

Aids Ark (AA) - The Full Record to 2016

See also the complimentary / downloadable / printable Aids Ark Picture Book which accompanies this Full Record

<https://jndflife.com/aids-ark-picture-book/>

See also the Aids Ark Web Site

<https://aidsark.org.uk/>

This record is dedicated to the memory of our many gay friends who became infected by the Human Immunodeficiency Virus (HIV), before the arrival of Anti Retro Viral Treatment (ART), and who, in consequence, died young from Acquired Immune Deficiency Syndrome (AIDS). Male homosexuality and AIDS were sadly and inextricably linked.

Introduction

Sometimes, something bad presents the opportunity for something good to happen. For me, as for millions around the world, the bad is Aids; the good is Aids Ark (AA).

Some Prior History - from 1986

In 1986, we see Larry Kramer's play *The Normal Heart* which dramatises the horrors associated with the AIDS epidemic in New York City. The play is angry, powerful and full of foreboding.

In response we take action and together with David McFarlen & Geoff Henning, Jeremy announces to a large gathering of gay friends, the birth of a funding initiative to support those who are People Living with HIV/AIDS (PLHA). Crusaid becomes a UK registered charity and Jeremy it's first Chairman.

Crusaid garners considerable support. Both gay and straight friends prove generous beyond our expectations. Crusaid funds ward improvements and medical equipment in hospitals. It contributes to London Lighthouse and Mildmay Mission Hospital, the first two AIDS hospices in Europe. It operates

a hardship fund for PLHA in need. A high proportion of those who Crusaid help are young gay men in their twenties and early thirties.

Freddie Kobler, a gay man, donates £500,000 to Crusaid, stipulating that it be spent on a single project. This is to be a custom built HIV outpatient clinic and day centre at the Chelsea and Westminster Hospital called The Kobler Centre. I work with the architectural team and design its interiors. British artists Howard Hodgkin and Patrick Procktor, both gay men, make 'art glass' for some of the larger windows. The centre is opened by Diana, Princess of Wales in September 1988. We are delighted to meet her and to have her support.

Princess Diana publicly hugs an HIV+ gay man at a time when many are fearful of such physical contact. This significant event is reported across the world. This hug really helped.

Over the next few years Crusaid raises several million pounds which are used to support UK based PLHA needs. Some years later we meet Larry Kramer in New York and are able to tell him how his play inspired us and gave birth to Crusaid. His pleasure is evident.

Jeremy resigns as Chairman and Trustee of Crusaid in 1988 to take up a position as a Trustee of the National Aids Trust (NAT)

The crashed tycoon Robert Maxwell, the monstrous Captain Bob, otherwise known as 'the bouncing Czech', sees the emerging AIDS pandemic as another media platform for self-promotion. He publicly declares his willingness to contribute £500,000 to the cause and offers to place his Mirror Group of newspapers behind a national fundraising campaign. The British Government decides he should head the fundraising arm of the nascent NAT. Jeremy becomes a member of its fund raising committee. Sadly the Trust proves an empty shell masking only Captain Bob's egotistical ambitions. He never makes his much publicised donation. After a year of committee meetings the Trust has not initiated a single fundraising project. Jeremy resigns in 1989 and his resignation letter, which throws mud onto the face of 'the bouncing Czech', receives considerable publicity:-
'I can no longer sit here talking while my friends are dying.'

London Lighthouse was started in 1986 by our friend Andrew Henderson and his then lover Christopher Spence, with generous funding from Simon Sainsbury, another friend and famously one of the UK's most generous philan-

thropists of recent times, plus others including Crusaid. It's a loving and supportive place to go if you're Positive and a beautiful place to die.

The great Elton John started his Aids Foundation - The Elton John Aids Foundation (EJAF) in the US in 1992 and in the UK, together with our friend Robert Key, in 1993:-

'To support innovative HIV prevention, education programs, direct care and support services to PLHA.'

It quickly becomes one of the most successful independent AIDS charities. 'AIDS is the most devastating modern day disease. By the end of the 20th century, 50 years worth of public health gains were annihilated by AIDS. Our vision today, along with thousands around the world, is to create an AIDS free future through science, support and most of all compassion.'

EJAF are, with their commitment and close connection to celebrities from every sphere, hugely successful fundraisers. By 2017 it has raised over £145 million to support HIV related programs in fifty-five countries. July 1999 Simon Sainsbury, invites us to join his table at EJAF's first glamorous White Tie and Tiara Ball held at Elton John's home in Windsor.

We are inspired by the efforts of EJAF, London Lighthouse and others like them and want to get re-involved in helping others who are Positive. Our attention turns to the many countries where levels of HIV infection and death from AIDS are exploding; where ART is unaffordable and therefore unavailable to the vast majority; where poor quality medical care, nutrition, hygiene and housing are the norm; where Positive people are still dying and often in terrible circumstances. We feel great sadness for and empathy with these people. We feel the need to repay in some tangible way the provision of free treatment which has saved Jeremy's life and the lives of so many of our friends.

June 2001 Jeremy writes:-

'We want to investigate setting up a pilot treatment project in a third world country where many are dying of AIDS through lack of available free treatment. A few HIV+ patients who meet agreed criteria will be selected by local Doctors.'

In this same note Jeremy first calls our unborn initiative Aids Ark (AA) and says:-

'The name of AA is inspired by the book Schindler's List which was made into the movie Schindler's Ark - itself a reference to the Bible story of Noah's

Ark. Schindler took the view that just because he could not save all the Jewish people who perished in Nazi death camps during the horrors of World War Two, there remained every reason to save the few who were sent to work for him in Poland. We have applied the same reasoning to AIDS. Oscar Schindler (1908 - 1974) saved the lives of over one thousand Jewish people. Through AA we hope to help as great a number.'

The British 18th century visionary William Blake wrote:-
'To save one soul is to save the world entire.'

Robert Key heads EJAF UK and introduces us to Dr. Arnaud Marty Lavanzelle of AIDS Ethical Trading Initiative (ETI):-
'Sometimes we obtain recycled ARVs and supply these to PLHA activists overseas. If others in their communities see that ARVs keep these people well then they will start to demand more access to these drugs.'

The largest numbers of Positive people live in under resourced and over populated sub Saharan Africa.

Since our last visit to the South Africa in 1992 there have been seismic changes. Apartheid has come to an end. Free elections have been held. The white population has ceded power to the majority black population and the African National Congress (ANC), now govern the country. Nelson Mandela serves as the country's first black President from 1994 to 1999.

During Mandela's tenure in office a higher percentage of the population of SA is Positive than any comparative percentage worldwide. Mandela never addresses or speaks publicly about this calamity despite losing a son to the disease. He is the first of the many SA Government officials who are HIV/AIDS denialists.

HIV/AIDS denialism also has a tragic impact on SA public health policy during the presidency of its second post-apartheid leader Thabo Mbeki - 1999 to 2008. Immediately after his election Mbeki criticises the scientific consensus that HIV causes AIDS. In 2000, he organises a Presidential Advisory Panel to look into the causes and treatment of HIV/AIDS. Several so called experts who deny HIV causes AIDS sit on this panel. During the remainder of his presidency, Mbeki continues to support HIV/AIDS denialism, delays providing ARVs to his people and publicly describes them as poisons. Dr. Manto Tshabalala-Msimang his Health Minister, nicknamed Dr. Beetroot, promotes herbal remedies such as ubhejane, garlic, beetroot, and lemon juice to treat AIDS.

This policies is responsible for the preventable deaths of as many as 400,000 South Africans from AIDS.

At this time there were even some who claim:-
'AIDS is a White Man's Disease.'

Doctors, activists and others take a different view.

Generic 'copy cat' drugs are an identical chemical formulation to their patented originals. They are equally effective and also much cheaper. In the UK, patented triple combination ARVs are provided free of charge through the National Health Service (NHS). Bought retail, in 2001, we understand that their cost may be as high as £12,000 per patient per year (pp/pa). Generic alternatives of the same drugs then cost £360 pp/pa.

The sale and use of generic versions of patented drugs is illegal in those countries which conform to international patent law. Some countries choose not to conform and in those, patents cannot be enforced and the sale of generics is considered lawful.

South Africa conforms to patent law. However, in April 2001, bowing to mounting public pressure, the international Pharmaceutical Manufacturers Association drops its legal effort to prevent SA from licensing generics. Even though the case is won by default, the South African Medical Controls Council (MCC) doesn't license the drugs until September that year and then only on a strict named patient basis. By this, they prolong the suffering and death of many.

In spite of this victory, Dr. Beetroot, still refuses to authorise the purchase of generics claiming that the country does not possess either the money or the infrastructure to permit a roll-out of treatment and says:-
'My government is coping with the HIV/AIDS epidemic adequately.'

The history of the fight to make generics available worldwide is well told in the film documentary Fire in the Blood. Many of the doctors that we come to know through AA feature in the film.

AIDS denialism is not confined to SA. This and the stigma attached to HIV infection still prevents many worldwide from testing. It is tragic when friends, despite all the warnings, fail to pay attention to the threat of HIV infection and forget the basic rule:-
'If you're sexually active you must take a regular HIV/STD test.'

This rule must, in my view, apply to everyone including straight people in, supposedly, monogamous relationships.

First AA trip to South Africa, April 2002

In April 2002 I celebrate my 50th birthday - a good time to start focusing on achieving something new and worthwhile. We go to Cape Town, with the specific purpose of giving birth to what we are already calling Aids Ark. I wish we had gone sooner. By now four million South Africans are Positive - many of whom will die. In 2002 in SA there are no freely available ARVs; no national ART programme exists.

Our initial enquiries in SA are advanced by Andrew Satow, a British friend now living in Cape Town. Andrew is gay, his former lover is Positive. He shares our ambitions and over subsequent years proves tireless in helping give birth to AA. Without Andrew's persistence AA might not have survived its early challenges.

Through the introduction of Andrew and others, we meet representatives of various groups including Caring Network, Nazareth House (NZH), Joy for Life, Triangle Project and Treatment Action Campaign (TAC). The latter is led by the well known gay Positive activist, Zackie Achmat, who makes public his refusal to take ARVs until they become available to all others infected by the HIV virus in SA.

We meet a number of doctors including; Linda Gail Bekker, Ashraf Grimwood, Kwezi Matoti, Catherine Orrell, Basil Peterson, Jenni Pitt and Robin Wood. All have Positive patients who are unable to access ART.

Robin and Linda have already contacted Crusaid requesting funds for ARVs. Sadly Crusaid turns down this request; their focus remains supporting UK based PLHA needs even though the dying there has now stopped. AA, in contrast, determine to focus where the dying continues and in ever greater numbers.

We are shocked to discover how many people in SA believe that ARVs are ineffective; that the message from on top has got through; that some consider ARVs a western poison designed to harm Africans. Many people believe in the efficacy of traditional African medicine. Its practitioners, the Sangomas, do not wish to see their status and power reduced by Western medicine. We

learn that Sangomas teach those who come to them for treatment, to fear and distrust Western medicine.

Is it this, together with the cost of ARVs, which encourage the SA Government to deny the efficacy and delay the provision of Government funded medication? Does the cost of providing ART influence their view?

We quickly learn that different cultures operate by different truths and rules.

Rose Smuts, CEO of the Caring Network, tells us:-

‘We might be able to persuade some of our Positive carers to take ARVs.’

Rose introduces us to Johan Viljoen, an Afrikaner, who works for the South African Catholic’s Bishops Conference (SACBC), and is responsible for allocating their funds for HIV/AIDS care. Johan is Positive and his health is not good. He shares the distrust of ARVs current in much of Africa and is speeding his own death by choosing not to take these proven life-saving drugs. Worse, by denying funding, he prevents access to these same drugs to the thousands under the SACBC’s care. This makes me angry and I tell him so.

We learn that the MCC still prohibit the use of generics except under a ‘special licence’ which is strictly controlled. We learn from Medecins sans Frontieres (MSF), that their MCC Section 21 licence allows them to use generics only for clinical trials; that generics can be purchased in SA for a fifth of the price of their patented alternatives.

From the Doctors we meet we learn that MCC licence can only be obtained on a named patient basis; that the application process is arduous and often not successful.

Aspen Pharmacare, SA drug manufacturers, tell us they are ready to manufacture generics at a lower price than the imported alternative. However, for commercial reasons, they are unwilling to do so until the MCC allow their unrestricted use.

Cipla, the Indian drug manufacturer, have a generic triple combination ARV available and combined into a single pill called Triomune. Cipla Medpro, their SA agents, tell us that Cipla are not willing to ship their ARVs to SA due to MCC restrictions.

It’s a cruel madness that makes no sense.

One of the Caring Network staff take us to meet Nonkosi and her wheel chair bound mother at their simple home in the township of Gugulethu, one of the many sprawling communities, some would call slums, surrounding Cape Town. Nonkosi is a young girl in her early 30's. She is frail and thin and clearly not well.

'Nonkosi had the courage to speak out in her local church and tell the congregation that she is Positive and has AIDS. Such bravery is rare when others have been killed, some by stoning, for making such declarations.' Jeremy is able to tell this young lady that he has been Positive for over ten years and that due to access to ARVs he is healthy again. Her initial disbelief turns to a broad smile of hope and joy.

At the NZH orphanage we are introduced to 12 young orphans who are all Positive. They sit in a line along a shady wall and evidence of their varying OIs are clear to see. They are a muted, sad group. I wonder when last each was taken into adult arms and hugged. We tell the Nun who runs the centre that we have sufficient funds to purchase ARVs for only four of this group. 'If you can't help all our children then we prefer to help none.'

The doctors we speak to are of a western persuasion and training and understood that ARVs save lives. They are excited by our offer to fund this medication - one so overwhelmed that he breaks down in tears. These doctors are suffering. It is hard for them - knowing that the medicine is available, having no funds to access it, watching their patients die for lack of it.

We, as AA, decide to fund only generic as opposed to patented ARVs. By this, the same amount of funding will allow a five fold increase in the number of lives saved. This decision raises the challenge of their legal use in SA.

We return to London with a greater understanding of the challenges that lie ahead.

May 2002 we apply to the UK Charities Commission (CC), to make AA a UK Registered Charity. We understand that spending other people's money will be a serious responsibility.

2002 AA's stated Objectives to the UK Charities Commission:

'To identify suitable medical practices who treat HIV+ patients. To fund the supply of generic ARVs to those of their most needy patients who are unable to access this medication. To fund medical costs for these same patients. To

provide additional support to ensure ART is effective. To leverage funding by introducing these opportunities to other larger NGOs.'

We consider our operating terms. On what basis will we offer funding? What do we need to know from Doctors who apply to us for funding? What subsequent reports should we require from Doctors post funding? How do we ensure AA funding is spent as intended? We are aware of the many stories about donor money being misused.

2002 AA's original Mission Statement:

'To supply funds for the sole purpose of providing World Health Organisation (WHO), approved Triple Combination ARVs at the lowest price available worldwide to a pilot project of HIV+ patients in the Western Cape Province, South Africa. Thereafter and only when the project is seen to be working properly, it is our wish to seek further funding with the aim of assisting as many beneficiaries as proves possible.'

We will seek out Doctors treating patients who are demonstrably unable to fund their own ARVs. Following WHO guidelines we will only fund their Positive patients who first present with a CD4 count of less than 200, or those with higher counts who first present with OIs.

Using our own money we commit 'seed funding' for 20 beneficiaries.

Our initial named patient application and reporting requirements prove too demanding. Applications for funding from the doctors we met in SA are slow in arriving for reasons we now better understand. Will AA, who have no track record, prove a reliable source of funding? As we only offer to fund ARVs who will meet these patient's other medical and nutritional costs? Gathering the information our applications require is time consuming for already overworked doctors. Submitting applications to the MCC for their licence to use generics will add further demands on the doctor's time. Our requirement for reporting will be an additional task for them to undertake.

We source a supply of generic WHO approved ARVs from Swazipharm, a pharmacist in neighbouring Swaziland, where the sale of generics is lawful. Swazipharm's price, August 2002, for WHO approved Cipla manufactured Triomune is £350 pp/pa. Swazipharm tell us they are already sending drugs direct to SA doctors in the post.

August 2002, Dr. Jenni Pitt, then working at Somerset Hospital, applies to us and we accept our first AA beneficiary. Jude is a 36 year old Nigerian, hetero-

sexual man. He is studying for a PhD at the University of Cape Town (UCT). He has only just learnt his HIV+ status, has a dangerously low CD4 count of 18 and multiple OIs. Jude is already very ill. With the application we hear direct from Jude:-

‘There is no cure, I cannot afford the medication to prolong my life. I am too sick to work. Where am I going to find money even for food? I can no longer support my family back home. There is no hope. The honourable thing is to commit suicide.’

Jude’s immediately starts on ART.

Through Triangle Project’s Dr. Basil Peterson we are introduced to our second beneficiary. He is handsome Bonga with sad eyes, a gay man and an active volunteer for Triangle Project.

‘Although homophobia is particularly rife where he lives in Guguletu, Bonga allows his face to be used in our publicity material which is widely distributed in all the townships around Cape Town. This puts Bonga at risk. He is also open about his Positive status which, due to stigma, amplifies this risk.’

AA is keen to find beneficiaries who are already helping others in their communities. Bonga is a perfect candidate. Unfortunately treatment comes too late for Bonga and in December 2003 he dies.

Our third beneficiary is Jacqueline from Zimbabwe. She starts AA funded treatment in September 2002.

Jacqueline tell us, June 2003:-

‘My health is improved beyond all expectations. The South African Government does not fund HIV drugs because it has no confidence in them. It is my wish to be a living testimony to others that these drugs do work.’

Our fourth beneficiary is Mary M. Her husband and one of her children have died from AIDS. Her two other children are both Positive. Her CD4 is 26 when she starts AA funded treatment in October 2002. By August 2004 her CD4 count is 436 and she has no clinical symptoms.

From Mary M:-

‘I deliver food parcels and medicines to others who are too sick to get out of bed. I am determined to help others know that life does not end when you have AIDS.’

Nonkosi becomes another early beneficiary and our original poster girl. She is cared for by Dr. Kwezi Matoti under the overall charge of Dr Catherine Orrell. ART is amazingly effective at halting the relentless attrition of the HIV virus. Nonkosi is keen to help us demonstrate this fact and has the courage to allow us to use images of her then ravaged body for this purpose. Pictures of

Nonkosi when she started ART and again in April 2004, together with the text 'Nonkosi after 1 Year on ARVs' says all that needs to be said.

More beneficiaries come from Dr. Ashraf Grimwood. One is Ajita who looks after two abandoned children and has adopted two more. She supports her Positive husband and teaches youngsters in the townships. She lives under extremely poor and difficult conditions. She is not open about her HIV status and doing so, we are told, would have dire consequences.

Our work has started.

Back in London we initiate a 'sponsorship scheme'. We ask our friends to make a commitment of £350 per year for a minimum of 5 years. We undertake to link their donation to a specific beneficiary and to send annual reports on their progress to each sponsors.

In January 2003 we tell Jude's sponsors that he is doing well on ARVs and that his health is improving. In January 2004 we forward them Dr. Jenni's report:-

'Jude's CD4 count is now 129. He no longer has clinical symptoms and is looking fantastic.'

To this Jude adds:-

'I am feeling much better than before. I have energy for my studies. At UCT I have organised an International HIV Treatment Summit for Refugee Students. ARVs have saved my life.'

January 2005 we tell them that Jude's CD4 count is now a healthy 445.

Our sponsorship scheme proves successful.

September 2002 AA receives it's official charity registration from the UK Charities Commission - we are number 1093966.

We expand our search for funding. 'You can save a Positive life for less than £1 per day' is our original banner. Our friends prove generous. One of our first donations, £5,000, comes from Simon Sainsbury. He offers to repeat this annually.

In London, October 2002, we are introduced to the SA Constitutional Court Judge, Edwin Cameron, a gay man and Positive. He is a much admired critic of SA Government's Aids denialism and of the then President, Thabo Mbeki. Edwin is an outspoken advocate for freely available ART in SA.

Subsequently we receive from Edwin:-

‘ I have read your documents with admiration. You have prepared minutely , carefully and respectfully. I am convinced that as your intervention grows in strength it will eventually prove pivotal to many thousands of people’s lives. As someone who like Jeremy owes my life to privileged access I am deeply moved by your caring initiative and the painstaking steps you have so far taken to put it into practical effect.’

Second AA trip to South Africa, November / December 2002

November 2002, I return to SA to meet doctors in Johannesburg. At the Chris Hani Government Hospital in Soweto I learn about their fledgling Prevention from Mother to Child Transmission Programme (PMTCT), which involves an inexpensive and simple drug intervention given to the mother just prior to the birth of her baby. PMTCT is now regular practice in most countries around the world. It has saved countless numbers of children from becoming infected by the HIV virus during birth. The drug used, Nevirapine, is described as a non-nucleoside reverse transcriptase inhibitor - science comes up with some extraordinary names.

There are many reason why people then, and sadly still, don’t take a freely available HIV test - fear of rejection when stigma levels are high, shame at being Positive, distrust of ARVs and fear of knowing you have a life threatening infection.

The PMTCT programme forces all pregnant women in SA and elsewhere to take an HIV test and this serves to expose HIV infection and to reduce it’s spread. Mostly it’s men who refuse to take this test; many also refuse to practice safe sex.

To doctors I pose the question:-

‘Should we fund treatment for two or multiple members of one family?’

Their answer:-

‘Fund only one member of each family; each family needs only one healthy bread winner to survive; to do more for one family would be to waste the rare and valuable resource AA offer.’

Back in Cape Town I meet AA’s first 17 beneficiaries and will always treasure that memory. When you meet someone, who knows that your help allows them access to medication which will save their life, the exchange is deep. Such meetings will be repeated with other beneficiaries and in different coun-

tries over the years to come. These meetings are the great reward that this work brings us.

Since 1988, the 1st of December is celebrated as World AIDS Day and is dedicated to raising awareness about the AIDS pandemic and to remembering those who have died from it.

On World Aids Day 2002 Andrew and I go to Gugulethu. We are invited to celebrate with Dr. Kwezi and approximately thirty of his Positive patients including Nonkosi. His clinic is a simple tin roofed shack set along a dusty pathway where similar shacks lie packed one against the other. You hear multiple sounds of conversation, music and domestic chores. There are smells of food and rubbish. The atmosphere is curiously colourful and upbeat. These people's lives are desperate but despite this they smile. Kwezi asks me to light a candle on his desk. Quietly we all form a circle and join hands. A good looking boy sings a prayer in a beautiful deep voice in his language Xhosa. We are all moved by his song. Many in the circle face imminent death. There are tears.

The majority tribe in the Western and Eastern Cape are Xhosa.

We hear that the MCC is becoming concerned about the number of generic drugs, particularly ARVs, being imported into SA. They threaten prosecution and raid the clinics of several SA doctors.

Early 2003, due to pressure from the MCC in SA, our supply of ARVs from Swazipharm comes to an abrupt stop. We currently have a commitment to 19 AA beneficiaries and diminishing stocks of ARVs. Strict adherence to the daily drug regimen is essential. Any departure from treatment compliance, even for a few days, can result in drug resistance quickly developing and ARVs becoming ineffective. Assured supply of the medication is therefore essential.

Andrew learns that WHO approved ARVs are available from Tripharm, a pharmacy in neighbouring Lesotho. We make immediate contact and agree to purchase the drugs from them. We find others who are prepared to hide these drugs in private cars and smuggle them into South Africa. It's a great relief to have found a new source of ARVs

First AA Trip to Lesotho, May 2003

May 2003, Andrew, his husband Alistair and I, make our first trip to Lesotho.

Romantically described as Africa's forgotten mountain Kingdom, Lesotho is landlocked by SA. At its lowest, it lies 1,400m. above sea level from where it rises to over 4,000m. amongst the Drakensberg Mountains. The country has a harsh beauty. Towering peaks enclose high valleys filled with dark red soil. The weather is extreme. Drought currently plagues the land despite intermittent heavy rains which strip the now largely treeless land of its topsoil. There are few tarred roads. For most, transport is on foot or horse. The people are mainly pastoralists. Rural Lesotho is without electricity. Its population of 2 million Basotho are poor, some of the poorest in Africa. Much of their meagre income is derived from remittances earned in the mines of SA.

Tripharm located in Maseru, the capital. There we meet Maud Boikanyo who shows us their stock of WHO approved drugs including Cipla Triomune.

We find others who are prepared to hide these drugs in private cars and smuggled them into SA. AA are now party to drug running. It is a great relief to have a new source of ARVs even if through an illegal route.

We travel around the country meeting people who are engaged in the battle against AIDS. Levels of infection and stigma are as high as in SA. Distrust of western medicine and faith in traditional Sangomas replicates what we have encountered in SA. Amongst all the many people we met in Lesotho not one admits to being Positive.

In Semonkong we meet Sister Benedict, a nurse at the Roman Catholic St Leonard's Mission.

' Men returning from the mines in SA come back Positive. My mission does not advocate condoms but promotes abstinence as per the teaching of the Church. I acknowledge that sex is one of the few pleasures available to these people. Amongst my congregation I have seen many HIV/AIDS cases but, due to cost and fear, few take an HIV test. No financial help is available from the Government. I can offer only immune boosters and vitamins. Other problems are poor nutrition, no money and no prospect of work. Many die - from skin problems or pneumonia, with no knowledge that AIDS is the primary cause. Instead people believe they are bewitched and this adds terribly to their fear. I have not heard about ARVs or PMTCT. No doctor comes to Semonkong.'

We hear similar things from others.

Mr Thato is the leader of a Government initiative to train local chiefs, traditional healers and local people about HIV/AIDS issues.

'I do not know any people in this area who are definitely HIV+ although many people are dying young from mysterious causes. I understood that AIDS cannot be cured but we must support those who are ill and not drive them from the town. The people are too frightened to go to Maseru for HIV testing.'

In Mafeteng we meet Dr. Mphu Ramatlapeng, a lady GP with Positive patients. Mphu is Russian trained, impressive on many counts and is from one of the leading families in Lesotho. Her sister is Director of Health Services in the country. Mphu's patients are too poor to self fund ARVs. Mphu has no funding from other sources for this purpose.

'AA funding will allow me to set up the first ART programme in the Kingdom. My government will see the success of this programme. It will encourage them to seek large scale international funding for ARVs for our people.'

Dr. Mphu makes application to us for 8 of her Positive patients which we immediately accept. Lesotho has its first ART programme - The Karobong Clinic.

We meet Mrs Mosisili the wife of the Prime Minister.

'As many as 31% of our people are HIV+; many Lesotho men work in SA mines and when retrenched return Positive; Africans have a relaxed attitude to sex and in consequence have multiple sexual partners; men will not agree to practise 'safe sex' thus speeding the spread of HIV infection; few doctors and nurses are trained in HIV care; the Government is applying for 'Global Fund' (GF) money but is unlikely to be successful as Lesotho will present as having little expertise in how best to use these funds.'

The GF is:-

'A 21st century partnership organisation designed to accelerate the end of the AIDS, Tuberculosis (TB) and Malaria pandemics. Founded in 2002, it is a partnership between governments, civil society, the private sector and people affected by these diseases. The GF raises and invests nearly US\$4 billion a year to support programmes run by local experts in the countries and communities most in need.'

We are granted an audience with Lesotho's leader, HM King Letsie III, at the Royal Palace. The King seems knowledgeable about the HIV/AIDS crisis in his country. He tells us he is grateful for our efforts and offers his support.

Shortly after our visit, the King's brother Prince Seeiso, together with the UK's Prince Harry, starts Sentebale with the aim of:-

'Supporting orphans and vulnerable children, many of whom are affected by the HIV/AIDS epidemic.'

I send word of our small role in Lesotho to both Palaces but hear nothing back.

The Sentebale's 2017 web site states:-

' HIV remains the number one cause of death in 10-19 year olds in Africa (WHO Global Health Estimates 2014). Stigma is the Greatest Barrier to Youth Accessing Care (Ban Ki-Moon - UN Secretary General UN 2007-2016 - The Stigma Factor 2008). Lesotho has the World's second highest HIV infection Rate (CIA World Factbook 2014). 82% of Adolescents Living with HIV are from Sub Saharan Africa (Unicef 2015).'

Together with Doctors, we consider our responsibilities. You fund ARVs for a specific person. Then, due to lack of funding or other reasons, you withdraw that support. You know that failure to be treatment compliant can cause drug resistance; that long term withdrawal from ARVs will result in death from AIDS.

I ask myself - what would any person dying of any disease want for themselves, for their families? There can only be one answer. Surely any opportunity to increase the length of my healthy life is better than no opportunity at all. Who would want other?

As policy we decide AA must, de minimis, have sufficient funds in hand or promised, to allow us to make a three year financial commitment to each new beneficiary we accept. At least, this will provide them with the chance of three years of extra life and the increased likely hood that long term access to ARVs will become available to them during this period. At most, it will help to save their live and the life of their family.

In the event, the doctors we work with, prove successful, in all instances, in finding alternative, often more secure, ART programmes, for our beneficiaries before our 3 year commitment ends. It also pushes the doctors to transfer patients to other programmes thus releasing AA funds to help others for whom ART are not available.

By summer 2003, we have nine sponsors and receive generous donations from The Beaverbrook Foundation and The Mackintosh Foundation - both make repeated donations over subsequent years. This together with other funds raised allows us to make a commitment to 33 beneficiaries in SA and Lesotho.

To our sponsors we send further reports from beneficiaries:

Alison is a 38 year old Hospital Assistant when she starts on AA funded ARVs in September 2002. At that time her CD4 count is 228 and she is taking chemotherapy for KS. She has an immediate positive response to ART and is treatment compliant. By September 2003 her CD4 count is up to 387.

November 2003 Alison tells us:-

‘My eating is well, I picked up weight fast and my health is good. I am feeling much better now. Thank you Aids Ark for saving my life and protecting the future of my family.’

Deloris is 32 and an AIDS widow when she starts on AA funded ARVs in February 2003. At that time her CD4 count is 65. She is too sick to work and lives on a disability grant of £50 per month on which she supports herself, her mother and her 2 children. Despite her illness she visit schools and churches to:-

‘Inform youngsters about HIV and to teach them how to protect themselves. I want to help the young people. I want to walk with them.’

By December 2003 her CD4 count is up to 275 and she had regained her weight, health and strength.

‘I no longer feel tired or get sick. People no longer push me aside. I have courage to tell the people in my community about the strength of these pills. I am so grateful to receive this help.’

In July 2004 her CD4 count is 390.

Shepherd is 21 and studying Fashion Design when he starts on AA funded ARVs in May 2003. His CD4 count is only 11 and he presents with OIs including CMV. By March 2004 his CD4 count is up to 170 and his health is described as well.

‘I have gained a lot of weight, my vision is so improved that I can again get around on my own. I no longer have frequent illness and feel so much better. With my new strength I have been able to form a new relationship. I have returned to my studies. I have started counselling patients at the clinic about the benefits of ARVs.’

Merrilyn is 39 and an AIDS widow when she starts on AA funded ARVs in March 2003. She is a domestic worker. She has a child who is also HIV+. At that time her CD4 count is 90 and she presents with OIs. Merrilyn’s greatest concern is that she might die before her child. In June 2003 Merrilyn contracts TB and loses her job. Despite this her CD4 count rises to 179 and her health is much improved. In February 2004 her CD4 count is up to 207 and her Doctor tells us:-

‘Merrilyn is now clinically well and asymptomatic. She openly declares her status and that she is on treatment. This gives a very powerful message to her community where HIV is equated with fear, stigma and death.’

We also hear from Merrilyn:-

‘My health is much improved. Soon I will go back to work and start contributing to the cost of my ARVs. Thank you Aids Ark. Please keep up your help, our people are really suffering.’

We tell our donors:-

‘AA is run entirely by volunteers. All overheads are covered by our Trustees. 100% of all money raised is used to advance our objectives.’

This becomes AA policy and still remains the same.

John McLaren’s sister Anne Aslett works for EJAF. In September 2004 we tell her about AA’s work in Lesotho and are pleased to receive a small grant from them for the specific purpose of funding eight more beneficiaries at Dr. Mphu’s Karobong Clinic.

October 2004, Edwin Cameron invites Jeremy and I to dinner at All Souls Oxford where, as a Visiting Fellow, he is taking time out to write his powerful personal testament *Witness to Aids*. With pride we show Edwin the double image of Nonkosi our original Poster Girl. To our amazement Edwin is furious. It is a further example of differing cultural norms. To us we are making a powerful visual statement about the efficacy of ARVs. To Edwin, with his background of apartheid guilt, we are white people demeaning a black woman. Edwin’s response saddens us. Subsequently Edwin distances himself from us and AA. We had not expected this from such a wise and seemingly urbane man.

First AA trip to India, December 2004

We expand our search for doctors and beneficiaries to other countries where infection rates are high, where extremes of poverty are commonplace, where Government funded ART is not available. In December 2004 this takes me to India.

In Delhi I meet Shivananda ‘Shiv’ Khan, Founder Director of the Naz Foundation International (NAZ), an organisation that does much HIV/AIDS work at a time when the Indian Government does little.

NAZ focus on:-

‘Providing services to Lesbian Gay Bisexual Transgender (LGBT) people impacted by HIV/AIDS.’

With Shiv, I visit Love Life Society (LLS), run by and for gay men who are Positive. Instead of the term ‘gay’ they and much of the world, use the term Men who have Sex with Men (MSM). This term includes straight men who, for various reasons, are also MSM. We meet Dr. Chinkolal and Francis de Mello, founder of LLS, who becomes our first Indian AA beneficiary.

I meet Anjali Gopalan, a Director of NFI, at the home she runs for Positive orphans. Together with the children, we enjoy a boisterous curry lunch sitting on the floor.

With Rita Devi, founder of the ILA Trust, I head out early down dusty, empty streets. The first shards of sunshine cut through the departing Delhi fog. I’m travelling in one of their mobile clinics which daily visit the city’s slums to provide free medical care. We park at a mean looking street market where people still sleep wrapped against the cold in thin rags. The clinic is soon busy serving the poor and destitute. With Rita we visit sad, dark brothels where others need help.

Elizabeth and Siddhartha Vatsayan, founders of Aids Awareness Group (AAG), work in Delhi’s jails and brothels helping those who are Positive. They also run an AIDS hospice.

‘Despite the high levels of MSM in our jails, condoms are forbidden.’

Shiv takes me to visit NAZ’s headquarters in Lucknow. I meet some of the splinter groups they have spawned. India is home to many complex, ancient social structures of different groups and castes. UDAAN focus on assisting Positive ‘Kothis’ - feminine sexually passive, gay men and ‘Hijras’ - people whose birth sex is male but who identify as female or as intersex. Many ‘Hijras’ elect to be castrated and to live in all-Hijra communities led by a guru.

I am invited to a ‘Kothi’ dance. The young boys dancing tell me:-

‘None of us have the courage to take an HIV test – we are too scared.’

‘Men having sex with a prostitute or a ‘kothi’ boy will rarely bother to practice safe sex and we are powerless to insist on it.’

I visit Lucknow’s King George’s Medical Hospital and meet its Medical Director Dr. Razamakan:-

‘Despite being a Government Hospital we can only offer care and drugs to those who can pay for it.’

Many of India’s people are too poor to access even basic medical care.

In Indian, pregnant women traditionally return to their parent's homes for the last months of pregnancy, the birth of their child and sometimes for a month or two after the birth. During this time it is usual for their husbands to stay away; a time when they often stray into other arms. Wives return to find their husbands Positive. They in turn become infected. Their second child may then become Positive at birth. This cultural tradition is the cause of much HIV infection.

In Bombay I meet Dr. Janak Maniar:-

' More than 15 million people in India are Positive; Indian Government statistics on HIV/AIDS cannot be relied on; adulterated drugs, inconsistent supply and substandard medical care is commonplace; only a handful of Doctors in India know how to implement and manage ART; there is huge corruption and 98% of AIDS money coming to India is misappropriated; token giving is a waste of time if not properly administered.'

From others I hear more encouraging information.

From Dr. Alaka Deshpande, Medical Director of JJ, Bombay's enormous Government Hospital:-

' We currently have 730 Positive patients receiving ARVs at JJ. I am confident the new Government initiative to provide free medication will grow dramatically.'

She shows me JJ's AIDS ward and offers to approve and if necessary train any doctors with Positive patients who apply for AA funding.

Dr. Alaka suggests I talk with Ashok Row Kavi and Vivek Anand, joint founders of the Humsafar Trust, the oldest LGBT organisation in India. The trust is partially funded by the Indian Government through its National Aids Control Organisation (NACO).

'Many of our members are Positive and don't wish to be treated at JJ Hospital for fear of their MSM status being exposed.'

With regard to India's sexual conservatism Ashok tells me:-

'India is the bastard child of Victorian prudery and Marxist puritanism.'

I visit the Sahodva Community Care Centre which combines a medical and spiritual approach. Among the hospital buildings there are small temples and shrines of all persuasions. Dr. Meenal Mehta, a young German trained Doctor, has a patient load which includes 15 who are dying from advanced OIs. 'These are all young people who don't want to die – leaving their bodies is difficult for them.'

In India, straight sex outside marriage is almost impossible – prostitutes and boys are the only alternative. Extramarital sex happens mostly on the streets, in brothels, toilets, parks, taxis etc. There is a huge invisible world of primarily heterosexual men, who have sex with other men. The police are poorly paid and often corrupt. Regularly they site carrying condoms as evidence of breaking the infamous Section 377 law. So called offenders are regularly black-mailed and even sexually abused by law enforcers. The mass of truly homosexual people hide within the heterosexual world.

Section 377 of the Indian Penal Code, introduced during British rule in 1861, criminalises ‘carnal intercourse against the order of nature’ - interpreted to mean all forms of sexual activity other than heterosexual vaginal intercourse.

Indians, in general, have a low opinion of anyone who is Positive. Levels of stigma are high. To be both MSM and Positive is to find yourself doubly despised. In contrast to women, many men, and MSM men in particular, delay taking the HIV test until it is too late for doctors to save their lives. Stigma contributes to the spread of HIV infection and death from AIDS in many countries.

December 2004, the Indian Government, through NACO, are reported to be starting a national access programme of 1st line ARVs but the Doctors we speak to tell us that any start remains sporadic, unreliable and limited.

1st line describes the cheapest effective triple combination ARVs. 2nd line describes more expensive alternative ARVs which are effective in treating patients who become resistant to 1st line. 3rd line are to follow.

At this time AA offers funding for only 1st line. To do otherwise would mean fewer lives saved.

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The price of ARVs worldwide is falling thanks to increased demand, competition among manufacturers and lobbying for cheaper drugs. August 2002 1st line generics in Swaiziland cost £350 pp/pa. By October 2004, in Lesotho, we are paying £254 pp/pa for the identical drugs. In India, December 2004, where these same generics are manufactured, the price is now £204.00 pp/pa and even as little as £156 pp/pa through some sources.

January 2005 we are funding ARVs for 53 beneficiaries in Africa and have funds in hand, or promised, for an additional 25 in India. The number we support soon climbs to 78.

Our friend, Mark Lloyd, sits on the US board of FXB International (FXB). October 2004, he suggests I contact its founder Countess Albina du Boisrouvray. In Delhi, December 2004, at a non AA event and therefore entirely by coincidence, I met FXB's Indian Legal Advisor, Tasneem Ahmadi. I tell her about our work and she invites future contact.

From the FXB Web Site 2017:-

'FXB is an international development organisation with over twenty seven years experience in breaking the cycle of poverty. It's mission is to provide people living in extreme poverty with the tools and support they need to become self-sufficient.'

The FXB story started in 1986, when Albina du Boisrouvray's only son, François-Xavier, a rescue helicopter pilot, is killed in an flying accident aged 24. His death prompts Albina to end a successful career as a film producer and to dedicate her life to improving the lives of vulnerable people including those affected by AIDS. In 1989, Albina used her substantial personal wealth, as much as \$450 million it is said, to fund FXB in memory of her son. Their mission:-

'To perpetuate the values of generosity and compassion that guided François-Xavier's life and to keep his mission alive by also seeking to rescue some of the poorest people on earth.'

I contact Albina. We meet for tea at Plaza Athene in Paris early 2005 - a setting as glamorous as this charismatic and passionate lady also proves to be. FXB run their own medical clinics in numerous countries around the world; many of their patients are Positive. FXB provide palliative care to these patients but chooses not to fund the supply of ARVs.

'A commitment to fund ARVs for an individual must be a lifelong commitment. We are not in a position to make such a commitment.'

'We also have concerns about compliance - if patients do not take their ARV's regularly they will develop drug resistance.'

AA take a contrary view. I explain our three year as opposed to life offer. AA know that a small number of patients, from whatever background, will fail to be compliant and will therefore develop resistance. They do not believe that either issue is a reason to withhold treatment.

It is regrettable that FXB, EJAF with regard to our future Moreh clinic, and other NGOs, appear to allow fear of damage to their reputations to take

precedence over the moral imperative of offering life-saving support albeit for a limited period. It is a policy which has cost lives.

Albina introduces me to FXB's Medical Director, Dr. Alejandro Haag. We have a lengthy exchange by email but never meet. Initially I think that FXB may fund us. This changes when I start to understand that FXB may have shifted their position; may now be thinking to allow us to fund their patients' ARVs. We are pleased and flattered that they may trust us enough to do this.

Currently AA are offering to fund only the cost of ARVs. Dr. Alejandro reminds us that the cost of doctors, nurses, other medicines, premises, transport, nutritional support, etc., are essential components in providing effective treatment. FXB clinics are already providing and funding these. Using AA funds for ARVs alone will allow FXB to offer their HIV+ patients 'effective' treatment as opposed to only 'palliative' care. We are a good fit.

By the beginning of 2005, the doctors we are working with in South Africa tell us about the new Government ART clinics. We encourage them to transfer AA beneficiaries to them as soon as they feel happy these are adequately staffed, run to an acceptable standard and able to source a secure supply of ARVs.

April 2005, from Dr. Jenni now working with the Desmond Tutu HIV Foundation (DTHF):-

'Support from Aids Ark has unquestionably spearheaded Government funded ARV access in South Africa.'

The Desmond Tutu HIV Foundation (DTHF), previously the HIV Research Unit - 1995 to 2004, was founded in 2004 with headquarters at the University of Cape Town (UCT). The Foundation is headed by Professors Robin Wood, Linda Gail Bekker & Catherine Orrell, who helped us in the Cape in 2002 and through whom we found many of our original AA beneficiaries.

DTHF describe their mission as:

'The pursuit of excellence in research, treatment, training and prevention of HIV related diseases and infections in Southern Africa.'

DTHF play a major role in devising national HIV strategies and saving Positive lives in South Africa.

From Richard Stern of Agua Buena Human Rights Association May 2005:-

'For nearly a full year, \$122 million of additional funds specifically for ART has been available to India's NACO from the GF, but not one dollar has been disbursed from Geneva to India for this purpose. In India only 5,000 Positive pa-

tients are receiving ART through the public sector. Incredible negligence on the part of NACO and their Health Ministry combine to systematically create a form of bureaucratic genocide contributing to the deaths of thousands who are Positive and who need treatment now.'

From WHO at this time:-

'700,000 people in India urgently require ART of whom 100,000 will die from AIDS related diseases annually.'

Dr. Alejandro decides to trust us and introduces us to Dr. PSKP Raju, Medical Director FXB India. Dr. Raju's FXB clinic is located in Vizakapatanam (Vizak), Andhra Pradesh State. which is classified as a 'high prevalence state'

From Dr. Raju:-

'My HIV+ patients in Vizak are without ARVs. Many are severely traumatised, depressed, withdrawn and fearful. Many have attempted suicide.'

July 2005, AA agree to fund ARVs for 22 FXB Vizak beneficiaries and their ART starts immediately.

I receive a wonderful communication from Dr. Raju. He and his FXB team have made a big event of the first distribution of AA funded drugs. A special banner is painted, 12 local Doctor who provide 'pro bono' care to Dr Raju's patients are invited together with two local Cipla officials. The selected 22 Positive patients receive the first issue of their life saving medication with a handshake. The event is important in all their lives and in ours also. It is splendid that Dr. Raju chooses to celebrate the occasion in such a way.

August 2005 I write to Edwin Cameron:-

'We have just finished reading your book Witness to Aids. We admire your personal courage and honesty and how this has strengthened your essential plea that the SA Government and its President acknowledge the full extent of the Aids crisis in SA and undertake to provide greater national access to the same drugs which are keeping both you and Jeremy healthy, productive and alive. Bravo to you – you are indeed a hero.'

Sadly we don't receive a reply.

By this time we are funding ARVs for a total of 61 beneficiaries in SA, Lesotho and India. In addition, 21 previous beneficiaries in SA have come off our programme and are receiving ART from Government clinics. 23 'sponsors' have each undertaken to fund ARVs for a 'named' beneficiary for 5 years.

AA's first web site goes live.

Second AA trip to India, February 2006

I return to India in February 2006. My first stop is Vizak where I am excited to meet Dr. Raju, our original 22 Indian beneficiaries and their families. Dr. Raju is a saintly man. I immediately feel total trust in him, his skill and his good intentions. He spent much of his medical career in Government service in Mizoram State, from which he retired in 1998. He joined FXB at the end of 2000.

The dramatic positive physical and psychological changes which access to ARV's has brought to our beneficiaries is amazing – seemingly a miracle. Within months of starting treatment each describes new strength and hope streaming back into their bodies. They now know they have escaped premature death, that they will be well again. Their joy is thrilling. All who attend our first meeting are moved and inspired by what they see and hear. There are many joyful tears. Our beneficiaries try to kiss my feet but I don't feel comfortable allowing this. Their joy is our reward.

Together with his grandmother Chandramma, I meet AA's youngest beneficiary, Benzemen, then aged 7.

Dr. Raju describes him as:-

'The most deserving candidate amongst AA's beneficiaries.'

Benzemen was born HIV+ to parents who both died of AIDS. His remaining family and the community in which he lived thought him cursed and rejected him. Only his grandmother showed the boy love and cared for him. Chandramma struggles to survive selling fish from a road side stall and is, like so many others, illiterate. Benzemen was constantly sick. At the age of two he caught TB Meningitis which caused him some permanent brain damage. By 2004 he had fought off 3 bouts of bacterial pneumonia and from 2002 to 2005 he suffered from recurrent chronic diarrhoea and skin infections.

'He was too weak to stand and stayed mostly on the bed.'

My first meeting with Benzemen happens 7 months after he begins taking ARVs.

From Dr. Raju:-

'His health is remarkably improved. He is completely symptom free. His weight and physical activity have increased. His community think he has been visited by a God and now revere him. This is the power of ART.'

I meet a happy, laughing boy and his delighted grandmother. Benzemen is a lovely child with the sweetest smile.

There are special days in one's life filled with a particular joy and gratitude.

Dr. Raju becomes one of AA's closest friends and is wise and compassionate beyond words. He wishes to develop a Model of Complete HIV Care, comprising medical, psychological and social components. He suggests that we might want to part support the cost of running this initiative.

'FXB Doctors maintain close working relationships with Government Doctors. It is important, for the sake of the larger community, that we demonstrate a high standard for the Government Doctors to learn from and replicate.'

I feel confident that any money AA give FXB will be spent precisely as intended. With other doctors we meet, I do not always feel this. I have heard too many stories about them inventing patients and stealing money.

NACO are slowly starting to roll out ART clinics across India including in high prevalence' states such as Andhra Pradesh, but Dr. Raju advises:-

' The quality of the care they provide is poor; the supply of ARVs is unreliable; there is no counselling or nutritional advice; there is no education for adherence and resistance; the service is impersonal and harsh. I am not yet happy to move my patients to these clinics.'

People living in remote places and those without suitable residence papers are unable to access even these meagre services.

NACO clinics do not provide ARVs in solution, meaning in liquid rather than in pill form, although this has been available from Indian generic manufacturers for more than a year. It is the only safe way to treat young children. Dr. Raju has three patients under the age of 10 and we agree to fund their ARVs in solution.

In Delhi, I meet Tasneem Ahmadi once again - we are now associates working together with a shared mission. We reflect on the extraordinary coincidence of our chance first meeting 15 months back and what has now been initiated between us.

From here I go to Indore, Jaipur and Bombay where there are other FXB clinics requesting collaboration with us. Following these visits, we commit to fund drugs for 24 additional beneficiaries making a total, to date, of 85 beneficiaries in three countries.

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We tell our sponsors that linking their donation to a specific beneficiary and reporting accordingly, is proving too costly in time. All sponsors accept this and our future reports become more general.

April 2006, from Dr. Mphu, in Lesotho:-

‘ Three years ago, when ARVs were but a distant hope for most of the Basotho people, AA arrived and made this dream a reality. Many patients, who in all likelihood would have died without the treatment made possible by AA, are today not only alive, but productive, happy, and eager to do what they can to help those who continue to suffer. AA has truly been a pioneer of ARV treatment in the Kingdom of Lesotho and for this I express my overwhelming gratitude.’

July 2006, the Government of Lesotho pledge, thanks to funding from the Clinton HIV AIDS Initiative (CHAI), to provide universal access to 1st line. We are credited with helping to expedite this significant development. More correctly, credit should go to Dr. Mphu, who effectively, spread word to others and particularly to CHAI, about the success of Lesotho’s first ART programme, the Karobong Clinic.

From CHAI 2017:-

‘ Two-thirds of the people who need medical treatment for HIV infection in the developing world are still not receiving it. When CHAI was founded in 2002, only 200,000 people were receiving treatment for HIV/AIDS in low and middle income countries, with medicines costing over \$10,000 pp/pa. Over a decade later more than eight million people are receiving treatment and CHAI has helped reduce the cost of medicines to around \$100 to \$200 pp/pa. Countries have repeatedly proven that it is possible to rapidly scale up treatment services. For the first time, there is real promise that we can turn the tide against HIV/AIDS.’

Our funds for the purchase of ARVs are no longer required by Dr. Mphu’s Basotho patients. Scarce AA funds can now be redirected to help save lives elsewhere.

August 2006, Dr. Mphu is appointed Minister of Health and Social Welfare for Lesotho.

In India we commit ARV funding for an additional 15 beneficiaries making a total of 100 beneficiaries. More than 40 others previously received our help but now have access to ARVs through alternative programmes. Together with FXB we implement a system where as beneficiaries regain their health and are able get back to work they start to contribute to the cost of their medical care. It is in everyone’s interest to ensure that AA funds assist as many individuals as possible.

In London, Soho Gyms has expanded to 6 gyms and adopts Aids Ark as its official charity. They have a mailing list of members who are entirely new to AA. Both staff and members are generous in their support and continue to be so to this day.

I work to build connections with bigger players in the NGO AIDS world. Anne Aslett is playing an increasingly large role at EJAF. We are also friendly with their Treasurer plus one of EJAF's Trustees. Sadly EJAF give us only token support. Simon Sainsbury's Monument Trust continues to be give away substantial sums of money - much to AIDS related causes, and is run by his widow, once a friend. Since Simon's sad demise there has been no further support from them. I am increasingly 'in the field' but neither EJAF nor Monument Trust respond positively to my suggestion that I bring them projects needing funding which are beyond AA's slender means.

Crusaid is run by people we know until it is taken over by the Terence Higgins Trust (THT). Crusaid has never supported us. Why are THT so well supported by private UK donors when they are focused on UK based needs already well funded by the State? Why does THT remain the fashionable HIV/AIDS give?

Absolute Return for Kids (ARK) continues to raise vast sums of money in London through it's Hedge Fund Trustees. Dr. Ashraf is now charged with deciding how this money is spent across southern Africa. We remain in contact with him. This might have allowed AA to access increased funding.

Friends might have left us substantial legacies in their wills but this hasn't happened.

Perhaps I should have been more focused on 'how to raise money' rather than on 'how to spend it'?

For a period the slow pace of our growth disappoints me. It seems that AA might be on the edge of becoming bigger and more useful but that this isn't going to happen.

October 2006, Jeremy & I make a trip to Geneva to meet Bilge Bassani, ex CEO of UNICEF and now the new head of FXB. Her experience soon proves a valuable asset to them. Bilge is very complimentary about the role we play within FXB and elsewhere.

Her wisdom eases my disappointment and particularly when she reminds us about the starfish story. How important it is to the few starfish that are saved, amongst the millions that perish, that a caring individual passed by and found them; that by casting them back into the sea saved their lives; that small is beautiful and important.

Third AA trip to India, February 2007

February 2007, I return to India. Much has changed since we started to fund FXB India in July 2005.

From Aditya Bondyopadhyay, NAZ's legal advisor, about NACO's ART programmes:-

'1st line is becoming available across much of India. The new challenge will be access to alternative more expensive 2nd & 3rd line for those who are failing on 1st line. These are currently not available through Government programmes. If AA are not prepared to fund these alternative combinations they should redirect their funds to countries where Government provision of 1st line remains unavailable.'

Aditya is based in central Delhi where standards are high. His view is based on best practice. In poor, rural Bihar and many of India's States, ART is, we understand, barely available at all.

More from Dr. Raju about NACO clinics:-

'They remain inadequate. They are not friendly and lack 'human touch'. Clinics are only located in large cities and towns - those from rural areas must travel long distances to reach them. Often patients are required to stay for 1 to 2 days to avail required services. How can people afford to be away from their work; to pay for transport and accommodation? Waiting areas are overcrowded. There is little privacy or confidentiality. Stigma remains high and many who are Positive prefer to commit suicide rather than be recognised by others during clinic visits. There are few counsellors and physicians cannot provide quality care due to the ever increasing numbers of patients. As a result about 30% of patients fail to be 'adherent' leading to drug resistance.

2nd and 3rd line currently cost 5 -15 times 1st line. We still only fund 1st line. It's hard to compute conflicting advice and to decide how best to spend scarce funds. It's hard to consider only numbers when you know individuals.

FXB follow updated WHO guidelines and now provide ARVs for patients who first present with a CD4 count of less than 250 - this figure was previously 200.

First AA Trip to Burma, March 2007

I continue my trip east to Myanmar - still called by many Burma and the name I will use. I last visited this country when I was 21 and travelling 'the hippy trail'. I am excited to be visiting a new country for AA.

From 'Preventable Fate' published by Medicines sans Frontiers (MSF) late 2006:

'Burma's Government spends the lowest percentage of its Gross Domestic Product (GDP) on health care than any other country in the world. International donor organisations give less to Burma, per capita, than any other country except India. Unsafe medical practices, like the reuse of unsterilised equipment, as well as insufficient blood screening, is a regular source of HIV infection. The paucity of accessible health care in conflict areas along the Burmese border make it difficult for AIDS patients seeking medical help. The criminal nature of sex work in Burma, prohibited by the Suppression of Prostitution Act, contributes to lack of awareness, minimal condom use and poor ART coverage for sex workers. In Yangon, there are over 100 brothels and up to 10,000 sex workers of whom less than 25% have been tested for HIV. An anecdotal study found that nearly half of all sex workers in Yangon are Positive.'

UNAids estimate at this time that as many as 350 - 500,000 people in Burma are Positive and that 75 - 85,000 are in immediate need of ART based on WHO recommendations. There is no effective Government ART Programme and it is estimated that more than 25,000 people die annually from AIDS.

MSF Burma, provide ART for 4,000; Population Services International (PSI) and Medicines du Monde (MDM) together for 2,000; FXB Myanmar for an additional 70. That leaves a minimum estimated number of over 70,000 Burmese people in urgent need of ART.

1st Line generics are available in Burma at £296 pp/pa. In India these same drugs cost £216 pp/pa. MSF Burma purchase the same drugs through an arrangement with UNAids for £117 pp/pa.

Kathy Shein heads FXB Burma and hosts a regular 'Sunday HIV Empowerment Group' which approximately 60 of their Positive service users and their families attend on the day I join them. Food, mostly rice and vegetables, is cooked in great steaming cauldrons over open fires. There is conversation and laughter despite the ever-present fear that must sit with these people.

Children find shady places where they play. These are threatened people who are happy to be in a welcoming place and together with others who are similarly afflicted. I tell them about Jeremy and how well he is doing on ARVs. This fact gives them comfort and hope. Everyone sings together.

There are only 2 Government hospitals; both are in the capital Yangon. Foreigners are not permitted to visit them. Doctor's salaries are paid by the Government but all other costs must be met by the patient and their family - hospital charges, procedures, medicines, etc..

Kathy's family appear to have money and have endowed a monastery in Yangon - it's abbot is her teacher. Together we attend an evening of chanting and dharma teaching which her venerable monk leads.

We agree to fund 1st Line for 20 FXB patients all of whom first present with CD4 counts of less than 250 or OIs. Dr. Frank Smithuis who heads MSF in Burma agrees to supply these drugs at the lower price available to them.

There is an urgent need in Burma to help Positive people access ARVs and for the additional funds to make this possible.

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We have known Alexander Johns since he was a boy and are thrilled, when, still in his early twenties, he decides to run the London Marathon for our benefit. When a young person with little connection to AIDS decides such a thing this moves us. Alexander raises a substantial sum, in excess of £10,000, and directs us to use the money for the care and treatment of sick Positive children. Ten years later, in 2017, after only 4 years of marriage, Alexander loses his beloved wife Sammy, also our friend, to an aggressive cancer. No one could have fought harder for life than Sammy and this fact reminds us how lucky Jeremy and others are to have survived a time before ARVs became available and to have gone on to enjoy many more years of health and happy married life.

For their Summer 2007 'White Tie and Tiara Ball', EJAF fly Lesotho's Dr. Mphu and one of AA's original beneficiaries, Keketso Serobanyane, to the Ball. Talk about Cinderella.

' My name is Keke. This is the first time I have been on an aeroplane and out of Lesotho. In 2002 my husband died of AIDS. In 2003 I became very ill and was diagnosed HIV+. I also had TB and could not breathe. I was so thin and my CD4 count was only 2. I owe my second chance of life entirely to Dr.

Mphu and Aids Ark. That same year they gave me the ARVs which saved my life. When I got better, I formed a Positive support group and started to give talks in schools and other public places. I am now the founding member and vice president of the Lesotho HIV+ Network. My CD4 count is 593. Recently I met the man of my dreams - he is also Positive. We plan to get married and together to continue to help save more Positive lives.'

What can Keke think of the extravagantly and provocatively dressed celebrities at Elton's Ball?

Spring 2007, through the introduction of Anne Aslett of EJAF, we meet Jamie Cooper Hohn, co-founder of the Children's Investment Fund Foundation (CIFF). By 2016, this extraordinarily well funded organisation - due entirely to the patronage of Jamie's now ex husband Chris and one of the world's most successful Hedge Fund Managers, can report:-

'CIFF's endowment has grown to a value of nearly £3.765 billion. In the 2016 financial year our grant disbursements totalled £181.5 million.'

We rather hope Jamie might embrace our small efforts and that we might suddenly find ourselves catapulted into the 'big boy' league. This doesn't happen.

However, what does happen, is that in July 2007, CIFF does us all a great service when Jamie introduces us to Anil Soni, CEO of CHAI India. She asks Anil if CHAI might agree to make 1st line available to FXB at the lower price negotiated by them, £148.00 pp/pa, as opposed to the price we currently pay, £216.00 pp/pa.

From Anil:-

'The prices we have negotiated with the drug manufacturers apply to national programs as well as large-scale procurements. Your program is unquestionably laudable, but the volume, whether for 100 patients or 500, is so small that it will not qualify for these prices. Instead CHAI will agree to supply FXB from their own stock at the negotiated price.'

This, with the assistance of FXB India's CEO Gourishankar Ghosh, is what happened. In addition CHAI supply free ARV's for all AA FXB Beneficiaries for 1 year. If you don't ask you don't get.

From Prof. Robin Wood who heads DTHF in Cape Town:-

'32,000 people are now accessing ART in the Western Cape Province. This represents 50% coverage for those, as per WHO treatment criteria, who first present with CD4 counts of less than 250 or OIs. This criteria will shortly be raised to 300 which will mean that the number eligible for ART will increase dramatically. Outside the Western Cape coverage is only 10 - 20%. In SA 1.5 million people currently need treatment. Every day 800 - 900 die from AIDS

related diseases and 1,200 become infected. Currently 5.5 million SA citizens are Positive.'

Coverage may mean lack of doctors, lack of medical facilities, lack of available ARVs and in this enormous and under resourced country it often means an amalgam of all of these factors. It's frustrating to know about high levels of unmet need, to be ready to help, but find it hard to connect with reliable rural Doctors. We continue to try.

It also means that, to many, the message to test and to treat is not getting through; that stigma, ignorance, traditional healers, machismo and poverty remain the reason. In a country where the levels of HIV infection are in excess of 18% of the population everyone who is sexually active should test. Clearly this isn't happening. Until the AIDS pandemic is brought to an end, everyone who is sexually active, wherever they live, should have, at least annually, an HIV and STD test.

More from Cape Town from where Rose Smuts tells me about their treasured family retainer:

'Thandi Nyalunga looked after our youngest daughter when I worked full time in politics. When Thandi got sick we tried everything. I brought her to CT; Jess was older then and tried to speak to her; I took her to Nozipho the clinic in Kyahelitscha; to Churchill Madikida's shocking art exhibition, Status, at Michael Stevenson's CT Gallery in 2005; to World AIDS day celebrations. We took her to a private clinic. She refused to engage, to test, to admit to being Positive, to go onto treatment. She died.'

Second AA Trip to Burma, January 2008

January 2008 I return to Burma with Jeremy. Our first call is to Dr. Frank at MSF. Since the previous year MSF have scaled up the provision of ART from 4,000 to 8,000 patients. Otherwise numbers on ART in the country remains largely unchanged. A critical shortage of trained Doctors is the main reason for the slow increase in the numbers helped.

From Dr. Frank:-

'It is important to keep this in mind. There is little effective Government ART in Burma and therefore most people with AIDS die - thousands of them. The number of those dying exceeds the number becoming infected and therefore the percentage of the population who are HIV+ is decreasing. This decrease therefore does not signify good news.'

PSI tell us:

‘80% of our HIV/AIDS Patients are also infected by TB.’

From Kathy Shein, FXB Burma:-

‘Great news, the 3 Diseases Fund (3DF) have agreed to fund ART for 150 PLHA. My plan is to integrate all 20 AA beneficiaries into this enlarged group. Funding becomes available March 2008.’

3DF is a consortium of European Government Funders and has a 5 year budget for Burma of \$US100 million of which \$US22 million has so far become available – split 60% HIV, 20% TB & 20% Malaria.

Kathy seems better connected than we appreciate and maybe has an additional agenda that she chooses not to share with us?

We are taken, by others, to visit one of several hostels which serve the Government hospitals. They provide shelter to outpatients who come from distant places. By chance we find Kathy there. She seems unsettled to be found by us addressing a meeting of elderly monks. In this country there is a troubled relationship and much friction between the monks and the military - a toxic mix. Progress towards bringing about a more democratic state must, of necessity, be cloaked in secrecy.

We attend another of FXB’s Sunday Empowerment Groups and meet two Norwegian representatives from 3DF. We also have the happy opportunity to sit down and talk with many of our beneficiaries. Jeremy tells his story to all attendees - recounts that he has been Positive since 1991 and remains healthy on ART. This wins a great roar of approval.

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In South Africa, in 2008, Thabo Mbeki's successor, Kgalema Motlanthe, appoints Barbara Hogan the country’s new Health Minister.

On the first day of Motlanthe’s presidency, Hogan announces:-
‘The era of HIV/AIDS denialism is over in South Africa.’

Shortly after, Motlanthe’s Government announce a mass rollout programme to provide freely available ART. This is a great day that is sadly much delayed in coming.

Fourth AA trip to India, February 2008

En route back to London we visit FXB in Vizak. On arrival we are delighted to be greeted by the members of the Elizabeth Frost Fellowship Community (EFFECT). The group have decided to honour the memory of my recently deceased Mother. They have applied a 'tilak' (the red henna dot that Indians apply between their eyebrows to signify a recent visit to the temple) to a large photo of her and have garlanded the image with strings of marigolds. They make puja, light candles and sing songs to honour her. Both Jeremy and I are greatly moved. Mum would have been both amazed and delighted. This newly formed group of approximately 40 Positive ladies, many of whom are AA beneficiaries, support each other and learn income generating skills. As elsewhere, where HIV/AIDS stigma runs strong, these ladies are excluded from mainstream society. Dr. Raju hopes that other FXB centres across India will form EFFECT groups.

During this visit we meet more than 20 beneficiaries. It is amazing to see the many changes which have occurred since we first spoke to Dr. Raju, July 2005. At that time most of his Positive patients believed their HIV+ status meant early death and their mental state reflected this. Most were withdrawn, fearful and in many cases suicidal. Now there is quite a different mood.

We meet Benzemen and his grandmother Chandramma:-

'I am happy that my grandson is healthy again. His appetite and his energy are good. I thank AA and my beloved Sponsor for extending life saving support to people like us.'

The following day we join members of the FXB family at the Albina Relaxation Camp. It's a joyous event with sari clad ladies running races, cricket of course, children playing games and having fun. These are people who formerly felt isolated, despairing and lost. Now there is joy and laughter - positive energy predominates.

Adequate nutrition is an essential component of effective ART. World food prices are rising and Dr. Raju recommends providing nutritional support to a number of his poorest Positive patients. We agree to contribute funds at a rate of £11 pp/pm.

From Dr. Raju:-

'The standard of Government ART in the cities of Indore, Bombay and Jaipur is now of sufficient quality and I am happy to allow existing AA beneficiaries in these cities to transfer to Government clinics. I am hopeful that this will soon be the case in Vizak. In time, we hope, that FXB clinics will only need to pro-

vide intensive care treatment to those who present with urgent or complicated medical needs. Subsequent treatment can then be provided, as with all other patients, at NACO clinics.'

Many of our 71 beneficiaries will be transferred. This is the development we have hoped for and have encouraged FXB Doctors to action.

It has always been our particular wish to help Positive MSM. With the exception of a few AA beneficiaries from Triangle Project in Cape Town and NAZ and LLS in Delhi, we have not been successful.

Again from Dr. Raju:-

'At the Government Clinics MSM are shunned and pushed to the back of the queue. Sometimes they are not seen at all.'

He tells us about Nestam, an MSM group in Vizak, and we ask him to find out more.

I write to our Soho Gym Members in July 2008:-

'Your generosity is saving lives. Currently AA fund ART for 90 HIV+ patients - 11 of whom are children. 75 additional people remain alive and healthy due to our earlier intervention and have now found places on alternate ART programmes. Sadly 5 people joined our programme too late and died. We continually search for new opportunities to extend support in countries where ARV's are still not freely available.'

Summer 2008, in London, I am contacted by David Primost who wants to know more about AA. We have mutual friends but have never previously met. I quickly realise that Dave is wise and compassionate. Earlier in his career he was a Research Fellow at Trinity College, Cambridge. He has a big heart and wants to further involve himself in good works.

I tell Dave:-

'I'm going to Asia later in the year to visit AA projects and to look for new funding opportunities. If you want to know more you're welcome to join me.'

I'm surprised when he immediately agrees. Given that we will be visiting Nepal, Dave suggests we also make a trek in the Himalayas.

I think we both feel nervous at the prospect of making a trip together when we know so little about each other; intense travelling with such a serious purpose and when one will be exposed to sadness and challenge.

During the trip Dave is respectful and patient with me. On a few occasions however, my pushy, passionate nature pushes him further than he is prepared to be pushed and he tells me so. This is good and after a short time we learn how to get the best from each other. I quickly develop a huge respect

and fondness for Dave. He is one of the finest people that I have had the pleasure of knowing and working with.

First AA Trip to Nepal, November 2008

November 2008 we arrive in Kathmandu the capital of Nepal.

Sunil Pant is famous as the first 'out' gay member of parliament in Asia. Nepali society is reflected in the make up of the government and Sunil was selected, rather than voted in by the electorate, to fill this role for the country's LGBT community. Sunil started and heads Blue Diamond Society (BDS) who:-

'Work throughout Nepal to improve the sexual health, human rights and the well being of sexual and gender minorities.'

BDS run a medical clinic for their service users many of whom are Positive. We invite BDS to submit applications for AA funding.

We meet others working in the field of HIV health. There is limited access to free ART in the capital and none, we are told, in rural areas. There is a shortage of trained HIV doctors. The country is poor and many parts of this mountainous kingdom are hard to reach.

Phillip Holmes - chorachori.org.uk, is an ex British Gurkha officer who in 1999 set up the Esther Benjamin Trust in memory of his late wife and with the objective of:- 'Rescuing and caring for vulnerable children in Nepal.' Jeremy and I have supported EBT since that time. We discuss with Phillip how AA funds might help Positive children in his care.

Our visit to Nepal coincides with a wonderful event - The Federation of Sexual and Gender Minorities Talent Contest 2008 - Beauty and Brains in Action to Tackle HIV/Aids. BDS are one of the organisers and we go with them, first to one of the regional competitions and then to the grand final.

In Pokhara, Nepal's second city, we follow up contacts including Star Children an orphanage for Positive children. Many of the funding opportunities we encounter fail to materialise due to an inability to communicate clearly in each other's language - an understandable but unfortunate reality. With Star Children we encounter a staff leader who speaks perfect English.

Fifth AA trip to India, December 2008

In Kolkata we meet members of the local FXB team plus others who run projects in neighbouring states. Khoi Dinesh is the Country Director (CD), of FXB Manipur - a State in the North Eastern Region of India:

‘ Ours is a border state which is visited by a large number of Burmese refugees who are unable to access ARVs - either in their own country or in India. It is a lawless area and the main route of heroin into India. In consequence many people on the border are either or both Intravenous Drug Users (IDU) and Positive . The sex trade there is especially active.’

People Like Us (PLUS) Kolkata was founded by the late Agniva Lahiri in 2000 and:-

‘Works for the promotion, protection and advancement of gender variant people and their health and sexual rights.’

Many of it’s members are LGBT and a high proportion are TG. PLUS have also set up shelters in Kolkata, Bihar and Uttar Pradesh.

Agniva, TG man to woman, tells me:-

‘ I understand the reasons for society’s hostility towards me and people like me. They reject us because we challenge their entrenched notions of gender and sexuality. Many people are afraid of the unknown and because of this do not want to know us.’

In conservative Indian society such people are often rejected by their families, forced from their family homes and scorned by mainstream society. Many feel forced to become sex workers. Amongst this group there are high levels of HIV infection as well as other STDs. PLUS members are badly treated at NACO clinics so are scared to go there for treatment. Agniva proves to be charismatic, fun and the inspired, passionate leader of PLUS. We visit their Kolkata centre and meet some of the group’s members. Dr Manabendra Sau of the Kolkata National Medical College provides their medical support. Based on his statement of medical needs we agree to assist 40 Positive PLUS members.

We attend a clinic at Calcutta Rescue which works for the poor and dispossessed. At the NACO ART Centre we learn about the the progress of India’s national treatment roll out.

In Vizak, Raju has organised a beautiful ceremony attended by a large number of the ‘FXB family’, including AA beneficiaries, to remember the 1st anniversary of my mother’s death. This group understands what contribution we have made to their lives and demonstrate this with singing and clapping. All attendees make ‘ puja’ to the photo of Mum. I give a speech of thanks.

We visit two of the initiatives set up by EFFECT's income generating groups - candle makers and dress makers. It is touching to find, in both of their small workplaces, the photo of Mum, freshly garlanded, together with the words:- 'Dear Madam - you live in our hearts now and forever.'

In order to encourage the candle makers I put in a decent order which arrives in London a few weeks later, candles in a range of spectacular colours. They look great affixed to the pair of tall glass candlesticks which stand on our dining table. Sadly there's a problem.... cheap wicks, poor quality wax. The candles have a habit of exploding.

Back in Vizak we meet FXB CDs from Kerala, Calicut, Goa, Tamil Nadu and Pondicherry. Dr. Raju and team continue to provide 'Medical Care and Support' for the benefit of 60 PLHA Vizak families which AA part fund.

Nestam run an organisation for MSM. They come to meet us and on the recommendation of Dr Raju, we agree to make a contribution toward the medical needs of thirty of their Positive members.

Dave and I visit some of our beneficiaries and families in their homes.

An 'Albina Relaxation Camp' is held to coincide with our visit and Dave proves to be a great star with the kids, playing cricket and running races. The joy of this event compared with the harsh reality of most of the participant's lives is both moving and humbling.

Third AA Trip to Burma, December 2008

Dec 2008 - In Burma our 20 FXB AA beneficiaries are now receiving ART courtesy of 3DF funding and are no longer our responsibility. Dave and I attend a FXB ' Sunday Empowerment Group' and I have the pleasure of introducing him to 15 of our former beneficiaries.

Dr. Frank has not found it possible to get additional funding from MSF to provide ART for more than his current 8,000 patients. He has therefore left these people in the care of MSF and has set up his own initiative, Medical Action Myanmar (MAM). We visit MAM's first clinic, the Thazin Clinic, outside Yangon. We agree to fund drugs and additional medical care for 50 of their Positive patients at a cost of £320.00 pp/pa.

We have high hopes that the PSI MSM group led by Habib Rahman will give us an opportunity to fund medical care for more positive MSM. We meet the

group's doctor who identifies areas of need. We are keen to help but, as is often the case with large international NGOs, their complicated methodologies makes it difficult for them to work with a small independent funder like us. This frequently occurring problem is disheartening when the need is clear for all to see.

Despite this disappointment we have fun with members of the group. They take us to a location in the city, a confluence of road bridges, where gays cruise each other and to a bustling evening fair, where a beauty competition of boys in 'drag' is being enjoyed by a large crowd of local people. We attend the group's X'mas party at which many of their members appear in lavish female outfits. The male gay world in the West mostly presents as overtly masculine. This is in contrast with what we have observed in both Nepal and in Burma during this trip. Dave proves very popular with the 'girls'.

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By the time we return to London Dave certainly knows more about AA. I am thrilled when he tells me that he wishes to commit both his time and money to advancing our ambitions. He quickly becomes an indispensable member of the AA team.

January 2009 from Rose Smuts:-

'You will remember meeting Johann Viljoen, SACBC in 2002. He heard your angry words and shortly thereafter started on ART. His health is now fully restored. Now SACBC are funding ARVs for more than 19,000 people.'

Spring 2009 I write to Benzemen's former sponsors:-

'We last met Benzemen and his Grandmother when we visited Vizak in December 2008. He is growing up and now is a healthy, happy, lively child albeit with some brain damage. He seemed delighted to see us when we met and rushed up to give us a hug. Together with others we played cricket 'of sorts' - needless to say he was much better than me.

April 2009 from Dr. Raju:-

'Aids Ark is doing God's work for our people with HIV/AIDS. They have helped us save many lives and work tirelessly to leverage funds from other larger donors. There is a chronic shortage of trained HIV Doctors in our country. It is very hard to access ART in remote areas.'

We are sad to learn about death of our friend Robert Key following a courageous fight with cancer. In the year before his death he was awarded an MBE

(Member of the Order of the British Empire) for his service to charity over the past fifteen years. Anne Aslett replaces him as EJAF's new Executive Director.

During the 2009 / 2010 grant period AA makes grants totalling £64,883. which fund ARVs and medical care of 75 individuals plus associated medical care (excluding the cost of ARVs now funded by others) for an additional 273 individuals - a total of 348 people.

In December 2008, through the introduction of our friend Rob Common, then working for Hope for Children (HFC) and focusing on their African projects, we receive an application for funding from the Kawempe Home Care Initiative (KHCI) in Uganda. By May 2009, through HFC, we start funding ARVs plus additional medical costs for 80 KHCI Positive patients. Uganda, now joins the list of countries where we work.

The North Eastern Region of India comprises eight states; 7 of which, including Manipur and Mizoram, lie to the east of Bangladesh almost entirely separated from India. The region borders Burma, Bangladesh and Bhutan. Since independence from the British in 1947 it's isolation has increased and there are many in these states who wish to become independent of India. Separatist insurgents hide out in the mountainous terrain fighting to become free. In consequence much of the area is heavily militarised and the Indian Government keeps these states poorly resourced.

We follow the advice received from Khoi Dinesh concerning Burmese migrants. In July 2009, at Moreh, a town that lies on the Indian side of the Manipur border with Burma, an FXB AA Clinic opens to provide ART and medical care to 100 Positive patients at a cost to us of £287pp/pa. (£176 pp/pa for the cost of ARVs and £111 pp/pa towards associated medical costs including salaries). The beneficiaries are Burmese migrants who cross the border on a day pass to access treatment.

In India the movement to repeal Section 377 was led by the National Foundation for India (NFI). They filed a lawsuit in the Delhi High Court in 2001 seeking legalisation of homosexual intercourse between consenting adults. In 2006 NACO filed an affidavit stating that the enforcement of Section 377 violates LGBT rights. NFI versus Government of Delhi 2009, was a landmark case, decided by a two-judge bench of the Delhi High Court, which held that:- 'Treating consensual homosexual sex between adults as a crime is a violation of fundamental rights as protected by India's Constitution. The verdict result-

ed in the decriminalisation of homosexual acts between consenting adults throughout India.’

Mid 2009 we add the following statistics to our AA website:-

‘Over 22 million people have died from AIDS. Over 33 million people are Positive. 74% of those who are Positive live in sub-Saharan Africa. Over 19 million women are living with HIV/AIDS. Currently, there are 14 million AIDS orphans. 14,000 people become HIV+ each day. HIV/AIDS is a disease of young people - half of those who become Positive are aged between 15 and 24.’

By September 2009 AA has directly helped to save 569 lives and by default become life savers to many additional family members. To date just twelve people on our programs have failed on treatment and died.

Second AA Trip to Lesotho, December 2009

At the end 2009 Jeremy and I, together with our friend Maurits Kalff, accept Dr. Mphu’s invitation to visit Lesotho and:-

‘View first-hand the direct impact AA has had on our country; to witness the inspiring advancements that continue from the foundations AA helped lay.’

Dr. Mphu is flattering given the much larger contribution she has made.

She tell us:-

‘No country can galvanise the forces necessary to meet the challenge of HIV/AIDS unless this country’s Government is itself truly committed to do just that.’

About Lesotho at this time:-

‘Average life expectancy is 34 years. 49% of the adult population is unemployed. Average annual income is \$US150. 26% of the population is Positive. 90% of those living with HIV/AIDS also have TB. There are an estimated 95,000 AIDS orphans - many of whom are Positive. Only 80 Doctors serve a population of 2.2 million. Many of the people are severely under nourished and there are no current food welfare programmes.’

Also from Dr. Mphu:-

‘Our newly developed Expert Patient Programme is an example of how the initial assistance provided by AA has made continuing improvement a reality. The Expert Patient (EP), is an Positive patient who is open about their status and demonstrates to others the efficacy of ART. They support patients at the first point of medical contact. They are trained to provide basic nursing and

administrative services and to assist an understaffed and underfunded health service. They support and motivate other patients and teach them about the importance of adherence. CHAI pay each EP a monthly stipend of \$US 85 per month. We hope that AA will help us expand this initiative in the pursuit of complete care for the people of Lesotho suffering from HIV/AIDS.'

Again mention of complete care, repeating Dr. Raju's ambitions.

Much has been achieved since the birth of the Karobong Clinic, started in May 2003, for the initial benefit of eight of Dr. Mphu's Positive patients.

5,400 Positive patients come for treatment to the Karobong HIV/AIDS Treatment Centre each month. The centre offers the best care available in Lesotho. Despite this, we meet only one Doctor and most of the work is carried out by nurses and EPs. The facility is overcrowded, many of the attendees are profoundly ill, most are undernourished. There is limited counselling, which results in low standards of adherence and high levels of resistance.

At the Centre we meet 5 former AA beneficiaries including Keke. We were happy to learn they are working here as EPs:-

'Once people hear that medicine is available more come forward for testing. Men are still not testing even though they are the main cause of infection. Most refuse to practice safe sex. Levels of stigma are greater among men who often remain in denial. We do not see them at our clinics until they are already seriously ill and sometimes beyond help. In many areas of our country there are no doctors or medicine.'

Later in our visit, Keke invites us to her house where we are thrilled to meet the man of her dreams, now her husband.

Thabang is another of our original Lesotho AA beneficiaries. With his health restored he again works as a teacher. We visit him in his classroom.

We ask about assisting MSM in Lesotho where homosexuality remains illegal. 'We don't know these people, they are hidden, their need must be very great.'

The CHAI representative tell us:-

'Securing trained medical personnel is the biggest challenge facing the country. Many trained staff leave the country in pursuit of higher salaries abroad.'

The need to expand ART in Lesotho remains pressing.

Following our visit AA offer £22,500 pa. to advance the EP Programme. Dr. Mphu directs us to arrange this through CHAI. Sadly the methodologies of CHAI prove so complex that our offer flounders within CHAI and never goes live.

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Simon Sainsbury has been true to his word and has donated £5,000 to AA annually since 2002. Sadly he falls victim to Parkinson's Disease and dies in 2006. We are moved when, in December 2009, two of Simon's closest friends, James and Clare Kirkman, also our friends, having learnt about Simon's annual gift, decide to donate in his place and at the same generous level through their Aldama Foundation. This 'replacement' donation has continued every since. Simon would, I'm sure, be as grateful as we are, that his generous friends continue what he started.

Third AA trip to South Africa, January 2010

January 2010, in Khayelitscha, one of the sprawling townships outside Cape Town, I meet Rosalie Mashale - Mama Rosie. Rosie is a big hearted lady from the Eastern Cape and founder of Baphumelele, meaning progress in Xhosa. Baphumelele comprises a Children's Home for 100+ orphans, a Day Care Centre for 230 children and a Respite Centre - in effect a mini hospital for those who are infected by multiple infections including HIV and TB. Many people know about Rosie's amazing achievements; her work has attracted funding from many sources including EJAF. She now wants to set up a medical outreach programme and asks us for funds to help. We agree and Hospice in the Home (HinH) is born. Working in conjunction with their Respite Centre medical team, Baphumelele appoint a senior Nurse and two carers to work in the townships locating and caring for patients who are failing to access the medical care which is available at the local Government Hospital. There are many who die in their beds for want of this care. AA contribute to the HIV component of this work.

Only AA trip to Uganda, February 2010

February 2010 from the activist organisation Avaaz:-
'The Ugandan parliament is preparing to pass a brutal new law, the Bahati Bill, which proposes life imprisonment for anyone convicted of having same-sex relations and the death penalty for serial offenders; seven years in jail for

promoting homosexuality; three years in jail for any member of the public who fails to report homosexual activity to the police.’

I visit Uganda the following month March 2010 - perhaps my darkest and most depressing AA field trip. In the capital, Kampala, I meet the HFC CD, Immy Kijza. We visit a HFC orphanage and take four of their young residents out for lunch. They leave not a crumb of food on their plates. After lunch Immy and I take them on a boat ride on Lake Victoria. They have never been on a motor boat before.

Immy takes me to visit one of the many slums that lie adjacent to the railway lines into Kampala. HFC and KHCI both work here. These are desperate places - some of the worst and ugliest that I have visited. Open sewers run along muddy litter filled alleyways. Broken materials provide the most basic kind of shelter. People defecate amongst the train tracks in full sight of others.

I visit the Kawempe Clinic run by KHCI. It is a dirty disorganised place; file drawers hang open and empty; the dispensary is almost empty of medicines; a 3 bed ward is miserably furnished. It is not a clinic day and there are no patients. The KHCI Doctor, Dr Guma, arrives in a large shiny 4x4. I chase the administrator who accompanies him for overdue reports.

We head to their second clinic driving there through communities of dejected looking people along broken dirt roads. The Kasangati clinic is housed in a substantial brick building. On arrival staff and patients, greet us with song. The older ladies are wearing striking traditional dresses. I am asked to talk with the assembled company who sit, partially out of the incessant rain, under a leaking plastic cover. We exchange stories through a translator. A high proportion of the patients are Positive. It is sad to hear tales of their hard lives. After, I sit in with Dr Guma and one other doctor while they consult. I am shown the basic dispensary where ARVs are in evidence and where patients come for their ARVs and other medication. They give us lunch. What I eat looks and tastes horrid - something black and mushy served on an old banana leaf.

In the afternoon Immy and I accompany Dr Guma and two of his medical team visiting patients in their homes - basic shacks dotted amongst farm land. The landscape is lush, green, wet and muddy - the typical red soil of Africa. It has been raining most of the day. On our last call we meet an old sick man who appears to live alone. He is in terrible shape and during the consultation his gangrenous wound is cleaned and redressed. The man is in pain and looks weak. One of the accompanying nurses, Joyce Guardian An-

gel, is a large lady with an equally large voice. Before saying goodbye to the patient she sings, most movingly and beautifully, a prayer asking for God's help.

On the way back we are taken to see the old Government Hospital. It is empty and dirty with rusting beds stacked up in derelict rooms.

Through an introduction from Peter Tatchell in London, I met various individuals heading clandestine activist LGBT groups. To be openly gay in Uganda is to put one's life at risk. You can feel that these people live in fear. I meet David Kato from Sexual Minorities Uganda (SMUG).

I ask what AA can do to help:-

'Anyone suspected of being gay will not be treated in the public hospitals or by most doctors; they are considered scum - not worthy of help.'

I suggest that AA fund doctors known to these groups and who are treating Positive LGBT people.

Our friend and landlord at Needsore, Lord Montagu of Beaulieu, gives me an introduction to the Kabaka (King) of Buganda. Edward sits on a Foundation run by the Kabaka which, so he tells me:-

'Does excellent humanitarian work including HIV/AIDS initiatives.'

However, since 2008, this Foundation has published no accounts.

I write to the Kabaka telling him that AA funds HIV work in his country and receive an invitation to an audience. Should I mention the proposed Bahati Bill? The King was educated in the UK; surely he will have a western view; surely he will seek to prevent the adoption of a law that condemns gay men to death? In the event I do not have to decide. On the day prior to my audience there is a fire at the Royal Palaces and my meeting with the Kabaka is cancelled. Later I am saddened to learn that the Kabaka supports the Bahati Bill.

Much of the Uganda I see feels dark, sad, dangerous and cruel; a place where bad things go on and where a person might simply disappear. My visit to Uganda scares me.

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During the 2010 / 2011 grant period AA makes grants totalling £50,360 which fund ARVs and medical care of 95 individuals plus associated medical care (excluding the cost of ARVs now funded by others) for an additional 306 individuals - a total of 401 people.

On my suggestion, FXB make two applications to EJAF for funding. Both applications are unsuccessful. Applications to AA for funding have become progressively simpler whilst remaining, we hope, secure. EJAF have gone the other way with an application process which I, with a perfect command of English, find dense and complicated. If my English skills were limited I would find their process impossible to follow. The same applies to their reporting requirements.

I try my hand applying to EJAF. July 2010 I make an application for funds to fund the expansion of the FXB AA Clinic in Moreh.

After too long a delay I hear back from Mohamed Osman, Head of Grants, EJAF:-

'Thank you for submitting your revised concept note titled Medical Care and Support for Myanmar Migrants in India Infected with HIV/AIDS. Unfortunately it doesn't score enough to be invited to the next stage. Although the concept scores highly in some regards including working with highly marginalised beneficiaries in difficult circumstance, we are unsure about the provision of ARVs. We believe this to be a lifelong commitment. We completely get the need. HIV+ migrants in Manipur State are dying because they are ineligible to access ARV therapy. However providing ARVs to 100 people for 3 years will not necessary solve the problem. Perhaps it might be more prudent to invest efforts at challenging legislation which prohibits migrants from accessing ARVs and which would potentially change the landscape for migrants in relation to healthcare.'

If I were one of those 100 people access to ARVs will most assuredly solve my problem - at least in the short term. It will give me 3 more years of healthy life as opposed to a premature death. It will give me the opportunity to care for and love my family and to keep us complete for 3 more years. It will give me the extra time I need to ensure my children a better start in life. It will give me the opportunity of being alive to take advantage of future longer term solutions that may become available to me.

What would you, in similar circumstances, want for yourself and for your family?

EJAF are adopting a macro position - I understand this. Providing ARVs to 100 people for 3 years will not necessary solve the problem, the bigger problem, the long term problem, the numbers problem. AA however take a micro view and considers the person who actually has, who actually owns the problem. We consider those one hundred individuals' needs and wishes, the

needs and wishes of their families. We're not going to change the world. We're in the starfish business.

In the meanwhile, maybe our example of micro care will be noticed by others and will encourage others to address and maybe even resolve the macro need.

AA helped do just this in Lesotho.

Not being good at taking no for an answer, I dispute this response with EJAF who agree to fund, for three years, medical care and support but not ARVs. It's a fudge which allows EJAF to escape the possible future censure for providing and then withdrawing life saving medication.

EJAF funds will not allow us to increase the number of patients we treat in Moreh - the chronic shortage of trained medical staff prevents this. However, sharing the cost burden of running the clinic at this present size will release AA funds for use elsewhere. We are grateful to EJAF for that.

Hopefully others better funded than us, NGO's run by paid experts as opposed to volunteer amateurs, will address the important objective proposed by Osman:-

'Challenging legislation which prohibits migrants from accessing ARVs and which would potentially change the landscape for migrants in relation to healthcare.'

Maybe EJAF will take on this challenge? I hope so.

Add here the importance of EJAF re macro - their proposed reorganisation described by JB 2018 - their huge achievements and far larger numbers ultimately saved - a compliment not a criticism

October 2010, great news, the greatest news to me - Dave Primost agrees to become an AA Trustee.

Nov. 2010, from Steven Kraus, UNAids Director for Asia and the Pacific:-

'The key propagators of the Asian epidemic are well known: sex workers, intravenous drug users, and MSM. It is MSM that are proving the most difficult segment to reach. We have underestimated the MSM issue.'

Recently, the Global Fund made two grants - \$128M & \$25M, specifically to fund MSM, TG and Hijra needs projects. FXB & AA wish to support such

projects in relation to HIV. FXB tell us about their MSM project in the north eastern Indian state of Mizoram.

I decide to try my hand as a film maker, to shooting video to better promote our work. I have no knowledge how to do this properly. I have no understanding about the requirements of film editors. It's pretty tough to appear in an event whilst also recording it. I'm thinking of actors who direct while at the same time play leading roles; of concert pianists who simultaneously perform and lead their orchestras. Nonetheless I have a go. I return to India and Vizak in November 2010 together with my excellent stills camera which doubles as an HD video camera. I have all the add ons to hand - microphone, tripod, etc.. I take my camera to Dr. Raju's clinic and film clinic exchanges. I visit former AA beneficiaries in their homes and they tell me their stories to camera - of course we speak different languages. I film from taxis and rickshaws. All participants are patient with my untrained and rather muddled efforts. I add film maker to my AA roles.

The Vizak MSM group Nestam have proved incapable, despite chasing from Dr. Raju, of sending us reports and updates. We have warned them of the consequences. We must know that AA funds are used for the agreed purpose and to what effect. We are not satisfied and with Dr. Raju's agreement discontinue Nestam funding. AA remain particularly keen to support LGBT/ MSM groups and loosing Nestam is a sadness to us.

Sixth AA trip to India, November 2010

FXB have obtained the special permission, an internal visa, that is required for foreigners wishing to visit Manipur State. I am disappointed to learn this permission will not allow me to leave the capital Imphal. I fly there - Khoi and Dr. Raju greet me at the airport. It's comforting to arrive at an unknown place to such a welcome. Together, we visit two FXB community projects in the city. They advise me that's it's not safe to go out at night.

From Khoi:-

'In Moreh, ART was not available to Indian citizens until a few months back; the supply of ARVs is still only enough for 25 patients. ART for Burmese migrants is available only at our AA FXB Moreh clinic. Over the border in Burma there is no ART for these people.'

It is frustrating to be near to our clinic but unable to visit it. Instead FXB have arranged for a few of the Moreh patients to make the arduous five hour road

trip to Imphal to meet me. I am anxious when I learn that they have made this trip illegally and at some risk to themselves; that to get here they have been stopped at numerous military roadblocks; that they have compounded their risk by overstaying their single day border passes. Our conversations assure me of their great need and the success of our small Moreh clinic. They confirm there are no clinics providing ART on the Burmese side of the border. I am relieved, when I learn that they have all return safely and without penalty to their country.

In the adjacent state of Mizoram I am registered as the first foreigner to visit the State that month. I take a rather decrepit taxi from the airport to the mountainous capital Aizawl. The road climbs through dense jungle, multitudes of colourful butterflies flit between tropical flowers. The air becomes cooler and fresher. It's a beautiful drive.

FXB runs projects in Mizoram and tell me:-

'Maybe 5,000 of our Mizo people are Positive. Some 1,500 are registered with the ART Centre at Aizawl Civil Hospital. Most people live in rural areas that are hard to access and where ART is not available.'

Doctor Vanlalhriatpuji heads the ART Department at Aizawl Civil Hospital and seems satisfied with the standard of care they provide.

However, a doctor from another Hospital tells me:-

'At Civil Hospital you have to buy medicines; it's a crowded place; the quality of care is uncaring, critical and abusive; many present with late stage AIDS and die.'

I learn that Burmese migrants to Mizoram share the same ethnicity, speak the same language as the local population and are allowed to cross the border and access the limited available ART.

From FXB Mizoram I learn:-

'Sex workers operate illegally - penalties are severe. As with MSM people, they are a hidden group, at high risk of HIV and STDs and reluctant to attend clinics for testing and care. The Christian Church is powerful here and exercises great moral authority. It's teaching is not supportive of these minorities and their needs. The Church turns the people against MSM. All problems come from the pulpit. Alcohol is illegal and heroin is readily available. The Government Rehabilitation Centre is closed due to lack of funding. There is only one needle exchange programme.'

FXB Mizoram run an MSM programme which has, they tell me, as many as four hundred service users. Boys from this group welcome me with dancing and singing.

Only 53 of their number have taken the HIV test:-

‘ Most of us are too scared too test.’

Of this number 15 are Positive and receive ART from Aizawl Civil Hospital. Dr Didiki provides weekly medical care to this group and asks for funds to help her extend this support. The application we subsequently receive from FXB Mizoram is so poorly written and ill considered that, with regret, we decide not to support their work.

What happens in such instances? It happens time and time again. The need is present. The need matches AA objectives. We have contact with the doctor or the organisation who serves the need and who know that AA may agree to provide the necessary funding. The will and the ability to apply appropriately, using our now simplified application process, so often falters, responses to our email questions lessen, the application fails. Why? Is language at fault? I think it's also something to do with lack of confidence on the side of the applicant. A sense that the world has so often failed them and why should AA prove any different. Why make the effort? Laziness, inertia, overwork? Writing and advancing applications is a specialist task often left to unspecialised people for whom the application language is not their own. Sadly, over the years there have been many instances of failure to convert funding opportunities into funding realities. Something gets ‘lost in translation’. The need is there, many continue to die from lack of ART, but finding a way to serve that need securely is so much harder than one might think.

At the airport leaving Mizoram for Kolkata, I meet Baroness Caroline Cox - Deputy Speaker, UK House of Lords 1985-2005, and Founder President of Humanitarian Aid Relief Trust (HART). Caroline and her team are returning home following a mission to assist the Chin People, another beleaguered group, living in adjacent Burma.

From Caroline:-

‘There is no medical care or health education available to the Chin People.’

Third AA Trip to Burma, November 2010

Since my last visit ,Burma has received a grant from the GF of \$US 3.5million, to be paid over 5 years, to fight Aids, Malaria and TB.

Despite this Dr Frank at MAM tells me:-

‘By comparison, international humanitarian aid levels to this country remain low - \$US25 per head of the population in Cambodia, \$US20 in Laos and only \$US4 in Burma. As many as 50,000 PLHA people in Burma remain unable to access ART.’

The cost to MAM of 1st line has dropped, reducing the annual donation we need to make them for the same benefit from £320 pp/pa to £263pp/pa. Instead, by keeping the value of our grant unchanged, we can now help Dr. Frank and his team save eleven more lives; a new total of 61.

I spend World's Aids Day, 1 December 2010, celebrating with FXB. It's very well attended by young and old alike and is a joyous event. There is singing and dancing. I give a short speech that is simultaneously translated and is received with clapping and cheering. I meet with 19 of our 20 former beneficiaries. Sadly one of this group has died but the rest are enjoying good health and now lead normal lives.

'Through the assistance of AA and FXB we are reborn.'

First AA Trip to Thailand, December 2010

Burmese persecution of the Rohingya and Chin people that live in the west of the country is echoed by their persecution of the Karen people in the east. Many Karen people are driven over the border into Thailand and most particularly to the border town of Mae Sot.

I go to Mae Sot to meet some of the NGOs who work there and the PLHA Karen refugees who live there.

'Some of us have hidden here for years. When there is no fighting over the border the Thais try to send us back. Thai people get free ART, but this is only available to very few Karen. There is no free ART on Burma side – no money, no treatment.'

In 1988, in Burma, during the ruling military junta's violent suppression of the pro-democracy movement, Dr. Cynthia Maung was among the many Karen who fled across the border into Thailand. Shortly after arriving in Thailand she established a makeshift facility in Mae Sot to treat the injuries sustained by fellow refugees. The clinic, called the Mae Tao Clinic (MTC), has grown and now offers a wide range of health care and social services. Dr. Cynthia is now highly respected internationally for her humanitarian work. MTC continues to care for sick and wounded Karen refugees who are still forced from their villages; villages which are invariably burned to the ground in the junta's ongoing scorched earth policy.

MTC comprises a collection of mostly single story buildings scattered around a peaceful tree-filled compound. Despite being a residential hospital with mul-

tiple wards, treatment rooms and even a small operating theatre it feels more like a rural village. There are communal kitchens, washing facilities, food stalls and benches for all the many people who come and go during the day. Children play. Medics stride-by focused on their urgent work. There is the constant sound of voices, laughter, vehicles and bird song. There are umbrellas and shade. It is a happy and safe place for these people.

MSF recently closed their ART Karen programme in Mae Sot.

From Dr. Cynthia:-

‘We have the capacity to provide ART for some of this group but no available funds. Their need is urgent. Without immediate ongoing access to ARVs they are at risk of developing drug resistance.’

AA agree to fund ARVs for twenty of these ex MSF patients at a cost of £286 pp/pa - £183 for ARVs and £103 towards additional medical costs. Other NGOs in Mae Sot have pressing ART needs but with limited funds we decide to focus our support on MTC.

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We first met Martin Franklin, a young South African, through a mutual friend in 2005. He becomes a close friend. He has a commercial background in branding and marketing and despite his young age has a senior position with an international company. He is focused, talented and has a good heart. He has helped us with the rebranding of our growing gym group, Soho Gyms. He volunteers to turn his attention to AA.

November 2010 I introduce him to Dave who reports back:-

‘Martin is offering to use his expertise to review the AA brand and the website to help make what is important about our work clearer. This contribution will be really valuable.’

Martin, who starts to do just this and to great effect tells us:-

‘I particularly admire what AA does in the field. The pioneering nature of this will be attractive to young people who are looking for a life-changing experience by association.’

Martin speaks about the ‘Brand Equity Illustration Pyramid’ and sends me a graphic image relating to AA to clarify the meaning of this. We are very pleased when Martin starts to become ever more involved in advancing AA’s work.

December 2010, Dave hears about an opportunity to leverage the donations we receive through The Big Give (TBG), an NGO that has substantial funds to promote charitable giving. TBG have decided that a good way to encourage this is to match donations made to the charities they select. Not surpris-

ingly this becomes so successful that available funds are exhausted almost as soon as their telephone lines open. TBG now have a better regulated system and we have been a beneficiary of their matched funding, except for two years, every since. Extra income from TBG is a substantial addition to our funding.

Dr Reon van Dyck, based in CT, is a young doctor with a big reputation. He's a successful infectious disease's specialist, who also founded and runs Positive Lives, an initiative which offers complete HIV management.

'It still excites me to notice the shine in the eyes of new patients when I tell them about the growing number of my existing patients that have been HIV+ for more than 20 years. The chances are good that they too will attend their grandchildren's weddings one day.'

Reon and his team have successfully obtained the agreement of many Positive SA celebrities to go public about their status and to become Positive Heroes. In a country where levels of infection, stigma and fear of HIV infection remain so high, these Positive Heroes have encouraged many more people to come forward for HIV testing and medical care. Positive Heroes undoubtedly helps to save lives in SA.

Dr. Reon provides pro bono medical care to the patients at the Nazareth House (NZH). Respite Centre, which is where we first meet. Since that time he has become Jeremy's HIV Doctor and our friend.

In January 2011, David Kato, whom I met in Uganda less than a year ago, is murdered during a brutal homophobic attack.

The Ugandan Minister of State for Ethics and Integrity declares:-

'Homosexuals can forget about Human Rights.'

His death unleashes great upset and anger around the world but the Ugandan Government remains unmoved. I knew this man. He was gay just like I am gay. I also am upset and angry.

From Baphumelele HinH, Khayelitsha, Cape Town, February 2011:-

'With the assistance of AA funding, HinH is now one year old. We provide the sick people in this community with ARV & TB treatment, physical, social and emotional support, wound care, symptom control and access to health and social services. We are valuable to these people. The HinH team live in this community and know where those in greatest need can be found. The working relationship between the staff at our Respite Centre and HinH is good. The Respite Centre staff can now be confident discharging patients to their homes, knowing that they will be followed up by our team. The current number of HinH registered patients is 120. It was a pleasure to welcome Derek.

We had a valuable and moving morning visiting patients in the community. His visit was much appreciated.'

Despite several requests for reports etc. we have still received little information from KHCI in Uganda. We are continually mindful of the potential abuse of AA funding and in April 2011, with regret, we discontinue their funding.

Our friend Ian Greer runs the Helderberg Street People Project serving the desperately poor community of Helderberg located in a rural area outside CT. In April 2011 and annually thereafter, we make a contribution of £2,000pa towards the medical costs and related medical needs of 40 of his Positive service users.

Since the early days of AA we have sent intermittent reports to donors. Dave and Martin now decide to replace this with a regular electronic newsletter which they do to great effect. The newsletter is sent to all on our funders' and supporters' database - now, under their lead, a fast expanding list of names.

From our first newsletter Spring 2011:

'In December 2010, AA took part in TBG's Christmas matching campaign where each £ donated is doubled with matched funding. The campaign raised an incredible £25,640. AA overheads are paid for by the Trustees so 100% of all donations we receive go directly to AA beneficiaries. Supporting one individual with ARV medication and medical support for one year costs £263 in Burma. This matched donation will now fund ART for thirty additional people for three years.'

During the 2011 / 2012 grant period AA makes grants totalling £48,594 which fund ARVs and medical care of 125 individuals plus associated medical care (excluding the cost of ARVs now funded by others) for an additional 335 individuals - a total of 460 people.

In September 2011 the AA web site is redesigned and modernised and our operating systems are much improved. We hear of other charities spending thousands on their web sites and operating systems and are grateful to have been able to achieve all this at no cost. We start to develop a Social Media presence. Martin speaks about the 'Brand Equity Illustration Pyramid' and sends me a graphic image relating to AA to clarify the meaning of this. We are moving forward in the hands of newly involved, motivated and skilled 'young bloods' - so exciting, and much appreciated by Jeremy and myself.

Dave and Martin tell me about their new fundraising concept which they are calling Dinner for One (DF1).

'There's a group of people who are keen to form a Fundraising Committee and to make this happen. We feel that targeting thirty dinners and a £10K fundraising target is a good starting point and in line with your growth goals. We like the idea that one dinner saves one life for a year, £300 pp/pa.'

They form a Fund Raising Committee and Events Team of enthusiastic, multi talented friends, mostly gay friends, and DF1 is born. Each host will invite their friends to dinner. Each guest will be asked to donate at least £50. Six guests means a total donation of £300 or more. Later the same evening a London 'after party' is planned. Diners from all over the city will converge to party and hopefully make further donations. It's a great concept - modest, simple, effective and fun for all who attend.

September 2011 the number of beneficiaries that AA support through MAM increases from 53 to 75.

From our Autumn 2011 Newsletter:

'AA, the charity at the frontier of ARV availability - working to transform the lives that need help most; How We Do What We Do; The Best Way To Give; Project Snapshot Burma; Frontline Doctor Profile; Dinner for One; New Promo Video; Ultra Runner.'

Richard Hewitt, is our Ultra Runner, donates his sponsorship funds to us and has raised over £4,000 to date.

'One of the joys of running is that I get to give something back through raising money for charity. I made the choice to commit my running charity efforts 100% for Aids Ark because of the real difference they make to the lives of Positive individuals.'

Recently Richard ran the challenging Marathon des Sables - a cross Saharan event of three marathons in three days.

Aids Ark Founder Trustees Derek Frost and Jeremy Norman become regular November - March residents in Cape Town, South Africa

Annually, from November to March, we are based in CT. In 2011 - 2012 I take advantage of this to become a volunteer at NZH CT. We first visited it in 2002 when the NZH Nuns rejected our offer to fund ARVs for a few of their young resident Positive orphans - a rejection which shocked and saddened us. NZH provide caring services to the local community. Under the inspired leadership of SRN Lizette Robbins (now Oliver) they also run a Respite Centre - a small scale medical facility and short stay residential home, for indigent people with

chronic health issues - many suffering from late stage AIDS. It is a sunny calm place filled with colour and run by attentive and caring staff. I enjoy my days there, assist as I am instructed and otherwise spend time making portraits and chatting with the residents. I form a particular attachment with a young Xhosa girl Zandile. We really connect and I am happy to have added some moments of joy and comfort to the last days of her life. I feel honoured to be holding Zandile's hand when she dies of AIDS related OIs. Despite the expansion of ART worldwide, many like her still continue to die from AIDS.

New friends at Home Brew Films in CT, give me pro bono access to one of their brilliant young film editors and together we craft AA's first promotional video. I'm very proud of it. It proves to be useful in showing others what we achieve and for fundraising. This video can be seen on the AA website www.aidsark.org.

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Early 2012, Martin tells me:-

'I've met a really great man - maybe THE man.'

I'm pleased for him but have absolutely no idea that the man in question is Dave. When I learn this I am amazed and delighted. Dave and Martin have now become a couple - as wedded, it seems, as the two of us. We are thrilled to have inadvertently played the role of cupid between two such dear friends, important people in our lives and both now AA Trustees.

The current world recession is causing funders, including even the biggest such as GF and The US President's Emergency Plan for AIDS Relief (PEPFAR), to slash budgets. Many humanitarian programmes across the world are being forced to close. The advance of national ART roll up schemes slows. At the same time the number of those infected by HIV continues to grow. Many PLHA continue to die.

February 2012, AA hold their first fundraising event - DF1. A total of 45 dinners are hosted in London, New York, Malta and South Africa – raising over £16,000. The London after party raises an additional £2,000. We are not in London at the time but it is evident from the images sent to us, that a high proportion of those supporting us are gay and young. This is due, in part, to the make up of our Fund Raising Committee, most of whom are also gay. There is however something else at play which touches me deeply. Many of these young gay men never knew the world pre AIDS; may not know that AIDS was first considered The Gay Plague; do not have friends who died of AIDS; know that HIV infection will only inconvenience them and will not kill

them. Yet here they are, supporting AA, when so many in the straight world have moved on to support more fashionable causes, and giving money to help those who are Positive and who still die. It seems that the gay world still retains a particularly empathy with and sympathy for those who become Positive even though they may know little about the history of this tragic pandemic.

Following DF1 I write to the members of our Fund Raising Committee:-
'You all know about AA's life saving objectives; that £18,000/300 equals 60 lives saved for a year; that sixty lives actually means sixty families; that effective ART reduces the spread of infection to others; that more healthy Positive people means less stigma and more people testing. Your efforts will save the lives of people we know and many more.'

Since 2006 Soho Gyms has been a great supporter of AA. Annually they have planned events to promote us and to raise money. Since this time they have donated more than £7,000 annually and their continuing support has become an important source of revenue to us.

Up to this time we have mostly been funded by the Trustees, Soho Gyms, a small number of Foundations and, most particularly, by our generous friends and other private supporters. Now, due to the recent changes initiated by Dave and Martin, our work is becoming known to a wider audience and our support base is dramatically broadened.

To meet changing needs, December 2012, we restate AA objectives:-
'To identify suitable medical practices who treat Positive patients and to fund those essential components of their HIV medical care which these patients are unable to self-fund. These components include generics, medication to treat OIs, associated medical costs, nutritional support, and all that is necessary to ensure the provision of effective ART. We work to leverage this funding by introducing these opportunities to other larger NGOs. All AA overheads are paid by the Trustees. AA has no paid employees - all who support us are volunteers. 100% of every donation is used to meet AA's stated objectives. AA is a registered UK Charity.'

Martin agrees to become an AA Trustee in Jan 2012.

'I'm delighted to become a Trustee and to take on this responsibility - it's a life changing opportunity to do something really worthwhile.'

To have both David and Martin so fully involved is the best possible news and can only mean that more lives will be saved. Too many people around the world still continue to die of HIV/AIDS.

In Cape Town, South Africa, February 2012

I re-connect with Dr. Catherine at DTHF in Feb 2012. It's like meeting an old and valued friend. The meeting is positive - there have been so many HIV related advances since we last met. We discuss DTHF's unmet financial needs. 'In SA, at most large Government clinics, Positive patients who become resistant to 1st line are able to access 2nd line. This is not the case for the much smaller number who become resistant to 2nd line. Patients can only access 3rd line if they are able to show the results from a Genotype Blood Resistance Test (GBRT). This test shows exactly which ARVs still work for them. The cost of this one off test is approximately £130.'

DTHT are looking for funds to test approximately 15 HIV+ children annually and AA agree to fund this need.

DTHF's application for funding tells us about one of these children:- 'Thulani was born HIV+ and soon presented with advanced AIDS diseases. He started to fail on 1st line after 3 years and then changed, successfully, to 2nd line. Recently he has started to fail on 2nd line and now urgently needs a GBRT so we can get him onto 3rd line. Currently his CD4 count is a dangerously low 29.'

I go to the township clinic at Gugulethu to meet Thulani and his mother and to watch nurses taking his blood for the test. The clinic is called the Hannan Crusaid Treatment Centre. It is heartening to learn that funding from Crusaid, started by Jeremy, David McFarlen and Geoff Henning back in 1986, continues to provide these people with their local treatment centre.

Dr. Catherine introduces us to Dr James Nuttall, Consultant HIV Paediatrician, at Red Cross Hospital (RXH) in Cape Town. Dr. James has the same GBRT needs and AA agree to also fund tests for 15 of his young patients. Dr. Reon asks for the same for 10 of his Positive patients. AA are now funding GBRT for 40 Western Cape patients annually.

Events have turned full circle and I do not forget an important moment in 2000, when, courtesy of the 'super rich kids' in Key West, Jeremy had the opportunity to consult Dr Redfield at the IHV in Baltimore; how this Doctor used exactly the same test for exactly the same purpose; how his findings acted as a 'life saver' for Jeremy. We are very grateful, through AA, to have this opportunity to give back.

Mary M became one of AA's early beneficiaries in November 2002. She recovered her health and for many years has worked as an EP councillor at the

DTHF Clinic located at Groote Schuur Hospital in CT. Mary M would make a great subject for an AA promotional video and an excellent 'Positive Hero' for AA. We meet April 2012 and I suggest this.

'I would love to help; AA have done so much for me; without AA's help I would have died. Please understand that in my community I work as a 'sangoma', a witch doctor, and that with my people I cannot be honest about my HIV status and the work I do here at the DTHF Clinic. For this reason I cannot be seen in your video.'

Together with Mary M, I meet Nonkosi, AA's original poster girl, whose double image - 'Before ARVs and One Year Later', caused our unfortunate spat with Edwin Cameron. It is good to see them both in good health so many years later.

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During the 2012 / 2013 grant period AA makes grants totalling £54,331 which funds ARVs and medical care of 168 plus associated medical care (excluding the cost of ARVs now funded by others) for an additional 149 individuals - a total of 317 people.

In India, in 2013, the 2009 verdict which resulted in the decriminalisation of homosexual acts between consenting adults is overturned by the Supreme Court who rule that the 2009 order of the Delhi High Court is:-

'Constitutionally unsustainable as only Parliament can change laws, not courts.'

Homosexuality is once again illegal in India.

Jan 2013 we receive a cheque for £69.55 from Durham High School for Girls following a cake sale. How did Durham High School hear about our work? This donation probably thrills and touches me more than any other received.

AA has taught us much about the generosity of others.

We worry about Benzemen's future and who will care for him when Chandramma dies. We inform Dr. Raju that, through our increased donation to AA, Jeremy and I wish to fund Benzemen's long term future at the rate of £500 pa. He will outlive us and we have made arrangements to cover this eventuality. Payments to Chandramma start immediately and allow her to retire from a job she is too old to perform.

March 2013, in London and other cities around the world, AA hold their second DF1 fundraiser. This time, through 60 dinners, we nearly double the amount raised - £18,000 to £33,000. London diners then head to an after party at the Adam Street Club where they are entertained by the fabulous Dame Edna Experience. Jeremy is in London to attend the event and gives a short speech under the watchful eye of Dame Edna before a crowd who are mostly gay. AA fundraisers are becoming a well supported regular feature in the Gay London calendar.

I am sad to learn, May 2013, that Shivananda Khan, born 1948, has died. He and NAZ, the organisation he founded in 1994 were supportive of our work when we first visited India in 2004. Shiv was of Anglo Indian descent and, despite his long years living in and serving the needs of LGBT communities in India and other Asian countries, was a British citizen. He was awarded the Order of the British Empire (OBE) in 2005.

From some of the many tributes:-

‘The global AIDS movement has lost a leading advocate on HIV/AIDS, MSM and TG issues.’ - from UNAIDS Michel Sidibé.

‘Shiv was the torch bearer in the fight against HIV/AIDS and a great human being who inspired thousands of LGBT activists. We feel respect and gratitude for this brave soul.’ - from Boys of Bangladesh.

‘Shiv is a great hero amongst the MSM HIV/AIDS communities of India and Asia.’ - from Sunil Pant, BDS, Nepal.

During the 2013/14 grant period AA makes grants totalling £74,900 which fund ARVs and medical care for 237 individuals plus associated medical care (excluding the cost of ARVs now funded by others) for an additional 193 individuals - a total of 429 people.

October 2013, Dave and Martin and our volunteer team host a presentation in London at Soho Hotel’s very smart screening room lent to us by the hotel’s owners, friends Kit and Tim Kemp.

At this event they are able to tell a full house of supporters:-

‘AA has now helped to save over one thousand Positive lives; we have been credited, in more than one country, with speeding the arrival of large scale ART programmes; almost all of those we have helped are again healthy, working and supporting their families; AA is run entirely by volunteers and it’s overheads are paid by it’s Trustees.’

In Cape Town, South Africa, November 2013

November 2013, Dave and Martin are in Cape Town. We visit Dr. Catherine at DTHF where we learn that both DTHF and RXH will shortly be able to access funding for GBRT from other sources. Dr. Reon tells us, that as a private practitioner, this alternative funding will not be available to him and we assure him of our continued support. The work of HinH in Khayelitscha continues to save lives. It's good to share a morning with the HinH team. A car takes you so far, but eventually you need to get on foot in order to thread your way down winding sandy Cape Flats alleyways, past innumerable poorly constructed corrugated shacks and under lines of drying washing, to where their patients live. The smells are both gritty and spicy. It would not be safe to come here unaccompanied. Despite the deprivations we hear chatter and laughter and are invariably welcomed with smiles.

First AA Visit to Cambodia, January 2014

January 2014, Jeremy and I visit to Vietnam, Laos & Cambodia. En route from Ho Chi Minh City - Vietnam to Phnom Penh - Cambodia, we tell our driver about our work. He calls a friend, and by the time we get to Phnom Penh, our first visit is to his doctor contact. The following morning this meeting results in breakfast shared with an American Buddhist Nun, Beth Kanji Goldring, diminutive but with a passionate personality and a surprisingly large appetite. No fasting for Beth this morning.

Beth founded and runs the Brahmavihara Foundation, an NGO:-
'Dedicated to the cultivation of the divine abidings in accordance with Buddhist teachings.'

She tells us that as part of their work they give refuge to dying street people and that they care for them and chant with them during the last days of their lives. Beth is excited to hear about AA and seems certain that her medical contacts here will have unfunded HIV needs which meet AA objectives.

First AA Visit to Laos, January 2014

In Luang Prabang - Laos, we make the same enquiries. It quickly becomes clear that here there is a similar urgent need for funding. However, as elsewhere, we need to locate trustworthy doctors with whom we can communicate clearly in a language understood by us both. Our visit to Luang Prabang proves too short and, as yet, we have not been successful at finding a route through which to offer AA support to selected doctors in this country. We continue to try.

Second AA Trip to Thailand, February 2014

Jeremy returns to Cape Town and, in Bangkok, I meet up with Dave and AA volunteer Sarah Haddon Grant. The three of us fly to Mae Sot to update ourselves with progress at MTC. It's good to be back enjoying the very special atmosphere of clinic - a sense of refuge suffused with calm and comradeship. It is a pleasure to spend time here amongst these brave people.

Dr Terry Smith, a doctor from California, is a long term supporter of MTC and works there pro bono for up to three months annually. Since our last visit the first small ART programme, funded by UNAids, has started over the border in Burma at Myawaddy. Terry takes us there but UN agencies are not set up to work with small scale funders such as ourselves.

In Mae Sot a few registered Burmese refugees can now get limited access to ART through Thai Government Clinics. MTC currently provide ART to 103 unregistered refugees, 30 of whom are funded by AA. We agree to expand our support by an additional 10 beneficiaries.

From Dr Cynthia:-

'The quality of our care mustn't be compromised by exceeding our medical capacity. It's more important that AA continue to support their existing beneficiaries into the long term rather than MTC take on additional patients and then find we have over extended ourselves and fail to provide long term support. Sadly this leaves many others, also in urgent need, untreated. We also desperately need help funding the cost of HIV related OIs.'

Fourth AA Trip to Burma, February 2014

In Burma we visit Dr. Frank at MAM's Thazin Clinic where we fund ART and a contribution to medical care for 106 of their Positive patients at a reduced cost of £257 pp/pa. The Clinic has expanded and now offers a wider range of care. Many of their patients also suffer from TB or Malaria. Many are mal-nourished. Dr Ni Ni Tun, Frank's medical partner and now his beautiful wife, has developed a speciality for treating CMV, the AIDS related OI, which causes blindness.

'With extra funds we can prevent more of our HIV+ patients from losing their sight and dying of AIDS related diseases.'

With Dr Ni Ni we visit some of our beneficiaries at their homes.

Sixth AA trip to India, January 2014

Our next stop is Manipur State, India. We are excited that Khoi Dinesh has obtained permission for us to travel with him into the mountains to visit our clinic. En route to Moreh we are held up by repeated army roadblocks. Armed soldiers are in evidence all along the road. How many more guns are held secretly in private hands, we wonder? Many of the camouflage clad soldiers keep their faces covered for fear of reprisals. Our journey takes us past well tended paddy fields and rural villages which, as we climb, give way to dense jungle. We are put to stay in the Government guest house where three sets of gates are locked behind us at night. The army are clearly frightened that we may be kidnapped. Armed guards are a constant presence around the guest house.

We visit the Government Hospital where we are told that a limited number of Indian citizens receive ART. It is a desperate place, crumbling and dirty with few medical staff in evidence.

Our clinic, jointly set up in 2009, is a simple place but hygienic and well organised with a part time doctor and a full time nurse. A hundred Burmese refugees have been receiving ART since that time. With few exceptions they are all enjoying good health once again. Approximately twenty five of these beneficiaries together with their families, have made the trip across the border to receive their 'meds' and to meet us. Many have travelled long distances within Burma in order to cross the border into India for the single permitted day. We have moving exchanges. It gives us great pleasure to watch them consulting with the medical staff and receiving their ARVs.

In 2013, MSF set up a higher quality clinic in Moreh with a larger capacity than ours. They provide a wide range of medical care including ART and can make long term commitments to patients in a way that is not possible for us. We visit them and are delighted when, at our request, they agree to take on the provision of ART and medical care for our complete cohort of one hundred patients. For us and for our beneficiaries this is the perfect next step. For them they will receive assured long term care from better trained medical staff. For us, our limited funds can be redeployed to serve unmet needs elsewhere.

In Vizak, Dr. Raju tells us that 11 of his patients, some of whom are former AA beneficiaries, are failing on the 1st line they receive from Government clinics. In order to access 2nd line a Viral Load Test is required. In order to access 3rd line a GBRT is obligatory. At this time such tests are not freely available

through NACO. He requests that we fund a Viral Load Test (£22 per test) for these 11 and estimates that 30% of this group will also prove resistant to 2nd line and will need to take the GBRT (£70 per test) in order to access 3rd line. The total cost of this pilot project, which includes courier charges for transporting bloods to Chennai, will be approximately £500. We agree to fund this need during our annual Grant Period May 2014 - April 2015. We also agree to fund 2nd and 3rd line for the limited period until they become freely available through NACO.

In 2003, through mandatory testing during pregnancy, Padma Anga discovered she was HIV+. Srinu, her husband, tested Positive at the same time. Padma was given single dose ARVs during the birth through PMTCT and Sekhar, their son, was born Negative. The family were introduced to FXB Vizak in 2004 and both parents started on AA funded ARVs in July 2005. At that time Srinu had TB, a CD4 count of only 91 and weighed 40kgs. He was sick and unable to work. I first met the family in 2006 and again many times since during subsequent visits to Vizak. Srinu, now has a CD4 count of 450, is back to his normal weight and for many years has been fully re-employed as a 'rod bender' in the construction industry. Padma works as a Peer Counsellor at The Vizak Govt ART Centre where she has now helped hundreds of women like her. Sekhar, student class 8 wants to become a police officer. (see multiple images of the family 2006 - 2018)

Dr. Raju tells us that approximately 30% of his Care & Support service users, of whom we currently fund 60, achieve independence annually and leave the programme. This allows a similar number to join. He tells us there have been intermittent failures in the supply of ARVs to many local Government Clinics and that he needs funds to support his patients, plus for others through other Doctors he trusts, to cover these supply gaps and to prevent the emergence of drug resistance amongst them.

Mandatory testing during pregnancy identified Kalpana Hariyali as HIV+ in 2001. Sekhar, her husband, a three wheel auto driver, also tested HIV+ at this time. They came to FXB Vizak in 2004 when Sekhar had a CD4 count of 111 and weighted only 42kg. Both started on AA funded ARVs in 2005. I met them for the first time in 2006. Sekhar did well on 1st line until 2013 when he developed resistance and presented with clinical and immunological failure. He is now on 2nd line, his viral load is again undetectable and he is healthy. Kalpana continues to do well on 1st line although she had a battle with TB in 2013. She has also regained her health. They have 3 children all born Negative through PMTCT. Abhisek, their oldest boy, student class 11 wants to join

the Airforce or the Army. Akshitha, their daughter, student class 9 wants to become a nurse. Amit their second son is also doing well at school. 'FXB and AA have given us and our family second life.'

In the early days our long-winded application process required doctors to provide details about the medical health of each proposed beneficiary. This was very time consuming for them. As our trust in specific Doctors strengthens we no longer demand this. Instead we simply ask them to tell us about their unmet HIV medical funding needs to which we then do our best to respond positively. It allows us to be greatly more responsive and useful to them. With Dr. Raju, Dr. Frank and others this trust is now implicit.

Ganivada Rushikeseva Rao started on AA funded ARVs in 2005. When he regained his health he was able to return to work. He is not willing to attend the Government ART centre and now self funds his medical care. He developed resistance to 1st line in 2015 but is now doing well on 2nd line. His health is good. His wife Ramalakshmi is also Positive but did not need to start on ART until 2015. Her medical care is provided by the Government ART centre. Their son Abhinay, born 2004, is Negative, student class 9 and wants to become a computer or electronics engineer.

(see multiple images of the family 2006 - 2018 - U in .pdf sent to Raju 16 March)

Dr. Raju invites Sarah, Dave and I, together with former AA beneficiaries and their families to attend a get together on the roof of the FXB clinic. Colourful panels of fabric are fixed over us for shade and vertically around the building's perimeter to provide privacy from others on nearby roofs. A cooling breeze is very welcome - roof tops become popular when the heat of the day finally lessens. Many people we now know well attend. Benzemen, now a healthy teenager is there with Granny Chandramma. From 2005 to 2014, a great deal has changed for these people. They are healthy, have put on weight and are working again. They have fulfilled their role as parents. There are young, smiling faces at the party, who, without our intervention, might have had different lives, might have become orphaned and uneducated beggars. All those at this special event know what we have achieved together. There is singing and dancing. This is a joyous event for all. For me this party is one of the greatest gifts that AA has bestowed on me.

During the trip I have been both in front of and behind my video camera. Dave, Sarah and others have been patient with me subjecting them to endless 'retakes'.

We have a high regard for FXB India's CEO, Mamta Borgoyary At the end of this trip we visit her in Delhi. Funding from FXB Head Office in Geneva to FXB India is being reduced and this concerns us all.

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March 2014, we hear from Beth Goldring in Cambodia. As with Dr. Ni Ni at MAM, there are no funds to treat CMV. The course of treatment in Phnom Penh costs £186. Beth has spoken to Doctor Narom, previously a MSF doctor, who sees approximately 5 patients per month in need of this treatment. Doctor Narom has additional funding needs for medication to treat other OIs. AA agree to make him an annual grant of £6,500 which he estimates will assist 40 of his Positive patients annually. AA funds will be channeled through Brahmavihara so that Beth can monitor progress.

During the 2014/15 grant period AA make grants totalling £56,812 which fund ARVs and medical care for 246 individuals plus associated medical care (excluding the cost of ARVs now funded by others) for an additional 388 individuals - a total of 634 people.

We have know Paul for many years, but it wasn't until he joined the Yoga classes I led at London Lighthouse in 1995 that our friendship deepened. By then Paul had already been Positive for several years and his health was poor. He had fought off several OIs and had lost his sight in one eye due to CMV. With a weakened immune system he had contracted a rare tropical disease which had nearly killed him. Long term use of ARVs have caused him multiple side effects which add to his current health challenges. Despite this his resolve to live a full life remains indomitable. At that time, UK resident Positive people in his position were awarded disability grants. Many were unable to work and all assumed they were going to die young. Triple combination ARVs then arrived and the dying stopped. What next for such people? You're going to survive but, for some, health is severely damaged and energy lessened. You want to get back into the working world but fear the pressure might compromise your frail health. You don't want to give up your disability benefits because you might get sick and you probably won't get them back. It's a dilemma. Paul is a talented and formerly a successful designer. His old design school want him back to teach. Now Paul teaches design master classes and the remuneration that should be his, he pays to AA. Paul, who has suffered so much and has survived is now one of our most generous long term donors.

In Cape Town, South Africa, March 2014

As part of our next DF1 fundraiser, March 2014, Jeremy and I co-host a dinner with our friends Dr. Ashraf Grimwood and his husband Kim Bill at their home in CT. Dr. Ashraf has, for many years, been one of the principle medical specialists advancing national ART strategies across southern Africa. Alongside this public work he continues his work as a clinician. Dr. Ashraf is a great South African hero.

From my short speech at the dinner:-

‘We started AA in 2002 when ARV’s were not freely available in South Africa. One of the first Doctors we helped was Dr. Ashraf. At that time he ran his clinic from this house. It was here in this very room that Jeremy and I met the first of now hundreds of Positive people whose lives our funding has helped to save.’

Since this time Dr. Ashraf has lost both sweet gentle Kim and his younger brother to cancer.

.....

Running a charity demands higher standards of accountability than a commercial company - you are spending other people’s money entrusted to you for a charitable purpose. The regulatory and administrative needs are no less stringent than for any other business. Finding ways to spend this money wisely and securely is not easy - there are many rogues and charlatans out there. There is a moral dilemma which has always weighed heavy. You give money to one group and lives are saved - in consequence you are unable to give the same money to others and people in that group may die.

Jeremy and I are aware that our wandering lives put us less in touch with AA’s life blood, our funders; that our friends have more than done their bit; that AA need to access a younger generation in pursuit of funding. Through DF1 fundraisers and multiple other means, Dave, Martin, their committee and contacts are now successfully raising the lion’s share of the funds needed to continue our work. Both David and Martin travel incessantly to monitor existing projects and to look for new opportunities. The changing nature of AA’s work takes them to increasingly frontier places, a challenge which they welcome but which Jeremy and I, who are older now, no longer wish to meet. With the increase of drug resistant TB amongst many who are Positive, it is not wise for Jeremy, who already has lung damage from childhood TB, to put himself at further risk from such contact. Dave became a Trustee in 2010 and Martin in 2012 and both have proved wise, dedicated and skilled.

October 2014, Jeremy and I take the decision that it's time for a change of guard and to pass on the torch into now better equipped hands. We ask Dave and Martin if they are prepared, two years hence, to assume full responsibility for running the charity. We are more than delighted when they accept. AA, our beneficiaries and doctors, could not be better served. Jeremy and I will continue to provide whatever assistance and support they request. Our personal funding to AA will remain unchanged. The time has come to be free ourselves from the responsibility of spending other people's money; a responsibility that has always weighed heavily on us and that we feel confident passing onto Dave's and Martin's younger shoulders.

We will resign as Trustees in October 2016. To effect such an important and successful hand over is a significant achievement. Lives will be saved by it; so much more important work remains to be done.

April 2015, we receive an application from Sister Ellen Curran, a SRN, who, as part of NZH, runs a Hospice and Outreach Programme for a destitute rural community near Warrenton, SA. We are humbled to learn that this fine lady, formerly a NHS nurse in UK, donates the totality of her pension towards her work there. Sister Ellen's application meets AA objectives and we agree to support her with a grant of £6,500 annually, as a contribution toward the medical and related medical needs of her Positive patients.

ART should now be available to all HIV+ people in SA but, in reality, there remain many under-resourced areas where people are still dying of AIDS. This reality is repeated in other countries around the world. AA make it their business to search along the frontiers of medical provision to identify individuals, such as Sister Ellen, who provide care in places where death from AIDS continues and who desperately need funds to help them with their work. Finding these people, often in remote areas, is increasingly challenging.

MSM concerns continues to be dire in Uganda. The politician and pastor Dr. Abed Bwanika of the People's Development Party is standing for President. 'I will set up a moral re-correction centre that will tackle social evils such as homosexuality. Uganda is no area for homosexuals. We cannot accept to be pushed into homosexuality by the West. All homosexuals will be rehabilitated because they have demons and we have specialists to chase out demons.'

During the 2015/16 grant period AA make grants totalling £74,257 which fund ARVs and medical care for 116 individuals plus associated medical care (excluding the cost of ARVs now funded by others) for an additional 600 individuals - a total of 716 people.

Through Sunil Pant's BDS in Nepal, Dave identifies, June 2015, unmet needs in the MSM and TG communities they serve. In the remote under-resourced parts of the country where BDS work, death from AIDS continues. AA now fund BDS with £3,600 annually.

Second AA Visit to Cambodia, 2016

David and Martin visit Beth Goldring in Cambodia where they meet Dr Narom. In addition they find a second key figure with urgent needs. Dhammayietra Mongkol Borei (DMB) is another Buddhist group providing medical care to under resourced Doctors. AA are now funding Brahmavihara with £11,849 and DMB with £6,857 annually.

Stigma and fear still contribute to deaths from AIDS. Even under our own roof we are reminded of this fact. Asande, a Xhosa lady, has been our domestic cleaner in CT for over 3 years. She knows Jeremy is Positive and kept healthy on ARVs. She has had recurrent health issues including pain from ulcers and scratchy eyes. She has told us repeatedly that she is Negative. On many occasions we have advised her to take regular HIV tests. Just before we return to CT we hear that Asande has CMV, is going blind (one eye sees light but not shape or colour, sight in the other is 80% destroyed). She has tested HIV+ with a CD4 count of just 28; she must have been Positive for years.

We share this sad truth with Rose Smuts who repeats this to Nomthandaza 'Euni' Matadi, her housekeeper of 18 years and also Xhosa.

From Euni:-

'Asande will be summoned to the Eastern Cape by her father in order for her to see a Sangoma. She will not speak to the Sangoma about her HIV status - there is too much shame. Her problem with ulcers is not due to worry about lack of money but because of her shame at being HIV+. The Sangoma will tell her that she has been loya-ed (spell cast) and will give her traditional medicines. Sangoma 'muti' will not be effective. She will get sick and she will die.'

From Rose:-

'I shocks and saddens me, that with 3.5 - 5.5 million people successfully on ART in this country, such events are still commonplace.'

In South Africa, January 2016

Jan 2016, Jeremy and I drive up to Warrenton in SA to meet Sister Ellen. She and her team impress us enormously and we are pleased to offer her increased funding.

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Govinda Vanka tested Positive in 2002 and started on AA funded ARVs in 2006. His wife Ramu is Negative. To have a child, an heir, is of the greatest importance in Indian culture. This discordant couple, one HIV+ and the other not, believed, as do many, that such an ambition must be denied them and that they should only ever practice protected sex. On our 2014 visit to Visak, together with Dr Raju, we persuaded them both that his low viral load - the result of successful ART, combined with Ramu taking HIV prophylactically, will allow Govinda to both protect his wife and conceive an healthy child. Govinda and Ramu give birth to their first child, a boy, Janardhan, in April 2016. Both mother and child are Negative.

From Govinda:-

'We are grateful to FXB and AA for helping make our dreams come true. May God bring you both blessings.'

During the 2016/17 grant period AA make grants totalling £72,388. In SA we are currently funding HinH Baphumelele with £7604, NZH Warrenton with£8,330 and Dr Reon with £825, annually.

Up to the end of 2017 AA received a total of £76,531 from TBG matched funding. Related to this gift we have received an additional £16,525 in Gift Aid making a total of £93,056.

Under the leadership of Dave and Martin, we now have a volunteer Committee of Members. These multi skilled, well connected volunteers, have succeeded in bringing AA's life saving work to the attention of a new generation; people who, in increasing numbers, share AA's ambitions and support us with their time and donations. All the above mentioned are volunteers; all are more than 20 years my junior. A high proportion to those who support AA are gay; among this growing number many are young.

So many young gay people; many dear friends; those named here and to whom this record is dedicated; would be alive today had access to ART been available to them. That a new generation connect to this history, empathise with this earlier generation and choose to help Positive people, is significant

and worthy of notice. I am proud and happy that they have found, through AA, an opportunity to express this in tangible form.

From April 2002 to year end 2017 AA received total donations of £858,987. Year end 2017 we had £177,276 in the bank. This computes to £681,711 spent advancing AA objectives during this period. Let's divide this sum by 1,000 - by now an under estimate of individual HIV+ lives, meaning also 1,000 families, that AA have helped save during this period; then again by 14 - the number of years. The result is £48.69. How do you value a life saved, a family saved? Such a calculation against such a gain must surely be considered good value?

Since the advent of the internet and 'hook up' sites we understand that the club and bar scene in many cities has become quieter. Dave, Martin and team have identified, amongst their gay friends in London a reaction to this; that this group welcome the opportunity to meet in glamorous places and to party together while also raising money for AA. That the owners of these venues know that this group is influential and well heeled and that entertaining them is good for business. Its a win win concept which is proving popular with a growing audience.

One of our most recent fundraising parties was held at London's Playboy Club. The gorgeous Bunny Girls and Boys seemed to enjoy the party as much as our supporters.

The time has come to hand over our AA responsibilities to others. We want to be free to fully engage with new challenges and adventures. I have again remembered Dorothy's advice about stopping something in order to create space before starting something new. The time remaining to us seems increasingly finite and we must carefully craft how we use this precious commodity.

In October 2016, I write to those with whom AA worked - many now friends. 'Jeremy and I have resigned as Trustees of Aids Ark. It has become clear to us that our younger Trustees, Dave and Martin, are now better equipped to steer AA into the future. You already know what skilled and committed people they both are. With them AA is in good hands. Jeremy and I are happy and grateful that they have assumed responsibility. We will continue to fund AA and to take great interest in it's future progress. We started AA in 2002 and since then funds from us and our supporters have allowed us to help you save the lives of more than 1,000 of your HIV+ patients. We are proud and happy to have started and run AA to such great effect. Knowing you and

many of your patients is a great joy to us and the source of priceless reward. Thank you for trusting the commitment made to you by AA and for allowing us to play a part in your humanitarian efforts. We send you love and thanks. Your friendships have enriched our lives.'

We receive some beautiful replies:-

From Mamta Borgoyary (CEO FXB India):-

'Our association with AA has always been of immense value and will remain the same. Thank you for your support and guidance.'

From Kathy Shein (FXB Myanmar):-

'AA play a key role in Myanmar for the live saving of PLHA people in need.'

From Beth Goldring (Brahmavihara, Cambodia):-

'Congratulations on having brought AA to the point where such a promising handover is possible and achieved. Our gratitude to you is unlimited. May your lives blossom in response to the goodness you have created and continue to create by your wonderful kindness.'

From Dr. Frank Smithuis and Dr Ni Ni Tun (MAM Myanmar):-

'Thank you for your commitment and support. You were the first donors who provided the sustained support which gave us the opportunity to start treating HIV+ patients.'

From Dr. Raju (Medical Director FXB India):-

'Both of you are soul to AA's humanitarian services. You are founding pillars of the FXB program which has saved the lives of hundreds of HIV+ people. Many of the children whose HIV+ parents AA have assisted are now becoming adults. Many will pursue college educations. Without AA support they would have become orphans and illiterate street people.'

From Sister Ellen Curren (NZH, Warrenton, SA):-

'You started AA at a time when Aids was not understood and those infected were treated like outcasts - this took great courage and compassion. I thank God for you both. You are great men. You leave a lasting legacy which will continue to reach out to people in need. Thank you for your love and support. I will remember you in my prayers.'

..... infinitely precious gifts.

From UN Aids 2017:-

'Since the start of the AIDS pandemic to end 2014, AIDS has caused 39 million deaths worldwide. In 2016, 36.7 million people worldwide are HIV+. In 2016 one million people died from AIDS related diseases.'

Amongst these enormous numbers we continue to search for a few individuals, representatives amongst these vast numbers, who are still dying; who, when we find them, will not.

We met Jayaraj in Indian in February 2014. Both his parents died of AIDS and he was born Positive. He lives with his grand mother who works as sweeper. He became resistant to 1st line in 2014 and we helped him with funds to access 2nd line. Now he has become resistant to 2nd line. 3rd line are not available for him at NACO clinics and without them he will die. AA now fund his 3rd line and Jayaraj will not die.

From Ommar Win Zaw, AA Beneficiary, FXB Burma:-

' My parents born me with first life. ARV drugs give me second life. AA who support me with ARV drugs is my life saver. My health improves. Now our family can live again, we have a future. This is the miracle AA bring us.'

August 2018 - from Mphu Ramatlapeng MD, ex Lesotho Minister of Health and Social Welfare and who now works for CHAI we received the following:

Dear Derek and Jeremy,

Greetings from a rather frosty Lesotho.

Today of all days, I am thinking of you. I am thinking of how you changed my life, changed and saved many, many lives in my country and in South Africa. Had I not met you Derek, I would not be in global health today. You made it possible for me to get out of the terror of witnessing so many of my patients die, you made it possible for me to demonstrate to the Government of Lesotho that with treatment, life belong HIV infection was possible. I am grateful on behalf of all of us.

I am now a grandmother of two beautiful girls! My only daughter is about to complete her second degree in Law.

My father turned 100 in July, and all my siblings came together for the first time in many years.

I am still working for CHAI, I get to travel to UK a lot.

I know you are now "retired" and are always elsewhere in the world.

I have never met Jeremy, I would like to meet him and say thank you in person if that is possible.

My warmest regards,

Mphu

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The important work of Aids Ark continues.....

Conclusions

'Fucking without Fear' is the mantra of a new generation of young, sexually active people from some of the richer parts the world. It describes a sexual freedom made possible by Pre Exposure Prophylaxis (PREP). Take PREP, the identical ARVs you take if you're HIV+, and you can stop worrying if you or your sexual partner are Positive or not; you can forget about using a condom - safe sex. If you're Negative and on PREP you won't become Positive if you're exposed to the virus. If you're Positive and on PREP you'll have a low viral load and you won't infect others. Some of the world's richer countries now make PREP available on demand and free of charge.

People who are sexually active and on PREP must make a regular visit to their STD Doctor to ensure they remain infection free. There is always the danger of resistance to ARVs and the increased risk, through unprotected sex, of infection from STDs.

In the poorer countries of the world, where PREP is not freely available - or even known about, always using a condom remains the only way for sexually active people to avoid becoming infected or spreading HIV infection and other STDs.

Needless to say if you're Positive and you don't take PREP or practice safe sex you will infect others.

Many people around the world still don't know their HIV status. Ignorance and stigma remain the principle reasons. Many people are still ashamed to be exposed as Positive.

Too often men, safe guarding their perceived machismo, or simply because they don't care, fail to test their HIV status and refuse to use protection. Their powerless sexual partners and offspring continue to reap the dire consequences.

Homophobia, often extreme, still keeps many LGBT people away from test centres and medical clinics. MSM still remain one of highest at risk groups.

For many, and particularly in African countries where levels of HIV infection remain some of the highest in the world, the authority of traditional doctors, the 'sangomas' and their fake medicines of muti, still attract many away from proven science and, as a consequence, they die.

Amongst those, within what has become an enormous global AIDS initiative and industry, there is now the much lauded ambition of achieving an AIDS free generation of adolescents' by 2030. This ambition can only be achieved if all those who are infected are identified, start on ART, and achieve invisible viral loads which render them unable to infect others. Alternatively all sexually active people need to be on PREP and to have regular check up's with their STD Doctors.

Much work still needs to be done if this ambition is to be achieved.

At a macro level the work will be advanced through national AIDS strategies, international government agencies and large NGOs.

At a micro level multiple small initiatives such have Aids Ark must continue to play their life saving role.

Acknowledgments

There are many to thank:-

Scientists who identified that HIV causes AIDS and developed the drugs to treat it. Big Pharma who made these drugs available. The doctors who focused on treating Positive people. Those who devise and lead strategies to end the AIDS pandemic.

Those named in this record who helped and who continue to help Aids Ark play their role in saving Positive lives. (in their role saving Positive lives)

Others amongst the AA home team, all volunteers and always on a pro bono basis:-

Our Fund Raising Committee currently Dominique Gagnon, Richard Masters & Malcolm Russell.

Our events supremo Alasdair Brown

Also; Nick Barrington, Richard Bee, David Clarke, Ed Comber, Richard Cristina, Peter Haigh-Lumby, Alvaro Picardo, Nick Pollitt, Conor Russell, Gido Schimanski, Pierre Scott and Tim Warmath.

Peter Ellis who designed our original logo. Chris Jepson who developed our first web site. William Clement who updated this site and modernised our operating systems. Sarah Haddon Grant promoting our work through Social Media. Jim Turnbull a Cape Town based film maker. Jonathan Hellyer, a.k.a. The Dame Edna Experience - a huge favourite at our fundraisers. Becky Rui who makes great images of these events. Daniel Brosson who now keeps our web site and other technical tools sharp and up to date.

Those owners of the numerous venues who have make these freely available to us for fundraisers and their managers and staff who have always been so helpful.

Those generous companies and individuals who give us gifts which allow us to raise additional funds.

AA's Accountants, Begbies, who generously provide their services for a reduced fee in lieu of donation.

Most importantly all those who have donated so generously

Duncan & Amanda Baird

Those who I have failed to mention above and for which apologies.

..... and to Jeremy, who in addition to all that has been said above, has, in the setting down of this record, proven to be my wisest critic and greatest support.

© **Derek Frost 2020**

Postscript

BENZEMEN IN MEMORIAM

1999 - 2022

7 June 2022 - from Dr Raju to Derek Frost

With profound grief and deep sadness we inform you sudden demise of our beloved BENZEMEN yesterday due to accidental electrocution near his house yesterday 6th June 2022 in the afternoon.

At that time there was heavy rain with thunderstorms.

Final rites will take place today afternoon.

7 June 2022 - from Derek Frost to Dr Raju

Thank you for sharing such terribly sad news. You and your excellent FXB team have worked so hard with Benzemen's health over the years and to such great affect. That he goes in this way seems particularly hard. Our young man had worked diligently to remain well and joyful. He was successful, in many ways, in doing so. We should all feel blessed that he was able to enjoy a much longer length of good healthy life than you might have expected when you first met him as a young child.

Chandramma will be in terrible pain. The beloved grandson who she had raised so lovingly and carefully, suddenly gone. A ghastly shock. We're so so sorry.

We are hopeful that Dave will agree to continue the required level of support necessary to allow Chandramma to live a comfortable life until the end of her days. He will let you know.

Please deliver our deepest respect, affection and tears to Chandramma and to her other family at this time of their great loss.

..... to you also dear Raju.

May Benzemen go in joy and with our love.

7 June 2022 - from David Primost to Dr Raju

Thanks for sharing the news.

Such a tragic accident and so sad. He was so young and should have had so much of life ahead of him.

It must also be incredibly tough for you and the rest of the team who have worked so hard to give him a good future.

Our thoughts go out to Chandramma and the rest of the family.

We are happy for Derek and Jeremy to dedicate as much of their annual Aids Ark donation as a stipend to Chandramma as they wish.

Raju - what are your thoughts about continuing the stipend to Chandramma? Should we keep it at the same level as previously?

10 June 2022 - from Dr Raju to David Primost

Thanks for your kind words.

I will convey your condolence messages to the family particularly his grand mother Chandramma who has looked after him insight of many problems.

We will talk to her and assess her needs and also who else is supporting her from her family and government welfare schemes.

20 June 2022 - from Dr Raju to David Primost

Discussed with Chandramma about her financial condition. Taking into consideration of other supports she gets I recommend 50% of what we have been giving.

As of now she has high blood pressure and arthritic problems and we are providing medicines for that as well.

22 June 2022 - from David Primost to Dr Raju

Thanks for the update about Chandramma's financial situation. We are happy to follow your recommendations about how best to proceed.

26 January 2024 - from Dr Raju to David Primost

All fine here. Benzemen's grand mother Chandramma is being supported by her son. She is suffering from Arthritis due to old age. We are providing medicines for her knee and back pain.

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9 June 2023 from Dr Raju to Derek Frost

Both of you are God gifts to me and our beneficiaries who are active and healthy.

You both made my life meaningful and memorable last two decades. Jeremy and you lead an adventurous and meaningful life . Very few can contribute to humanity the way it is done by you.

I cherish your motivation.

You both remain in our hearts forever.

Our beneficiaries are managing well with our guidance.

17 May 2024 - from Dr Raju to Jeremy Norman

I along with our beneficiaries wish you a wonderful birthday.

Aids Ark humanitarian services made a difference in the lives of hundreds of poor families in restoring their health and lead a dignified life. Many of the children born after AA support are employed and supporting their parents.

Wishing you a happy and healthy life.

With affection and appreciation.

