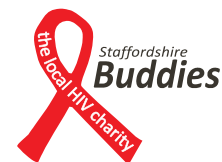


# Positive Lives



On Saturday 8th August 5000 people descended upon Northwood Park to celebrate Stoke Pride. Staffordshire Buddies volunteers and staff had a great day supporting this event giving out plenty of health information ... and we had an amazing dancing condom!  
See page 4 for full details and more pictures.

**Also in this issue:**  
**NLTSG weekend**  
**Stoke Pride**  
**Facial Wasting Treatments**  
**Positive Families**  
**Maurice's Angle**

## Positive Lives

Address: P.O. Box 474 Hanley ST1 3HX

e-mail:

positive.lives@staffordshirebuddies.co.uk

This publication is available in

full colour online at:

[www.staffordshirebuddies.co.uk](http://www.staffordshirebuddies.co.uk)

Editor : Steve Manley

Design and layout: Bob Lishman

Contributors (articles and photographs):

Joanne Kemsley, Maurice Greenham

Jenny Crowther, Scott Ormerod

Andrew Colclough and people living with or

affected by HIV/AIDS (published

anonymously)

Staffordshire Buddies is a registered charity (No.1047375) governed by a committee of trustees.

Views expressed in this publication are those of individual authors and not necessarily those of Staffordshire Buddies.

Copyright of the articles remains with the author and items may not be reproduced without their permission. Any mention of treatment or therapy does not constitute an endorsement by Staffordshire Buddies.

The mention, contribution or likeness of any person or organisation appearing in this publication is not to be taken as any indication of their sexual, social or political orientation nor of their HIV status.

© Staffordshire Buddies 2009.

All rights reserved.

## Experienced Facilitators.

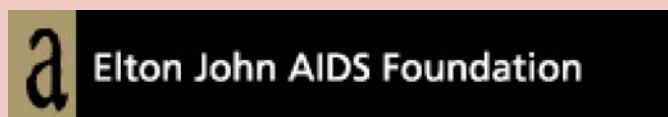
Enthusiastic facilitators are currently required to provide group facilitation, individual counselling and general support at residential weekends of the National Long Term Survivors Group (NLSTG). The weekends are run four times a year at a peaceful location in rural Staffordshire. Applicants should have appropriate professional qualifications, experience and good references. NLSTG pays its facilitators a fee, travel expenses as well as providing meals and accommodation (should this be required).

Applications should be sent to:

**National Long Term Survivors Group**  
**BM LTSG, London, WC1N 3XX**

The NLSTG is a vibrant user-led group that provides support to people living with HIV for 5 years or more, and is a Registered Charity, No. 1040586.

The group has recently secured funding from the **Elton John AIDS Foundation** to enable people living with HIV, aged over 50, or who live in an isolated location, or are paid or unpaid workers with an HIV Group, to attend a weekend.



### Cover photograph:

Cover Photograph taken by Andy Cole,

The dancing condom arrived at Northwood Park to help celebrate Stokes 4th official annual Gay Pride. Scott Ormerod, Staffordshire Buddies Health Promotion manager said "it was very hot and very sticky inside that condom".

# Summer Weekend at the NLTSG

The NLTSG (National Long Term Survivors Group) is a charity which provides four "Living Proof" weekend retreats each year in rural Staffordshire for people who have been diagnosed with HIV for five years or more. The retreat can accommodate up to forty people. The weekends provide a safe environment for people from all corners of the country to come together to share experiences and discuss issues that may be affecting them.

I attended the weekend in July which had a great atmosphere.

The weekends start on a Friday with an opening circle, which enables everyone to introduce themselves followed by a "Getting to Know You" session, which is split into small groups to help you decide what you might like to do throughout the weekend and to discuss any expectations. This is then

followed by an evening meal after which you have free time to mingle with the other residents and visit the downstairs bar for a drink.

On Saturday and Sunday morning, there are discussion groups, workshops and complementary therapies. I opted for the Swedish Hot Stone Massage which was excellent and was an hour of pure luxury and relaxation. Throughout the weekend there is plenty of spare time to just sit outside in the sun, play croquet on the lawns or visit nearby Staffordshire.

The weekend is fully catered and there is a bar which is available in the evenings. I have met many new friends from the weekends that I have attended and would thoroughly recommend a visit.

If you wish to attend or need more information, leaflets are available from Staffordshire Buddies or the web address

is [www.nltsg.org.uk](http://www.nltsg.org.uk). Some funding is available for new members to attend the weekends.

## **Service User and Volunteer – Staffordshire Buddies**

There are still places available for the Winter Weekend (Friday 11th – Sunday 13th December.... including a limited number of free places available under the Elton John Aids Foundation scheme.

For application forms, please leave a message on 07967430797 or email; [bookings@nltsg.org.uk](mailto:bookings@nltsg.org.uk)

Or write to;

BM LTSG

London WC1N 3XX (website: [www.nltsg.org.uk](http://www.nltsg.org.uk))



# Stoke Pride 2009

Staffordshire Buddies Health Promotion Team had a successful day at Stoke Pride this year with 7 staff members and 7 volunteers working at the prominently positioned health promotion information stall throughout the day. The borrowed inflatable condom suit proved to be very popular, with hundreds of people wanting their photos taken with it.

Over 1000 free condoms were accessed over the weekend and the printed information also proved to be very popular. The lollipops that we had to give away were all gone by mid afternoon and, at the end of the event, there were hardly any resources left!

The deputy mayor of Stoke on Trent was very impressed with the work that Staffordshire Buddies does in educating people around safer sex as well as raising HIV awareness on the day, particularly with younger people.

The team was also very impressed with the event and look forward to Stoke Pride 2010.



The Staffordshire Buddies Health Promotion Team stand at Stoke Pride 2009



Staffordshire Buddies Health Promotion Team enjoying the sunshine and ice-cream at Stoke Pride 2009



... never turn your back on a free condom !

## Sanity Fair 2009

Well done to everyone who helped to organize and staff the Staffordshire Buddies stall on Saturday 30th June.

The North Staffs Media Action group (organisers of the event) chose a theme with a culinary flavour – 'Sanity Fare; A Recipe for Well-being'. Staffordshire Buddies responded to the theme with a healthy hamper of fruit as prize for a guess the number of peas in the jar competition. Children were also invited to enter a healthy eating quiz. At the same time, visitors to the stall came into contact with information

about the services we offer and general HIV awareness messages as well as having a chance to pick up a red ribbon to wear. Despite the small space, the Staffordshire Buddies Stall attracted a steady stream of visitors both adults and children throughout the afternoon. Its presence was fitting, not only to make people aware of our existence and show solidarity with other health promotion agencies, but also because good mental health is important for people living with HIV who are disproportionately affected by mental health issues such as depression.

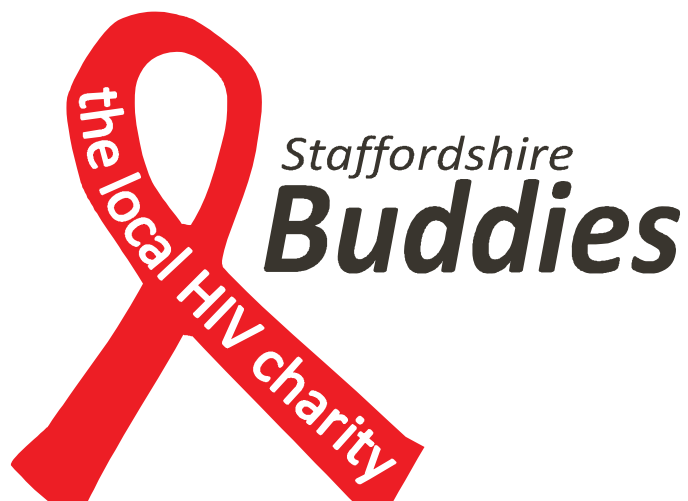
## Petition against discrimination of HIV positive children in schools

The online petition reached close on 2000 signatures and appears to have had a positive result. Deborah Jacks of the National AIDS Trust had tried to get an appointment with the Government for over 18 months to discuss the issue of discrimination against pupils and teachers with HIV. Following the petition she got an appointment with the Department for Children Schools and Families. Whilst discussions are underway about the revision of the confusing advice to teachers on [www.teachernet.gov.uk](http://www.teachernet.gov.uk), the space points people to the NAT website.

Well done all those who signed the petition – you appear to have made a difference.

## New Staffordshire Buddies Logo

Staffordshire Buddies is adopting a new logo which will start to appear on materials over the next few months. The new logo is intended to be bold, clear and eye-catching when used in our posters, leaflets and World AIDS Day campaign materials - we hope you like it!



# Facial Wasting Treatments – A Patient's Perspective

## What is facial wasting?

Basically, it is a depletion of fat from the cheeks and temples, a common form of lipodystrophy, clinically termed 'lipoatrophy', which is related to certain antiretroviral drugs, most typically the 'D' drugs: d4T, ddI, ddC, but it has also been connected with AZT and HIV itself. Nowadays with improved forms of HIV medication, it is a problem that people recently diagnosed with HIV should not have to confront. However, for many HIV long-term survivors, it has been and, for some, still is a distressing issue. What is the point of living well with HIV when you look as though you were dying of AIDS? The adverse impact on mental health is clear. What follows is a brief account of one person's experience of benefiting (and suffering) from the treatments for facial wasting currently available in the UK.

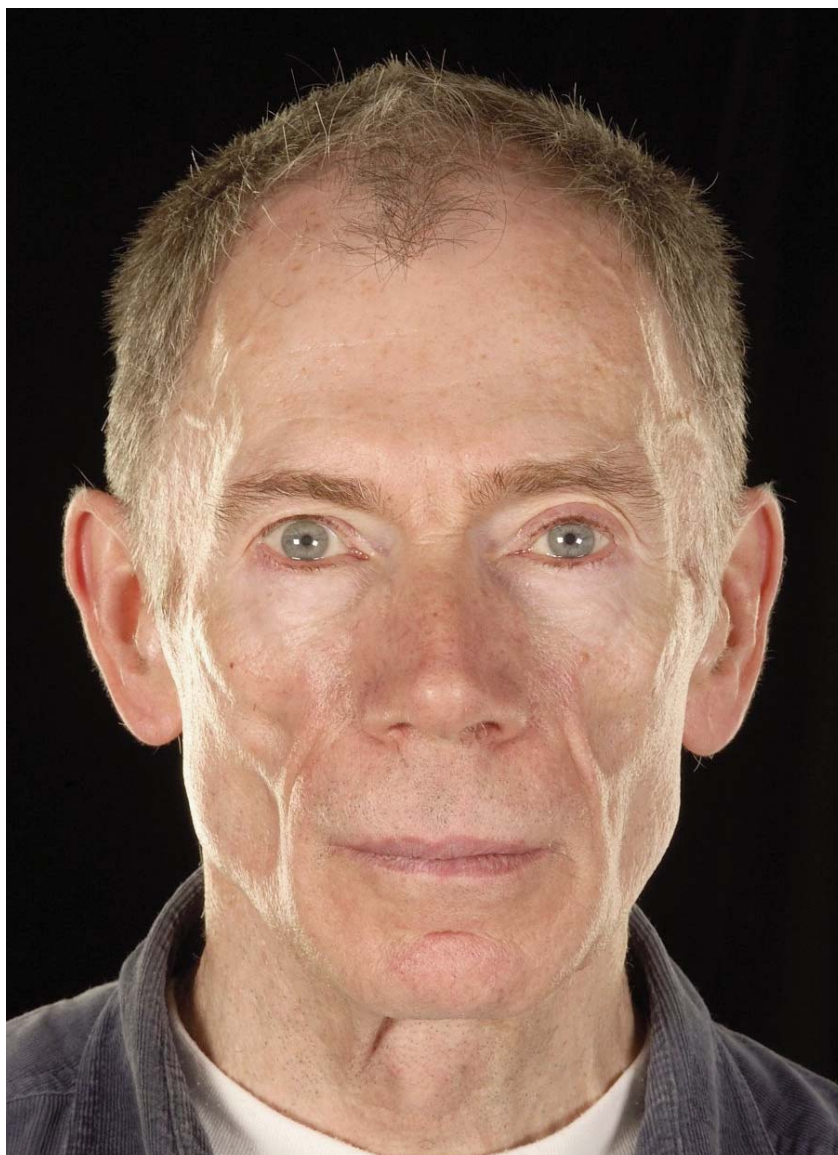
## Newfill

The first time I noticed that something was wrong was when I saw photos of myself and I was horrified. Let me be clear, I have never been mistaken for Brad Pitt or John Barrowman, but neither do I normally look like a survivor of the Holocaust. That was how bad it seemed. Fortunately, in 2001 I was under the care of Dr Ed Wilkins at North Manchester

General Hospital and was offered a place on a study with Newfill, a polylactic acid water gel commonly used in plastic surgery as an anti-wrinkle device and in surgery in other situations. Needless to say, I jumped at the chance.

Looking back over the Patient Information sheets I was given, I noticed that it said that I would have three injections into the skin in both cheeks, each two weeks apart and that local anaesthetic

was not usually necessary. The reality, however, was quite different. The three sets of single injections turned out to be five sessions of multiple injections (16 in each cheek), which were very painful and bloody. After the first operation, I understood why I had been advised not to wear white! From the photographs taken before and afterwards, you can't really detect a marked change; but there was a measurable increase in the thickness of skin. More important, I knew my looks had improved. When people



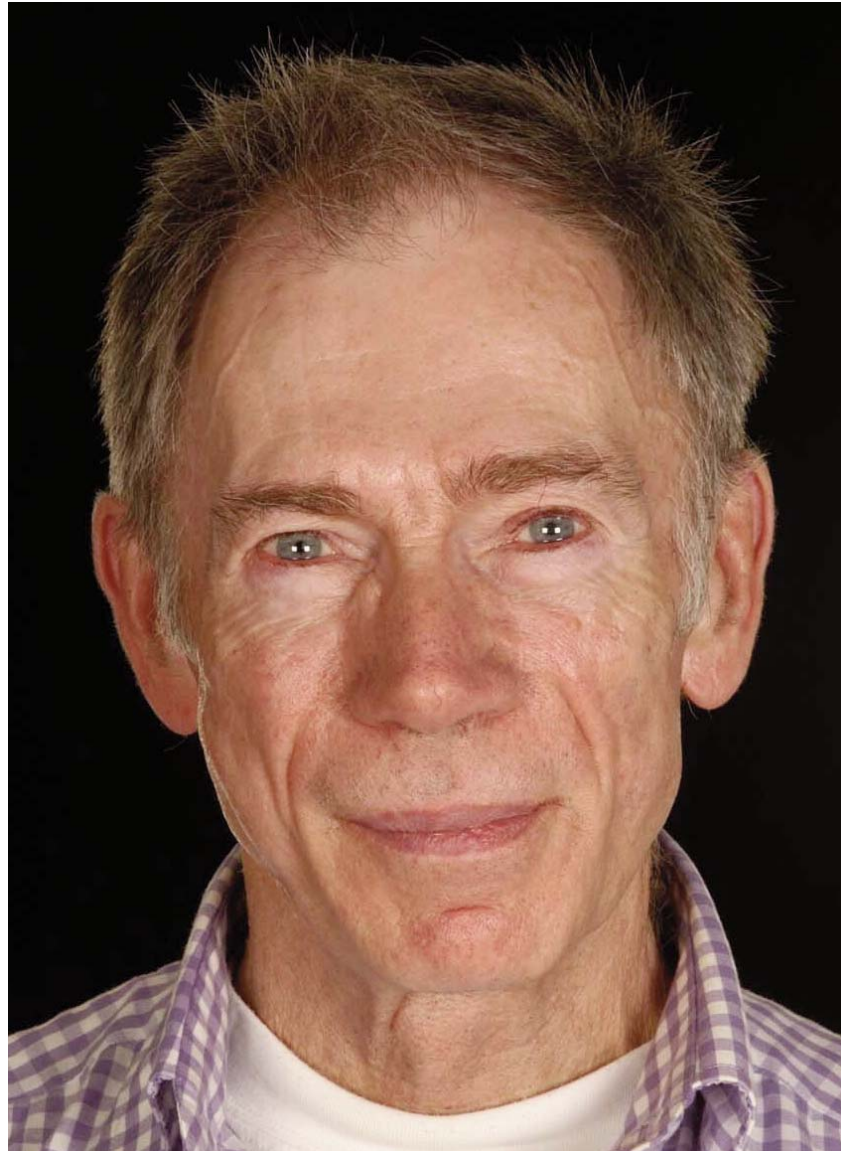
**June 2006: before treatment with Bio-Alkamid**

began to say how well I looked; that also made me feel better. The major drawback was that Newfill didn't last very long.

## Bio-Alkamid

My second chance for facial wasting treatment

came when I transferred my care back to North Staffs University Hospital. Patients with facial wasting were being referred to Birmingham University Hospital, Selly Oak, where Miss Ruth Waters was using Bio-Alkamid. In 2006 I had my first set of injections. A preliminary injection of local anaesthetic numbed the entry for a larger needle to insert the substance in each cheek. Regrettably, the pain of positioning Bio-Alkamid was not dulled in the least; if anything, I found the experience even more painful than Newfill. On the positive side, there was only a single injection into each cheek and there was no mess. It took two operations about a year apart to achieve the desired effect. After the first implant I had no side effects, but after the second, I had a post operation infection that caused the left side of my face to swell up like a balloon! Thankfully, a short course of antibiotics swiftly remedied the situation to produce a result that I am still pleased with three years on.



**June 2008: after treatments with Bio-Alkamid**

discovered that the Aquamed treatment they were being offered was painless! Aquamed seems to be very similar to Bio-Alkamid in substance and in the way it is implanted. Moreover, the results appear to be just as good – the big difference is the absence of pain during surgery. People who have had the treatment told me that apart from the tiny prick of the local anaesthetic, it was truly a painless operation.

For my part, I don't regret the discomfort of either of procedures I underwent. Apart from countering the physical disfiguration of facial wasting, I believe the operations have helped me to develop greater self-confidence. What saddens me is that the pain of the treatments currently available here in the UK is a real deterrent for some people. I am grateful to Bruce Kilmister Director of Body Positive New Zealand, for giving me all the published information on Aquamed that I passed on to Selly Oaks Hospital. Wouldn't it be

wonderful if Aquamed became the preferred option for facial wasting treatment in the future?

**Maurice Greenham**

Photos: Patient records, Medical Illustration, University Hospital Birmingham Foundation Trust

## Aquamed

Having had two painful experiences of 'extreme botox', you can imagine how envious I felt of my New Zealand and Australian comrades when I

# Positive Families

## Young People's Residential at Plas Gwynant, Wales

**Date; Monday 20th—Friday 24th July 2009**

20 young people and 4 adults from Staffordshire Buddies attended a week at Plas Gwynant outdoor education Centre in Wales. 6 of the young people who attended were HIV positive.

This residential was funded by the Youth Opportunities Fund, Children and Lifelong Learning Directorate, Staffordshire County Council.

The aim of the residential was to enable young people who are affected by HIV to attend a venue where they would feel safe enough to openly discuss HIV and its effects on their family and themselves. The young people had the opportunity to access one to one sessions or small groups that were lead by themselves with adults as facilitators. Extremely important issues such as medication, side effects, and adherence were discussed and also other issues such as when to tell, who to tell and sexual health worries.

The young people were also able to build upon peer friendships new and old.

The main aim was for all to have fun and access activities otherwise not available for families on low/no income.

This residential also benefited families; parents/carers were able to relax knowing that medication would be administered in a safe non judgemental environment.

The week consisted of; Canoeing, abseiling, rock

climbing, beach exploration, orienteering, mine exploration, mountain walking, and problem solving/team building exercises.



**One last comment comes from a parent;**  
"I could relax at home knowing he could discuss things in confidence, things I can't always answer as its difficult for me because it came from me (HIV), I was also completely reassured his meds would be strictly adhered to which in turn gave me a rest. Thanks."

# New Vaccine Trials

A combination of two HIV vaccines reduced the risk of infection by almost one-third in a large trial in Thailand, the trial's sponsor has announced. It is the first proof that a vaccine against HIV can protect against infection, but scientists say a lot more research will be needed before a vaccine emerges that can be given to large numbers of people.

"This is a historic day in the 26-year quest to develop an AIDS vaccine," said Dr Alan Bernstein, executive director of the Global HIV Vaccine Enterprise.

"This is the first HIV vaccine candidate to successfully reduce the risk of HIV infection in humans. We are very excited and pleased with the outcome of this trial and congratulate all those who participated in it," said Lieutenant General Eric Schoomaker, Surgeon General, U.S. Army, the trial sponsor.

The trial, called RV 144, compared a regimen of vaccination with two products against vaccinations with a dummy, inactive substance in 16,000 adults enrolled since 2003.

The study recruited adults in the community in two provinces of Thailand with high HIV prevalence (Chon Buri and Rayong), but did not specifically target individuals at high risk of HIV infection. Volunteers for the study were adults aged 18-30 who gave informed consent to participate in the trial.

Participants were randomly assigned to receive an initial set of vaccinations with ALVAC, and follow-up booster vaccinations with AIDSVAX, a product previously tested in large trials without evidence of success, or the placebo vaccination.

The presence of AIDSVAX in the vaccination regimen was one reason why many vaccine experts had not expected the trial to show a positive result.

In the event, the prime-boost combination of ALVAC(R) HIV and AIDSVAX(R) B/E lowered the rate of HIV infection by 31.2% compared with placebo. This reduction was statistically significant, meaning that the possibility of the result being due to chance is very low, but the confidence intervals for the estimate in the reduction in risk were wide ( $p=0.039$ , 95% confidence interval 1.1% - 51.1%).

In the final analysis, 74 placebo recipients became infected with HIV compared to 51 in the vaccine regimen arm. The vaccine regimen had no effect on the amount of virus in the blood of volunteers who became HIV-infected during the study.

More detailed results of this study will be presented at the AIDS Vaccine Conference, October 19 - 22 in Paris, France.

The vaccine products used in the study will not go forward for immediate licensing. Instead, the results from the study, which was considered to be a 'proof of concept' trial, will be used to inform the design of future vaccine trials.

Collaborating partners on this study include the U.S. Army, the Thai Ministry of Public Health, the United States National

Institute of Allergy and Infectious Diseases, part of the National Institutes of Health, sanofi pasteur (the developer of ALVAC), and Global Solutions for Infectious Diseases (GSID), the current developer of AIDSVAX. The collaborators are already working with external experts to determine the need for additional studies on this vaccine regimen and consider the impact of this study's findings on other HIV vaccine candidates.

This article is courtesy of NAM

For the full story and more go to;

<http://www.aidsmap.com/en/news/FC15FEF3-3CA0-41F5-A4BF-72C145D583A2.asp>



# Perspectives

One day i woke up and the world renew  
There was no pillow or my waking brew  
Had i suddenly been to Spec Savers?  
Or am i still delighted in my madly, wildly ravers?

During morning's ritual i don't say "where's me tweezers?"  
Nosey prickly extensions bristle, in early morning freezers  
Once misty bathroom mirrors, now reflect clearly, infinity  
Perspectives so clear, is this some sort of divinity?

Pound, pound i hear my heart begin to race, race, race  
Yesterday's ritual clock belling twelve to a distant, distance place  
Belly laughs. Oh the aching joyous pains  
Finally released, reborn, from drudgerly stains

Every sound of the new day a previous unrecognised symphonic  
My obsessed hypersonic life so completely monophonic  
I fumble at the window, hands trembling, "such butter fingers!"  
I must release it all in fear any of it lingers

Icy the wind of change blow across my naked body  
Stinging, uplifting, a piercing threnody  
I embrace it – prickly wet skin – shivering i scream  
"Please, please oh i hope this is not a dream!"

Tears flood and rolls, oceans for Neptune  
How did i miss all this fortune?  
Breathless, exhausted i collapse, am i dead?  
No ..... I've finally woken instead

For hours in minutes, minutes in seconds  
I can't wait my new life beckons  
So ironic but c'est la vie  
Today i finally live and have HIV



*Perspectives*, written by a service user.

# Positive Housing Support Worker

Hello Everyone, my name is Jenny Crowther. I am new into post as a Positive Housing Support Worker at Staffordshire Buddies. I am based in Hanley but am responsible for HIV Supported Housing work throughout Staffordshire. To give you some insight into my background, before I came into post I worked for the YMCA in Hanley for several years providing professional and relevant services to young people across Staffordshire. I have also worked for the Citizens Advice Bureau, on a voluntary basis, where I helped resolve a varied range of issues, including legal, money and housing related problems, by providing free independent advice. I have worked voluntarily on several projects over the years, this is the reason, primarily, that I continued my education in the substance misuse field. These previous experiences have given me a better understanding into the different social and economic issues people face in their daily lives.

On a personal note I am 31 years of age and live alone with my dog Marley. I love horses and spend most of my spare time now either walking or riding.

(Well, less about me, I bet your all getting



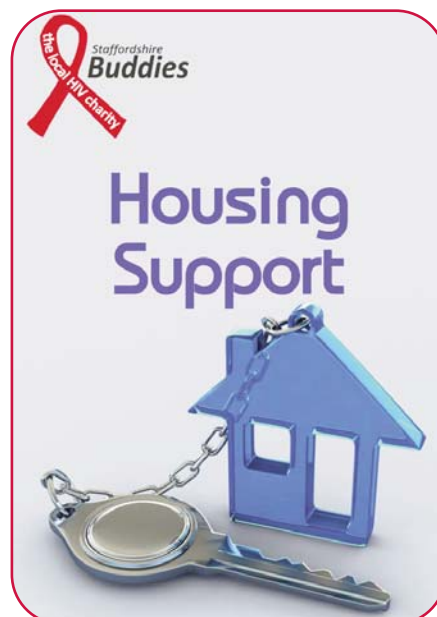
bored by now ...)

One last thing before I go I should just like to say a big **THANK YOU** to the Staffordshire Buddies team for making me feel so welcome. I look forward to meeting you all soon. If you would like to contact me in the meantime, please don't hesitate to do so on **01782 201280**.

Kind Regards

J.Crowther.

Positive Housing Support is a FREE service provided by Staffordshire Buddies to help people with HIV find suitable housing and live independently in their homes. Please ask for a copy of our guide to this new service.



As Health is the theme of this issue of Positive Lives, I will begin with that. After the apparent viral rebound in December last year, subsequent results came back 'undetectable'. Likewise, my cholesterol levels and immune system seem to be in reasonable shape. A more comprehensive reporting system has been introduced here in North Staffs, which now includes CD3 and CD 8 counts along with CD4. It gives a fuller profile at the price of a more complex readout that includes percentages and ratios as well as absolute counts. Don't worry: if you don't get written results, you won't notice the difference.

Given that I have increased my workload considerably, it is hardly surprising that I feel tired more often. My strategy is to take naps when I need them. These don't seem to make any difference to my manageable chronic insomnia, but they do seem to give me that extra bit of energy to get through the day. I manage to keep on top of my ingrowing toenails by following the advice given me by the North Staffs Chiropody Department to file my toenails straight rather than cutting them at an angle. Diarrhoea is a problem that I have to confront from time to time – at home it is easily managed – abroad far from a toilet; it can be a distressing and embarrassing experience. So far this year, it's only happened once in Germany – but once is more than enough!

#### **New Zealand**

It's hard to believe the year is well past the halfway mark. In January I fulfilled my long held wish to visit Stewart Island, the southernmost part of New Zealand and its closest point to the Antarctic. The week I spent there was well worth the long journey down, it was like stepping back in time to a slower, gentler, more people-centred way of life. For instance, both front and back doors of the backpackers' hostel where I stayed were left unlocked day and night. On my second night I was surprised by a visit from the police. A uniformed officer walked into the kitchen and held up a jacket asking if anyone knew to whom it belonged? "Yes" I said, "It's mine!" He handed it over with a smile and stayed for a chat. Now that says something about law and order on the island, as well as police priorities. My jacket had been returned to me before I even realised that I'd lost it! The constable had deduced where I was staying from the map in a jacket pocket with the hostel circled in biro. Whilst on Stewart Island, I was roped into a team for the weekly pub quiz, made two trips to the wildlife sanctuary of Ulva Island, joined a sunset kayaking excursion and went kiwi spotting at night by torchlight. Sheer magic!

#### **Germany**

Last year, parishioners from the Bernogemeinde in the ancient city of Schwerin, North East Germany paid a visit to St Mark's Church, Basford; a delightful couple stayed with me. They kept in touch though bi-lingual emails, and invited me to stay with them when a small group from St Mark's paid a return visit to Schwerin in May. Apart from the embarrassing accident, already mentioned, it was a wonderful experience. I got a chance to play an historic organ in the beautiful Schelfkirche as well as being given a free ticket to a magnificent performance of Mendelssohn's Elijah on the last night of our stay. There were fun excursions to fascinating historical buildings, beautiful gardens and a quaint harbour town; needless to say, there was an abundance of fine food and drinks. Naturally, I was cautious with the latter and purchased some Loperamide capsules from the local chemist for additional security.

#### **OU Study & Music**

I am approaching the end of this year's Open University Intermediate French Course. Although I haven't had any 'A' grades' for assignments...my marks have been pretty good and it has certainly been less stressful time than last year's German course. Excellent tuition from City Organist Michael Rhodes and regular practice has resulted in my passing my ASBRSM Grade 6 Organ exam with merit. I am now working

towards the next exam, but hopefully, by learning a wider range of the organ repertoire, I will also gain a sound technique in the process.

#### **Volunteering**

In October, I am going to South Africa as a volunteer with Hands@Work who aim to help the most disadvantaged children orphaned by AIDS. It seemed appropriate and felt right to be doing something special this year. World AIDS 2008 was the 15th Anniversary of the launching of Staffordshire Buddies. I was quite overwhelmed by the kind eulogy given by Andrew when he invited me to cut the cake at the combined Annual General Meeting and 15th Anniversary Celebration in July. However, 2009 is a special year for me as it marks 25 years of living with HIV. Whilst I am still able, I would like to continue to try to make a difference: the Africa project provides an opportunity to do something that could be really useful.

Keep well,

**Maurice**

