



Humanitarian
Aid Relief Trust

HART VISIT TO UGANDA

4 – 9 JANUARY 2011

DRAFT REPORT

THE PAORINHER PROJECT



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1 INTRODUCTION

A team from HART briefly visited Northern Uganda in January 2011, where it has been working since 2006 when the LRA (Lord's Resistance Army) was still active, and where it has been funding a Project in Patongo since 2007.

The objectives of the visit were:

- To monitor our project and to nurture our relationship with our Partners;
- To assist with planning the next steps forward for the Project;
- To gather information regarding continuing conditions in the North of Uganda – so marginalized and different from the Uganda one meets in Kampala and the South;

The name of the Project is PAORINHER, standing for:

Patongo Orphan Infants' Health Rehabilitation
Centre, Northern Uganda



Carers and staff, dancing as exuberantly as any of the children – and setting an example of maintaining the expression of their northern Ugandan culture, which could have died during the years of the LRA activity and “the Camps”. [See “The Background.”]

THE HART PROJECT: PAORINHER

2:1 The Background.

Northern Uganda suffered from civil war for 20 years, at the hands of the so-called 'Lord's Resistance Army - a rebel army which terrorised the region, displacing more than 1.6 million people, killing, torturing and maiming innocent civilians as well as abducting at least 25,000 children. These were taken to Army training camps, brutalised, tortured, forced to kill each other and sent into battle against the Uganda Army. ***[See HART's previous reports of visits in 2006, 2007 and 2009 for personal testimonies of the atrocities perpetrated by the LRA on individuals and the suffering inflicted on communities.]***

95% of the population living in rural areas had to flee to camps for security. These were overcrowded, with inadequate sanitation or water supplies. There was massive unemployment, poverty, destitution and hunger. In the dry season, huts would ignite spontaneously, and people would lose even such meagre belongings as they had brought with them – and would have no shelter when the rainy season came.

Caroline Cox visiting the Camps in 2006 during the days of the LRA's activity in northern Uganda..



Hundreds of people died every week in the camps; there were many orphaned babies and children. In traditional African societies, an orphaned child would be cared for by an extended family, the dislocation of local communities and the conditions in the camps mean that there was no-one to care for other people's orphans.

In 2006, a HART delegation visited Patongo, a town which had been a centre of LRA activity. We asked the local people their priority for such help as we could give. They identified provision of care for OVCs [orphaned and abandoned children] as their greatest

need. Land was given by a local family; funding was obtained by HART and the Paorinher Centre was established with the inspirational leadership of Christine Okot.

By June 2009, 60 children were benefiting from the holistic care provided by the Centre, receiving love and all kinds of care, including good nutrition, medical care and excellent pre-primary education.

2:2 Transition.

By 2009, the LRA had come to some agreement with the Ugandan government, withdrawing from northern Uganda – but continuing its terrorist activities in Democratic Republic of Congo [DRC] and Sudan.

The ensuing cessation of conflict in northern Uganda made it possible for the population to leave the camps and to return to their villages.

The staff at Paorinher decided that it would be preferable for the children in their care to find homes in the community, returning to Centre for daily activities, food, medical check-up, and going back to their homes in the afternoon.

Among these, there were 18 HIV+ve children. HIV children are the most vulnerable; the rate of spread of HIV was very high and there was no Centre anywhere in Northern Uganda to facilitate holistic care for HIV +ve children. Sometimes, children staying with caregivers could easily default because their parents are busy and/or there is no transport.

Therefore, in January 2009, the idea was born to develop a centre for care for HIV+ve children in partnership with the JCRC [Joint Clinical Research Council] which was then operating a Clinic in Patongo.

The JCRC was treating all HIV/AIDS patients and the staff were highly concerned about their inability to provide adequate diagnostic resources of personnel and time to provide for children. They were also worried about the need to provide more comprehensive holistic care for children.

It was therefore envisaged that JCRC would continue to give medical treatment & Paorinher would provide social support, nutrition & other basic requirements such as education and clothing.

2:3 The Objectives of the Centre, as stated in the original proposal of 2010, are to:

1. Raise the health status of HIV positive and vulnerable children with nutritional and psychosocial support, both through day care and by follow up at home.
2. Build an effective partnership with Patongo Health Centre and Kalongo Hospital, so that HIV positive children receive appropriate treatment and support, with both the availability of and compliance with ARV treatment, improving throughout the three years of the project.
3. Reduce the impact of stigmatisation in the community, so that HIV positive children no longer suffer adverse social effects, whether at home or in school, because of their health status.
4. Improve the self sufficiency and long term sustainability of the Centre's operations.

2:4 The extent to which these objectives are being fulfilled is reflected in the current situation at THE PAORINHER CENTRE TODAY

- The Centre is caring for 68 HIV-positive children: 18 through regular attendance at the Centre and 50 in their communities through the work of the Field Officers and Nurses. The children range from 2-12 years; the majority are in the 2-4 age range.
- The Centre can provide care for younger infants and babies – and has previously done so.
- In addition 87 children (tested negative) from the local community attend the Nursery School at the Centre alongside the 18 local HIV-positive children who attend the Centre. Placing these children together in education, play activities and sharing meals and sanitary facilities is seen as a powerful part of the campaign against the stigmatization of HIV-positive children. It also provides a valuable link with the Community, demonstrating the local people's appreciation of the quality of care and education provided by the Centre's staff; it is also a good use of present spare capacity.
- The present facilities and staffing of the Centre are estimated as sufficient for caring for a maximum of 125 – 130 HIV-positive children.
- Present staffing consists of 16 full-time members plus 3 college students in child-development on long-term placement. The 16 include 2 members of the Executive, 2 Nurses, and 2 Field Officers responsible for maintaining contact with HIV-positive children in their homes.
- The Centre works with the following organizations:

- Patongo Government-Clinic (grade 3)
- Kalongo Mission Hospital
- Mildmay Uganda Mission Hospital
- the Probation Service
- It seeks further cooperation with AMREF and Save the Children

2:5 Paorinher: Current Policies and Procedures

2:5:1 Referral:

Children are tested, and referred to the Centre, by either the local Grade 3 Primary Health Care Clinic in Patongo or by Kalongo hospital, predominantly the former. The catchment area includes the whole of the Agago district [a recent sub-division of Pader District] with its 11 sub-counties.

Problem: the Clinic is at present only able to carry out rapid tests for HIV. It is not able to perform either CD4 counts or PCR tests (RNA copies and DNA viral count).

Mitigating actions: During our visit we took part in various meetings to provide solutions to these problems [see below].

2:5:2 Medical Care:

From the beginning it was envisaged that the Centre would offer nutritional and psychosocial care, but not complete clinical care, for HIV+ve children. The Centre does give general medical care which includes treatment for opportunistic illnesses; malaria, skin diseases; respiratory tract infections and eye infections at a daily morning Clinic.. One nurse, Pius, is employed by the Centre who also works in the local Government-Clinic, thereby functioning as the essential liaison between the two. A second nurse has been appointed and commenced work in January 2011.

The Centre continues to follow up children who have attended. For example, if the health status of any child who is or was associated with the Centre deteriorates, he or she may return to stay at the Centre. Additionally, if carers have problems, such as illness, they can be residential for a short period in order to recuperate. 3 beds are now available for stay if necessary [as the children have grown, it has been necessary to expand the size of the original infants' cots.]

Problem: The supply of ARVs (and of Septrin) to the Government-clinic is highly unreliable and sporadic. Such supply is reliable at Kalongo hospital but the hospital is only able to make the drugs available to a restricted intake of children.

Mitigating action: Meetings during our Visit resulted in the decision to register all the children, currently registered with the Government Clinic, with Kalonogo hospital, thereby rendering them eligible for the free provision of these drugs.

2:5:3 Holistic Care, including Compliance with Treatment regimes,

Nutritional and Psychosocial Care:

From the beginning this, including monitoring of compliance with treatment, has been seen as a priority of the Centre's work.

Recognition of the essential need for good nutrition has resulted in the provision of a well-balanced diet for all children attending the Centre. The HIV+ve children receive a nutritious breakfast and lunch, returning to their homes for an evening meal. The Outreach worker monitors the general well-being of the children in their homes as well as undertaking a subjective assessment of their nutritional status. Discussions were held with Dr. Martin Panter to ensure application of their knowledge of accurate assessments.

Psychosocial care includes counselling for children and their carers, including the most appropriate ways of informing families about diagnoses and care as well as enabling children to understand, according to their age, their situation and its implications.

According to Dr. Panter, the extent of their knowledge and understanding places them in the top 10% of HIV+ve people globally.

Activities, including games, singing, and dance are all designed to enable children to develop positive self esteem, confidence and an appreciation of their spiritual and cultural heritage.

Pre-primary education gives the children a valuable foundation for learning [see below] and a strong basis for starting primary schooling [see below].

2:5:4 Field Work:

- The majority [50 out of 68] of HIV+ve children remain in their local communities.
- The Centre therefore has a strong commitment to provision of support and monitoring for these children. The Community worker, Patrick, visits every child on a regular basis to:
 - Monitor compliance with treatment regimes;
 - Assess nutritional status and to supply food supplements to ensure a balanced diet;
 - Encourage the families' and local communities' awareness of HIV and ensure the child's full integration of each child into the community
 - Educate the community to eradicate stigmatisation of HIV+ve children and adults.

2:5:5 Community Educational and Training Programme combating stigmatization and developing understanding of HIV/AIDS:

Paorinher has been active in initiating an Outreach Programme with several initiatives including:

- General promotion in the community of understanding of the nature of HIV/AIDS.
- In collaboration with the Government Clinic, encouraging people to come for testing. Men have been especially reluctant and, when tested they have a much lower rate than women of return for treatment. There are confirmed stories of men using their wives' supplies of medication and/or destroying the medication and additional material relating to HIV in order to remove any evidence of HIV in the family. Therefore, educational programmes to encourage compliance and also to reduce the fear of stigma are designed to try to reduce these problems.
- Meetings with community leaders and members of the community have been held to address these issues.
- A Conference was arranged at the Centre, in co-operation with other organisations and personnel, including War Child and the local Probation Officer, to which Community leaders and teachers from local schools were invited. Those attending were very appreciative and requested further similar Conferences and other Community initiatives.
- Paorinher is now planning to conduct Conferences at local schools in order to include all teachers and some of the parents in these educational programmes.
- 4 staff from Paorinher [Christine, Vincent, Pius and Patrick] attended a course at the Mildmay Mission Hospital in 2009.
- It is hoped to co-operate with Mildmay Mission to run courses for local personnel in Patongo to develop knowledge, understanding and good practice for both clinical and non-clinical staff, such as community outreach workers and school teachers [see below].

2:5:6 Education at the Centre:

- A nursery school has been operational at Paorinher since 2008, which has won the respect of the local community. A 'Graduation Ceremony' from Pre-Primary Education was held in January 2010 [see HART visit report] which celebrated the achievements of the children and their teachers as they were preparing to move into Primary Education.
- On this visit, the Vice-Chairperson of the local Town Council and Sub-County District Authority commended the education at the Centre, saying it is the best in the town.
- To utilise spare capacity and to demonstrate effective integration of children who are and who are not HIV+ve, 87 children from the local community attend the Nursery School, in addition to the 18 HIV+ve children who regularly attend the Centre.



The education of future Ugandan citizens for democracy – an organized debate at the school (subject: English or local language to be the language of primary education).

- The families of the non-HIV+ve children pay fees and the children bring their own food. The fees [30,000 Ugandan shillings for 3 months] subsidise the additional teachers' salaries. The free food provided by HART is limited to the HIV+ve children registered at Paorinher.
- In addition to basic subjects, the teaching of music, dance and appreciation of the children's spiritual and cultural heritage are seen as important elements of the children's Nursery education.

2:5:7 Possible Development of Primary School

From the very beginning the relationship with the local community has been carefully fostered. The initial establishment of the Paorinher Centre came as a result of meetings with local leaders. The community and its leaders continue to be strongly supportive and appreciative. At present, as noted, more than 80 children (not belonging to the Centre as

being HIV-positive) attend a Nursery School at the Centre. Because of its excellence, there is an increasing request from the community to continue the schooling in to the Primary stage.

In this potential development the local community would pay for the establishment of the School. Contributions have already been pledged in respect of building materials. Ongoing payment would be as with the nursery school, the families providing food for the children & 30k shillings/ 3 months to pay for teachers. This is self-sustaining in terms of payment of teachers & self-feeding. However, the 30k shillings pay no costs beyond the teachers. If the project develops beyond Primary One class, although parents may continue with cost-sharing to sustain the teachers, more resources will be needed for additional cooks and other support personnel, etc. This idea may only survive while Paorhiner has other funding. It will be necessary to move one step at a time. If Primary Two becomes too much of a burden, the Project may have to stop there.

Where the children now play, the army camp once stood to protect them from the LRA.



3 COLLABORATIVE RELATIONSHIPS

3:1 Kalongo Hospital.

Staff from this hospital have provided invaluable clinical support for Paorinher Centre. Dr Josephine helped to establish the programme and she, followed by Dr Buyinza Kenneth have visited regularly to monitor the children's health and to provide support for the Centre's nurse, Pius.

Children needing hospital treatment have been referred to the hospital. Additionally, 4 HIV+ve children were referred directly to Kalongo and have been enrolled on their register for CD4 tests and ARV treatment.

On this visit, HART personnel revisited the Hospital to discuss possibilities of further co-operation, particularly with regard to solution to problems identified above [lack of availability of ARVs and Septrin in Patongo and difficulties obtaining results of CD4 tests from Gulu].

Very helpful meetings with the Director of Monitoring and Evaluation [Kibwota Paul Muliya] and the Hospital Administrator [Obonyo Alex] indicated potential areas of collaboration, including co-operation with community outreach initiatives and the provision of CD counts.

3:2 Mildmay Uganda Hospital.

The HART delegation revisited this hospital, internationally renowned for treatment of HIV/AIDS, to continue discussions on possibilities for partnership. 4 Paorinher staff members [Christine, Vincent, Pius and Patrick] have already attended one update course. They are now keen for Mildmay staff to conduct a training programme on location at Patongo, as this would be more widely available for local staff and could be tailored to meet local needs.

It was agreed that the staff from Paorinher would prepare a proposal, identifying the staff [clinical and non-clinical] who would benefit from such training, which would be prepared to meet the needs of clinicians and other professionals, including social/community workers and school teachers. Once this proposal is submitted, including information on the educational level of the participants, the Mildmay staff will probably send one member on a preliminary visit to assess the situation and provide costing for the course. HART will then need to try to obtain the requisite funds.

Dr Emmanuel also strongly recommended Paorinher to register as an accredited Centre with the Ugandan General Medical and Dental Council.

Provision of CD4 & PCR tests was discussed and it was suggested that Mildmay could probably provide these at a nominal cost.

3:3 Meeting with Dr. Buyinza Kenneth

Dr Kenneth has been closely involved with supporting the work at Paorinher and offered to visit Dr Emmanuel at Mildmay Hospital during the next week to discuss the process of registration.

After an examination of various ways forward for Paorinher, it was agreed that the best would seem to be the enrolment of all the HIV+ve children at Paorinher with Kalongo hospital. Then be able to have free access to ARV treatment as well as CD4 tests. PCR for testing viral load can also be provided; but at present, there are no children under the age of 2 years at the Centre.

It was agreed that Pius will begin the process of phased enrolment the following week – continuing on a regular basis, until all children are enrolled. With Ugandan government policy, any additional HIV+ve children will be entitled to enrolment together with the access to free tests and treatment.

3:4 Meeting with Canon Hamlet & colleagues.

A wide-ranging discussion resulted in a number of possible initiatives, including an invitation to a week-end Seminar/consultation, to be hosted, generously, by Canon Hamlet at Guerrilla Mountain Lodge, for a 'brain-storming' discussion on applications for funding.

Stuart Notholt generously offered to give his time to represent HART and it was agreed that it would be very valuable if Christine and Vincent from Paorinher, together with Lydia Tanner from the UK, would also attend.

4 ACTION POINTS

- To register all children of Paorinher Centre with Kalongo Hospital.
- To register Paorinher Centre with the Medical and Dental Council.
- To ensure reliable supply of ARVs for children through either of above.
- To arrange regular testing (CD4 and PCR) with either Kalongo hospital or Mildmay Uganda.(with MAF perhaps assisting with logistics for latter).
- To develop further the use of monitoring and physical measuring techniques with HIV-positive children, especially important for those treated in own communities.
- Executive of Paorinher to submit plan for joint training to Mildmay Uganda.
- To set up agreement with Mildmay Uganda.
- To submit regularly stories to HART office and HARTBEAT section on the Website in UK
- To develop the agricultural work of the Centre both in the individual Guardians' gardens and in the Centre's own land.
- For explore the most efficient use of own land, to develop a relationship with Reverend Canon Hamlet and attend a conference in March.
- To investigate provision and use of a tractor, and other matters.
- To investigate further the potential of a community funded Primary School in relationship with Paorinher Centre, but not physically adjacent.
- To examine budgetary implications of potential new costs.

Caroline Cox and David Thomas

14th January 2011

5 ACKNOWLEDGEMENTS

We are most grateful to the following:

The Administrator of Kalongo Hospital, Alex Obonyo

The Director of Monitoring and Evaluation at Kalongo Hospital, Kibwota Paul Muliya

Dr. Buyinza Kenneth, Head of the ART Unit at Kalongo Hospital

The Director of Mildmay, Dr. Emmanuel Luriyika, and his colleagues

The Nursing Officer at Patongo Clinic, Anjuleta Bimeny, and Laboratory Technician, Ayo Welborn

Christine and Vincent and all the staff at PAORINHER Centre

The Reverend Canon Hamlet

The pilots and all the staff at MAF (Mission Aviation Fellowship).



“Mrs. Millet” – who as a foster-guardian has given one of “our” children her beautiful smile.

“Mrs Millet” humorously bears her name because of the role she once took at the Centre in an educational presentation, arguing the respective nutritional merits of different crops.