



## NEW HEPATITIS VIRUS IDENTIFIED

**A**nother letter has been added to the hepatitis alphabet soup with the identification of Hepatitis G. This brings the number of hepatitis virus strains currently identified to six A,B,C,D,E and now G although experts expect that the list will keep growing.

Consultant haematologist, Dr Lesley Kay, said in an article in *The Independent* on Sunday that this latest discovery was "the story of the blood transfusion service over the last 15 years. We are always chasing the next virus.

New viruses will continue to appear while we have exotic holidays, foreign travel and sexual freedom. These viruses often exist in small human or animal populations for many

public health education and cut the rate of infections.

A DoH statement says: 'Much of the available data results from those who acquired the infection as a result of contaminated blood or blood products. There is less evidence about likely disease progression in those who have acquired the virus by other modes of transmission.'

British Liver Trust director, Alison Rogers, warmly welcomes the announcement. "We have been talking to the DoH now for 18 months about the need for such a study, and we are naturally delighted that this money has become available. We now need to make sure that everyone who needs treatment is being offered it, and that the difficulties of funding interferon experienced by many liver units are overcome."

years without spreading. Visitors travel to the region, contract the disease and take it back home. It enters the blood supply and is spread by that route or by sexual transmission."

Hepatitis G (HGV) was first described in 1995 by a team from a Chicago pharmaceutical company, Abbott Laboratories, although there is evidence that the virus had been lurking for some time prior to this. The sample from which they isolated it was taken from a surgeon who developed a mysterious inflammation of the liver.

HGV belongs to the same genus as the viruses that cause hepatitis C (HCV), yellow fever and dengue fever. Like HCV it is thought to be transmitted through infected blood and blood products eg blood transfusions, shared drug injecting equipment, shared razors, tattooing

etc. As yet there is no simple test to identify carriers, but research is currently under way to rectify this.

HGV was found in one to two per cent of US blood donors, although the prevalence in the general UK population is thought to be lower than this. Earlier this year the number of identified cases in the UK stood at less than 100, with most patients being in high risk categories such as intravenous drug users or haemophiliacs.

Like HCV it causes fatigue in sufferers and may go on to cause serious liver disease, but as yet not enough clinical information has been gathered to put answers to the many questions raised by the identification of a new virus.

Professor Arie Zuckerman, of the WHO Collaborating Centre for Reference and Research on Viral Diseases at the Royal Free Hospital in London, said: "We don't have a lot of data about it (HGV). Much more work needs to be done on the virus, but there is inadequate support for hepatitis research in Britain.

## HCV NUMBERS GROWING, BUT TREATMENT AND SUPPORT SERVICES REMAIN INADEQUATE

**A** survey conducted by British Liver Trust with UK liver units earlier this year confirms that hepatitis C patient numbers are increasing, but that treatment, counselling and support services are inadequate to deal with the growth.

All 15 units taking part in the survey had experienced significant growth (average 64%) in their patient lists over the last 12 months and all anticipated this growth to continue at a higher rate (average 71%) in the coming year. In addition, three quarters of the units were experiencing problems funding the drug interferon, currently the only licensed treatment for HCV, and less than 15% of HCV patients were receiving interferon.

There was also widespread agreement that as well as increasing spending on interferon, there was a need for counselling services, an upgraded virology service, nursing assistance for antiviral therapy, and patient information.

Only 49 patients, out of a total survey population of 2,805, had been identified as a result of the Department of Health's look-back study, despite it having been in operation for nearly ten months. In addition, nearly half the units felt that GPs and district general hospitals were not referring all the patients that they should to specialist liver units. The

survey underlines the Trust's fears that HCV patients are not receiving the counselling, treatment and after care services that they need and should rightly expect. "This survey confirms continuing feedback from patients that they are simply not getting access to the counselling, support and treatment that they need. We know that there was a log jam in patients getting to see specialists, but were even surprised ourselves that only 49 people identified by the look-back study had made it to a liver unit. Clearly the HCV issue is not going to go away and this study provides solid evidence that the specialists are, without exception, reporting markedly increased patient numbers," said British Liver Trust director, Alison Rogers

"We are particularly keen that counselling and support services are put in place, both for people debating whether to take a HCV test as well as for those who've tested positive. We are also gravely, and from the evidence justifiably, worried that a patient's access to interferon may be dictated by the vagaries of the NHS funding system, rather than patient need.

"Clearly services are not adequate for the current level of patient numbers, and we are concerned that the situation will worsen over the coming months unless a concerted effort is made to develop services nationwide," said Ms Rogers.

## HIV PROTEASE INHIBITORS AND HAEMOPHILIA

**F**DA has recently learned of approximately 15 case reports of spontaneous bleeding episodes in HIV positive patients with haemophilia who were being treated with HIV protease inhibitors at the time of the event.

Of the cases of spontaneous bleeding primarily associated with these drugs, 11 have involved haematomas and 5 haemarthroses (one patient reporting both). None involved serious injury or death. The majority of patients have been able to continue taking their protease inhibitor therapy in spite of the bleeding event.

To date, there is no conclusive evidence to establish that the protease inhibitors are the cause of these spontaneous bleeding episodes. However, as these products were all approved under FDA's accelerated approval mechanisms for treatments for life-threatening illness, FDA believes it is important to investigate and question about safety that arises early in the marketing experience.

There are three HIV protease inhibitors currently approved for marketing in the United States for the treatment of HIV infection: saquinavir (Invirase) from Hoffman-LaRoche, zidovudine (ZDV) from Abbott Laboratories,

and indinavir (Crixivan) from Merck Research Laboratories. To date, all cases reported have involved European patients.

At this time, it is unknown whether there is a causal relationship between the use of protease inhibitors and bleeding episodes in patients with haemophilia. All of these reports involved patients with haemophilia and advanced HIV infection who were receiving multiple drug treatments. Clinical studies using these drugs have not reported an increased incidence of either bleeding or coagulation abnormalities in patients with or without haemophilia.

However, in light of these reports, the FDA and the drug manufacturers recommend that health care providers monitor haemophilic patients for spontaneous bleeding episodes whenever any of the protease inhibitors is used as part of treatment for HIV. Patients with haemophilia and HIV infection who are currently using protease inhibitors should not discontinue using their treatment but should instead consult with their health care provider if they have any concerns. Health care providers and patients should not hesitate to initiate therapy with these drugs.

## PARTNERS MEETING

**T**he next partners' meeting is on Sunday October 6th at The Miskin Manor Hotel in Llantrisant. The stay includes dinner, bed and breakfast and the use of all leisure facilities.

Any partners interested in participating in this relaxing and therapeutic day, (which doesn't include any meetings or flip charts !!) will have to be quick to book as there are a limited amount of places available due to financial constraints and room availability.

There are only ten places available so if you wish to come along please can you book your place in writing, and send it with a deposit of £5.00 to the Birchgrove office as soon as possible, thus avoiding disappointment!

## POSITIVE ONLY SUPPORT MEETING

The Positive Only Group are holding a two day support and alternative information seminar.

It's been a while since we last held a positive only meeting and this time together will allow us to plan for the forthcoming events which will take us into the millennium.

We will be meeting in a central hotel in Cardiff.

The Dates For this meeting are Friday 4th October to Sunday October 6th. which will give you time to get home a to let your partners leave for the partners meeting.

A £10 deposit will be required for this event

We need to confirm places as soon as possible so please ring the office.

Tel : 01222 373560

## VITAMINS! ARE THEY ANY USE?

**O**ver the last few months a few of us at the Birchgrove office have been on a trial of various Vitamins. We have been taking them on a daily basis for the last six months to see if they are of any use.

Vitamin C, Mega-B, Coenzyme Q10, Acidophilus, Multi Minerals, Beta Carotene, Garlic and Evening Primrose are the tablets we have taken.

Have they had any effect I hear you ask, well apart from taking a lot of room up in a storage cupboard at home I don't really know. I will definitely carry on taking the Vitamin C as I have found that I haven't had a cold since I began on it so that must be a good sign. I do feel better in myself, but I don't know if this is physiological or not. I think that at the end of the day, it is up to individual choice, there are a lot of people out there who are for large daily intakes of vitamins and there are equally as many against.

What I will say though is that large quantities of Mega-B and Vitamin C do make your piss go day glo yellow. Try explaining to the bloke standing next to you in the gents that you're on a vitamin trial when he thinks he's pissing next to an alien from the planet Tharg is a bit of a teaser, but that's another story.

Martin



## THOUGHTS FROM A HAEMOPHILIAC WITH HIV, HEP A,B,C,D..

There are days when a person like myself gets up (late as usual) on a normal day and asks themselves why am I still here? Haven't I, and the rest of us, been through enough already? How many more times most we go through the same thing?

*There is a time in life when one evaluates oneself and I am sure that this period is short. What I mean is that people generally only have a short time to evaluate themselves because they have so many activities going on in their 'LIFESTYLE'.*

*With us these are not the people with Haemophilia and HIV and Hepatitis but the ones who are dear to us. Our wives and partners who sit back and look at us pondering our next move.*

*Our partners evaluate us more than we do and I suppose they have every right to. After all their the other half of us, the other side of our sanity. Their always there for us and always providing a listening ear when you have a gripe about the Inland Revenue or the DSS or the bills and that oh so familiar unwell feeling.*

*What I tend to forget when I'm moaning about life to my wife, my match, my gem, my saviour, my provider and my sanity is that there is no one there for her!!! She has*

*decided in life not only to take me on even when I'm being a little rat*

*and only coming to the surface to feed and take baths and squeak when the water is to hot and squeak when the water is to cold, and she really doesn't get very impressed with the little things in life.*

*When I look at my partner I realise one factor in life which is very hard for me to understand, especially when your well being is constantly being ridiculed by others in what ever form, this factor is the stamina my partner has, and I am sure everyone else's has.*

*Think about it this way, would you marry someone who is terminally ill? who is a pessimist, who has very little money and who thinks about himself first before anyone else? I wouldn't marry anyone who fitted the above description so why did my partner decide to marry me? The answer of course is simple but if it is so simple why has it taken me so long to discover? Well the answer to that is a little more complex but hopefully by reading the rest of this article it will explain, firstly how easy it is to loose the grasp of thought and secondly how easy it is to forget the good times and replace them with bad ones.*

*When I think back to how my life started out, it was, I suppose, what you would call normal - normal is the only word I can find at the moment because society has an overwhelming affect on us and when something is out of the ordinary it is referred to as 'not the norm' - yes of course there were times when I hated going to the hospital because all I remember was pain and anguish as doctors and nurses stuck very BIG needles into me without a thought as to how I felt.*

*In my teenage years there were good times and bad also. The good ones being the girls who showed an interest in me because of the Haemophilia and the bad ones being the boys who showed an interest in picking on me because of the Haemophilia.*

*Coming up to my career moves I decided to be adventurous and become an Engineer, with the help of parental pressure, after all my elder brother who missed loads of school, even more than me, got 10 'O' Levels and 4 'A' Levels so why shouldn't I get the same? Looking at what I achieved in life seems big to me, but was it worth it?*

*I left school with 4 'O' Levels and decided to go to tech college to do a City and Guilds and National Diploma in General Engineering and quite enjoyed it as a subject, but not to keen on the nerds who thought fun to punch me and see what would happen.*

*After completing Tech I went to University College Cardiff to achieve my goals....sorry my parents goals!*

*It was here that things started going wrong. In my first year I thought that the lecturer and students were a bunch of snobs, and so I kept a reasonably low profile. It was around my second term that rumours started to circulate about this new killer disease called AIDS and that if you caught it it killed you in seconds and was so contagious that you had no chance of going to the pub without catching this killer virus!!! This didn't stop any of us going to the pub of course. What did stop them was that it got around very fast that I had AIDS.*

*It all started something like this... I went on a megga drinking session with a mate who was at the other university in Cardiff (UWIST) we got rather drunk and missed our usual bus so decided to get the train Unfortunately the train timetable had been altered and we'd missed the last one back. I suggested a taxi, as my ankle was not very good on long distances, my mate said he had no money left so we ended up walking about 8 bloody miles to get back to my*

*continued on Page Eight*

## FINANCIAL SETTLEMENT FOR PERSONS WITH HAEMOPHILIA AND HIV/AIDS IN AMERICA

On Wednesday August 14, Judge John Grady gave his preliminary approval to the settlement offer, a final fairness hearing will be held November 25, at the Federal Court Building in Chicago, ILL. Anyone who opts in to the settlement, will have the right to address the Court if they disagree with the settlement.

On or about August 20, the legal notice will be mailed to all Haemophilia organisations for immediate distribution to the members of the Haemophilia community. The legal notice will explain the legal rights of all claimants, who is a claimant, and how to file a claim.

The claim process has been developed in such a way that if a person wishes to file a claim, that person will NOT need a Lawyer to do so. If any person filing a claim hires a Lawyer anyway to file a claim on their behalf, then that person will be responsible for the legal costs for that Lawyer.

As a condition of the settlement, any legal fees incurred outside of the

filing of a claim (such as from prior work done to pursue your case), will be deducted from the forty million dollar fund set up to pay legal fees.

The current settlement offers \$100,000.00 to each person with Haemophilia who contracted HIV/AIDS through the contaminated Factor products manufactured by the four defendants: Bayer (Cutter) Baxter Armour, and Alpha Pharmaceutical Companies.

Also included in the settlement are the HIV/AIDS infected wives, children, and those who lived a monogamous relationship of at least two years. This settlement also applies to those families who have lost their loved one, whether or not the cause of death was AIDS, as long as that person had Haemophilia, a diagnoses of HIV or AIDS, and used at least one product manufactured by one of the defendants. Any person who wishes to either opt into, or out of the settlement, must do so by October 15, 1996.



# THE SHITS, THE SQUITS AND THE TROTS

**D**iarrhoea is a common symptom among people with HIV, especially if your CD4 count is low. Its severity can vary from a semi-loose to a completely liquid bowel movement or 'stool'. There may also be other symptoms such as abdominal pain, loss of appetite and weight loss. If you have diarrhoea for more than a few days, consult your doctor.

Severe diarrhoea is usually caused by opportunistic infections. The best way to treat the diarrhoea is to identify and treat the underlying infection.

Doctors used to think that many cases of diarrhoea in people with advanced AIDS were caused by the effects of HIV on the gut. Today, this is not thought to be a common cause of severe diarrhoea.

Apart from infections, other possible causes include antibiotics (which may disrupt the normal gut bacteria which help to digest food); other treatments including many anti-HIV drugs; other medical conditions such as Crohn's disease; malabsorption; and irritable bowel syndrome.

## DIAGNOSIS

You may be asked to provide stool samples to be tested for infections. Some infections live in the tissue lining the bowel but cannot be detected in the stool, so your doctor may also suggest a biopsy. A tube is inserted via your

mouth into your stomach or small intestine (endoscopy), or via your anus into the rectum or lower bowel (sigmoidoscopy or colonoscopy) and a tiny piece of the lining is removed for tests.

If no infections can be found and you are taking drugs that are known to cause diarrhoea, your doctor may assume that these are the cause.

## TREATMENT

There are three issues to address in treating diarrhoea: the cause, the symptoms, the effects.

The commonest gut infections that cause diarrhoea are Cryptosporidium, Microsporidium, Shigella, Giardia, Campylobacter and Salmonella. Other opportunistic infections that can affect the gut as well as other parts of the body include cytomegalovirus (CMV) and Mycobacterium avium intracellulare (MAI). Once your doctor has identified the cause, specific treatments can be offered, although some of these infections can be very hard to treat.

If your diarrhoea is thought to be caused by drugs, it may be possible to reduce the dose or use a different medication. Irritable bowel syndrome may respond to a change in the fibre content of your diet, or to anti-spasmodic drugs.

As well as treating the cause, your doctor can

offer standard anti-diarrhoea medicines such as Immodium or codeine to reduce the symptoms.

It is also important to deal with the secondary effects of diarrhoea. You are likely to be losing a lot of liquid and minerals such as sodium and potassium from your body, so it is important to drink plenty of fluids and consider special rehydration drinks such as Dioralyte.

You may also experience weight loss, because loss of appetite means that you are not eating enough or because you are not absorbing enough nutrients in your gut. Sometimes you can regain weight simply by eating more. If this fails, see a dietician at your clinic who can recommend food and supplements to increase your nutritional intake without worsening the diarrhoea. Avoiding foods that are high in fat, fibre or lactase content may also help reduce the diarrhoea.

Diarrhoea often leads to soreness around the anus. Your doctor may be able to suggest soothing medications. Incontinence (loss of bowel control) causes other practical problems such as increased laundry. Ask your clinic, social services or voluntary organisation if you need help with this.

## DIARY DATES

Nia Wyn Jones Leaving Bash.

Will be held at the Post House Hotel Cardiff on Thursday 12th Sept 96.

Ring us for Details

Partners Support Group will be meeting on

Sunday October 6th at The Miskin Manor Hotel in Llantrisant.

For an overnight support meeting

Positive Only Alternative support meeting will be held on the 4th & 5th October.

You must ring the office for further details, due to the problems of confidentiality and the nature of this meeting and it's contents.

Remember the drop-in's every Wednesday at the office.

Ring the office for further details 01222 373560

**A** lady woke up one morning and discovered her dog was not moving. She called her vet who asked her to bring the dog in. After a brief examination, the vet pronounced the dog dead.

"Are you sure?", the distraught woman asked. "He's a great family pet. Isn't there anything else you can do?" The vet paused for a moment and said, "There is one more thing we can do." He left the room for a moment and came back carrying a large cage with a cat in it. The vet opened the cage door and the cat walked over to the dog. The cat sniffed the dog from head to toe and walked back to the cage.

"Well, that confirms it," the vet announced. "Your dog is dead." Satisfied that the vet had done everything he possibly could, the woman sighed, "How much do I own you?"

"That will be £330," the vet replied. "I don't believe it!", screamed the woman. "What did you do that cost £330???" "Well", the vet replied, "it's £30 for the visit and £300 for the cat scan."

**I**t seems there was a hard core Pessimist and an incurable Optimist which a group of research scientists were called upon to study.

The Pessimist was placed in a room that was filled floor to ceiling with beautiful things, such as flowers, toys, balloons and lovely poetry. The Pessimist proceeded to go on a rampage, smashing everything, breaking and destroying all these positive symbols to smithereens.

While the hard core Optimist was forced into a room which contained floor to ceiling horse shit. The Optimist proceeded to jump up and down in the shit and just laugh and play as best he could.

After the experiment, the participants were asked about their behaviours. The Pessimist said that the toys and goodies in his room would all be destroyed eventually anyway. The Optimist was asked to explain his uncontrollable joy playing around in the horseshit. The Optimist simply stated that "With all this horseshit, THERE'S GOT TO BE A PONY IN HERE SOMEWHERE!"



## PILOT STUDIES LOOKING PROMISING

A number of pilot studies investigating the effects of combined interferon and ribavirin treatments on hepatitis C patients are beginning to show promising results - although virologists still advise caution until full scale trials can be conducted.

One such study was carried out by four Swedish researchers at the Departments of Infectious Diseases at Lund and Malmo University Hospitals.

They ran an open study on 15 patients with chronic HCV infection, treating them with a combination of alpha-interferon and ribavirin for 24 weeks.

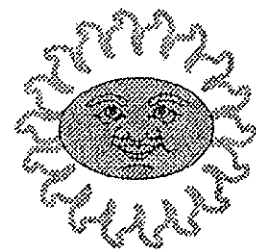
Nearly six months (24 weeks) after treatment finished nine out of the 15 patients (60%) had complete clearance of HCV-RNA as measured by a PCR (polymerase chain reaction) test.

The only drawback to the treatment seemed to be a moderate decline in haemoglobin and an increase in bilirubin levels, both of which returned to normal after the treatment was discontinued. There also seemed to be a more sustained response to the treatment by those patients who had a 'purer' form of the virus, as opposed to those with mixed genotypes.

Professor Geoff Dusheiko, one of the country's leading experts on HCV said, "Promising preliminary results are being tabled in several large studies being conducted worldwide. The combination regime seems to reduce relapse rates, but it is not yet clear to what extent poor responders to interferon will be converted to good responders."

At the time of going to press a multi centre trial, involving 350 patients in 10 UK hospitals led by Professor Howard Thomas, was still awaiting confirmation of funding from the Medical Research Council.

# IT'S A FUNNY OLD WORLD



**T**here are five levels, of drinking - six if you live in Abertillery. But never mind that we'll be dealing with five. See if these look familiar...

**Level One:** Lets say it's eleven o'clock on a weekday night, you've had a couple of beers. You get up to leave because you've got work the next day, and one of your friends buys another round, one of your UNEMPLOYED friends. But here at level one, you think to yourself "Oh well, come on, for goodness sake, as long as I get seven hours sleep - I'm OK"

**Level Two:** It's midnight, you've had a few more beers - you've just spent twenty minutes arguing against artificial turf - You get up to leave again, but at level two a little devil appears on your shoulder. And now your beginning to think, "Hey - why shouldn't I be out with my friends? What am I working for anyway? As long as I get five hours sleep - I'm OK!"

**Level Three:** One in the morning. You've abandoned beer for Tequila. You've just spent twenty minutes arguing for artificial turf, and now you're thinking, "That waitress is the most beautiful girl I've ever seen." You see, at level three, you love the whole world. On the way to the gents you buy a drink for the stranger at the end of the bar just because you like his face. You start to get drinking fantasies, "Fellas, hey fellas, if we all bought this bar we could all live together forever!" But at level three that devils a little bit bigger, and he's buying! And you're thinking, "Well c'mon now, as long as I get three hours sleep - and a complete change of blood - I'm OK"

**Level Four:** It's two in the morning, and the devil is bartending! For last orders, you bought a bottle of Rum and a coke. By now you are artificial turf! This time on your way to the gents, you punch the stranger at the end of the bar, just because you don't like his face. And you're thinking "That bartender is the best looking man I've ever seen!" You

and your friends decide to leave right after you get thrown out. But it's OK, one of you knows an after hours bar. And it's here at level four, you actually say to yourself "Well as long as I'm only going to get a few hours sleep anyway, I might as well - Stay up all night! It'd be good for me - I don't mind going to that board meeting looking like Keith Richards. Besides, as long as I get thirty one hours sleep tomorrow - I'm OK"

**Level Five:** Five in the morning. After unsuccessfully trying to get you're money back at the Tattoo Parlour, "Yeah - but I don't know anyone named Ruby". You and you're friends wind up in a bar, in a backstreet, filled with guys who had been in prison as recently as that morning. The kind of place where even the devil is saying "Look guys - I gotta turn in, I gotta be in hell at nine - I got lunch with Hitler, I can't miss it". You're all drinking some kinda of thick blue liquor, usually reserved for cleaning combs. A waitress with fresh stitches in her head comes over, and you're thinking "Someday I'm gonna marry that girl" Suddenly, one of your friends stands up and screams "We're driving to Florida!" and passes out. You crawl outside, and it's then that you hit the worst part of level five - the sun! You walk out of a bar in daylight and the day has started, people are on their way to work or jogging along the pavement. And they look at you - and they 'know' - and they say, "Who's Ruby?"

Let's be honest, if you're nineteen staying up all night is a victory, it's like you've beat the night, remember the feeling? But if you're over thirty, that sun is like God's searchlight burning into you. And we've all said the same prayer, but you say it again, "I swear - that I'll never ever do this again - as long as I live!

And this time I mean it.



# NEWS FROM AROUND THE WORLD

## HIV EXPULSION STOPPED

The planned expulsion of a Zairian woman with AIDS who immigrated to France illegally has been stopped following protests by the AIDS group ACT-UP.

## HIV TESTS FOR BOXERS

The Californian state assembly has recently passed a bill that requires boxers to test HIV negative in order to be licensed in the state. The bill came in response to the announcement that former heavyweight Tommy Morrison has HIV. Seven states and Puerto Rico required yearly HIV tests before Morrison's announcement and other states have since implemented the requirement.

## LIGHTHOUSE DIRECTOR RETIRES

London Lighthouse director and founder Christopher Spence MBE has announced that he will be retiring at the end of the year, after ten years at the helm. His departure will follow agreement of restructuring proposals to support the future development of London Lighthouse. These proposals will include the appointment of a new chief executive.

## THT LIBRARY CHANGES

The Terrence Higgins Trust has announced changes to make their library more accessible to people with HIV. From June 17th, the library, housing the largest non-medical HIV/AIDS collection in Europe, will be open every Monday evening until 7pm. Visitors will

be able to get free access to the internet, free photocopying and free refreshments.

## NEW CHAIR FOR ALL PARTY GROUP

Robert Key MP, Conservative member for Salisbury, has been appointed Chairman of the All Party Parliamentary Group on Aids, with which he has had a long association. He was Vice Chair from 1987-1990. The role of the All Party Group is to provide a parliamentary focus for all issues relating to HIV/AIDS.

## THAI STUDY ON MOTHER BABY TRANSMISSION

At least 400 women participating in a joint study by the United States and Thailand will receive AZT during their nine months of pregnancy and during labour to determine the drug's efficacy in preventing mother to child HIV transmission. If AZT is effective, it is expected to help reduce perinatal transmission of HIV among the 20,000 HIV-infected women who give birth each year in Thailand. An earlier study between the United States & France, found that AZT could reduce mother to child transmission by two thirds. The dosage being tested in the Thai study, however is cheaper and therefore more feasible for developing countries.

*The views expressed in each of the articles are those of the individual authors, and not necessarily those of Birchgrove Wales. We would encourage anyone who may have strong views regarding any of the items published in this newsletter to write to the Editor. No assumptions should be made regarding the health status of any individual whose name appears in this publication.*

## SOCIAL WORK REPORT.

As you will all probably be aware the big news is that Nia is leaving for pastures new in North Wales. In order to wish her all the best and give her a good send off I would encourage as many as possible to attend her leaving do at the Crest Hotel here in Cardiff.

Apologies for confusing everyone with the date but I can confirm it is Thursday 12th September at 7.30. It is almost certain at time of writing that z will be going full time to cover Nia's hours.

It will also be good to welcome Dr Collins the new Consultant at the Haemophilia Unit who is starting at the beginning of September.

There has been a few events since the last newsletter including a Social evening a Bereavement meeting and a Positive persons get together. The Social evening in particular was a lot of fun featuring a skittles evening at the Cower pub in Cathays, Cardiff. Some hitherto hidden talents revealed themselves whilst some others no names mentioned did not perform to expectations. It has to be said that whilst Nia will be missed for her commitment and energy in her post her contribution on the skittle alley is best glossed over.

Tim Hunt

**NIA'S LEAVING BASH WILL TAKE PLACE ON THURSDAY 12TH SEPT 1996**

Ring the office for details 01222 373560



# SAYING GOODBYE FROM NIA WYN JONES

## MFT NEWS 1

Having been in my present post as a part-time Social Worker attached to the Haemophilia Centre at the University Hospital of Wales for the last two and a half years I find it a difficult and sad process to prepare for my departure.

As most of you will know, since February of this year, I have been commuting from North Wales to Cardiff every week - travelling down on a Monday morning and returning on Wednesday afternoon.

Following a recent trip to Llandudno, Gareth, Martin and a few other Birchgrove members will know first hand what a long, winding tedious route the A470 from Cardiff to North Wales is! But perhaps the most difficult part of this for me was, not necessarily the difficult route, but rather, the fact that every Monday morning would start with the alarm bell waking me up at the very unsociable hour of 5.00 am and then having to drive the 4 hour journey to Cardiff. On a more serious note though, what I have found to be most difficult is not being able to offer the same flexible service to those people I work with and this is mainly why I eventually decided to give up the post. Had my husband and I not moved to North Wales I would not even have considered leaving my post at this stage as I can honestly say that I have thoroughly enjoyed and appreciated doing this particular work.

Working with my colleague Tim has been a wonderful opportunity and experience, as I regard Tim as an extremely able and competent Social Worker. I have learnt a great deal from him during our time together at the University Hospital of Wales. Knowing that my replacement will do an even better job than me makes moving on a little easier for me.

I've also thoroughly enjoyed my contact and involvement with the Birchgrove Group and again I feel that I've benefited a great deal and learnt an enormous amount from the group. It has been a privilege to work with and be part of the group and it has been so wonderful to see the Birchgrove Group develop and grow from strength to strength. The local Birchgrove Group has every right to be proud of itself and the working group deserves much credit for all their efforts and hard labour. The working meetings, social events, information and support they provide and arrange for fellow members is, I think, invaluable.

I must also mention how much I have appreciated the way many of you readers accepted me as your Social Worker and allowed me to enter into your lives' as it were. I can well

appreciate that it is never easy to allow an outsider - especially a complete stranger as I was two and half years ago - into your life and to share with that person some of the issues and concerns that confront you and your families due to the difficult situation you find yourself in.

Many of you have been asking what my plans are for the future as regards work. If all goes according to plan I'm hoping to start a new post at the beginning of October but nothing is definite yet. However, one thing I do know is that all the knowledge experience and expertise I have accumulated while doing this post will not be wasted as I intend to be quite involved with Mudiad Mercy House Foundation and their respite care centre in Penmaenmawr, North Wales. It is mainly due to my experience in this post that I am able to contribute to this project which aims to help and support those infected / affected by HIV in North Wales and throughout Wales.

I must admit that I'm one of those people that doesn't necessarily like 'goodbyes', they leave me feeling empty and lost. On these occasions I feel that I'll be leaving good friends and very supportive colleagues at the hospital and whom I shall miss a great deal. But I also feel that I shall be leaving a group of good friends some of whom are members of the Birchgrove Group and others I visited regularly at home to offer a social work service. In a recent conversation, Tim and I concluded that it is almost impossible to restrict our relationship to a purely 'professional-only' one with those people to whom we provide a service in our present post. There are occasions where friendships are established between the Worker' and the 'client' and this is mainly due to some of the difficult, intricate and often painful issues both parties work on together in this particular area of work. Another reason for this is that the work often necessitates long-term social work contact, therefore as time goes on the relationship develops. And of course another factor is that the Birchgrove Group in arranging social 'get-together' gives us all an opportunity to relax together and to enjoy each others company.

This inevitably contributes towards making saying 'goodbye' much more difficult! But good old reliable Birchgrove are there again when one needs help - the farewell will be made so much easier by saying 'goodbye' in style by having a real good Birchgrove party. I Thank you Birchgrove - I look forward to seeing many 'friends' at the party on the 12th September. *Nia Wyn Jones ( Social Worker )*

I assume everyone has received a copy of the latest Handbook together with the new application form that we can now fill in rather than having to write our own begging letters because we are, of course, all stupid and quite incapable of putting pen to paper. I find the section on 'health' very helpful and will of course be filling in this section 'Haemophilia and HIV Positive' which I am sure will help the Trustees no end in their deliberations on whether or not I NEED their assistance.

How dare they ask what the state of my health is? What gives these people the right to know. To my knowledge there is only one person on the trustees who is medically qualified and even that person is not my doctor and therefore has no right to know.

The handbook also states that if anyone asks for assistance, and before being turned down, the matter is put to the trustees but the trustees are not aware who the request is from.

So the scenario must go something like this:

Tudur: "we've had a request from registrant number 1996 but he is being most uncooperative about his current state of health."

So I recommend the trustees refuse the request".

Trustees: "absolutely right

Tudur you do what you think best". "Next sucker".

I have, in the past, spoken to Tudur about this 'state of health' requirement creeping into the trusts policies and Tudur has assured me that the information is only seen by qualified trustees. But how can it be? Someone must open the mail at the trusts offices, probably the office gofer I in which case it could end up anywhere, once opened it will then presumably pass on up the line to Tudur who, in turn, passes it to the 'qualified trustee' but if the trustees are unaware of who the registrant are what's the point? The point is that the trust will use the information to start a new system whereby if your ill, and by ill I mean an AIDS defining symptom, your going to get more help and if your well you can wait until your dying. Now I have no problem with people who are poorly getting more however, in my opinion, the trust should not be differentiating between us, we're all in the same boat and we should all be treated the same. - we should all be told to .....!!!



# £1M GRANT FOR HCV STUDY

The Department of Health is providing £1 million for an investigation into hepatitis C to try to discover how widespread it is in Britain.

Estimates suggest that between 0.1 per cent and one per cent of the population is infected with the disease, which could mean as many as 500,000 people in Britain alone. The research money is for investigations into the prevalence, transmission routes and

natural history of the infection. This will be the first research programme in the UK to look into the epidemiology of this newly identified virus and tenders from researchers are currently being invited.

The DoH says the project is needed because little is known about infection rates in the UK, making it difficult to plan future health needs. It says it will use the findings to improve

# WHAT'S IT ALL ABOUT "ALFIE" ?

Why do people often confuse the work of Birchgrove Wales with that of the National Group, OK most of the work for the National Group is done here in Wales, but the two groups are completely separate and should not be confused with each other.

If you are upset by something in the National Newsletter. Please don't take this out on us poor bleeders who work endlessly in the local office. Please write to the National group.

Well that's that bit over and now for something completely different, do you remember the old saying it never rains it only pours, well it seems that in the voluntary sector it is continually pissing down. As you may be aware both myself and Mr Jenkins are both trustees of the local Cardiff Body Positive group, YES were sad gits I know. But that's life, if you think Birchgrove is exciting then you need to get involved in the wider world of care within the HIV & AIDS community.

It never ceases to amaze me, when I see what is happening in the world of care and support for those people who are HIV positive. Do these people even understand the basic need for confidentiality, I was recently sat in a drop-in room for positive people when my status was revealed to a wife of one of the social workers linked to the GUM clinic, and this person is trained to look after your needs, when he does not have the basic understanding of what confidentiality means. Well it makes me cringe! Oh well I've had my moan for this month. So lets get on to something a bit more exciting and that is Nia's leaving do. I hope you can all make as it will be a really good opportunity to all meet up and have a ball.

Yours slightly Happier than last Time

G a r e t h

*Continued from Page Three*

*hall of residence.*

*The next day I awoke with this huge bleed on my ankle and was completely unable to walk. Being a student my first thoughts were, of course, how do I get some food? I*

*was at a loss to know what to do there wasn't even phone a to hand to order a donner kebab and after a skin full of beer I was really looking forward to breakfast so! so what to do? It wasn't as if I could get out of bed and fake it. My brother, -who lived in Cardiff, was on holiday for two weeks so anyway, after thinking about going without food for a long time an idea came to me, it went something like, if I could hobble over to the door and open it when there was no one around and then hobble back to bed and wait for someone to pass I could ask them to fetch me some food from the hall telling them some porky about my ankle being swollen.*

*Eventually someone did pass my door, Serif a 4th year Mechanical Engineering student who was quite helpful to me concerning engineering matters, and so I asked if he could fetch me some food as I wasn't feeling to well. When Serif returned with the food he asked what was wrong and, perhaps it was the smell of the food, I very foolishly explained that I had a swollen ankle due to a haemarthosis as I have haemophilia. He asked what haemophilia was but I just put him off and he left. The next thing is that people are sticking rather nasty articles to the door of my room. Needless to say I failed my course and left to do my engineering course elsewhere, keeping a very low profile. I eventually achieved my Prod Eng. Hnd and went on to teach Design and Information Technology.*

*I suppose what I am trying to say is that I am still here no matter what barriers or walls have been put in front of me and I still have my*

*health, to a degree. Even though my memory is not very good and I stumble in normal conversation by forgetting what the conversation is about half way through. all I can say to you is no matter how life has dealt its cards to you, you still have the main key elements to life, they are your sanity, your family and even your relatives providing they treat you accordingly. You being you not you with an illness!*

*I have evaluated myself and it took quite a while especially as I have more activities in my life now than ever before. My 'lifestyle' is quite choker even though fatigue plays its toll. Regardless of that I am very fortunate to have an understanding wife who is subject to the same pressures as myself. My wife has a stronger hold on life than I do and because of that I am getting stronger by the day. Before long I will be strong enough to go public and fight for what we need and what we want. Our lives are very important to us and we must have fair hearing in order to achieve what other people get out of life simply. We should not be pushed out of society nor be treated as lepers because we are just people who never deserved what we got.*

*Life presents many tasks for people to overcome and I'm sure all these events are tests to pass in life and once passed you may find that things are not as bad as they seem. Remember everyone is unique and handles things differently and making mistakes is okay. And yes I do know why my wife married me because she loves me for who I am, warts and all.*

