

UGANDA Programme: 1998 – 2009 Honorary Country Directors (Dr Margaret Nakakeeto, Professor David Southall, Professor Mike and Dr Jenny Green)

1. Improvements to the management of critically ill children and new born infants at Mulago Hospital in Kampala

Between 1998 and 2005 a series of paediatricians from MCAI in the UK (Dr Christiane Ronald, Dr Simon Parke, Dr Jo Venables and Dr Bernadette O'Hare) each worked for periods of 1-2 years in the children's emergency ward, which cared for between 150 and 200 critically ill children every day, and also in the special care baby unit. Senior paediatric nurse (Jasmine Heslop) worked on the wards and became the Hospital Matron for part of her time in Uganda.



Dr Ronald outside the ward for children with malnutrition

The published paper: "*A day in the children's unit of Mulago Hospital, Uganda*" available for download on this website illustrates the conditions and many serious problems in this hospital.



Patients in the acute care ward at Mulago Hospital

In addition to adding to and helping to educate the local health work force, renovation was undertaken and essential emergency equipment provided for both the children's ward and special care baby unit.

The hospital was formally linked to James Cook University Hospital in Middlesborough through Dr Kibirige (a Ugandan consultant paediatrician).



Special care baby unit before (on left) and after renovation

Courses in neonatal resuscitation, paediatric life support and pain control were undertaken on a regular basis. The support and assistance of Dr Phillippa Musoke, Dr G Mukasa and Dr Margaret Nakakeeto, local experts in paediatrics, were essential in the progress made with this project.

2. Training of nurses in neonatal resuscitation (Dr Bernadette O'Hare)

In 2001, Mulago Hospital had a very busy labour ward. A baby was born every 15 minutes (22,000 deliveries per year). Many births had serious complications because of poverty, poor ante-natal care, prematurity, AIDS or other serious illness in the mother. The midwives on the maternity unit were required to care for the mother before attending to the baby, but as in hospitals in other resource limited countries, many babies (approximately 10%) were born who needed assistance in starting to breathe. Babies who do not breathe for several minutes after birth may suffer permanent neurological damage or die. Many babies needed to be transferred to the Special Care Baby Unit (SCBU) where they died some days later because of this lack of breathing immediately after birth (called birth asphyxia).



Nurses about to start their work in resuscitating caring for newborn infants



Nurses receiving training care on manikins

Through MCAI, six midwives were trained in neonatal resuscitation and basic newborn care including temperature control, birth registration and the administration of vitamin K to prevent serious haemorrhage (an important cause of brain injury in babies). Their salaries were paid for by MCAI as additional staff on the labour ward solely for the purpose of attending to the newborn. The team provided 24 hour cover on the maternity unit. Their presence greatly reduced the need to send babies to the SCBU and reduced the rate of newborn deaths, especially in those infants weighing more than 2000 g at birth.

The service was subsequently incorporated into the local health service strategy in Kampala and by 2006 was implemented in maternity units outside Kampala.



Dr Nakakeeto supervising the training of nurses in the resuscitation of the newborn infants

The published paper *"A pilot study to determine if nurses trained in basic neonatal resuscitation would impact the outcome of neonates delivered in Kampala, Uganda"* is available for download on this website and describes the design and benefits of this project.

During 2006, the Ministry of Health set up a national programme for neonatal care. Dr Nakakeeto became the Senior Neonatologist for Uganda and was able to roll-out a similar programme across Uganda. Funds to keep the service going, while the national programme became underway, were donated by the British High Commission and Save the Children in Uganda.

3. Home based care for orphaned children infected with HIV/AIDS (Jane Nalubeg programme director, Irene Nabalamba social worker, John Yiga driver Funded by the Elton John Foundation, the Dorothea Ross Foundation)

This project started in 2001 and was still continuing when the local charity CAI Uganda took over from MCAI in 2009. In 2001 a large proportion of families were affected by AIDS in Uganda, and in some areas it was estimated that about 20 - 25% of young children had been orphaned. They often lived with a sick surviving parent, or with a grandmother or aunt, who may have been caring for several orphans. There was much poverty, and a carer often could not leave the other children and take an ill child to the hospital. The distance may have been too far and expensive.

The published paper *"Home based care for orphaned children infected with HIV/AIDS in Uganda"* available for download on this website describes in detail this programme.

MCAI had been working with the department of paediatrics at Mulago Teaching Hospital for many years, mainly in acute paediatrics (see above). Local paediatricians expressed the urgent need for special care for HIV-positive children, in their own homes. This need was identified when they noted that, after the initial diagnosis was made, children were often not brought to the clinic for on-going care. They believed that this situation was due to limited resources in vulnerable families.

Many families were bringing their child to a clinic in the hospital when they suspected HIV. This clinic had an open door policy without any charge for attending. Each parent/carer received pre-test counselling and, if the carer gave permission, the child was tested for HIV-1 antibodies. The carer received the result during post-test counselling. The HIV positive child then received care at the clinic whenever the family was able to bring them along. Despite the expertise of the doctors, antibacterial and antifungal drugs were often unavailable and the family may have been required to queue for many hours only to find that there was no medication left in the pharmacy. This situation often contributed to a family's decision not to use their limited resources to return to the clinic.



Jane holding a workshop for the outreach team



John distributing food and medical supplies

After a full explanation in the local language, carers attending this clinic were offered the opportunity for their child to be enrolled in the programme. The carer was told that every month, a member of staff would visit their home (in a vehicle with only the charity emblem on it). The offer of enrolment was rarely declined. If a family asked to be enrolled without home visits, (usually because of the possible worry of stigmatisation) this option was arranged with the same level of support as for other families. Carers were informed that a record of their child's health would be kept but they were also encouraged to keep a patient-held record in the event of the child receiving additional health care from other professionals unfamiliar with their past medical history.



Outreach nurse visiting families in their home

The outreach team comprised a nurse with qualifications in HIV counselling and special training in the management of HIV related infections. She was supported by a driver. Medical advice was provided by one of the paediatricians from the hospital clinic, either at the weekly clinical review of children visited, or in an emergency situation, by mobile phone. Other personnel

available to the programme included a social worker and a nutritionist with expertise in HIV/AIDS. Families were visited on the same day of the same week each month and the date of each pending visit was circled on a calendar. It was rare not to find families at home.



Jane and John preparing drugs and food for a family

Medical treatment

Vitamin A was given every six months and mebendazole (for worms) every three months to all children in the family. The family were supplied with oral rehydration solution (ORS) and anti-fever medication and educated in their use. Each visit was an opportunity to give nutritional advice, with particular emphasis on the value of using local produce. The World Food Programme provided food security for all families enrolled and they attended a nutrition clinic to collect food and receive education about its optimal use. Opportunistic infections due to the HIV infection were diagnosed and treated according to guidelines designed for this programme and based on MCAI's Manual of International Child Healthcare 2002. The guidelines were algorithm-based and easily followed by a nurse in the field. The recommended drugs were available in the medication trunk carried in the vehicle. It was clearly indicated on these algorithms when the child would need to receive more expert care and when admission to hospital should be offered. When children were hospitalized all medication was provided and sufficient food also given for the child and carer. Without this level of support, most carers could not afford to stay in hospital and may have taken their severely ill child home to die.

The hospital clinic was also open two days a week to 'all comers'. If children on the programme become sick between home visits, they could also attend this clinic.

In 2005, the African-American AIDS Initiative based at Mulago Hospital provided 25 of the children enrolled in this programme with anti-retroviral drugs and monitored them at their clinic.

Families could attend the MCAI programme office, open six days per week, for both physical and psychological support at any time.

Psychological support

This was provided by a team, well known to the family, who visited them regularly in their homes and whenever they attended the clinics. Support was also available when the child was admitted

to hospital or when the child died. Quite simply 'knowing that someone cares' has been the most frequently quoted benefit of this programme.

Each month there was a meeting to which all carers were invited and assisted with travel expenses. This meeting was well attended by more than 100 carers each month. The meeting was led by elected chairpersons and facilitated by the programme's counsellor and social worker. At the beginning of each meeting those attending were asked which issues they would like to discuss. Basic health education, education about HIV and its prevention and nutritional advice were covered. Frequent questions included how to avoid getting infected when caring for a child with HIV and how to provide nutritional support for a child when they have an intercurrent infection. Psychological issues such as how to deal with losing the child or how to deal with one's own HIV status were discussed. Carers who have lost children frequently continued to attend after the child's death for on-going support and to provide support to others. Invited speakers included child psychologists, nutritional experts and paediatricians. The meetings were part-educational and part social, with drama groups, singing and dancing, to enhance the understanding of AIDS.

The main benefit for people who attended this support group was empowerment of the carers through education and openness. Self-confidence visibly improved as they become increasingly aware and realized they were not alone. Individuals become more confident and expressed opinions. People shared practical tips about the management of common ailments and carers often made notes at these meetings in order to share the information gleaned with their neighbours and friends. These meetings provided a forum for discussion among carers and this resulted in the formation of support networks.

A similar forum for the HIV-positive children was also developed and called "the children's club". It was attended by around 60 children on a regular basis. These children only attended with their carers' permission and only after their diagnosis had been disclosed to them by their carers. An older child led this children's group, with close supervision by an experienced social worker and counsellor.

Carers often discussed concerns with the team nurse in the privacy of their home. It was usually in this setting that a carer would seek support and advice about the gradual disclosure of a child's diagnosis to him/her. This would usually be prompted by questions from the child. If the mother was still alive but unwell, and at her direction, discussion around the on-going care of her children after her death was introduced during the home visit.

Social support

The programme supported income-generating projects by giving small loans to the carers. This programme allowed carers to invest in projects, for example setting up a stall to sell cooked food, and thus to support their families in a sustainable manner. By 2005, 50 of the carers had taken part in this scheme. The carers used the profits to buy a plot of land just outside Kampala where families in the programme could grow food.



Carer weaving to raise funds for her family

By 2005, 280 children and their families had been supported by the programme. At this stage the African-American AIDS initiative had become established in Kampala. MCAI felt that it was not appropriate to duplicate services and handed over the care of the children to the African-American AIDS initiative. MCAI transferred to Kayunga district, 70 km from Kampala, where no other programme for children was in existence. There was much stigma attached to being HIV positive in this area. The MCAI team spent much time in the villages dispelling the myths and beliefs about AIDS and its treatment, encouraging people to come forward for counseling and testing and to bring their children too.

There were approximately 20,000 orphans in the district, 4,000 of whom had lost both parents. The total number of children who were HIV+ in the district was estimated to be almost 10,000 out of an estimated 154,000 under 15 years (15.4%). Negotiations had been carried out with the local District Director of Health and the Kayunga Hospital, both of whom welcomed MCAI and its work. Two teams, consisting of a nurse, social worker, medical assistant and driver, were based in Kayunga and able to provide an outreach programme. Antiretroviral treatment became available, free of charge, for children with HIV. By 2007, the teams had made much progress, supporting over 250 children and families at home and in clinics. By 2008, 360 children were being cared for by the programme.

This new programme in Kayunga continued until 2009 and included the use of anti-retroviral drugs as well as the support services described for Kampala above. The programme became the cornerstone of a comprehensive district AIDS programme that incorporated community sensitisation about HIV, voluntary HIV testing, prevention of mother to child transmission of HIV (PMTCT) and care of infected and affected children.

By 2009, a team of up to 16 professionals were involved.

1. Jane Frank Nalubega	In country Director	Kayunga
2. Peter Masaba	Clinical Officer	Kayunga
3. Ahmed Ssebidde	Driver	Kayunga
4. Monica Lyagoba	Nurse	Kayunga

5. Rhoda Nakyobe	Nurse	Kayunga
6. Martha Naluwooza	Senior Nurse	Kayunga
7. Josephine Tusingwire	Social Worker	Kayunga
8. Bernard Kahigi	Senior Social Worker	K'la/Kayunga
9. Luyinda Saad	Social Worker	Baale
10. Mukasa Nagadya	Nurse	Baale
11. Kyosiimire Jane	Nurse	Galilaya
12. Moses Kipanda	Programme Manager	K'la/Kayunga
13. Michael Kasozi	Social Worker	Kayunga
14. Wilson Mwesigwa	Social Worker	Kayunga
15. Sam Kyakonye	Driver	Kayunga

MCAI worked in partnership with other organisations operating in the district, offering voluntary testing and counselling for HIV, providing food support and school fees, establishing Carers' groups, food production activities, teaching and training activities – all of which enabled a large range of services to be offered to the HIV infected children and their families.

By 2009, CAI-Uganda had branched off as an independent organisation with its own Board of Trustees, financial arrangements and management plans. It continued to develop its own partnerships and funding arrangements within Uganda.

4. The Mothercare Project

Babies and young children were often abandoned in and around Kampala and brought to Mulago Hospital. Sometimes they were found in pit latrines or rubbish bins, or were left in the Acute Care Department of the hospital. Sometimes mothers who had just delivered left the baby behind when she was discharged from the maternity unit. The many reasons could only be guessed at but included illness in the mother, too many children to care for, extreme poverty or early teenage pregnancy and lack of social support. Between 40– 80 children were abandoned each year, and at any one time 7 or more needed care and attention in the hospital.

A child in a hospital like Mulago needed a caring adult to be there to provide the child with sheets, clothes, nappies, a laundry service, food and drink and warmth and love. An abandoned child had none of these things.

MCAI's "Mothercare" project employed a small team of 3 'mothers' who provided the support and care that a mother would provide, for the time that the child was resident in the hospital. Sometimes it was possible for the child to be returned to the extended family for foster care, sometimes social services provided residential children's home. A proportion of these abandoned children had some physical deformity or obvious ill health. Many were HIV positive. Often these



Abandoned twins left in the hospital after their birth

abandoned babies shared a hospital cot with one or two others.



Mothercare workers and nurses with abandoned baby

MCAI's project provided the food, the hospital provided the use of its kitchens, and the "mother carers" cooked the food. Many carers travel long distances to join the meeting.

5. Play scheme For The Children's Ward

The children's ward at Mulago Hospital was crowded, not just with very sick children, but also with their parents and carers, who had to 'camp' on the wards, under and beside the cots, to care for their children. There was no space for children who were well enough to play.

MCAI decorated one of the children's wards so that it was bright and 'child-friendly'. The hospital released a small room off the ward to use as a play-room. This was brightly painted and stocked with toys, books and educational materials. MCAI employed a 'play therapist' who helped recovering children to relax and play, and helped older children treated in hospital for long periods, to continue their education.

The playroom was also used for the benefit of the abandoned children.

This project was part of the MCAI/UNICEF UK/RCN child friendly healthcare programme (see links on this website) for more information.

