Commentary for donors

The attached report describes the work of the first twelve months of the project. It has been written for the National AIDS Commission. This commentary is written as a supplement for those who have donated funds for the project outside official government or overseas relief organisations.

By its very nature the official report is dry. This commentary tries to vitalise the facts and figures. In addition the funds donated by you are acknowledged.

Funding

All funds reach the Salvation Army, which is responsible for their financial governance. A system is now in place to allow funds to be sent directly to the Salvation Army together with a gift aid declaration to allow the Army to retrieve 28% income tax – boosting the funds available for the project substantially. For those of you who sent funds direct to our Malawi account in 2003 do not worry as the money was transferred in bulk to the Salvation Army with a gift aid declaration attached.

The address is:-

The Salvation Army
Overseas Projects Office
UK headquarters
Newington Causeway
London, SE1 6BN.
Attn: Lieut-Colonel Mary Elvin

Marked - for the Bangwe Salvation Army/ College of Medicine project, Malawi

I attach their gift aid declaration form to this email.

Donations for the year come to £9500 which has gone to the Salvation Army and £800 used for other purposes, but particularly expenses of the drama group.

<table>
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<th>Date</th>
<th>Donor</th>
<th>Gift</th>
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Looking back on the first twelve months

The unmet need

The unmet need is greater than one could have imagined. Limiting the project area to half Bangwe has not been possible and so one day is reserved for seeing people referred from outside the project area. The extra time taken to collect survey data is not required for these patients. 524 new patients were seen in the year which is about 10 a week. Many need frequent follow up visits particularly if in the terminal stages of the disease. The team made 1892 such visits. The time to do more follow up visits and to provide a complete service throughout Bangwe is our priority for 2004.

Meeting the need

Despite being a peri-urban area, Bangwe is surprisingly scattered and sometimes roadless, which means a high proportion of visits are on foot – called “footing” - which is time consuming. The plan is to buy one or two scooters for staff to get around quicker.

The therapeutic choices have been modified in the light of experience and a complete range of treatments are used to meet the common conditions which present. The analysis of the value of these treatments is underway - quite a difficult undertaking - the data are collected, in the computer and now are being analysed.

The food distribution component of the project has been disruptive to the project and the community. Food is scarce throughout the area and the fair identification of people in need brings many problems, conflicts and disharmony. The World Food Programme has its own varieties of mismanagement! For instance food distribution for this month starts today; maize is becoming scarce; there is no maize to distribute at all this month. The supplementation programme is planned to go on until July 2004 by which time we should have enough data to be able to assess the value of food for these patients and their families. We will try to assess whether the benefits outweigh the disadvantages.

The research

Our preliminary data were presented at an international conference on home based care in Dhaka by a senior official from one of the large American NGOs funding numerous AIDS projects. He was delighted to have real information from the coal face! We hope to publish our results this year.

Volunteer doctors help with this part of the work. The data collection remains the unenviable task of the nursing team. Our research reports are referenced in the official report and can be sent electronically on request.

Working with the Salvation Army

Surprisingly, this has not been easy! The excellent officer who helped set up the project was moved at Easter. Since then we have had no leadership - either expatriate or local from them till recently. Frustrations are routine in Malawi. The lack of management from the Salvation Army has amplified inevitable problems - the frustration is that there is so much to do without dealing with administrative ineptness.

Despite these temporary difficulties the long term benefits to our partnership are potentially great. Patience is a virtue! The scene makes good teaching material for would be health care managers.

An ambition for this year is to have a robust management and planning structure in place, largely run by Malawians.

Looking forward to the next twelve months

Service

Needless to say the needs will not be diminishing. We plan to extend the service to the whole of Bangwe. Mercy, the nurse with Claire for the second half of the year, is now the project manager of
the whole Bangwe initiative – hence our optimism of improved management from The Army! We have just appointed her replacement who is on a palliative care course this week and starts full time in two weeks time. We hope to train community nurses seconded from the government health centres in the field. The next step is likely to be the training of nurse assistants. Nurses are in such short supply.

**Research**

We plan a vitamin (anti-oxidant) supplement trial this year but need the funds to buy the drugs €20,000 - so will be on the scrounge to big funders!

The more mundane research effort will go on with the nursing team collecting the data (and doing all the real work) and a team of College of Medicine volunteer staff doing the analysis.

**Training**

The top priority is to fund Claire’s assistants to be able to take a Health Surveillance Assistant’s course as soon as possible. This will give them basic but important qualifications.

The second priority is to start a training course in home based and palliative care for nurses. The next priority is to start a similar course for nurse assistants, both to be offered in conjunction with the nursing college nationally.

**What it is really like**

A couple of anecdotes of Claire’s day help to put the whole thing into perspective.

There is nothing more gratifying in my work than to be able to relieve symptoms. It reassures one that we are doing a worth while job. Unfortunately the relief is usually only temporary – 25% of our patients die within 3 months of the first visit. I never cease to be dismayed at the cruel and destructive nature of the disease. To balance this negativity, we do visit a few patients, also chronically sick, but with non Aids related problems.

Mr Smart Guy is one. He was discharged from the Queen Elizabeth hospital 18 months ago following a stroke which left him speechless with a right sided paralysis to be cared for at home by his devoted wife. They live on a steep hillside with access only by a net work of rough paths. Wheel chairs and visits to rehabilitation or physiotherapy centres are out of the question, even if funds were available. Their only income generating source was the rearing and selling of muscovy ducks (there was usually one sitting on eggs in the corner of the room). Recently these were all stolen. Their youngest unmarried daughter of 16 has just had a baby and lives at home. We have been visiting him now for over a year and apart from support and advice, we are able to check his BP, provide a regular supply of convenes and drainage bags, (donated or purchased from the RHH (Hugh’s base) on our home visits) and medication to control his epilepsy, high blood pressure and the occasional chest infection. He is now able to feed himself and his wife has learnt to move him safely without injuring her back. She looks after him beautifully under such difficult conditions – hence our name for him, Mr Smart Guy, chosen by Fatima, my nurse assistant.

On a more sanguine note, Doreen is a 20 year old abandoned mum with a very disfiguring Kaposi Sarcoma on her nose which has now infiltrated her mouth and is disseminated throughout her body. (KS is a malignant tumour particularly common in HIV/AIDS). She now weighs less than 30 kg, and is too weak to fetch water, sweep her tiny hovel of a house or care for her little boy who is covered in sores from scabies. They sit huddled together on the ground, the child forlornly sucking on an empty flap of breast, which is the only comfort on offer in such a desolate world. Apart from pain relief there is little we can offer but we have asked our volunteers to visit daily to carry water and help with washing the child and clothing. BUT the stigma is still great and compassion a luxury in such a tough world that is not given automatically so this may not happen.
The work could not have been done without your support. Through you, we have contributed resources to such an extent as to convince the Salvation Army to try to get their act together. The test is whether they can deliver their part of the bargain.

The most important thing is the real ability to relieve suffering. This we have shown can be done in practice and soon hope to have the data to prove it empirically.

Needless to say we can use more cash! But there is something equally important. We hope this report reassures you of the good use to which your contributions have been put so far.

Claire and Cameron Bowie
College of Medicine
Private Bag 360, Chichiri
Blantyre 3, Malawi.