BHCC

(BARAGWANATH HOSPITAL COMFORTS COMMITTEE)
HOSPITAL AND CLINIC OUTREACH
~ESTABLISHED IN 1954~

PBO EXEMPTION NUMBER: 930 006 973

NPO REGISTRATION CERTIFICATE NO: 001/252 NPO

TRANSPORTATION FUNDING

For a number of years now, the BHCC has provided transportation funding to the various hospitals and clinics aimed mainly at chronic patients, enabling them to remain compliant with their treatment plans.

South Africa is currently facing numerous health crises of global proportions. One of these, XDR-TB, (Extensively Drug Resistant Tuberculosis) is a threat which should never exist, but which, if not managed correctly and *urgently*, may soon eclipse the SARS outbreaks that have recently galvanised world health organisations into feverish activities to contain the spread of this deadly virus. In the case of XDR-TB, which is bacterial, drug resistance would never have taken place if adherence to treatment plans had been strictly maintained.


KILLER TB HITS GAUTENG

Woman who left hospital could be spreading disease to unsuspecting people

THE SUNDAY INDEPENDENT

The Zuma saga

9/11 FIVE YEARS ON
Special Report

End of a dynasty

Killer TB tightens fatal grip

Prospect of an epidemic sets medics trembling

Government's 'hands tied' in preventing spread of TB

NIYANTA SINGH

Blamed

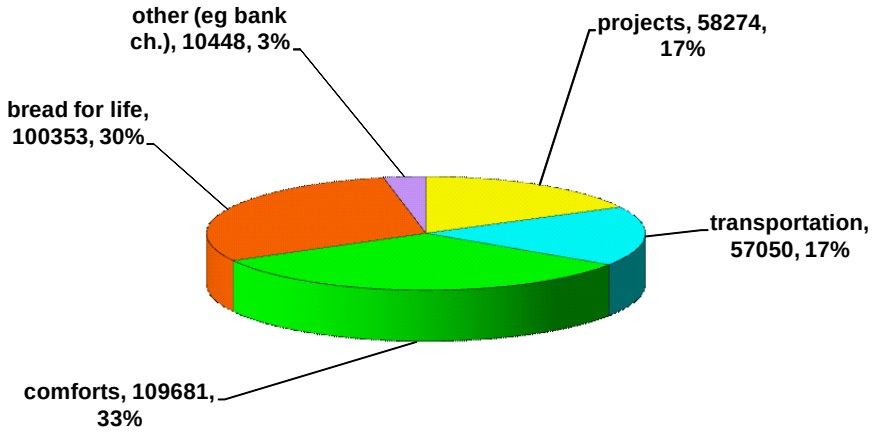
Many chronic treatment plans are lengthy and very onerous for the patient. It is already difficult enough to remain compliant with long drug programmes, but when a sick patient cannot feed himself nor afford the taxi fare to the clinic, and indeed, needs a day off work (again) to attend the clinic, the likelihood of sporadic treatment compliance is almost a "given". Thus the BHCC assists with taxi fares and the provision of daily food (see the report entitled "Bread for Life") in order to encourage chronic sufferers of TB and other conditions to maintain compliance with their treatment plans, to avoid resistance occurring and treatment plans failing, and thereby to play a vital role in the prevention of the occurrence of killer forms of diseases such as Multi-Drug Resistant and Extensively Drug Resistant TB.

This report sets out the importance of supporting destitute patients undergoing treatment for various conditions and outlines the broader issues facing Southern Africa if treatment plans are abandoned.

The Baragwanath Hospital Comforts Committee is a hospital and clinics based initiative, providing support and comforts to needy patients in a number of different ways at most of the State hospitals and clinics in the greater Johannesburg area. The charity is run entirely by volunteers who dedicate their time and expenditures free of charge. Our transportation funding initiative was started a number of years ago, and has grown to provide support not only to chronic patients (physiotherapy, occupational therapy, oncology, etc., whose treatment plans can suffer severe reversals due to sporadic attendance) but more urgently to ensure that HIV and TB patients do not default due to lack of a taxi fare.

During the financial year from April 2009 to March 2010, we spent just over R 57 000 on this very worthy need, R 50 000 of which was funded by the Anglo American Chairman's Fund. For the financial year from April 2010 to March 2011, our expenditures are expected to rise to around R 70 000, despite changes in policy at Chris Hani Baragwanath Hospital, with the advent of new management there, who have decided that they do not want this aid any more for their patients (see below), as the rejection of transportation funding at this hospital is more than offset by new needs elsewhere as we expand our work at other clinics in the area. We should like to try to secure the necessary financing for this current financial year's requirements, and are again appealing to our traditional sponsors for this funding.

Expenditures for the year to 31st March 2010



Forecast Expenditures for the current Financial Year (April 2010 to March 2011)

Budget 2011 Financial Year. Forecasts.										
Fin 2011 Quarters	projects		transportation		comforts		bread for life		other (eg bank ch.)	
	qtr	cumul.	qtr	cumul.	qtr	cumul.	qtr	cumul.		cumul.
Apr-Jun 10	0.00	0.00	13,920.00	13,920.00	22,507.00	22,507.00	12,230.00	12,230.00	1,690.00	1,690.00
*Jul-Sep 10	30,000.00	30,000.00	18,730.00	32,650.00	27,493.00	50,000.00	63,000.00	75,230.00	1,710.00	3,400.00
*Oct-Dec 10	15,000.00	45,000.00	19,260.00	51,910.00	25,000.00	75,000.00	22,800.00	98,030.00	1,700.00	5,100.00
*Jan-Mar 11	55,000.00	100,000.00	20,010.00	71,920.00	25,000.00	100,000.00	22,800.00	120,830.00	1,700.00	6,800.00
* forecast										
avg per qtr	25000.00		17980.00		25000.00		30207.50		1700.00	
total for year		100,000.00		71,920.00		100,000.00		120,830.00		6,800.00

Fin 2011 Quarters	all categ.	total cumulative
Apr-Jun 10	50347.00	50347.00
*Jul-Sep 10	140933.00	191280.00
*Oct-Dec 10	83760.00	275040.00
*Jan-Mar 11	124510.00	399550.00
* forecast		
avg per qtr	99887.50	
total for year		399550.00

Percentages by category of expenditure	
projects	25.0%
transportation	18.0%
comforts	25.0%
bread for life	30.2%
other	1.7%
salaries etc.	0.0%
total	100.0%

During the course of the current financial year, we have received several additional requests for transportation assistance, as well as requests for existing funding to be increased. We see this funding as a vital part of helping towards preventative medicine programmes – the more HIV+ patients remain compliant with their treatments, the less the Tuberculosis clinics and Oncology clinics will become overloaded in future, for example. The more compliant a tuberculosis (TB) patient remains with his primary course of treatment, the less likely he is to develop resistant forms of TB, thus overloading hospitals like Sizwe, where such a patient can remain for up to three years. The more a patient complies strictly with a physiotherapy programme, the shorter the duration of his overall treatment will be. The key to all treatment plans is compliance, and the transportation fund is a vital part of maintaining this compliance.

Another trend we are seeing with requests for transportation funding, is that of out-of-province transportation. Patients are admitted to hospitals in the Greater Johannesburg area because it is here where they work and here where they become sick. Yet on discharge, many patients need to be referred back to the communities from whence they came, because their follow-up treatment (several months of antibiotic treatment for TB, or a lifetime of treatment for ARVs, or simply a recuperative period until they are ready to return to Gauteng again to work), is preferably carried out under the care of their family, and under the supervision of the clinics located in their community of origin. One of our recent requests was from the Charles Hurwitz TB Hospital in Soweto, requesting monthly funding for long-distance patient repatriation, following 2 weeks of inpatient treatment (the remaining 5 and a half months needing to be completed at a clinic near the patient's original home).

Additionally, transportation funding in areas where clinics service a wide area geographically, necessitating longer taxi rides, or multiple taxi rides to and from the clinics, is needing to be increased dramatically, as not only are taxi fares increasing annually, but also, the safety of female patients in particular is now becoming an issue : the social worker at Muldersdrift Clinic on the West Rand is currently counselling an average of three women per week who were raped while walking to their destinations, as they cannot afford the taxi fares. The social worker herself is required to visit areas which are extremely unsafe, where rape, even of small children on a regular basis, is an ongoing problem, and there is a shortage of vehicles at the clinic to enable clinicians, therapists and social workers to travel out to the patients in the area served by the clinic. We have been helping both the Community Rehabilitation Facilitator with transportation assistance to enable her to go out into the wider community, to service bed-ridden patients unable to come to the clinic, and the social worker, helping her travel safely to the areas containing the largest density of patients requiring rape crisis or HIV counselling, for instance, rather than try to secure safe transportation for all those patients to travel themselves from their own areas to the clinic.

A further growing need for allocation of transportation grants is to give support to another of our initiatives, Bread for Life, which is targeted mainly at the very same patients that are being helped by the transportation grants : i.e., mainly outpatients needing help to remain compliant with long-term chronic treatments. We are needing to provide some funding now to the volunteers who keep our soup kitchens functioning, to ensure continuity with the supply of the food for the patients. A small monthly amount will enable these helpers to afford the transportation to the clinics each day.

We are hoping to raise sufficient funding from donors to cope with all these new requests, as well as continuing with existing funding and to cope with both new patient overloading at the clinics, and taxi fare increases.

<u>Transportation funding – how it operates</u>

The charity operates on the basis whereby representatives from the Committee are assigned to specific hospitals, clinics and projects. These committee members then work alongside specific contact people at each hospital, usually social workers, who identify needs in various areas and then submit their needs to the representatives on the Committee.

Taking the Johannesburg (Charlotte Maxeke) Hospital as a typical example, our contact there has identified a number of chronic treatment areas where there are patients who are unable to afford to report regularly for their ongoing medication or treatment, as well as some in-patients who, upon discharge from the

hospital, are too destitute to be able to return to their homes without assistance with a taxi fare. Individual patients each have a bar-coded series of stickers that are printed for their file, and each time moneys are dispensed from the fund to these patients, a list is made showing the bar-coded patient sticker and the amount of money handed to such patient.

Patients often travel from too far (for example, Sebokeng and other outlying areas) to be able to afford the transportation on a regular basis, and this is their only chance to keep up with their medication and treatment programmes. We have calculated, using average figures, that as a result of funding from donors via BHCC, approximately 25 out-of-province patients, about 650 medium-distance patients and 8000 short-distance patients can be helped currently each year directly with their transportation needs, and that extending the transportation grants to the Bread for Life volunteers has ensured the continuity of food being offered to approximately 120 000 patients annually. Hospital social workers have continued to report that there has been a marked increase in attendance at the various clinics and outpatient treatment centres as a result of this funding. Worked out on a daily average, over all the hospitals and clinics we support, however, this is clearly just the tip of the iceberg. With ever-growing numbers of HIV, TB, cancer and other chronic patients, the need for renewed efforts in finding sponsorship for this worthy cause cannot be stressed enough.

Our hospitals and clinics :

Charlotte Maxeke (Johannesburg General) hospital

R 800 is allocated monthly to outpatients, to help them remain compliant with treatments. A further two sums of R 500 each is being utilised for refunding the transportation costs of the soup kitchen volunteers running daily in the oncology, chemotherapy and the HIV clinics.

South Rand hospital

R 400 is allocated monthly to outpatients at this hospital to maintain compliance with treatments.

Chris Hani Baragwanath Hospital

Until January 2010, allocations for transportation funding to this largest hospital in the Southern Hemisphere were as follows :

- R 850 divided between Occupational Therapy, Cerebral Palsy and St John's Eye hospital to assist patients with compliance
- R 600 for in-patients to help injured patients return home if family could not step in
- R 200 for Speech and Audio therapy patients
- R 150 to assist terminally ill patients be transported to Selby Hospital
- R 250 to ensure that defaulters on HIV treatments (known to be unable to afford transportation) were able to continue to attend their clinics.

Although this funding was, hitherto, considered of vital importance, with the appointment of a new CEO at the hospital in January 2010, BHCC was informed that the transportation assistance was no longer required, for the following reasons :

- It was felt that “handouts create dependency”.
- We were informed that the policy of the past, whereby “white people did politically correct good deeds for black people” is no longer going to be tolerated at Bara hospital. (Despite our best efforts, our Committee continues to consist of white, female volunteers).
- For budget reasons, HIV patients will be discouraged from attending clinics within Bara hospital, as it is seen to be preferable to down-refer patients to primary healthcare clinics in the area. Funding these patients with transportation was seen as a disincentive for them to leave and go elsewhere.
- In an attempt to cut budgets, the mandate of medical social workers at the hospital has been restricted solely to tracing unidentifiable patients. Where social workers would have traditionally provided services to destitute patients, including assisting them with transportation to their homes or communities, this is no longer permitted, so any inpatients without family support to assist them home upon discharge are now obliged to walk or wait until someone else can help them.
- We have been told that accepting money from private sources creates a great deal of trouble for the Treasury department of the hospital, despite the fact that this grant is not a donation to the inventory of the hospital itself, and therefore theoretically not falling under the Public Finance Management Act.

Thus, approximately 5300 taxi fares annually, aimed at keeping patients compliant with long-term treatments, or assisting destitute injured patients to return home or help them to a palliative care hospital, are no longer allowed to be provided by this fund. We have endeavoured to plead the case of these patients on several occasions, but not even the intervention of the Opposition Minister for Health has helped.

Helen Joseph Hospital

R 500 per month is allocated to outpatients at chronic treatment clinics and a further R200 is given separately for use by stoma therapy, occupational therapy and chronic pain relief patients. The HIV soup kitchen funded by BHCC is operated by volunteers from another NGO called “Faith Based Initiatives”, who do not request a transportation refund to serve the soup, bread, peanut butter and vitamin-enriched fruit juice.

Rahima Moosa Mother and Baby Hospital (formerly Coronation Hospital)

R 250 per month is allocated to patients at this hospital. Occasionally this amount exceeds the immediate needs, so there will be months when this funding is not delivered to the hospital. Again, the HIV soup kitchen is funded by BHCC but operated by FBI, so no transportation refund is required for these volunteers.

Charles Hurwitz TB hospital

R 350 per month was allocated to this hospital. Many patients here were from out-of-province, and for a family member to come from the Western Cape or Limpopo to fetch a patient, this would entail the equivalent of three very costly long-distance bus fares. Instead, with the funding from the transportation grant, the hospital would take the patient to the bus terminal and ensure that they board the correct bus to reach their community. The funds were also utilised for destitute local patients, and occasionally to assist destitute mothers to visit very young patients from areas such as Sebokeng, where these infants would be without visits for up to six months, otherwise. However, during the recent public sector strike, the patients were sent home, many in a critical condition. After the strike was suspended, the staff at the hospital were informed that the hospital would remain permanently closed.

West Rand Health Area

This vast area stretches from Magaliesberg in the north, Carletonville in the south, and Muldersdrift, Krugersdorp and Kagiso further east. The catchment area for some of these clinics is vast, and patients often live far from major taxi routes, with the result that sometimes patients in outlying squatter camps need to take up to three taxis to reach the clinic. The decision to report to the clinic regularly, for these patients, clearly becomes very much an economic decision rather than a health one. In order to offset these issues for genuinely destitute patients, a sum of R1100 is allocated for transportation assistance for patients in the area, which is divided between four clinics, the main one being Muldersdrift Clinic, which has both a CCMT (HIV) clinic and a TB clinic (not available at all the clinics in the area), as well as the usual Mother-and-Baby clinics and other specialist outpatient clinics. Patients are further incentivised by a Bread for Life

soup kitchen funded by BHCC (including the premises from where it is run), and a further sum of R 400 per month is being allocated to refund a portion of the transportation costs of the helpers at the soup kitchen.

Orchards Clinic
This is an extremely overcrowded clinic in Louis Botha Avenue in the east of Johannesburg. We have recently provided extra consulting rooms there and are now providing a Bread for Life soup kitchen. The volunteers at this clinic are receiving a sum of R 400 per month to refund their transportation costs.

Mofolo Clinic
We have started a Bread for Life soup kitchen at the busy HIV clinic at Mofolo, and the volunteers here receive R 500 per month to refund their transportation costs.

Lenasia Clinics
We have been supplying soup for two community clinic outreach programmes (one at the Lenasia main clinic, where a new HIV and TB clinic has opened, and one at Thembelihle squatter camp, an area with large numbers of AIDS orphans). We are in the process of formalising a regular feeding scheme at these clinics, and will be refunding the transportation costs for the volunteers, in the amount of R 500 each per month.

Alexandra Clinics
A total of R 770 per month is allocated as a transportation refund for the Bread for Life volunteers at these HIV and TB clinics.

In total, up to about R 7300 is provided monthly for transportation assistance to the hospitals and clinics we serve.

Chronic treatment plans – what they consist of and why sponsored transportation is so vital

As already mentioned, regular reporting for a chronic plan of treatment is vital.

The trouble with treatment plans for chronic patients is that compliance is dependent on reporting regularly to the clinic or hospital and being able to take medication on a full stomach. Most of the patients involved here are so desperately sick that they can no longer work. Most TB patients, for example, are also already AIDS sufferers. Being unable to work, they have no money for transportation nor for food, thus the two initiatives by the BHCC – transportation funding and Bread for Life – are essential in the support of these patients to remain compliant to their treatment plans.

In the case of TB, if each patient could only return on a daily basis for medication, which needs to be taken on a full stomach, the development of MDR and XDR TB would never have taken place in the first instance, and would not be the alarmingly increasing serious health crisis it now is. This is a national tragedy, entirely preventable, which is now a health threat of unparalleled proportions. The incidence of new (normal) TB cases is on the increase, such that the health services can barely cope with new patients. It is estimated that more than 500 000 new cases of TB are reported annually by the health services, and not all patients report for treatment, so this will be an under-estimate. Over 60% of these are estimated to be HIV positive (in fact, well over 80% of the patients admitted as in-patients to the Charles Hurwitz TB clinic are HIV+, and the babies and elderly probably account for the remainder). TB treatments usually consist of at least a 6-month antibiotic course, using two main drugs, INH and rifampicin. The initial phase of treatment is vital to kill off the large population of TB bacteria multiplying in the patient's system, and the second phase is to kill off the last, more resistant bacteria. During the second phase the patient typically feels well (or at least significantly better than before), and the urgency to report for treatment becomes less of a priority, particularly if the patient feels well enough to work again. It is often at this stage that drug resistance becomes a problem. Once resistant to these two drugs, the TB becomes a serious general health threat and a complicated treatment plan becomes essential. Most of the XDR patients at Sizwe hospital, for example (the largest hospital in the area catering for MDR and XDR TB patients), are subjected to one painful injection per day and as many as two dozen pills to be taken at different times. Once the patient

becomes XDR, their confinement at hospitals such as Sizwe effectively becomes a quarantined "potential death row prison sentence". They are generally at this stage not allowed to return to their communities and may spend years in confinement. A large proportion face an inevitable death, there in the facility, away from their loved-ones. It is little wonder that many patients rebel against their "captors" and escape back to their families, where they spread their killer form of illness with abandon. The situation is actually very tragic. Patients arrive with 2-drug resistance and are told that they will be given a third drug for 6 months. If that does not work, they are now 3-drug resistant and face a further six-month course. This can go on until the patient is now 6-drug resistant (there are only 7 drugs available at present) and is facing being there for a full 3 years, without much hope of ever leaving. This often leads to the suspicion that the doctors have been lying to them all along, and some of the patients have recently been driven to commit suicide out of a feeling of hopelessness. It is our genuine wish, at the BHCC, to prevent these MDR and XDR cases ever occurring, by supporting the needs of destitute patients during the initial treatment stage, and this is where the transportation fund comes in.

HIV-AIDS clinics are also important places to which to extend the vital support given by our charity (nutrition and transportation). Not only is it a tragedy that after years and years of active campaigning by organisations like the TAC (Treatment Action Campaign) for the rollout of anti-retrovirals, it is the patients *themselves* that are often ultimately responsible for not adhering to the treatments that are now available to them (unfortunately in the case of ARVs, treatment will be daily for the rest of their lives, and to obtain their medication they will be obliged to take a day off work every week, which *also* entails declaring their HIV status to their employer, with all the repercussions that could engender), but it is also the reason why TB (and thus MDR and XDR TB) is so very prevalent : most TB patients are HIV positive or have full blown AIDS in the first place. HIV infection statistics in this country are extremely untrustworthy, especially as a very large proportion of sufferers resist reporting to the clinics as they realise that this will make their HIV status known.

More than 30% of mothers tested at the Chris Hani Baragwanath Hospital are HIV+, and it is certain that every one of their partners is likewise affected. Over 80% of TB patients are HIV+, according to staff at the Charles Hurwitz TB hospital (which has just closed). According to Médecins Sans Frontières, "In South Africa, it is estimated by the UN that over 5,5 million people are HIV positive and about a million are in urgent need of anti-retroviral (ARV) treatment, half of whom are still waiting. Tuberculosis (TB), including drug-resistant TB, is the leading cause of illness and death among those living with HIV".

What we do know, however, is that if a patient can be fully compliant with an ARV treatment plan, the chances of him contracting secondary infections such as TB are drastically reduced. Reporting to a clinic for treatment is a complicated decision for some, and not just because of the stigma attached to it, most often it is simply a case of pure economics : a visit to a clinic means a day off work, which means a day less of income every week. It may also mean losing out on a casual job, if an employer is aware that absenteeism will be a regular occurrence. If, in addition to the potential loss of earnings there is a loss incurred in savings or cashflow too – due to the cost of the taxi fare and the cost of purchasing food, both requirements for taking the treatment, the decision may just become an impossible one from the economic point of view. Thus, supporting the patient financially and nutritionally at the ARV level will inevitably improve attendance figures at the clinics, will encourage compliance, and should also significantly decrease the number of patients falling prey to secondary infections, including XDR TB. Our hospitals are delighted to report that attendance at clinics is greatly improved with transportation money and soup kitchens, funded by BHCC as a result of donations from our generous sponsors. We have recently tripled the amount of soup supplied to the Johannesburg (Charlotte Maxeke) Hospital in an effort to encourage patients to attend clinics there. With increased numbers of attendees at the clinics, there will be increased applications for taxi fares, and we continually need to review the amount we are donating for transportation assistance.

Cancer patients likewise require regular radiology treatments, chemotherapy and drug support. Missing one treatment could mean the difference between remission and relapse. Bearing in mind that there is a link between AIDS and certain forms of cancer, oncology clinics at present are experiencing huge increases in patient loads. At the Johannesburg (Charlotte Maxeke) Hospital's Oncology Clinic alone, the staff is seeing about 250 patients every day. The most common cancer types that are more likely to occur in people who are infected with HIV are Kaposi sarcoma and non-Hodgkin lymphoma. Other AIDS-related

cancers include Hodgkin disease and cancers of the lung, mouth, cervix, and digestive system. Once again, there is a definite urgency to make sure that patients receiving ARV treatments are kept compliant with their treatment plans.

Other chronic patients also depend on the fund for their ongoing treatments. These include cerebral palsied children, stoma patients (patients with colostomies), Occupational Therapy patients, Renal Dialysis patients, Sex Abuse patients (mainly victims of rape) and other general outpatients attending clinics run from the various hospitals in our area. Physiotherapy patients are also a major concern : recovery from an injury can be prolonged if the treatment is sporadic, and patients can miss weeks of much-needed pain relief if they are unable to report to their clinic. A small sum can mean so much to a needy patient.

Acute care / surgical patients

Over and above the chronic patients, who are normally receiving taxi fares on a regular basis, a large proportion of the fund is also allocated to once-off fares, for patients needing to be discharged after emergency, trauma, clinical or surgical treatment, and in State hospitals, budgets do not allow for lengthy recovery periods, so patients are typically not mobile enough to walk home. Nurses are frequently obliged, literally, to pass around a hat to raise enough money for a taxi fare for a destitute patient being discharged but with no means to go home. These nurses are already poorly paid, as are interns. Students completing electives receive no salary whatsoever, so it is useful to have a small fund available to these patients in case of real need.

The Transportation Fund is therefore becoming one of the most important initiatives sponsored by the BHCC to the clinics and the hospitals in the Johannesburg area. We have been extremely grateful to have received generous support from the Anglo American Chairman’s fund in this regard, and will seek to raise any shortfall for this ever-growing expense from other generous donors if necessary. We are already receiving more requests to increase the funding to yet more areas in the hospitals, and to cover higher expenses as the number of patients also increases and the cost of taxi fares escalates. The distribution of the funds is under constant review, and procedures can always benefit from stricter streamlining, so this will also be a priority for 2010 - 11.