day; thus, testing her bilirubin or performing other blood work was impossible. X-ray was not available either. We started an IV and tested her blood glucose (which was low) with some chemstrips. The beginnings of Kiwoko Hospital's future practice of administering 10% dextrose IV to all infants was started at this point. We cleaned up an old bassinet and used water bottles to provide warmth. An old bank of phototherapy lights found sitting in a corner was put to use. We used mosquito netting to cover the entire bed and taped it to the base. An airplane mask was used for eye shields.

The infant's parents were missionaries. After the infant was stabilized, she and her parents returned to the United States for repair of a patent ductus arteriosus and confirmatory diagnosis of Trisomy 21. This was the NICU's first patient, and her case typifies the problems of available resources. These types of challenges, common to developing hospitals, are rarely encountered in the Western world.

Maintaining adequate staffing levels is another challenge at Kiwoko due to high patient acuity, inadequate to patient ratios, and salaries lower than in the main Kampala hospitals. There are approximately seven doctors at Kiwoko (two of whom are hospital doctors), with one on call each night for the entire hospital. It is estimated that Uganda has one doctor for every 20,000 people.<sup>1</sup> Two midwives at a time cover the labor room, maternity ward (which includes sick infants), and any mother requiring a cesarean section. Despite what seems to be an impossible situation, the staff are positive, friendly, humble, and extremely dedicated to the patients they serve with unwavering compassion and hard work.

## **RETURN TO AMERICA**

Upon leaving Uganda, it was evident that there was much work to be done. The list of needs was long. We prioritized the equipment that was required urgently; incubators topped the list. One of the biggest problems in projects such as this is that old, outdated equipment is donated. Moreover, money is not spent on proper packing and shipping. Thus, equipment often does not work when it arrives. In fact, Kiwoko has a "graveyard" of old equipment. We felt this practice must be discouraged, especially when staff members are working so hard to save lives. Children's Hospital Medical Center in Seattle donated two incubators that were in excellent condition. We also obtained newer phototherapy lights and radiant warmers.

At the end of 2000, a highly skilled nurse employed by the ISIS Foundation lived onsite at Kiwoko for 4 months. She was able to visit other NICUs in Uganda to research how care was delivered. Her daily presence ensured continuity and support for the staff working in maternity and pediatrics. This nurse and I communicated regarding various case scenarios and, through resources here in the United States, were able to offer practical assistance to the staff in Kiwoko. She established a book of protocols and a

documentation tool for the NICU and guided a unit restructuring process before her departure.

#### **A RETURN VISIT**

Movement in a forward direction occurred in leaps and bounds in 2001. Early in the year I visited Kiwoko again and saw the progress in the care of sick infants. According to the hospital's medical superintendent, staff were excited about their new-found skills and improvements in outcomes for sick infants. I continued to train on a case-by-case basis and provided further NRP training as well. During many of the education sessions, target staff were chosen so that they could disperse the information to others.

A shipment arrived while I was there with the new incubators and boxes of supplies. What a contrast to see this equipment loaded into container on mechanical lifts in Seattle and then to see it being driven down a red dirt road and carried in by six men in Uganda! I will never forget the faces of the staff when the incubators were unloaded from the truck. They joined hands, formed a circle, and gave thanks for equipment we use on a daily basis here. One of the tallest boxes contained baby linen that had been donated. They folded the linens as if they were made of the most precious cloth. As we put away most of the supplies and stocked the shelves, the underlying atmosphere was one of excitement and anticipation. Although in operation for over a year, the NICU had not been officially opened; however, the target date was April 2001.

Despite the NICU being structurally complete, staffing was an issue. Because it was in a building separate from the maternity area, nurses needed to be assigned to the NICU. A nurse and two midwives were initially hired. As the census fluctuated, however, the challenge of staffing began. Partnering with Kiwoko Hospital, the ISIS Foundation agreed to fund a portion of the NICU salaries. It is currently increasing the number of nurses funded with the hope that in 2002 there will be from seven to nine full-time NICU nurses.

Local and national dignitaries, as well as the US ambassador, attended the official opening of the NICU in April 2001. From April to December 2001, the NICU staff treated 212 infants. Monthly admissions range from 15 to 30 infants. Of infants weighing 1.5 kg and below, 65% have survived and 35% have died; in infants weighing 1.6 kg and above, 92% have survived and 9% have died.<sup>iii</sup> The most common diagnosis in those infants who died was prematurity, followed by neonatal tetanus, prematurity with respiratory distress, and birth asphyxia.<sup>iii</sup> A pediatrician from Japan joined the medical team at Kiwoko Hospital and has been in the NICU on an ongoing basis. Enthusiasm, energy, and good humor continue to run high in the staff. They are making a difference.

Nowhere is the improvement and change more readily seen than in the positive outcomes of the children. Babies now live when before they likely would have died. To help ensure that these results continue and improve, a structures training program is being developed that covers all aspects of neonatal care. At the time of writing, a volunteer NICU nurse whose travel expenses were supported by the ISIS Foundation was teaching the first components – thermoregulation; managements of blood sugar, fluids, and electrolytes; and nutrition.

Equipment and supplies related to the training modules continue to be sent to Kiwoko. Two infusion pumps were purchased and donated by the ISIS Foundation for use in the NICU. These first-ever IV pumps in the hospital can be used to deliver milk, IV fluids, medication, and blood products. Notably, the pumps run on battery. This will enable them to sustain delivery during the frequent power outages. They alone will help to save lives. Additional linen, diaper covers, breast pumps and portable suction devices also have been donated.

## **THE FUTURE**

The future of the NICU at Kiwoko Hospital appears to be very positive. Improvements in place will be sustained as the hospital strives for upward growth. Major plans call for an assessment of the current training program so that further development of the next module content can occur. Specialized volunteer trainers will visit the site to implement the next step. Continued acquisition of much-needed equipment will be an ongoing focus. Eight additional incubators have been secured and will be shipped in the near future. Medical supplies will be transported from Seattle to Kiwoko on a regular basis. A radiologist and echo cardiac sonographer will visit the site to assist the medical team in interpreting crucial diagnostic tools.

## **LESSONS LEARNED**

For those interested in setting up an NICU in a foreign country there are certain “unwritten” rules that can help make it a success. One of the most important is not to impose ideals or standards of care. It is important to work within the culture being served. Help them to make it work within their capacity and comfort level. Remember that how things are set up where you work will not necessarily be effective in another place. Respect the individuals being trained. Be open to new ideas and learn from those with whom you work. Remember to train the trainer. The ultimate goal is self – sufficiency.

A positive attitude and a sense of humor will go a long way, even when the situation seems bleak. I have seen this tested at Kiwoko; their positive outlook enables them to work through situations unheard of in most places. Do not quit when in search for something, or if the acquisition seems impossible. Persistence and patience are key virtues. Do not settle for outdated and old equipment. It may provide short-term relief, but it will not stand the test of time and can potentially hamper the project. Hold out and hunt for newer and more durable equipment. Spread the word about the work you are doing. Finally, know when to put it aside if you feel drained. At times the needs can be so overwhelming that you become depleted trying to help. You can better serve the project being well rested and fresh. As I ponder this project, the adage “When you cease to dream you cease to live” plays repeatedly in my mind. I look at where we have been and how far we have come. This entire project grew out of a dream, a vision to make a difference in the third world. Those who work within ISIS also dream about the good this project does and those it helps. The Ugandans dream that one day the struggle to survive will be over and life will be easier. The staff of Kiwoko Hospital dream that one day they will be able to deliver care to the populations they serve with equipment,

supplies, and staffing levels that work. Most important, there are the dreams of the children who are saved. Winston Churchill called Uganda “the pearl of Africa.” Deep in the heart of the Luwero Triangle lies a magnificent pearl.

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